

Best Practices Confidentiality

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LONG TERM CARE OMBUDSMAN PROGRAM

BEST PRACTICES: CONFIDENTIALITY

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LONG TERM CARE OMBUDSMAN PROGRAM BEST PRACTICES: CONFIDENTIALITY

INTRODUCTION

This paper discusses Long Term Care Ombudsman Program (LTCOP) Best Practices related to confidentiality. It is one of a series of documents being developed by the Ombudsman Resource Center to address key issues facing state and local Ombudsmen. Because of the complexity of this topic, sections of the paper are presented in an outline format and the paper includes many examples of specific state practices that uphold confidentiality.

- The importance of maintaining confidentiality
- Underlying principles
- Promoting and preserving confidentiality in 4 areas of ombudsman work:
 1. Disclosure of Resident/Complainant Identity
 2. Ombudsman Program Files and Records
 3. Access to Resident Records
 4. Reporting Abuse and Neglect
- Measuring Outcomes

Examples of LTCOP policies and procedures from various states are included to illustrate how programs operationalize these concepts. Because many states have similar provisions, this paper uses a few key examples. It does not attempt to provide an analysis of all state LTCOP policies in each of the areas pertinent to confidentiality.

THE IMPORTANCE OF MAINTAINING CONFIDENTIALITY

One of the major foundations and guiding principles of ombudsman work is confidentiality. Such great importance is placed on confidentiality for compelling reasons.

Many residents are frail, vulnerable and dependent on staff for part or all of their care. They are frequently reluctant to voice their concerns or complaints in any way out of fear of mistreatment or reprisals. Often the only way residents feel comfortable bringing their concerns to the ombudsman or talking about conditions in the facility is with a guarantee that their confidences will be preserved. A relationship of trust must form between the ombudsman and the resident before an ombudsman can advocate on a resident's behalf. This trust only develops when residents can absolutely rely upon the discretion of the ombudsman. They must be confident that their identity and the information they divulge to the ombudsman will only be shared with their permission, and only to those to whom they wish the knowledge to be disclosed.

The critical importance of safeguarding identities and information applies to complainants as well. Family members or friends who are concerned about a resident's well being are usually reluctant to be identified because they are fearful of retaliation against a loved one. Facility staff who depend economically upon the facility for their livelihood must also be assured that the information they provide to the ombudsman will be protected.

Fear of retaliation is one reason confidentiality is essential to ombudsman services. Other reasons include: residents and other complainants not wanting to be viewed as complainers; desire to maintain a low profile; lack of confidence in the resolution process; and the need to protect a source of information. Anyone contacting the program must, therefore, know that the confidential nature of their communications to the ombudsman will not be breached.

Failure to uphold confidentiality can result in irreparable harm to residents and the ombudsman program. The impact on an individual resident can be devastating. The disclosure of a resident's identity may lead directly to retaliation against the individual. While such actions are clearly illegal, they are nevertheless very real. As a result, the resident's quality of care and quality of life may decline. Even worse, verbal and/or physical abuse could occur.

A resident whose confidence had been betrayed by the ombudsman program would certainly no longer turn to the program for assistance. She would very likely not raise her concerns to *anyone* after such a disastrous experience. This means that she might suffer in silence and her problems might never be addressed. Furthermore, other residents who observe the results of such disclosure will most certainly not turn to the program for the help they need. In fact, it is highly unlikely that they would turn anywhere for assistance.

Clearly the same consequences apply when confidentiality is breached with family members and friends of residents, and it is obvious that the betrayal of confidences from facility staff can lead to an employee's termination.

Protecting the identities and information communicated to the ombudsman is the only way to create the necessary trust in the ombudsman program that enables ombudsmen to advocate for vulnerable residents. Without this trust, the credibility of the program is undermined and its ability to improve the lives of residents is destroyed. For this reason the Older Americans Act (OAA) provisions governing release of resident and complainant identities and disclosure of information are extremely restrictive - far more restrictive than the confidentiality requirements for any other OAA program.

UNDERLYING PRINCIPLES

The resident is the focal point of all ombudsman work, and ombudsman practice must always be resident-driven and resident-centered. The ombudsman seeks first to educate and empower residents to advocate for themselves. When this is not possible, the ombudsman acts with them or on their behalf.

These principles apply not only to the problem resolution process but to confidentiality issues as well. Just as ombudsmen move in tandem with the resident through every step of the problem solving process, so must the Ombudsman be guided by the resident's wishes and pace in matters of confidentiality.

PROMOTING AND PRESERVING CONFIDENTIALITY IN FOUR AREAS OF OMBUDSMAN WORK

The promotion, preservation and protection of confidentiality must guide every aspect of ombudsman work. There are four areas of ombudsman practice in which State Ombudsmen need to ensure confidentiality:

1. disclosure of resident/complainant identity and identifying information;
2. disclosure of ombudsman program files and records;
3. accessing resident records; and
4. reporting of abuse and neglect.

The resident-directed focus of the ombudsman program must be applied to each of these areas.

The National Long Term Care Ombudsman Resource Center has published three resources relating to this topic. They are: *Working Through Ethical Dilemmas in Ombudsman Practice* (1989); *Ethical Issues in Ombudsman Advocacy*, Ombudsman Reporter (vol. 3, no. 1, Summer, 1991); and *Applying Ethical Principles to Individual Advocacy* (1992). These papers contain a discussion of issues relating to confidentiality and consent. Each document also lists key questions to consider in deciding what action to take and in developing program policies.

1. DISCLOSURE OF RESIDENT/COMPLAINANT IDENTITY AND IDENTIFYING INFORMATION

The Older Americans Act (OAA) language is very strict regarding revealing resident and complainant identities:

Disclosure –

(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-

(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.*

OBTAINING CONSENT

In general, consent must always be received from residents and complainants in order to disclose their identity to anyone. Most states have procedures in place that requires ombudsmen to obtain the written consent of the resident and the complainant (or their legal representative) before disclosing the identity of these individuals. Program consistency is promoted when uniform consent forms are developed by the State Office of the Ombudsman, rather than having each local program create its own forms.

Since the OAA permits oral consent if documented contemporaneously, many states have also included this in their procedures.

STATE PRACTICE

Ohio

Ombudsmen may receive oral consent if written consent from the appropriate person is not practicable. Such consent is then documented in the case record.

Michigan

Oral permission is the preferred approach. If permission is received, it is documented in the case narrative. When the ombudsman has any doubts about a resident's or complainant's verbal consent, he or she is instructed to seek written consent.

In general, oral consent promotes more informal, on-the-spot interventions. This approach can be particularly effective with volunteers.

Additional points that ombudsmen need to think about when determining the best way to obtain consent include informed consent and disclosing to whom residents and complainant identity will be revealed.

Informed Consent

Consent received from residents and complainants, or their legal representatives, must be informed consent. This involves discussing two important considerations: 1) the possible difficulties in investigating and resolving problems if identity is not revealed; and 2) the possible risks of consenting to the disclosure of identity and the limits of confidentiality.

1) *Difficulties of investigating without disclosure*

Complainants have the right to know how the Ombudsman investigation will be handled if there is consent and how the investigation would be handled without consent. Certainly, it would also be important to explore with the resident other ways to pursue problem resolution when the resident is not comfortable with disclosure.

“ STATE PRACTICE

Michigan

Resident Advocacy Services Operational Guidelines tell ombudsmen to:

- Explain exactly why you need to use the complainant’s or resident’s name to take needed action;
- Be honest about possible strategies and the likelihood of success or retaliation with complainants and residents; explain the limitations of acting without revealing their identity; and

Never harass or intimidate people who refuse to give consent; just explain that your work is unlikely to be successful or that, in fact, you will not be able to take any actions.

Colorado

Ombudsman policies state that the ombudsman should explain that a complainant or resident has the right to full confidentiality, but that actions and efforts to maintain complete confidentiality may in some instances inhibit proper and full investigation.

2) *Risks/Limitations of disclosure*

Because revealing a resident’s or complainant’s identity may in fact have negative consequences, it is essential that these individuals be informed in advance about this possibility. Several state ombudsman programs address this issue in their guidance to local ombudsmen.

“ STATE PRACTICE

New York

Ombudsmen must inform the resident, complainant, guardian or legal representative about the possible consequences of disclosure.

Michigan

In its operational guidelines for Resident Advocacy Services, ombudsmen are directed to:

- Explain the possible consequences of each proposed action they intend to take;
- Never dismiss concerns regarding retaliation or other negative consequences voiced by residents and complainants; and
- Not guarantee success of proposed actions.

Minnesota

Ombudsmen are required to provide each resident and complainant with a written explanation of the limitations on confidentiality as a part of the intake process. This explanation must be reviewed before the client consents to disclosure of his or her identity.

Knowledge of to whom identity will be disclosed

Ombudsmen should approach the disclosure of identity the same way that they approach the problem resolution process. This means that the ombudsman is working with the resident and/or complainant every step of the way and does not act without resident permission.

Since residents and complainants may not have an idea of the individuals or agencies that ombudsmen may need to talk to about their concerns, they should be told precisely to whom their identity would be disclosed. *Generic, blanket consent forms that request residents and complainants to consent to having their names disclosed to “anyone necessary for the investigation and resolution of your concern” do not provide clients with adequate information.*

“ STATE PRACTICE

Minnesota

To avoid a cumbersome process, the Ombudsman program has developed A consent form where the resident or complainant identifies the persons, companies or agencies that the ombudsman may contact. This form gives the ombudsman consent to use the individual’s name and discuss the case with the specified entities or people. A copy of this form is found in Appendix 1.

Should the ombudsman believe that s/he needs to disclose the resident’s and/or complainant’s identity to additional people or entities, the ombudsman needs to go back to the resident and/or complainant to explain what is needed and why.

WHEN CONSENT IS REFUSED

When residents and complainants or their legal representatives refuse to allow the disclosure of their identities, the ombudsman is prohibited from revealing this information and must work with the resident and/or complainant to find other ways to resolve the problem. The only exception to this is when a court order is issued.

Releasing resident/complainant identity is a serious matter. Any disclosure by the ombudsman program can potentially discourage residents or their families from seeking ombudsman help and can reduce resident trust in the program. State Ombudsmen therefore need to think about how the program will protect the identities of residents and complainants when faced with a court-ordered disclosure.

• STATE PRACTICE

Georgia

Policies and procedures have been developed to address both subpoenas and court orders.

- Subpoenas:

Georgia policy states that upon receiving a subpoena, the State Ombudsman must obtain appropriate legal counsel; and make a motion to quash the subpoena where the SLTCO determines that the release of records would be inconsistent with the wishes or interest of the resident.

- Court orders:

Georgia policy directs the SLTCO to release any records directly responsive to the order. The State Ombudsman may then provide an explanation to the court the importance of not revealing the identity of residents and complainants; and/or request the court to seal the LTCO records when the SLTCO determines that the release of records would be inconsistent with the wishes or interest of the resident.

Alaska

Alaska policy goes one step further than Georgia by directing the State Ombudsman to *appeal* the court order if he or she determines such an appeal to be warranted.

How does the SLTCO determine that the release of records is not consistent with the wishes or interests of the resident? Some of the factors for State Ombudsmen to consider include:

- What does the resident want?
- What is the potential benefit to the resident?
- What is the potential detriment to the resident?
- Is the information being sought for a retaliatory purpose?
- Is revealing the identity to subject a resident to adverse treatment or retaliation?

One state sought legislation to define the circumstances which would justify releasing LTCOP records without consent. The proposed bill said that an ombudsman may not be compelled to testify or produce documents without his or her consent and the consent of all the parties involved except when:

- the ombudsman is witness to a felony;
- a threat or threats of bodily harm are communicated to the ombudsman;
- a threat or threats of extensive property damage are communicated to the ombudsman.

The legislation was designed to protect the identities of residents and complainants under almost all circumstances. Although the proposed bill was NOT enacted, the principles might be worth consideration. If a LTCOP wants to pursue a similar course, it needs to think very carefully about the potential impact on cases of “resident to resident” abuse or issues involving residents with cognitive impairments.

WHEN CONSENT CANNOT BE GIVEN

Ombudsmen are sometimes faced with situations affecting a resident who is unable to give informed consent and has no legal representative. The inability to consent applies both to disclosure of identity and consent to work on the complaint. This raises an ethical issue which ombudsmen must address: *Does the ombudsman try to resolve the problem on the resident’s behalf without consent?*

“ STATE PRACTICE

Ohio

Local ombudsmen may investigate a complaint, reveal the identity of a complainant or client or resolve a complaint with the approval of the State Ombudsman when:

- there is no legal representative;
- the legal representative is unknown to the representative or the provider;
- the legal representative cannot be reached within 3 days of the date upon which a complaint was received;
- the estate of a deceased client has no legal representative; or
- there is no sponsor;

Michigan

The only exception to receiving consent for disclosure is when the ombudsman is the complainant. In situations where the ombudsman observes inappropriate care or violation of rights and the resident is incapacitated or comatose, the ombudsman is to assume that the resident would want the facility to meet the minimum standards of care. Under those circumstances ombudsmen can request that proper care be provided to a particular resident.

Georgia

Where a resident is unable to provide or refuse consent to a LTCO to work on a A complaint directly involving the resident, the LTCO shall:

- seek evidence to indicate what the resident would have desired and, where such evidence is available, work to effectuate that desire; and
- assume that the resident wishes to have his or her health, safety, and welfare and rights protected.

The wishes of residents who indicate in any way that they do not want the ombudsman involved or their name disclosed must be respected regardless of resident capacity.

The majority of the time, the issue of disclosure of resident and complainant identity arises during complaint handling. However, ombudsman programs must ensure that resident/complainant identity or any other information that would serve to identify a resident or complainant is safeguarded in other areas of ombudsman practice as well.

SHARING OMBUDSMAN PROGRAM INFORMATION

The strict OAA requirements governing the ombudsman program do not permit ombudsmen to disclose resident and complainant identities or identifying information without consent to anyone **outside of the ombudsman program**. This extra protection within the LTCOP frequently creates misunderstandings and a perception that the ombudsman program thinks it is “special,” or a prima donna among other programs. Since other programs, departments, or agencies have their own confidentiality provisions that typically permit sharing within the social services arena, the ombudsman program is viewed as not being a “team” player. The lack of equal sharing of confidential information sometimes leads to a view that ombudsmen want all the information from others, but are unwilling to share, or that ombudsmen think the confidentiality provisions of other programs are not good enough. The management challenge for ombudsmen is to maintain cooperative working relationships with others in long term care *while* adhering to the strict confidentiality provisions of the OAA. The LTCOP must continually explain the OAA requirements, educate others, and find ways to work together.

- a) **Sharing with state units on aging, area agencies on aging, and other agencies that provide ombudsman services**

Many ombudsmen work in settings where names of clients are freely shared and disclosed within the confines of the unit or organization. The “fences” of confidentiality are considered to be erected around the agency as a whole. State and local ombudsmen must work to “shrink” the fences to encompass the ombudsman program only. It was noted earlier that residents are often reluctant to voice concerns because they fear retaliation. Fear of reprisal is not limited to retaliation from the nursing home; it extends to agencies which house the ombudsman program and that provide other services upon which a resident may depend or that can affect his or her life. Examples of such services include adult protective services, guardianship programs, case management services, pre-admission screening for nursing homes, and providing monitoring and oversight duties in assisted living facilities. Unless residents know that their identity and information will be protected in *all* settings, many will not seek the help they need from the ombudsman program.

The critical importance of not disclosing resident and/or complainant identity can create tension for ombudsmen since other programs within the state unit on aging, area agency on aging or other agency housing the ombudsman program are not subject to such restrictive provisions.

One state has taken the following approach to resolve this tension:

“ STATE PRACTICE

Georgia

The Division of Aging Services (DAS), AAA, or provider agency may not review records which disclose or imply the identity of any resident or complainant.

No state agency, AAA or provider agency may require a LTCO to disclose the identity of a complainant or resident except as specifically provided by these procedures.

In light of the OAA confidentiality requirements, a concern expressed by agencies housing the ombudsman program is how they are to know what the program is doing and how it is performing. The monitoring of ombudsman programs by state agencies, area agencies and provider/sponsoring agencies is an important issue and is discussed under Section 2, Ombudsman Program Files and Records.

b) Sharing information with other state agencies and programs

OAA confidentiality requirements also apply to the sharing of information with *any* state agency or program, wherever the program is located – within or outside of an umbrella agency.

Ombudsman programs are frequently located within broad “umbrella” agencies that house a number of state programs and agencies. Umbrella agencies often do not consider

internal sharing of client names a breach of confidentiality. However, there are no exceptions written into the OAA that allows the release of information even within an umbrella agency.

Preserving resident/complainant confidentiality in this environment becomes critical because residents are often clients of several different state agencies or programs. It is quite common, for instance, for a resident being helped by the ombudsman program to be a client of the state Medicaid program. Residents on Medicaid know that they need such assistance in order to get the care they need. If they become fearful that their Medicaid assistance may be jeopardized because the ombudsman program shares information with the Medicaid Program, they may decide not to seek ombudsman assistance.

“ STATE PRACTICE

Georgia

No state agency ... may require a LTCO to disclose the identity of a complainant
Or resident except as specifically provided by these procedures.

When the ombudsman program is located outside an umbrella agency, the Ombudsmen can only refer complaints regarding a resident to the state survey agency when residents or their legal representatives have given consent to disclose their identity and the nature of the complaint. During the survey process, Ombudsmen may release names and information relating too specific complaints to the state survey agency, with the consent of the resident, complainant, or their legal representative. Otherwise, ombudsman programs can only disclose general information about a facility (trends, patterns). When developing procedures regarding consent, State Ombudsmen need to think about how far in advance it is appropriate to ask for consent since residents/complainants may feel differently about such disclosure over time.

Referrals to other state agencies and programs for programs outside of an umbrella agency are the same as complaint referrals to the state survey agency – only when the resident, the complainant or the legal representative have given permission to disclose their names and the nature of their complaints.

DAILY OPERATION OF THE PROGRAM

State Ombudsmen must be attentive to other ways in which the identity of residents and complainants can be revealed in the course of daily ombudsman work. Confidentiality can be enhanced through the establishment of separate offices, even within an umbrella agency, and by maintaining separate means of communication to and from the ombudsman program. Daily operation of the ombudsman program is another area where the OAA confidentiality provisions can create a perception that the ombudsman is seeking special privileges. Many ombudsmen have had to continually justify why a private office is essential to adhering to these confidentiality provisions. In some agencies, finding a way for the ombudsman to have a private office is a real challenge.

Care must be taken to protect confidentiality as office and communication technology changes over time. State Ombudsmen and local programs need to protect resident/complainant identities relative to:

- Computer systems
- Incoming and outgoing faxes
- Voice mail
- E-mail messages/websites
- Correspondence to/from the ombudsman program
- Incoming phone calls to the ombudsman program (for example residents/complainants giving their names to receptionists, phone messages left for anyone to see.)
- Phone logs that ombudsmen may be required to keep
- Accreditation processes for local agencies
- Staff meetings/group case conferences that include non-ombudsman program staff
- Ombudsman visits to residents in long term care facilities
- Discussions/conversations outside the office with ombudsmen and non-ombudsmen
- Access to ombudsman program files

-- STATE PRACTICE

Oklahoma

Privacy shall be provided for receipt of complaints by mail, telephone, or personal interview, in order to maintain confidentiality.

All mail addressed to an Ombudsman by name or title shall be delivered unopened to the Ombudsman.

2. OMBUDSMAN PROGRAM FILES AND RECORDS

Under the OAA, ombudsman program files and records can only be disclosed with the permission of the State Ombudsman. This excludes disclosure of resident and complainant identity, which can only be released with consent or by court order.

The OAA states:

(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).

These confidentiality standards are stricter than those for most programs within a state agency, area agency or a provider agency. In many programs, general measures to protect confidentiality within the agency are sufficient. Since this is not the case with the ombudsman program, State Ombudsmen need to consider several points in meeting the OAA requirements. These points and examples of state practice are described below.

SAFEGUARDING PHYSICAL ACCESS TO OMBUDSMAN PROGRAM FILES AND RECORDS

“ STATE PRACTICE

Alaska, Georgia, Minnesota, Oklahoma

Locked files are used to maintain confidential records. Access to such files is limited to designated local Ombudsman representatives and staff of the Office of the State Long Term Care Ombudsman.

ESTABLISHING TO WHOM OMBUDSMAN PROGRAM FILES AND RECORDS BELONG

“ STATE PRACTICE

Alaska, Georgia

All ombudsman files – including those maintained by local ombudsman entities – are the property of the Office of the State Long Term Care Ombudsman.

CIRCUMSTANCES UNDER WHICH RECORDS AND FILES CAN BE DISCLOSED

In general, requests for the disclosure of ombudsman records arise because:

- a) there is a need to share information for purposes of education or advocacy;
- b) an entity or individual wants information relative to a particular case; or
- c) the SUA, area agency or agency housing the ombudsman program wants to monitor the performance of the ombudsman program.

a) Education and advocacy purposes

Ombudsman program information can be very useful in educating people such as policy makers, legislators, reporters and the public about the problems faced by residents and in advocating for improvements. Aggregate data as well as carefully redacted cases can assist the public policy work of ombudsmen.

“ STATE PRACTICE

New York

The State Ombudsman delegates his or her authority to the Substate Coordinator to disclose records or file information in the following circumstance:

The Substate Coordinator may develop vignettes and case studies based on LTCOP file information for the purposes of advocacy, training, recruitment of volunteers, or public education, so long as all identifying information about the complainant, resident, staff and facility is removed and the identity of the complainant, resident, staff, and facility cannot be determined from the information presented.

b) A particular case

The State Ombudsman must carefully consider under what circumstances, if any, s/he will decide to disclose all or a part of a record or records.

“ STATE PRACTICE

Georgia

The State Ombudsman considers five factors when deciding whether to Disclose records. These are:

- whether the request is in writing.
- whether the release is consistent with the wishes or interest of the relevant resident (s);
- whether consent has been obtained for release of resident or complainant identity or whether redaction is necessary;
- the source of the request; and
- the type of request.

Pertinent sections from the Georgia manual are found in Appendix 2.

If a resident requests his or her own record, such a request should be honored, but names of all other residents should be removed (unless each has consented to disclosure).

Colorado

Colorado has developed a list of factors for the State Ombudsman to consider when determining whether to release ombudsman program records:

- Will the release of records benefit residents in long-term care facilities?
- What will be the potential benefit to the resident?

- What will be the potential detriment to the resident?
- What will be the potential benefit to other residents in the facility?
- What will be the potential detriment to other residents in the facility?
- How likely is it that the resident's identity would be discovered even with names and situations redacted?
- Is the potential for injury to the ombudsman/client relationships greater than the benefits?
- Is there a potential for retribution to the client?
- What information does the Ombudsman Program have that is not available elsewhere?
- What is the credibility of the person/agency requesting the records?
- How much time/effort would be involved in complying with the request (would it significantly detract from the ombudsman's ability to advocate for other residents)?
- Does the program have the resources to file a motion to quash and protective order? What is the likely outcome?

Additional criteria for State Ombudsmen to consider include: examining whether the request is sufficiently specific and narrow so that any incursion on confidentiality is limited and if the information is being sought for a retaliatory purpose. (April 13, 1995 letter to Sue Wheaton, a ombudsman specialist, from Alfred Chiplin, staff attorney, National Senior Citizens Law Center. See Appendix 3).

A recent court case provides an excellent example of the way in which one ombudsman program addressed a request for release of its records. In 1998, Genesis Eldercare Network Services, Inc. sued Courtland Health Care, Inc. In the course of this lawsuit, Genesis served Diane Menio, the Director of the Center for the Rights and Interests of the Elderly (CARIE), with a subpoena calling for all ombudsman files pertaining in any way to eight facilities in its service area. CARIE acts as the ombudsman program for Philadelphia.

Working with Robert Doig of Doig and Doig, a private law firm donating its services on a pro bono basis, CARIE sought to have the subpoena quashed. In its motion to quash and supporting memorandum, CARIE made the following arguments:

- The Older Americans Act gives the ombudsman the discretion to refuse to provide its files to any party, even with resident consent. The Aging Program Directive 98-10-01 of the Pennsylvania Department of Aging goes even further than the Older Americans Act and requires that disclosure of ombudsman information is only permitted: a) for the purpose of supervision and monitoring of residents' care; b) with resident consent; and c) at the discretion of the ombudsman.

Drawing upon both federal and Pennsylvania state mandates, CARIE then argued that ombudsman files are to be disclosed only where needed to address, improve, or monitor residents' care. Since Genesis was not seeking ombudsman program information for this purpose, the records could therefore not be provided.

- Disclosure of ombudsman records would violate the confidential relationship between the resident and CARIE and jeopardize the role of the ombudsman in helping the elderly.
- Complying with the subpoena would be overly burdensome to CARIE staff, which would have to cull through voluminous files and redact confidential information. This task would disrupt the ombudsmen’s performance of their duties.
- Complaint information about nursing facilities is readily, and indeed more appropriately, available from the Pennsylvania Department of Health. Moreover, Genesis had already subpoenaed and obtained Statements of Deficiencies from the Pennsylvania Department of Health, making its request to CARIE duplicative of documents already in its possession.

The court agreed with the arguments presented on behalf of CARIE. It found that federal and state legislative intent is to “permit disclosure where necessary only to promote, safeguard or manage resident care The public policy of honoring the confidentiality of these records/information far outweighs the need of a private litigant to discover them in connection with its civil suit for breach of contract.” The subpoena was quashed.

A complete copy of the motion to quash, the memorandum in support of the motion, and the Judge’s order quashing the subpoena are provided in Appendix 4.

c) Monitoring of ombudsman programs

State and local agencies that house the ombudsman program or that contract for ombudsman services want to ensure that the ombudsman program is operating well. They also want to be aware of the program’s work. State Ombudsman Programs need to think about ways to meet these agency needs for accountability within the boundaries of the OAA requirements of confidentiality.

Several ombudsman programs have come up with an approach that has been successful in their states.

“ STATE PRACTICE

Georgia, Ohio

The evaluation of local ombudsman program performance is shared by the State Ombudsman and the provider agency. Since client files are confidential, the State Ombudsman or state ombudsman program staff assesses those records to determine if casework is being handled appropriately and effectively and if complaint handling procedures are being followed. The local agency performs administrative and fiscal monitoring of the program to assure compliance in those areas. The general results of the local agency and the State Ombudsman review are shared so that a complete picture of the local program’s performance can be determined.

Oklahoma

Oklahoma State ombudsman staff evaluates **all** aspects of the local ombudsman program. This includes administrative and financial monitoring, as well as monitoring volunteer training, recordkeeping, continuing education and supervision, public speaking, press release documentation, routine visits, in-service education, etc.

In addition, both the state agency and the provider agency can monitor the program through the Long Term Care Ombudsman Reporting system. This report covers a wide range of ombudsman activities. In a number of states, monthly or quarterly reports to the State Ombudsman from the local program are also required, and these are shared with the provider agency. In these cases, care is given to assure that there is not sufficient and/or identifying information to reveal a resident or complainant even when their identity has been removed.

3. ACCESS TO RESIDENT RECORDS

Under the OAA, ombudsmen have the following access to resident records:

(b) Procedures For Access.-

- (1) IN GENERAL.-The State shall ensure that representatives of the Office shall have-*
 - (A) access to long-term care facilities and residents;*
 - (B) (i) appropriate access to review the medical and social records of a resident, if-*
 - (I) the representative has the permission of the resident, or the legal representative of the resident; or*
 - (II) the resident is unable to consent to the review and has no legal representative ; or*
- (iii) access to the records as is necessary to investigate a complaint if-*
 - (I) a legal guardian of the resident refuses to give the permission;*
 - (II) a representative of the Office has reasonable cause to believe that the guardian is not acting in the best interests of the resident; and*
 - (III) the representative obtains the approval of the Ombudsman.*

WHETHER AND HOW TO REVIEW RECORDS

While the OAA clearly intends for each state to provide for ombudsman access to resident records, reviewing the records of residents is not to be done lightly since such documents are highly personal. In fact, under the Nursing Home Reform Act, a “resident has the

right to personal privacy and confidentiality of his or her personal and clinical records.¹” Any review is an intrusion upon someone’s privacy. There is the additional risk that ombudsmen will appear more as regulators than advocates to residents if their focus is record-oriented rather than resident-focused.

Many concerns can be addressed through ombudsman facilitation of good communication among all parties. Record review should be conducted only if it is absolutely necessary for the resolution of a resident’s and/or complainant’s problem. When this is the case, the role of the ombudsman is best fulfilled when the records are obtained by the resident and/or complainant and then reviewed jointly by the resident and/or complainant and the ombudsman. Such an approach ensures that the resident is not left out of the process.

“ STATE PRACTICE

Michigan

Guidance to local ombudsmen states:

As with all other aspects of the complaint resolution process, your goal should be to empower the complainants so that they can use the experience to help deal with future problems. By helping and encouraging the complainants to obtain needed records, they will learn how to obtain sources of documentation that may be helpful to them in the future. When the documents have been obtained, you should help ensure that the complainant understands what they mean and how they may be used.

WHEN RESIDENTS CANNOT GIVE PERMISSION

Whether to review a resident’s records becomes a more complicated question when the resident cannot give consent or the legal representative refuses consent or is unavailable. While the OAA says that States must assure ombudsman access to resident records under those circumstances, how/if to proceed is an ethical issue that State Ombudsman Programs must address.

In these situations, factors to consider include:

- Is there any other way that the problem could be addressed? Is there another agency that could better handle this complaint? How likely is that approach or that agency to help this resident?
- Are there any possible negative ramifications on other residents when they see the ombudsman proceeding without consent? Will that deter residents from turning to the ombudsman program for help if they need it?

¹ Federal nursing home regulations: 42 C.F.R. 483.10(e)

“ STATE PRACTICE

Michigan

Guidance to local ombudsmen states:

If you cannot obtain written consent from the resident, guardian, or other legal representative of the resident and inspection of the records is crucial in resolving the complaint, consider filing a formal complaint with the regulatory agency that has access to the records.

WHO CAN REVIEW RESIDENT RECORDS

State Ombudsmen must decide exactly who within the ombudsman program can access resident records since the OAA simply refers to “representatives” of the office. States have approached this in varying ways.

“ STATE PRACTICE

Kentucky, New Hampshire

Volunteer ombudsmen who are trained according to the state’s standardized curriculum have the same access to records as paid staff.

Wisconsin

Access to medical records is limited to professional paid staff. If medical records are part of the investigation, the volunteer works with paid staff to access those records.

4. REPORTING ABUSE AND NEGLECT

REPORTING BY THE OMBUDSMAN PROGRAM

Ombudsmen frequently have issues of resident abuse, mistreatment and neglect brought to their attention. However, the OAA requirements previously discussed prohibit disclosure of resident and complainant identity without the consent of the resident and complainant or a court order.

These provisions are unique to the ombudsman program under Title 7. While the Act allows elder abuse prevention programs under Chapter 3 of Title 7 to release confidential information to law enforcement agencies and similar agencies, there are no such exceptions under Chapter 2 governing the ombudsman program. A legal review by AoA underscores this point, “ the specific provisions relating to the ombudsman do not include such an exception and

there appears to be no basis for reading in such an exception.” (Letter to Sue Ward from AoA, August 28, 1998. See Appendix 5).

The OAA provisions also do not allow for exceptions based on state laws requiring mandatory reporting of suspected abuse, neglect or exploitation. Such reporting laws are found in many states and usually do not exempt ombudsmen. However, the supremacy of federal laws means that the ombudsman’s duty to protect the identity of complainants or residents set forth in the OAA supersedes any state reporting requirements. Additional clarification on this point is found in the OAA mandate to state agencies to “assure that all of the requirements of the Act for this program are met” [45 CFR 1321.9(d)].

Congressional intent that identities and indeed, identifying information, should not be released without consent is made evident by the following statement made by Congressman Bonker and Senator Glenn. When asked whether mandatory reporting requirements in state laws conflict with the OAA in 1988. requirement that ombudsmen keep identities of nursing home complainants and residents confidential, the legislators replied:

Yes. The Older Americans Act is clear on this point. Section 307(a)(21)(D) of the OAA clearly prohibits an ombudsman from disclosing the identities of nursing home residents and complainants. It would also violate the spirit of the law to provide other information that would serve to help identify a resident of complainant without specifically naming them. The federal law, therefore, takes precedence over a state law that is in conflict with it. (Best Practice Notes, November 1988 issue, Center for Social Gerontology. See Appendix 6.)

The AoA interpretation mentioned above also points out that states with mandatory laws requiring everyone, including ombudsmen, to report should either: 1) modify their legislation; or 2) adopt an official interpretation excepting the ombudsman from this requirement, in the event that it is not possible to obtain the consent of the alleged victim.

The OAA laws requiring resident and complaint permission to disclose identities stem from the nature of the role of the ombudsman. The purpose of the long-term care ombudsman program is to serve as an advocate for residents of long-term care facilities. In their capacity as advocates, ombudsmen work to support a resident’s autonomy, preferences and rights. Ombudsmen serve as the agent of *residents* and help residents to achieve what *residents* believe is in their best interest.

Because ombudsmen serve residents, their role is fundamentally different from other players in the long-term care system. For instance, while adult protective services workers can be client- centered and advocacy oriented, they serve as agents of the *state* and take actions *they* believe to be in the best interest of the client. They must at times make decisions about a client’s future.

The federal requirements that abuse or neglect cannot be reported without resident permission raise difficult ethical issues for ombudsman programs. Are there, for instance, any times when confidentiality should be breached? Is there ever a point at which protecting the

resident becomes more important than protecting confidentiality and upholding a resident's decision?

This is undoubtedly a complex question. However, if ombudsmen are to preserve their role as advocates, they must not act in ways that are diametrically opposed to resident wishes. In many cases, residents only confide in ombudsmen when they truly believe that what they say will not be shared. To report abuse when a resident has expressly stated that she does not wish a report made destroys the trust that exists between residents and ombudsmen, often forever.

Moreover, the legitimacy and authority of the ombudsman program comes from the residents themselves. If the program ceases to take its guidance from residents, but instead makes decisions on their behalf, it loses that legitimacy and no longer has any basis for its work.

Examples of how some states have tried to develop policies that balance the protection of confidentiality with the protection of residents follow.

Residents with decision making capacity

“ STATE PRACTICE

Texas

Texas Department on Aging (TDoA), will not knowingly pursue an investigation involving abuse, neglect, exploitation or any complaint involving technical expertise beyond the capabilities of the ombudsman program, as determined by the State Ombudsman. Such complaints, with the consent of the resident or complainant, will be referred to TDHS (Texas Department of Human Services) or another appropriate agency by the regional staff ombudsman or TDoA.

Alaska

When a resident does not give permission to the LCTO to make the report and the resident acknowledges having been abused, the ombudsman:

- determines whether other residents have experienced similar circumstances, and whether any other such resident wishes the LCTO to take any action on his/her behalf; and
- makes repeated visits to the resident who alleged abuse in order to encourage the resident to permit the ombudsman to report the suspected abuse.

Residents without decision-making capacity

“ STATE PRACTICE

Georgia

If the resident is unable to communicate his/her wishes, the ombudsman encourages and provides assistance to any other person who is aware of the suspected abuse to make the report.

Michigan

The only exception to this principle [resident consent to reveal identity] involves cases in which you are the complainant. There are times you will be walking through a nursing home and see inappropriate care or violation of rights of comatose or clearly incapacitated residents. The resident will be exposed, laying in urine and feces, etc. Getting consent from these residents may be impossible. In such cases, you can and should assume that the resident would want the facility to meet the minimum standards of care. Therefore, you need not get the resident's permission to approach a staff person to ask that care be provided.

For all cases

-- STATE PRACTICE

Alaska, Georgia,

Policies direct the ombudsman to use his or her best efforts to ensure the protection of the resident from further abuse or neglect and to continue to monitor the safety of the resident.

REPORTING TO THE OMBUDSMAN PROGRAM:

Ombudsmen must be guided by resident permission not only when making abuse and neglect reports, but when receiving certain reports as well. In many states, nursing homes send or call incident reports or incident and accident reports to the ombudsman. These reports detail an event that has happened to a particular resident or occurrences of resident-to-resident abuse. Such information is confidential to each individual resident and should not be disclosed to ombudsmen without resident permission. Ombudsmen should not become involved in addressing instances of resident-to-resident abuse unless asked to do so directly by one of the residents involved. The ombudsman should be able to initiate discussion with the resident based on the information and inform the resident of the availability of ombudsman services. In addition, the ombudsman should inform the facility of the importance of filing the report with the appropriate agency (ies), and check to make sure that reports are actually being filed.

-- STATE PRACTICE

Connecticut

Ombudsman program policies and procedures have recently been changed so that ombudsmen no longer receive nursing home Incident and Accident Reports.

MEASURING OUTCOMES

How does a State Ombudsman know if the confidentiality provisions of the OAA are being upheld? Possible indicators include:

- Ombudsman program policies and procedures give clear guidance on confidentiality issues discussed in this paper.
- Policies and procedures have been implemented to ensure that ombudsman program mail, phone messages, phone conversations, faxes, interviews, etc are confidential. observation of the ombudsman's work environment indicates that confidentiality is upheld.²
- Review of ombudsman case records reveals that:
The permission of the resident and complainant was obtained for disclosure of identity during complaint handling and the appropriate forms were signed.
The permission of the resident and complainant was received for disclosure of identity to the survey agency and any other agency.
The consent of the resident was received for release of the resident's records.³
- Ombudsman program records are maintained in locked files and accessible only to ombudsman program staff.⁴
- Observation of the ombudsman when handling a resident's complaint indicates that confidentiality is protected.
- Ombudsmen do not pursue any action without working at the resident's direction.⁵
- Ombudsmen do not share information without resident permission.
- Ombudsmen seek information about the resident only with resident permission.⁶
- Contact with residents and complainants served by the program reveals satisfaction with the protection of their identity.
- Confidential resident information is not shared with the ombudsman by agents of other Agencies and programs and nursing home staff without resident permission.⁷
- Residents, family members, nursing home staff, state agencies and programs, agencies housing the ombudsman program and the public understand the confidentiality principles of the ombudsman program.
- Training curriculum for paid and volunteer ombudsmen include the discussion of confidentiality issues including procedures and sample forms to be utilized.

² Based on "A Menu For Excellence" (January 1993) and Oklahoma state practice.

³ Based on "A Menu for Excellence" (January 1993).

⁴ Based on "A Menu for Excellence" (January 1993) and Oklahoma, Georgia, Alaska and Minnesota state practices.

⁵ From: "Ethical Issues in Ombudsman Advocacy," Ombudsman Reporter (vol. 3, no. 1, Summer, 1991)

⁶ Based on Minnesota State practice.

⁷ Based on Connecticut State practice.

CONCLUSION

Confidentiality is related to every dimension of ombudsman practice – complaint resolution, systemic advocacy and public education. Maintaining confidentiality is essential to the integrity of the ombudsman program. However, these issues are complex involving ethical considerations and sometimes difficult decisions. The Ombudsman Resource Center invites further discussion and encourages both local and state programs to review their policies and procedures in light of the issues examined in this paper.