

OMBUDSMAN BEST PRACTICES: USING SYSTEMS ADVOCACY TO IMPROVE LIFE FOR RESIDENTS

Developed by Sara S. Hunt, Consultant

*Gwinnett police put more attention
on elder abuse*

*DENVER POST
"There is a higher rate of injuries
to Nursing home employees than
those in coal mining," says Virginia Fraser,
CO Ombudsman*

**THE ATLANTA JOURNAL CONSTITUTION
NURSING HOME RESIDENTS NEED RELIEF**

THE WALL STREET JOURNAL

"out in the cold"

"...family says nursing home orders mom to move by Friday"

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*Atlanta Ombudsman sees more
allegations against nursing homes*

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I. INTRODUCTION

Statement of Purpose

The intent of this paper is to provide support, guidance, and ideas for state and local long term care ombudsmen (LTCO) to use in pursuing changes in systems to improve the quality of life of residents. Systems advocacy in this paper means actions intended to impact residents in more than one facility or to enable families and residents in a facility to represent themselves.

Throughout the country, state and local Long Term Care Ombudsman Programs (LTCOPs) have a history of effectively achieving change for residents by changing systems. Sometimes the LTCOP is the only voice calling policy makers' attention to the needs and interests of residents. The LTCOP is in a unique position to impact long term care. Ombudsmen know what is going on at the community level as well as with state and federal policies, regulations, and laws. Therefore, the program is in a position to make a difference! In spite of inadequate resources, the LTCOP has been innovative in finding ways to effect change. Systems advocacy can be very rewarding personally and professionally, providing a balance for individual advocacy work.

Overview of the Paper

This paper provides a framework for engaging in systems advocacy on behalf of long term care residents. It discusses the LTCOP's responsibility and role in changing systems on behalf of residents in the *Guidance for Systems Advocacy* section. The *Tips for Sanity and Success* section describes basic principles for systems advocacy, i.e. strategies and approaches, and key questions for each stage in the process. *Real World Examples* gives "real life" examples of systems advocacy and discusses program policies and requirements that support such advocacy. A final list of reminders of decision points which can make or break systems efforts is the *Essential Elements* section. In *Resources* there are excellent "go to" sources for creative ideas, inspiration, sage advice, and lessons learned through experience. Supplemental materials are in the appendices.

II. GUIDANCE FOR SYSTEMS ADVOCACY

In addition to working on individual cases and complaints, ombudsmen must address and attempt to rectify the broader or underlying causes of problems for residents of LTC facilities. When working on the systems level, ombudsmen advocate for policy change by evaluating laws

and regulations, providing education to the public and facility staff, disseminating program data, and promoting the development of citizen organizations and resident and family councils.

“Systems-Level Advocacy,” *Real People, Real Problems*.¹

The above quote summarizes the responsibility of the LTCOP to seek macro-level changes in systems to benefit residents. This type of advocacy is multi-faceted, ranging from pushing for regulatory or legislative changes to educating others and enabling them to seek the changes they desire. The Older Americans Act (OAA) delineates the dimensions of the systems advocacy responsibilities of the LTCOP in the following excerpts.

Older Americans Act, As Amended in 2000

Sec. 712(a)(3)Functions--The Ombudsman shall serve on a full-time basis, and shall, personally or through representatives of the Office--

(E) represent the interests of the residents before governmental agencies and seek administrative, legal, and other remedies to protect the health, safety, welfare, and rights of the residents;

(G)(i) analyze, comment on, and monitor the development and implementation of Federal, State, and local laws, regulations, and other governmental policies and actions, that pertain to the health, safety, welfare, and rights of the residents, with respect to the adequacy of long-term care facilities and services in the State;

(ii) recommend any changes in such laws, regulations, policies, and actions as the Office determines to be appropriate; and

(iii) facilitate public comment on the laws, regulations, policies, and actions;

(H)(ii) promote the development of citizen organizations, to participate in the program; and

(iii) provide technical support for the development of resident and family councils to protect the well-being and rights of residents;...

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

(1) prepare an annual report--

(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;

(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;

(2) analyze, comment on, and monitor the development and implementation of Federal, State, and local laws, regulations, and other government policies and actions that pertain to long-term care facilities and services, and to the health, safety, welfare, and rights of residents of residents, in the State, and recommend any changes in such laws, regulations, and policies as the Office determines to be appropriate;

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

¹ Institute of Medicine. *Real People Real Problems: An Evaluation of the Long-Term Care Ombudsman Programs of the Older Americans Act*, 1995. p. 72.

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

Institute of Medicine Evaluation of the LTCOP

The Institute of Medicine's report, *Real People Real Problems: An Evaluation of the Long-Term Care Ombudsman Programs of the Older Americans Act, 1995*, identified key elements of system advocacy that are central to an effective LTCOP. Pertinent excerpts² follow.

² *ibid.* Tables 5.8-5.9, pp. 180-183.

Table 5.8 Systemic Advocacy Work, Institute of Medicine

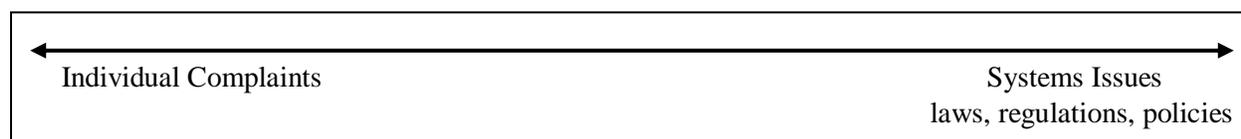
Exemplary Practices	Essential Practices	Unacceptable Practices
<p>The program’s systemic advocacy agenda includes items to improve the lives of residents and not merely to resolve identified concerns or problems in the LTC system. For example, the program works on improving the skills of residents in conducting council meetings, on improving reimbursement systems so that families can and will provide quality services or on improving the health care system’s overall standards of care.</p>	<p>The state ombudsman develops a systematic and participatory approach for local programs to analyze their individual resident advocacy service work to identify systems issues. The state ombudsman then analyzes the same data on a statewide level.</p> <p>Using such information, the program establishes a systems agenda for work by the entire program and describes it in an annual report. Under the direction of the state ombudsman, the program uses a variety of methods and broad coalitions of groups to pursue resolution of the identified systemic concerns.</p>	<p>The program (state and local) does little or nothing to address concerns affecting a large number of residents. For example, the program rarely, if ever, comments on proposed changes in state or federal laws, regulations, or policies; directly seeks changes, clarifications, or improvements in state or federal laws, regulations or policies; files complaints with responsible agencies about the operations of state or federal programs; or involves or assists residents, their families, citizens organizations, other agencies, or the public in securing changes in state or federal laws, regulations, or policies.</p>
<p>The program’s systemic advocacy is focused on a variety of LTC facilities, residents, and all aspects of residents’ lives and concerns. The work is coordinated with others, including those organizations not usually interested in LTC issues, so that broad-based coalitions, rather than the ombudsman program alone, seek systemic change.</p>	<p>The program consistently comments on proposed changes in state or federal laws, regulations, or policies; directly seeks changes, clarifications, or improvements in state or federal laws, regulations or policies; files complaints with responsible agencies about the operations of state or federal programs; or involves and assists residents, their families, other agencies, or the public in securing changes in state or federal laws, regulations, or policies.</p>	<p>The program (state and local) does not produce an annual report that discusses and makes recommendations for changes in state or federal laws, regulations, or policies.</p>
<p>The Office has ongoing interactions with the full range of regulatory agencies with specific agendas to discuss plans for future actions at “pre-decision points,” to plan and conduct joint training, to coordinate</p>	<p>The program’s systemic advocacy is focused on a variety of LTC facilities, residents, and all aspects of residents’ lives and concerns. The work demonstrates a willingness to take on vested interests of all kinds and bring to bear persistence, creativity, and multiple constituencies.</p>	<p>The program’s systemic advocacy does not focus on a variety of LTC facilities, residents, nor all aspects of residents’ lives and concerns. For example, the program’s work is targeted only on nursing home residents and their concerns with a particular owner, but ignores the inadequacies of the licensing or certification agencies, or the eligibility standards of Medicaid.</p>
<p>The Office has regular contact with regulatory agencies as required by the HCFA Medicare and Medicaid survey protocol. The Office also has the same type of contact afforded the public. This includes: ombudsman</p>	<p>The Office has regular contact with regulatory agencies as required by the HCFA Medicare and Medicaid survey protocol. The Office also has the same type of contact afforded the public. This includes: ombudsman</p>	<p>The Office experiences open, ongoing hostility or conflict with one or more state regulatory agencies. There is no sharing of information, strategies, or goals between any segment of the Office</p>

Exemplary Practices	Essential Practices	Unacceptable Practices
efforts wherever possible, and to maximize the different strengths, roles, and talents of each agency and the Office.	participation in committees and work groups related to LTC; and submission of comments on all proposed administrative policies that affect LTC facility residents.	and the management of the regulatory agencies. Each sees their relationship to the other as limited to protecting their agency or program or the residents from the other.
The Office works to foster direct resident participation in the regulatory agency's program and policy efforts and routinely advises the public (particularly residents, families, and citizen advocacy groups) of any opportunities for public comment or other participation in the regulatory process.	In an attempt to resolve conflicts with regulatory agencies, the Office holds open discussions with representatives of the relevant state agencies before any new systemic advocacy measures are taken.	

Table 5.9 Educational Services (included because it references systemic advocacy)

In conjunction with its systemic advocacy agenda, the program initiates and develops educational brochures, pamphlets, posters, PSAs, newsletters, and other written materials to advance its agenda.	Responding to requests, the program (state and local) produces and distributes educational brochures, pamphlets, posters, PSAs, newsletters, and other written materials that answer the questions asked by LTC facility residents, families, and others or that explain the services of the program.	The program (state and local) produces few, if any, educational brochures, pamphlets, posters, PSAs, newsletters, or other written materials that answer the questions asked by LTC facility residents, families, and others or that explain the services of the program.
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 interest 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. The state ombudsmen adequately responds to the informational and educational requests of local ombudsmen programs.	The program (state and local) presents few, if any, 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. The state ombudsman does not adequately respond to the informational and educational requests of local ombudsman programs.

Both the Older Americans Act (OAA) and the Institute of Medicine report show a clear connection between the individual advocacy services ombudsmen provide and the program's responsibility to represent publicly the needs of residents and work to effect change in laws, regulations, and policies. In essence, the individual complaint cases provide the basis for changing systems.



III. TIPS FOR SANITY AND SUCCESS³

Ombudsman Programs nationwide struggle with decisions regarding how to fulfill the range of federally mandated responsibilities with inadequate fiscal resources. When resources are limited, ombudsmen tend to focus on the immediate concerns of residents “rather than trying to impact the systems that are producing the residents’ complaints.”⁴ In spite of this ongoing tension of juggling resources—individual complaints versus systems changes—some programs have found ways to change systems. *A threshold issue is deciding to do systems advocacy in spite of limitations in fulfilling all of the program’s mandates.*

Once a commitment to pursue systems advocacy is made, the decision-making process shifts to one of focus. In listening to ombudsmen discuss the *why’s* and *how’s* of their systems advocacy activities, some consistent themes emerge. These themes are discussed: setting priorities, selecting an issue, maintaining focus, and coordinating local ombudsman activities with those of the state ombudsman office. Some questions to consider are included under each topic. Potential barriers are discussed to assist in planning and in laying the groundwork for systems advocacy. Thus, these *Tips* offer the collective wisdom from ombudsmen who have been *just doing it*. They are included as a brief guide to aid in deciding when and how to approach a systems issue.

Setting Priorities

Before plunging into systems advocacy, establish a basis for allocating the program’s time and resources. Programs that exclusively place highest priority on resolving individual complaints may find themselves resolving the same few issues in an unending cycle. For some complaints, the only lasting solution is to change a law, regulation, or policy, or the way these are applied. If a program’s complaint cases and facility visits take all of its time, achieving a permanent solution to a recurring problem affecting many residents may never occur.

If an ombudsman waited for enough time to participate in work groups, task forces, or coalitions addressing long-term care issues, most LTCOPs would never have a “seat at the table.” Thus, the resident’s voice might be absent from important deliberations resulting in an impact on residents. The LTCOP could be viewed as not interested in working with others to find solutions. An opportunity to add a resident advocacy perspective and to build working relationships with other stakeholders would be lost.

Conversely, placing strong emphasis on systems issues to the neglect of individual complaint handling subjects a program to criticism for being out of touch with residents and families. Without involvement with individuals’ problems, the LTCOP cannot identify enough people to make an impact when direct testimony or action by residents is needed. The ombudsman position cannot be substantiated by hard data and by specific examples of what is

³ Many of the tips in this section were gleaned from a conference call in February, 2001, with State Long Term Care Ombudsmen: Beverley Laubert, Debi Meyers, Esther Houser, and Arlene Franklin, and from feedback from Becky Kurtz.

⁴ C. Estes, D. Zulman, S. Goldberg, D. Ogawa. op. cit.

happening to residents. Although systems advocacy has the potential to impact large numbers of residents, the LTCOP is clearly required to respond to individual complaints.

There are some management strategies that LTCOPs use to increase their efficiency in other ombudsman services in order to engage in systems advocacy. One technique is providing printed resources, similar to the National Citizens' Coalition for Nursing Home Reform's (NCCNHR) Consumer Information Sheets, for the most frequently asked questions by family members. When families contact the ombudsman, they receive information and guidance on working through their issue. Pertinent printed information is mailed to enable the person to engage in self-advocacy. Another management strategy is sharing the systems advocacy load by asking local ombudsmen to represent the program in some of the statewide coalitions or groups addressing systems issues. A third strategy is identifying just one major issue per year for the statewide LTCOP to address in a unified way. The decision to engage in systems advocacy needs to be intentional and included in the LTCOP's priority services.

Questions to Consider:

- ◆ What proportion of the LTCOPs resources will be devoted to systems advocacy?
- ◆ In order to engage in systems advocacy, what changes in the program will need to occur?

Doing Your Homework

Once a commitment is made to engage in systems advocacy, take some time to do your homework before moving ahead. This aspect of systems advocacy is behind the scenes preparation that will pay off when the LTCOP seeks to represent residents on an issue. Failure to adequately prepare is likely to be exposed and weaken the LTCOP's credibility and position on an issue. It will erect unnecessary barriers for work on issues in the future.

Questions to Consider:

- ◆ Does the LTCOP, state and/or local as applicable, understand how the processes work that ombudsmen must impact in order to achieve a change in systems?
 - Do ombudsmen know how the Legislature works? What committees need to be contacted?
 - Do ombudsmen understand how to impact change through the State budget or through rules or policies?
 - Does the LTCOP know how to influence departmental processes and procedures?
 - Do ombudsmen understand other State processes and procedures relevant to the issue the program wants to impact?
 - Has the LTCOP spent time learning from individuals who have experience and expertise in the areas the program needs to understand?
 - Is the SLTCO providing leadership for local ombudsmen in understanding and making an impact on the pertinent process or system?

- ◆ Does the LTCOP understand the issue?
 - Before taking a public position on an issue, are the SLTCO and local LTCO knowledgeable about it?
 - Do the LTCO know what the LTCOP data and experience on that issue reveal, for a region as well as for the state?
 - Do LTCO know how others view the issue?
 - Are there other sources of data and experience that ombudsmen need to understand?
 - What, if any, national data exist?
 - What positions have other state organizations, national organizations, or citizen advocacy groups taken on the issue?
 - What work have others already done pertinent to this issue? How has the LTCOP related to that work?
 - How is the SLTCO helping local ombudsmen increase their knowledge of the issue?

Selecting an Issue

Historically, LTCOPs have used their individual complaint data as a basis for selecting which systems issues to tackle. Choosing a recurrent issue that ombudsmen have dealt with numerous times and/or an issue that occurs throughout the state ensures that the program works on behalf of residents. This means that the focus of systems advocacy is grounded in the real life concerns of residents. Basing systems advocacy on the program's complaint data also adds credibility to the program's message and proposed outcomes.

There are times when the program works on systems issues as part of an effort begun by someone else. Seizing an opportunity and using it to advocate for residents is a hallmark of an effective LTCOP. Typical examples are participating in a task force created to address a specific long term care issue, to draft legislation, or to respond to proposed regulations. Although the LTCOP does not choose the timing or the topic in such situations, the position the LTCOP takes is grounded in the program's data and information. To the extent possible in such situations, ombudsmen seek to involve residents, families, and others in the process as well.

Threshold question: *Is this issue significant to residents and supported by LTCOP data and information?*

In choosing an issue to address, many LTCOPs have used the following tips.

- 1) Be especially thoughtful and deliberate when picking your advocacy issues. Begin with the threshold question, *Is this issue significant to residents and supported by LTCOP data and information?*
- 2) Focus on issues proportionate to the LTCOP's time and resources.

Example: An issue like staffing will absorb a significant amount of LTCOP resources because of the size and complexity of the problem. The amount of background work, coalition building, and continuous follow through necessary to address all of the dimensions of staffing requires a major, long term investment. Tackling an issue of this scope makes it more difficult to balance systems advocacy and individual complaint work. The potential trade off in reducing services to individual residents may not be worth the investment in such a global issue.

Another issue may be less expansive, and therefore more doable while allowing the program to continue meeting the existing needs of residents. For example, taking one dimension of the staffing issue to address in a substantive way such as certified nurse assistant training, content, and hours, or staff turnover.

- 3) Be strategic and creative in identifying and naming the issue the program will tackle.

Example: After assessing multiple factors, a LTCOP decides that the most effective way to address staffing issues is to focus on nutrition or on a “culture of retention.” An initiative is begun to make this happen. Although the stated purpose is to improve nutrition or to increase staff retention, the LTCOP knows that accomplishing the stated objective will also address broader staffing issues while improving conditions for residents.

This is not to suggest that you would not be involved in critical broad-based initiatives, but rather that you would not be assuming full responsibility for leading the initiative.

Questions to consider:

- ◆ How is this issue supported and validated by the LTCOP’s data and experience?
- ◆ Does the impact on residents justify the amount of resources required to pursue this issue?
- ◆ What is the potential for achieving beneficial change for residents?
- ◆ Is this a long term or a short term commitment?
- ◆ If this issue is likely to require years of work, is the impact worth the program’s investment?
- ◆ Will the LTCOP need to take leadership in addressing this issue?
- ◆ Are there other groups or programs who already understand the issue and will be allies?
- ◆ Is a systems approach to change necessary to address the issue?
- ◆ How widespread does the strategy need to be implemented?
 - Can the issue be resolved by changing procedures within one facility?

- Can the issue be resolved by changing procedures within one corporation or a chain of facilities?
 - Can the issue be resolved by changing procedures in one region of the state?
 - Can the issue be resolved by changing procedures at the State level?
 - Can the issue be resolved only by changing procedures within a federal region or on a national basis?
- ◆ Is there likely to be a “down-side” for residents if the LTCOP is not involved in this issue?

Maintaining Focus

It goes without saying that “There are no quick fixes.” This truism is especially relevant to systems advocacy. A hallmark of ombudsman work in resolving problems for individual residents is that ombudsmen stick with a problem until it is fixed. The same type of persistence is usually required to address a systems issue. Ombudsmen have to be like the Energizer Bunny and keep on going and going and going!

Once a LTCOP has made systems advocacy a priority and carefully chosen an issue, success depends upon maintaining a conscious focus on that issue. There are always multiple issues that need to be addressed as well as numerous opportunities for ombudsmen to be involved in working with others on issues they have identified. It may be difficult to keep focusing on one primary issue. New issues may offer an unexpected opportunity for positive change or for the resident perspective to be heard. Sometimes an emerging “hot” issue may provide an opening to advance the primary issue. Being alert to possibilities and being creative in linking the primary issue to an emerging issue might lead to a real breakthrough.

While LTCOPs may pick up additional issues to address, if the primary issue is abandoned as a “hotter” issue erupts, ombudsmen will never achieve a lasting benefit for residents. There are also credibility and resource issues when a program puts energy and public activity into an issue, then drops it because the outcome seems unattainable. Effecting systems change may take years. It may necessitate outlasting the opposition, gathering sufficient political or grass roots support, and/or waiting for the right time. Maintaining focus on the issue and the desired outcome is even more critical to success when resolution is very long term.

Questions to consider:

- ◆ Is the LTCOP maintaining its focus on the systems advocacy issue?
- ◆ Are other issues and *opportunities* draining resources from achieving the systems advocacy goal?
- ◆ Is the program, as a whole, or individual ombudsmen becoming side tracked with other issues; thus diluting their contribution to the systems goal?
- ◆ If the selected issue seems impossible to achieve, consider the following.
 - Is the issue truly grounded in the LTCOP’s data and experience?

- Will renaming or reframing the issue move it along?
- Does the LTCOP's strategy need to change?
- Can other organizations or individuals be brought into this effort?
- What are creative ways to keep the issue visible?
- Is the LTCOP continually focusing on extending the support for change?
- What are concrete ways for local ombudsmen to stay engaged in this issue?
- Is there a more limited success that could be accomplished as a precursor to achieving the ultimate goal?
- Are there ways to advance the issue by linking it with other issues or new developments?

Coordinating Local Ombudsman Activities with those of the State Ombudsman Office

Ombudsman Programs that are successful in attaining systems goals beyond one area of the state are those in which local and state ombudsmen work together toward a common outcome. Just as local ombudsmen need to be involved in selecting statewide systems advocacy goals, their active participation in working for change is also important. Whether the program selects an issue, is asked to participate in a work group, or sees an opportunity to move an advocacy agenda forward, communication between state and local ombudsmen strengthens the outcome. In the *Real World Examples: State Level* section of this paper, specific examples of the strength in collective action are given. It is clearly a case of maximizing the investment and chance of success when the statewide program is unified in its focus. Some states have developed policies and procedures delineating these roles and coordination responsibilities. Appendix A contains one example from Illinois.

Questions to Consider:

- ◆ Has the SLTCO provided clear information to local ombudsmen about emerging issues or opportunities for systems advocacy? Has there been an explanation about the potential benefit to residents if the LTCOP becomes involved?
- ◆ Is the action agenda for achieving systems change jointly developed by state and local ombudsmen?
 - Are strategies for achieving change thoughtfully considered, discussed, and selected?
 - Are the ramifications of selected strategies considered—positive, negative, and potential unintended consequences?
 - Are the potential consequences for the LTCOP and for residents considered?
 - Are the short term and long term consequences discussed?
 - Are ombudsmen prepared with knowledge, skills, and opportunity to implement the strategies?

- Will the SLTCO provide information, training, guidance, and support to local ombudsmen to assist with their implementation of the action agenda?
- ◆ Is the communication between local ombudsmen and the SLTCO timely in exchanging information pertinent to the systems issue?
- ◆ Are there specific responsibilities for local ombudsmen in contributing to the statewide agenda?
- ◆ Has the statewide LTCOP discussed how to focus on the systems change while continuing to respond to the concerns of individual residents?
- ◆ How does the SLTCO provide leadership and support for local ombudsmen in achieving systems change?

Barriers

Acknowledging and dealing with barriers to systems advocacy is as important as setting priorities, selecting an issue, maintaining focus, and coordinating ombudsman activities throughout the state. While some barriers are implicit in the preceding lists of *Questions to Consider*, it is also important to identify barriers related to the placement and infrastructure of the LTCOP. Identifying the existence of such barriers will assist in selecting strategies and approaches to move forward on an issue. While the Institute of Medicine report⁵ and a follow-up report by Carroll Estes⁶ discuss barriers that exist related to program placement and infrastructure, each LTCOP needs to assess its own situation.

Questions to Consider:

- ◆ Does the LTCOP, state level *and* local level, have a clear state mandate to pursue systems changes on behalf of residents?
- ◆ Are systems advocacy activities articulated as LTCOP responsibilities in state law, program regulations, and/or policies and procedures?
- ◆ Is there a public expectation that the LTCOP will engage in systems advocacy in a direct way based on the history of the program?
- ◆ Are there citizen advocacy organizations or other organizations expecting leadership or direct participation by the LTCOP in seeking systems changes to benefit residents?
- ◆ Is the LTCOP located in an agency or organization that supports the program's obligation to act on behalf of residents even if the result is a public stance that differs from that of the placement organization or agency?
 - If so, does the LTCOP receive support if its advocacy actions are questioned by an umbrella agency or by the agency responsible for contracting for the statewide program?
 - Is this type of support available at the local level?

⁵ Institute of Medicine, op. cit.

⁶ Estes, C.L., Zulman, D.M., Goldberg, S.C., Ogawa, D.D. *Effectiveness of the State Long Term Care Ombudsman Programs*. A Report for the Henry J. Kaiser Family Foundation. June, 2001.

- ◆ Are individuals in the chain-of-command over the LTCOP being informed of the program's statutory responsibility in the OAA to pursue a variety of remedies on behalf of residents?⁷
 - Is the ombudsman advocating within the agency or organization regarding the need for and the Older Americans Act responsibilities relevant to systems advocacy?
 - Is this done in advance of a need to engage in systems advocacy?
- ◆ If barriers exist, what can the LTCOP do to effectively pursue systems changes on behalf of residents?

IV. REAL WORLD EXAMPLES

LOCAL LEVEL

While there are numerous examples of LTCOP involvement in systems advocacy, a few will be included in this paper to illustrate various strategies implemented to systemically address serious issues affecting residents. Other examples can be found on the National Long Term Care Ombudsman Resource Center's (NORC) web site⁸, in the Best Practices section of the binders from the annual spring training conferences for SLTCO or in the folders from multi-state regional ombudsman training conferences, and by contacting the clearinghouse at the NORC. The annual reports of many SLTCOPs also contain examples of successful systems advocacy by local and state programs.

Changing Practices Within a Facility

- ◆ *Chronic Problems in Personal Care Home:* The following example is excerpted from the Colorado SLTCOP 1999 Annual Report, Region 3-B, page 17.

Throughout the fall of 1999, some family members of one personal care boarding home for persons with memory impairments filed complaints with the local LTCOP and with the State Health Department. Interventions brought some improvements, but many problems persisted and new ones arose. In January, 2000, family members had their first Family Council meeting. A number of major concerns were quickly identified. The Family Council continued to meet monthly to address the concerns. The ombudsman has attended these meetings. Within the first three months of the formation of the Family Council, a number of changes were made in the areas of concern such as: hiring additional staff to do housekeeping and laundry, giving caregivers more time to provide resident care and improving the housekeeping and laundry services; written information was provided to families listing specific staff members to contact about concerns; and

⁷ For a discussion and delineation of OAA requirements regarding the ombudsman role in seeking systems change, see the Department of Health and Human Services Region V General Counsel's February 8, 2002, memorandum to Administration on Aging Bi-Regional Administrator Larry Brewster.

⁸ www.ltcombudsman.org

additional training was provided for the cook and new menu cycles were developed. Although there are still concerns, families are directly involved in working to resolve the problems. The Family Council President and other members have been involved in interviewing and selecting new staff. The President works closely with the administrator to address family concerns. Although the ombudsman continues to attend Council meetings and provides advice and support as needed, direct complaints to the LTCOP have significantly decreased.

Update as of April 2002 submitted by the local ombudsman, Lynn Osterkamp: “This facility has continued to have ups and downs during the remainder of 2000, throughout 2001 and into 2002. Staff has changed frequently, including top management level staff as well as caregivers, activity directors, nurses and cooks. The Family Council, however, has remained a strong and consistent voice for quality care. The Council has continued to meet monthly and has supported good practice as well as working to change areas of concern. Members of the Council donated money to provide bonuses to employees who completed a year of service at the facility. They also provided holiday gifts and parties for employees. At the same time, when family members noticed gaps in care, the Council continued to work for the quality services they were promised for residents. Their work on concerns such as declines in activities on weekends, inadequate cleaning and maintenance, insufficient checks on residents at night, poor hydration of residents, and medication mismanagement has resulted in improvements. The Family Council has taken on a proactive role of informing new top level management employees at the facility about past and ongoing issues and concerns. They have also communicated directly to the top levels of the corporation about major concerns and have stood together as a group rejecting rate increases until they got improvements in services. Currently the facility is for sale and the Family Council has taken the initiative to discuss areas of concern with a potential buyer, hoping to avoid repeating problems from the past. This Family Council has shown themselves to be both assertive and fair, which gives them significant power and credibility. The ombudsman has continued to work closely with the Council and attends all monthly meetings.”

Contact: Lynn Osterkamp, Ombudsman, or Frank Alexander, Lead Ombudsman, Boulder County Aging Services Division; Phone: 303-441-3986; Fax: 303-441-4550; Email: LynnOst@aol.com; flaag@co.boulder.co.us

Changing Practice on a Regional Basis

- ◆ *Abuse, Neglect, and Exploitation, a Team Approach:* In 1997, a police officer from Gwinnett County, Georgia, attended a national TRIAD training and became concerned about elder abuse. The officer returned and invited everyone in the county who had responsibility for serving senior adults to a meeting to discuss this issue. The initial meeting evolved into monthly breakfast meetings focused on exchanging information and learning about resources. These meetings are known as *SALT*, Seniors and Lawmen Together; anyone who is interested may attend. The meetings are regularly attended by: chiefs of police, sheriffs, district attorney, county prosecutors, probate court judge, LTCO, adult protective services, senior services personnel, senior citizens, and employees of assisted living facilities and nursing homes. The county medical examiner has begun attending these meetings. Following

a presentation in January 2002 by the LTCO, a group of bankers committed to joining the SALT meetings; thus, adding a financial dimension to the network. The bankers became very concerned about financial exploitation based upon the LTCO's discussion of issues in their county. Meetings are rotated monthly between senior centers and police departments. It took a couple of years for these meetings to really "take off" and gather a lot of momentum but the group continued meeting until this occurred.

The benefits to senior citizens from these meetings continue to accrue. In addition to forging new partnerships, the SALT group has sponsored activities such as: the File of Life, Safe Return, and Donate a Phone where donated cell phones are reprogrammed and given to seniors so they can call 911. The Gwinnett County Chief of Police decided there was a problem in senior abuse and had all seven police officers who were trained in child abuse cross-trained in elder abuse. The LTCOP and adult protective services provided this training. These officers are better equipped to respond to elder abuse in the community as well as in nursing homes. Prior to these meetings, many police officers had not heard of the elder abuse statute. Now cases are going forward under this law; prosecutors and solicitors are making these statutes available for people working on these cases. Sometimes police officers ride with LTCO, observing and learning how to talk to residents, how to see what ombudsmen see. The entire human services field, law enforcement, and the judicial system are more knowledgeable about elder abuse, neglect, and exploitation, and how to use the available legal tools. The SALT group has also engaged in issues advocacy with legislators which resulted in passing higher penalties for certain crimes and turning other acts into criminal penalties.

A primary example of effective coalition building was the spin-off from the SALT group. The LTCO identified a need for a smaller group to call with case referrals when an immediate response was necessary. This group is known as the *Human Services Team*. Its members are representatives of: the LTCOP, adult protective services, Gwinnett County's assistant solicitor, investigator, forensic nurse, and the director of the TRIAD. This team has found that when one person cannot act, someone else can. There is immediate reaction to referrals with no time delay. Team members have shared home phone numbers and beeper numbers; consequently they are more accessible to each other. They keep each other informed when something is going on. The result is better response to the client because the people who can act, do: looking at bruises, gathering and preserving evidence, assisting senior citizens in the community and in facilities. There is also more timely and efficient use of the various agencies and services.

This group has a training program including a PowerPoint presentation about this coalition and its results. They are going lots of places sharing information to try to inspire others to begin similar efforts. They have received lots of media coverage. The team wants to develop a written protocol for referrals to capture the process they have fine tuned. They are also trying to find a way of centralizing statistics across counties. They firmly believe there needs to be a *human services team* on the state level in every state.

Contact: Jennie Deese, Staff Ombudsman, Decatur, GA; Phone: 404-371-3800; Fax: 404-371-3811; Email: jddeese@yahoo.com

- ◆ *Dental Services for Residents:* In response to numerous complaints from administrators and directors of nursing about difficulties in finding dental services for residents, regional

ombudsmen, Tom Bell and Nicole Rieger, in North Carolina decided to look at the issue from a systems perspective. More information was needed to verify the complaints, to determine the nature of the issue(s), and to determine the extent of the situation. The LTCO developed an assessment instrument which regional ombudsmen sent to every nursing home and adult care home in the state in 1999. Based on a 41% return rate, the data analysis yielded four conclusions. (1) There is a lack of resources throughout North Carolina to take care of the dental needs of long term care residents. (2) The shortage of dental care is particularly acute for residents relying on governmental assistance. (3) Residents with special needs also have an especially difficult time accessing dental care. (4) Transportation to dental care offices is an obstacle for many residents, and impedes (if not prevents) their care. Because of the study, the LTCOP had sufficient information to guide it in determining the cause(s) of the shortages in dental care; then in advocating for solutions. By working together in identifying a common problem and gathering consistent information, the regional ombudsmen are in a stronger position to identify and seek changes to benefit residents.

The LTCOP reached out to others to address this issue. In 2001 a bill was introduced to increase the percentage of actual costs for dental services that is covered by Medicaid. The bill was not passed. In March 2002, the regional LTCO, a staff member of the Association for Retarded Citizens, and a board member of the North Carolina Friends of Residents in Long Term Care made a PowerPoint presentation to the legislative study commission on the need for dental services: routine and emergency. The goal is to increase the Medicaid rate for dental services from 50% to 85%. There is a legislative session in May which could act on this proposal. The advocates ended by asking each legislator to go home, phone a dentist and say, *“My mother has Alzheimer’s, is on Medicaid, and needs a dental exam. Will you see her?”*

Contact: Tom Bell, Regional Ombudsman, Western Piedmont Area Agency on Aging, Hickory, NC; Phone: 828-485-4214; Fax: 828-322-5991; tbell@wpcog.dst.nc.us. The reports from these surveys are on the NORC web site: www.ltcombudsman.org.

- ◆ *Theft and Loss:* In response to a recurring problem of theft and loss, 95 reports in three years, the Santa Barbara, California, LTCOP began a systems approach to address the issue. Toward the latter part of 2001, Kathy Badrak, Regional Ombudsman, and Westmont College intern Catherine Barba began gathering information on nursing home thefts, reviewing facility theft policies and developing prevention tips for families. Confronting this issue has been almost a year long process of investigation, gathering information, analysis, research, and brainstorming. The program began by asking every skilled nursing facility to fax to the ombudsman a copy of their policies on theft and loss. These policies were compared to the requirements in state law using a checklist developed by the LTCOP. A list was then compiled indicating how many requirements each facility’s policies met.

The LTCOP examined its complaint data on theft and loss cases during the past five years to determine what types of items were missing, for example seven out of sixteen thefts were jewelry. This led to identifying the number of cases by facility. The program decided to focus on a facility with numerous cases of jewelry theft. The ombudsmen interviewed the administrator and learned that he was willing to have the LTCOP help him find a “best practice” to address this issue in his facility. A “Tea Party” resulted coupled with a Theft and Loss Tip Sheet for residents and families. See Appendix A for a description of the “Tea Party” and the tip sheet. It is too soon to determine the impact of this activity.

Contact: Kathy Badrak, LTCOP of Santa Barbara County, California; Phone: 805-563-6025; Fax: 805-563-2849; Email: kbadrak@aol.com

- ◆ *Training for Providers in Small Assisted Living Facilities:* Seeing an unmet need for training for providers of small assisted living facilities, the Tarrant County Ombudsman Program in Texas began a three month demonstration project which has continued! The objective was to improve the quality of care and services for residents by training home operators. The training was targeted toward staff in unregulated homes (1-3 beds) where no training or skills are required of caregivers and in other small (4-6 beds) certified facilities or licensed assisted living facilities with minimum training requirements and limited access to training resources. The Ombudsman met with groups of providers and professionals to develop the logistics, select topics and identify training resources such as the Red Cross. After experimenting with various formats, the training is conducted in a one-day, quarterly sessions jointly sponsored by the Texas Department of Human Services Adult Foster Care.

Through their participation and networking, providers have become more knowledgeable of care practices, the quality of care given to residents has improved, and provider and resident access to resources has increased. This activity has given the LTCOP access and legitimacy to these providers. In addition to the formal training classes, these providers now call the LTCOP for information and assistance.

Contact: Gayle Welch, Tarrant County Ombudsman Program, Texas; Phone: 817-335-5405; Fax: 817-334-0025; E-mail: welchg@mhatc.org

STATE LEVEL

Changing Regulations and Laws

- ◆ *Increasing the Personal Care Needs Allowance:* The Indiana LTCOP has advocated for an increase in the personal care needs allowance (PNA) since 1996. An early attempt involved a resident forum with state legislators invited to attend. United Senior Action (USA), a citizen advocacy group, took the lead in inviting legislators while the LTCO worked to ensure that residents were able to attend. Media were contacted. In addition to testimony by residents, ombudsmen and other advocates, many common items for daily use were displayed with the current price beside each item such as: various articles of clothing, hair brush, and body lotion. Following the forum, petitions were circulated to resident councils throughout the state. The PNA was increased for Medicaid recipients from \$30 - \$50. Unfortunately, the PNA for residents receiving SSI-SSD remained at \$30.

In 2000 - 2001, the LTCOP worked with other advocates seeking to: increase the PNA to \$60 for all residents and to include an cost of living of living adjustment for the PNA amount. Among the numerous activities supporting this statewide advocacy are three major ones. (1) Local ombudsmen promoted having facilities invite legislators to the homes where residents had advocated for an increase. (2) In homes that did not host meetings, ombudsmen assisted with phone and letter writing campaigns and the circulation of petitions. (3) The LTCOP and USA sponsored a "PNA Rally Day" at the Statehouse to promote this legislation. More than sixty residents attended.

This bill, with some amendments, passed the Legislature only to be vetoed by the Governor. Nevertheless, legislators are much more aware of the issue of the PNA amount and of residents' perspective. Residents were empowered. They spoke in front of groups and directly to their legislators. They learned how to reach their legislators even when the Legislature is in session. Residents also learned that they have a voice, that what they have to say is important, and how to make their voices heard. In the 2002 Legislative session the Legislature voted to override the Governor's veto of the bill that was passed in 2001. The PNA is increased to \$52 and this increase now applies to all SSI recipients as well.

Contact: Arlene Franklin, Indiana SLTCO; Phone: 800-545-7763; Fax: 317-232-7867; Email: afranklin@fssa.state.in.us

- ◆ *Legislative Visits:* The Minnesota LTCOP asked the LTCO in the field to visit their legislators during the summer *before* the legislative session began. The ombudsmen took packets of information about facilities in their area and talked with the legislators about the meaning of the information on the survey reports. The objective was to help legislators be better informed about quality of care and quality of life issues as well as to have more specific knowledge about facilities in their district.

The visits did not go quite as well as the LTCOP hoped for two reasons. (1) The ombudsmen were not able to complete as many visits as they anticipated. (2) Legislators did not want to discuss nursing home problems. However, they were interested in hearing ombudsman recommendations about regulatory reform. Staffing concerns were dismissed as impossible to fix due to workforce shortage. Ultimately, these visits did result in giving some legislators a better understanding of the role of the ombudsman.

Contact: Sharon Zoesch, Minnesota SLTCO; Phone: (800)657-3591; Fax: (651)297-5654; Email: Sharon.Zoesch@state.mn.us

- ◆ *Veterans Pension Benefits:* A local LTCOP in New York state discovered that many veterans and service-related individuals and eligible surviving spouses were not receiving their Veterans Administration (VA) Reduced Pension. This benefit is for their personal spending and is not to go to the nursing home. The LTCOP checked with a number of facilities and learned that some of them had never heard of this benefit although a state law required facilities to advise eligible individuals about this entitlement. The LTCOP took this issue to the County Executive who signed an order that nursing homes must apply for veterans benefits for all eligible residents. This meant a \$90 allowance in addition to their personal needs allowance. The LTCOP developed a form to gather pertinent information. Then ombudsmen and the nursing home social workers went to residents, identified those who were eligible, and helped them apply for this benefit.

The local LTCOP took this information to the New York Ombudsman Association which supported statewide advocacy and legislative action on this issue. In 2001 a bill passed requiring all nursing homes to notify all veterans about this allowance and help them apply for it. Another provision in the bill enables the Department of Health to fine facilities up to \$100,000 if they don't follow through in identifying veterans. *(Some revisions will be made based on additional information being submitted by the local ombudsman.)* More information about this benefit as well as the form to collect information is in Appendix A.

Contact: George Pettingill, Suffolk County Ombudsman Program; Phone: (631)427-3700, ext. 273; Fax: (631)427-4282; Faith Fish, New York SLTCO, Phone: (518)474-7329; Fax: (518)474-7761; email: faith.fish@ofa.state.ny.us

Influencing Budgets

- ◆ *Financial Incentive to Improve Care:* In 2001, the Iowa Legislature passed a measure including an “Accountability Measure” in the Medicaid reimbursement rate. A facility will be able to receive an additional amount up to 3% of the Medicaid rate per day per resident, which is projected to be \$3.00, if the facility meets a number of criteria. There are ten criteria relating to staffing such as: a higher retention rate and a lower administrative expense, contracted nurse staffing expense per resident day, ratio of direct care costs to administrative costs, the facility’s willingness to work with the resident advocacy committee (LTCOP) to resolve grievances and to respond to issues about what residents want. It is hoped these accountability measures will provide a financial incentive to facilities to undertake staff retention efforts.

The LTCOP worked at this for over two years. In every informal meeting and discussion with heads of agencies such as Medicaid, Licensing and Certification, and Public Health, the State LTCO inserted her idea about performance measures. The LTCOP also laid this out in a budget meeting with all of these agencies, and the department heads indicated that they supported the idea. Then when budget changes were being made in Medicaid, the LTCOP worked with these agencies developing the accountability plan. The policies for implementation were drafted and the program is expected to begin in July 2001 - 2002. Facilities could actually receive the additional funding next year after they have developed their data measurement tools and collected information over the year.

Contact: Debi Meyers, Iowa SLTCO; Phone: (515)242-3327; Fax: (515)242-3300; Email: debi.meyers@dea.state.ia.us

Developing New Approaches to Long-Term Care Services

- ◆ *Broad Based Coalition Addressing Multiple Issues:* In Washington State in 1987, providers, consumers, and advocates came together to pass and fund a minimum wage for nursing home employees. This common advocacy effort formed a base of mutual respect. Building on this success, the Washington Association of Housing and Services for the Aging convened a meeting of this very diverse group in 1988 that continues to function today. The Alliance began with a focus on *shared values* and an agreement to say what each can do to address an issue or to move it forward. This group is known as The Long Term Care Alliance, an affiliation of organizations focusing on issues and common goals related to the quality of care and quality of life of elder citizens.

Historically, several of the organizational members of the Alliance were talking with each other on a one-on-one basis and participating in meetings which helped build understanding and appreciation of each other’s roles. The LTCOP has been one of the leaders in this coalition. The Alliance built upon those relationships and now encompasses many more organizations. Its membership includes the aging network, the provider organizations, the LTCOP, citizen and resident advocacy organizations, and other stakeholders in long-term care.

Alliance members agree to collaborate to benefit the state's elders and to focus on areas of consensus, building on each other's strengths. They also agree to keep other members informed about positions or agendas that a member organization is taking, e.g. "*We're going to issue a press release stating...*" They do this even if they know others will not agree with their position or if the position is critical of another member. The purpose of the Alliance is to work together when possible while acknowledging that members will not always support each other on every issue.

The state survey agency holds quarterly forums on emerging long term care issues. The purpose of these forums is to learn from each other and gain a better understanding of differences in perspective. The ground rules include being respectful in words and behavior.

In early 2001, the Alliance supported a legislative agenda seeking: a substantial wage enhancement for residential caregivers; maintaining funding for home, community, or residential long-term care services; a reasonable increase in provider rates, and continuing provision of a wide range of support for families to provider long-term care services to their loved ones. In the spring of 2002, some of the Alliance members have not adhered to the agreements among members; thus violating the trust that holds the group together. It is uncertain if the Alliance will continue to be the strong voice it has been. This development underscores the difficulty of holding a very diverse coalition together over a period of years as changes in leadership occur and other issues arise.

Contact: Kary Hyre, Washington, SLTCO or Louise Ryan, Assistant SLTCO; Phone: (253)838-6810; Fax: (253)815-8173; Email: Hyre: karyh@skcmssc.com; Ryan: louiser@skcmssc.com

Improving Care

- ◆ *Resident Directed Quality of Life Initiatives:* In 1998 the Massachusetts LTCOP and the Department of Public Health began exploring ways that the monies collected through Civil Monetary Penalties (CMP) could be used to the benefit of residents of nursing and rest homes (board and care). A committee was formed with representatives of state agencies, the LTCOP, community advocacy groups, legal services, the Alzheimer's Association and the nursing home industry. The LTCOP and surveyors used a questionnaire with nearly 1,000 residents to obtain their opinions on how they would like the CMP money spent. The effort documented the ideas, wishes, needs, and recommendations of the residents/family members who were interviewed. The committee agreed on how the money was to be used. This process was stalled until a mechanism was created to allow for the transfer of funds. Language was included in the state budget that allowed the Department of Public Health to transfer funds from its dedicated account for use in funding quality of life initiatives.

In the first year, the committee released a Request for Proposals (RFP) and funded three facilities. Two key requirements in the RFP are that the resident and family councils be involved and that there is an attempt to involve the community in the initiative. The initiatives in the first year included the following. (1) A facility with a high mental health/mental retardation population is joining forces with the local Boys and Girls Club for a variety of community activities. (2) A multilevel facility has purchased computers for the resident's use and has enlisted the help of local high school students to teach residents how to use the computers and the Internet. (3) Another facility has developed a multi-tier gardening

project with activities for all cognitive and functional levels with activities throughout the year. Students from the local agricultural high school will be providing assistance.

As of April 2002, a second round of Resident Empowerment funding has been completed with five more projects beginning. The current initiatives are: (1) introduction of the Eden Alternative; (2) computer program with an intergenerational component; (3) creation of a hand chime choir and a musical exchange program with junior high students; (4) intergenerational craft projects with children from a Salvation Army after school program; (5) massage therapy and outreach and education to families and other visitors on the benefits of touch.

The expected impact is an ongoing funding mechanism for quality of life initiatives in long term care facilities. Resident and family input is a key component to the grants and helps to ensure that any program funded meets the unique needs of the residents of that facility.

Contact: Mary McKenna, Massachusetts State LTCO; Phone: 617-222-7457; Fax: 617-727-9368; Email: Mary.E.McKenna@state.ma.us

- ◆ *Quality Initiative—Best Practices*: The Texas LTCOP began a handout, *Texas Nursing Home Quality Initiative*, for the purpose of demonstrating how care can be improved, resident satisfaction levels increased, and how direct care staff will be more satisfied with their jobs reducing the staff turnover rate. The newsletter shares succinct, cost-effective resident-centered practices in a number of topic areas. Each practice discusses the: background, application, quality initiative—best practice, implications, funding, person to contact for more information. Practices shared come from Texas facilities as well as facilities in other states.

Contact: John Willis, Texas SLTCO; Phone: (512)424-6875; Fax: (512-424-6890; Email: john.willis@tdoa.state.tx.us

- ◆ *Elderly Abuse and Neglect Hotline Evaluation*: This is a cooperative effort between the LTCOP and the Missouri Division of Aging's Institutional Services (licensing and certification), to determine the public's satisfaction with the handling of complaints called into the 24-hour, toll-free Elder Abuse and Neglect Hotline. Each month, an evaluation form is mailed to randomly selected family or friends of residents who have reported complaints. The completed forms are returned to the State LTCOP which then gives them to Institutional Services for evaluation and any necessary follow-up. This project has resulted in changes in the complaint handling process by Institutional Services.

Contact: Carol Scott, Missouri SLTCO, Phone: 800-309-3282; Fax: 573-751-8687;

Email: scotmwo@dssda.state.mo.us

- ◆ *Improving Nursing Home Complaint Handling by the Licensing and Certification Agency*: In the fall of 2000, the Atlanta LTCOP finalized its research on abuse in nursing homes, funded by a grant from the Ombudsman Resource Center. The report showed resident perspectives on abuse and was very critical of the complaint response of the Office of Regulatory Services, the licensing and certification agency. Media attention to the report added visibility to the problems in the complaint system and to the work of the LTCOP. A Cox Publications reporter provided in-depth coverage of Karen Boyles' presentation of the study at the 2000 NCCNHR Annual Meeting, came to Atlanta for follow-up interviews, and

attended the statewide LTCO training where Karen presented the study. There were several articles about the study in the Atlanta newspapers. The public response to the media coverage generated a number of calls to local and state LTCOPs, requests for presentations, and requests for copies of the study by other organizations.

As a result of the publicity, the Commissioner of Human Resources, the Office of Regulatory Services (ORS), and the Region IV Office of the Health Care Financing Administration (now Centers for Medicare and Medicaid Services) requested ombudsman recommendations to improve the nursing home complaint response. This was the first time this Commissioner had ever met with the LTCOP. The Director of the Long-Term Care Section requested a meeting with the State LTCO and Karen to discuss the study and ways to improve communication between LTCOP and ORS surveyors. Ombudsman recommendations to improve the complaint handling response were developed at the December 2000 statewide conference and were shared with each of these entities.

The outcomes of this systems advocacy are notable. The ORS complaint intake protocols have been revised, including creation of a new complaint unit and a requirement that surveyors contact the LTCOP during most complaint investigations. A joint training was held in May, 2001, for ORS surveyors and LTCO to enhance communication and develop better understanding of each other's roles. Individual ombudsmen and surveyors were surveyed for their recommendations. The STLCO and the director of ORS, Long Term Care Section, have reviewed these recommendations and are currently focusing on implementation of one recommendation prioritized by both ombudsmen and surveyors: more staff ombudsman observation of the survey process. (In Georgia, staff ombudsmen accompany a survey team and observe the survey process during certification training, but not after the initial certification.) Ombudsmen are continuing to advocate for a complaint review process available to complainants. The statewide LTCOP became involved in this issue and its ensuing publicity; relationships with the regulatory systems were changed in positive ways. Complainants are receiving better responsiveness from ORS to their complaints in nursing homes.

Contact: Becky Kurtz, Georgia SLTCO; Phone: (888)454-5826; Fax: (404)463-8384; Email: bakurtz@dhr.state.ga.us; Karen Boyles, Atlanta LTCOP; Phone: (404)371-3800; Fax: (404)371-3811; Email: kjboyles_alas@yahoo.com

Empowerment

- ◆ *Empowering Residents and Families in Facilities Facing Enforcement Action:* The Wisconsin LTCOP developed a protocol to head off public criticism of the licensure and certification agency when it takes action against a nursing facility providing substandard quality of care. Typically, families blame the licensing agency for threatening the future of the facility when new admissions are denied or Medicaid funds are to be cut off. Facility management will effectively convince family members and residents that the survey agency is placing onerous requirements upon them; that the state is being unreasonable.

The LTCOP has an agreement with the survey agency that in effect alerts the LTCOP to the pending issuance of substandard Statement of Deficiencies (SOD). As soon as the SODs are issued, the regional ombudsman calls for a "town meeting" of the residents, their family

members, and concerned citizens. The ombudsman describes the seriousness of the citations and the consequences. A representative of the licensing agency attends to answer technical questions related to the findings. The social service staff of the facility are asked to attend but not speak. The facility management are specifically discouraged from attending.

The LTCO leads the audience in discussing their role in achieving compliance and their future expectations of the facility. Following this meeting, if there is a family council, this group asks for a meeting with management to discuss the expectations that were identified. If there is no family council, the LTCO uses the initial meeting to generate interest in developing one.

This process has successfully given residents and families the information they need to be their own advocates. It has diminished the influence of suspect operators. And it places responsibility for poor care where it belongs, at the doorway to the administrator's office. Press coverage is more directed at solutions instead of focusing on "how could the state allow this to develop." Out of fourteen meetings held, eleven have been very positive and resulting in the formation of eight new family councils.

Contact: Claudia Stine, Director of LTCO Services for the Wisconsin Board on Aging and Long Term Care; Phone: 608-264-9760; Fax: 608-261-6570; Email: claudia.stine@ltc.state.wi.us

V. ESSENTIAL ELEMENTS

For LTCOPs to engage in systems advocacy, there are some essential elements that need to be included in the effort. These elements have been demonstrated by or are implicit in, the examples in the preceding section, *Real World Examples*. Several of these were discussed in Section III, *Tips for Sanity and Success*; therefore, a recap of the key aspects of systems advocacy follows.

- ◆ The LTCOP's responsibility to engage in systems advocacy is accepted, expected, and clear. LTCOP regulations, or standards, policies, procedures should clearly support the program's ability and responsibility to directly engage in systems advocacy. This includes pursuing a range of actions by the statewide program, the SLTCO, and individual ombudsmen. Several states have policies that are very similar to those promulgated by the Georgia LTCOP. Appendix B contains the proposed revisions to the Illinois *LTCOP Standards, Procedures and Practice Manual* section on issues [systems] advocacy. These build on those from Georgia which have proven effective.
- ◆ Choose wisely: the issue, the timing, the strategy, and others who need to be involved in the effort. Appendix A contains a *Checklist for Choosing an Issue*.
- ◆ Build a credible case to support systems change that is grounded in residents' needs.
- ◆ Bring others along with you.⁹
 - Provide leadership in developing and maintaining a coalition to address an issue.

⁹ Adapted from Catherine Hawes's presentation notes, SLTCO Spring Training Conference, April 21 – 24, 2001.

- Recognize that this type of coalition is inherently “unstable” and find ways to make them more stable.
- Be willing to listen to the perspectives and concerns of others, even those with whom there are frequent differences.
- Understand the needs, interests, and values, of others regarding the specific issue.
- Find common ground and act together.
- Put aside traditional enmities to join forces.
- Maintain communication and guidance as needed to keep everyone involved.
- ◆ Seize opportunities to advance an issue.
 - Be alert to unanticipated developments which provide potential linkages for achieving change.
 - Go along with others—if other groups are taking the lead on an issue that helps residents, ask if the LTCOP can support the effort. The LTCOP does not always need to take the lead.
- ◆ Remember that it does not matter who gets credit for the successes as long as the success benefits residents.
- ◆ Avoid turf battles. They destroy relationships and endanger the chance of succeeding.
- ◆ Be persistent. Sometimes achieving change takes years.
- ◆ Remember that individual residents need advocacy even when the LTCOP is focusing on systems change.

One seminal example of systems advocacy resulted in the enactment of the Nursing Home Reform Law in 1987. The National Citizens’ Coalition for Nursing Home Reform (NCCNHR) took the leadership in developing and holding together a coalition of disparate agencies and organizations under the name, Campaign for Quality Care. The consensus building work of this group formed the skeleton of the Reform Law. Through this process, these organizations learned the value of ongoing dialogue and education on common issues. The Campaign continues meeting on a regular basis. Key aspects of engaging in this type of systems advocacy are illustrated by a series of visuals in Appendix B, *Excerpts from a Presentation by Barbara Frank*.

VI. RESOURCES

The National Long Term Care Ombudsman Resource Center has numerous resources on systems advocacy: examples from state and local LTCOPs, NCCNHR’s experience, printed resources on various aspects of systems advocacy, and staff expertise. Other resources include skills building sessions and examples included in the *NORC Gazette*, the *Quality Care Advocate*, and in the resource manuals from the annual SLTCO spring training conferences, especially in the “Success in LTCOP’s” sections, and from the annual meetings of NCCNHR. Remember that

many resources are available via the Center's web site: www.ltcombudsman.org (look under Center Support – Systems Advocacy) and NCCNHR's site: www.nursinghomeaction.org.

VII. SUMMARY

While systems advocacy efforts can be challenging and may be difficult to sustain over a long period of time, the benefit to the LTCOP and to the residents themselves is substantial. The results of systems advocacy—whether it be improved dental care, an adequate amount of money to spend on personal items or better trained staff—produce daily rewards for all residents. Ombudsmen who have undertaken systems advocacy efforts report increased leadership capacity, improved morale and personal satisfaction, and sometimes better working relationships with other agencies. The Ombudsman Resource Center hopes that this paper encourages and supports state and local ombudsmen in their work to address resident concerns.

APPENDIX A

Illinois Draft Standards for Issue Advocacy

Illinois LTCOP
Standards Workgroup
Final Draft

Currently moving through the approval process March, 2002

CHAPTER 400: LONG TERM CARE OMBUDSMAN PROGRAM SERVICE DELIVERY STANDARDS

405: Issue Advocacy

- A. The Long Term Care Ombudsman Program shall assure that the interests of residents are represented to governmental agencies and policy-makers. (OAA sections 712(a)(5)(B)(iv),(v), and 712(h)(2),(3), 89 IL Admin. Code 270.110(j), (k), (l), (m)).

- B. Issues advocacy activities that the LTCOP and the SLTCO may undertake include, but are not limited to:
 - 1. Educating advocacy groups, governmental agencies, and policy-makers regarding the impact of laws, policies, or practices on long term care facility residents;
 - 2. Seeking modification of laws, regulations, and other governmental policies and actions, pertaining to the rights and well-being of residents;
 - 3. Facilitating the ability of the residents, resident and family councils, and the public to comment on such laws, regulations, policies, and actions;
 - 4. Developing or participating in a task force to study a long term care issue;
 - 5. Participating in a public hearing related to a long term care issue;
 - 6. Providing community education or information on a long term care issue; and
 - 7. Educating other aging services providers, advocacy groups, and the public on a long term care issue.

- C. The LTCOP and the SLTCO may seek to resolve resident complaints through issue advocacy where
 - 1. A complaint cannot be resolved due to a current law, policy, or practice;
 - 2. Many residents share a similar complaint or are affected by a policy or practice; or
 - 3. Other strategies to reach resolution with particular facilities or agencies have been unsuccessful.

- D. Regional LTCOPs shall:
 - 1. Determine which issue advocacy activity to use by considering:
 - a.) The potential impact of the activity on residents;

- b.) The most appropriate and effective method of addressing the issue;
 - c.) The potential impact of the activity on the LTCOP; and
 - d.) The possibility of joint efforts by the AAA, the provider agency, a relevant advisory council, resident councils, family councils, other advocacy organizations and/or residents and immediate family in the activity.
2. Inform the AAA, provider agency, and the SLTCO of plans to engage in the issues advocacy activity; and
 3. Attempt to involve residents and families in the issue advocacy activity whenever possible.

E. The SLTCO shall:

1. Link regional Ombudsmen and area or advocacy groups with mutual concerns or issues;
2. Coordinate issues advocacy activities within the LTCOP;
3. Develop and implement advocacy priorities and strategies;
4. Provide a clearinghouse on state and national long term care issues;
5. Identify and meet, to the extent possible, resources and training needs of LTCOs and others related to issues advocacy; and
6. Provide training and technical assistance to AAAs, provider agencies and others in the aging network regarding the Office's role in issues advocacy and the issue advocacy priorities as determined by the Office and regional LTCOPs.

Appendix B

Checklist for Choosing an Issue

Checklist for Choosing an Issue *Unknown Source*

This checklist was shared with ombudsmen at a national training conference and can be used as another framework for identifying an issue to address. It includes a wide variety of considerations that will be helpful to ombudsmen as they make strategic decisions about systems advocacy.

The issue:

- Has a clear target.
- Is non-divisive issue for the people you are trying to involve or organize.
- Has the capacity to build leadership.
- Has a “pocketbook” angle—will affect costs that decision-makers and consumers will care about.
- Can be used to raise money, if necessary.
- Will result in real improvements for residents if achieved.
- Will enable people to feel their own power.
- Appeals to a lot of people, has a wide appeal.
- People feel deeply or passionately about the issue.
- Is “winnable.”
- Is consistent with the values of the LTCOP.
- Can be explained to anyone in less than one minute.

Be really careful about what you [the LTCOP or residents] cannot shape but the issue or process can be used to shape you [the program or residents].

Appendix C

“Tea Party” Help Sheet

“TEA PARTY”

Developed and Shared by the Long Term Care Ombudsman Services
of Santa Barbara County, California
April 2002

Purpose: to get a picture of jewelry for description purposes, to inventory all jewelry, to get a list of those who own jewelry in order to send a theft and loss “tip sheet” to their families, while having fun with the residents, making them the center of attention as they share their jewelry.

Materials needed: a large assembly room, tables and chairs, table cloths, tea pots and dishes, and Polaroid camera.

Food: cookies, finger sandwiches, regular and/or flavored tea, sugar

You can have as much fun with this as you want, dress it up or down, the purpose is still the same: to get the residents to share about themselves and their precious momentos, to get the jewelry on the inventory list, and to get a picture description of the jewelry.

An option for those residents who do not attend the party or can not attend the party is to go visit them in their rooms and in a sense bring the party to them. Bring a tray of cookies and a cup of tea or punch with you, possibly “crown” them with a fun tiara, talk to them about their valuable jewelry and make sure to get it on the inventory list and to get a picture of it with the Polaroid camera.

If a special dinner event is already planned for the facility you can use that event to encourage the residents to wear their jewelry and use the opportunity to inventory it and get a Polaroid picture.

Long Term Care Ombudsman Services

Help Sheet

Safeguarding Your Personal Items in a Nursing Home

You have the right to handle your own financial affairs while you are in a nursing home.

You have the right to:

- * Handle your own bank accounts and money.
- * Have access to your funds on weekdays during business hours.
- * Withdraw as much of your own money as you choose.
- * Spend your money as you choose.
- * Keep your spending habits private-how you spend your money is your own business.
- * Receive an itemized account of your monthly bill.
- * Appoint a person to handle your finances.
- * Know that the information in your medical records is confidential.

If you request in writing that the nursing home handle some or all of your personal funds, you should know that the nursing home cannot refuse to handle your money. Neither can the nursing home force you to have them act as your payee.

If you have deposited your funds with the facility, the facility must:

- * Spend your funds only on you.
- * Have your permission to spend the funds.
- * Protect your funds—keeping them separate from other funds.
- * Let you or your representative know your balance on request.
- * Provide a quarterly statement concerning any money handled by them.

If your source of payment in the nursing home is Medi-Cal reimbursements, and your nursing home handles more than \$50 of your money, it must be placed in an interest bearing account separate from the facility's money. If your source of payment is Medicare, your nursing home must deposit any funds in excess of \$100 into an interest bearing account separate from the facility's money. Any interest earned will be credited to your account. If the nursing home handles less than the amount they are required to deposit for you, the home is not required to, but has the option of placing the money in an interest bearing account. If this is done, any interest earned will be credited to your account.

All of your money and valuables must be surrendered to you with three days of your discharge.

No owner, staff member, or representative of a public agency working in the nursing home, or their immediate family members, may purchase or receive from you any item that is worth more than \$100, unless the transaction is made in the presence of an Ombudsman.

Theft and Loss in Nursing Homes

Despite both California and Federal laws regulating theft and loss in nursing homes, theft and loss continues to be one of the most prevalent (and unreported) problems in nursing homes.

While theft and loss may never be entirely eliminated, it can be reduced by understanding the facility's responsibility and by using the remedies afforded under the law. Facilities that fail to make reasonable efforts to safeguard resident property must reimburse the resident or replace stolen property at its then current value.

Responsibilities of Nursing Homes

- * Establish and post policies regarding theft and investigation procedures.
- * Orient all employees on theft and loss policies with 90 days of initial employment.
- * Document efforts made to control theft and loss at least twice a year.
- * Establish theft and loss record for items worth \$25 or more.
- * Submit written report to police with 36 hours of suspected theft of item worth \$100 or more.
- * Establish and maintain written inventory of residents' property, add to the inventory list upon request, and provide a copy to you or your representative.
- * Mark all residents' property, including engraving of dentures and tagging prosthetic devices.

What You Can Do About Theft and Loss

- * Keep copies of all receipts for any items taken into the facility, if possible
- * Make sure old and new items are recorded in the inventory; keep a copy of the inventory.
- * Report any loss or suspected theft immediately to the administrator, Ombudsman Program and licensing agency.
- * Buy a lock for the resident's drawers—only the resident or resident's representative and the administrator need to have a key.
- * Write a demand letter to the nursing home for replacement or reimbursement (contact your local legal services if necessary).
- * Sue in Small Claims Court for a replacement value of any article up to \$5,000.

For more information, please contact Long Term Care Ombudsman Services,
Santa Barbara (805) 563-6025 or Santa Maria (805) 928-4809
current as of 8/2000

Appendix D

Coalition Building

**Excerpts from a Presentation by Barbara Frank
Used with Permission**

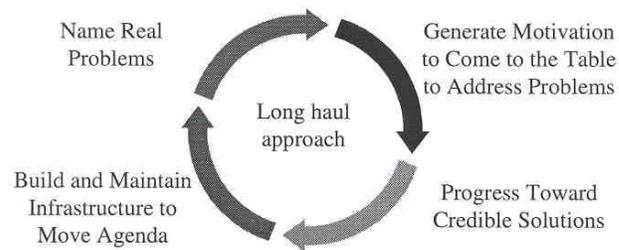
*Coalition Building:
An Advocacy Tool for
Policy Development and Social Change*

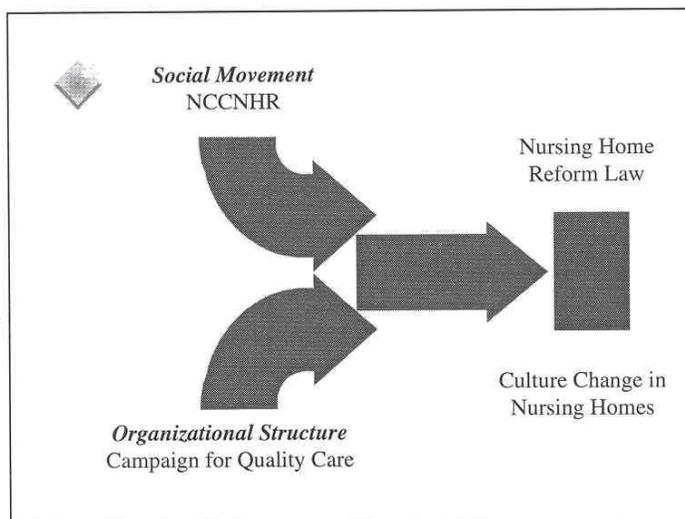
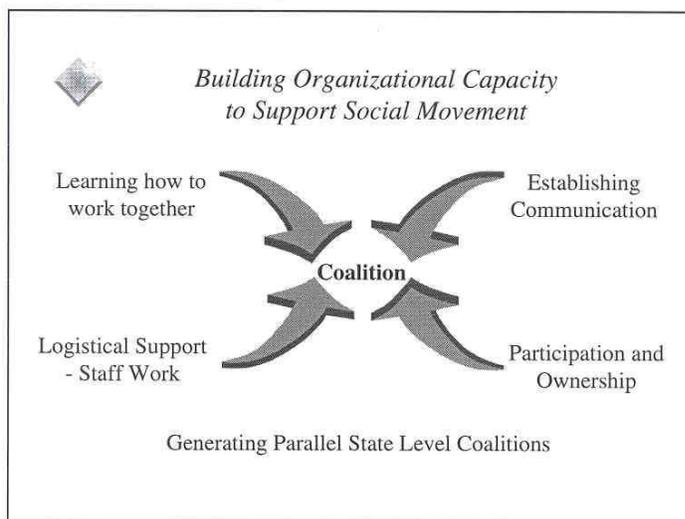


Presentation by Barbara Frank
to the Board of Directors
of the Paraprofessional Healthcare Institute
December 3, 1998
New York City



*Generating Social Movements:
A Dynamic Long-Haul Process*







Lessons Learned from NCCNHR

- ◆ Big Tent - Strong Pillars
- ◆ Strengthen network
- ◆ Be true to message
- ◆ Be the “go-to” place for information
- ◆ Make room for and make the most of allies
- ◆ Always give credit, never need credit
- ◆ Don’t sacrifice message for place at the table
- ◆ Work every angle - holistic, multi-prong approach
- ◆ Do your homework and keep your focus

• Big Tent - Strong Pillars

NCCNHR founded by coalition of grassroots consumer organizations

Bylaws established consumer focus but allowed others to join in

Plight of Nurses Aide - agree on problems, allow different solutions

• Create Informal Authority - strengthen network/true to message

Clearinghouse - to facilitate exchange of expertise among groups

All funding directed at strengthening the network, ex. VISTA

When govt cut off funding, stayed true to message

• Build From Foundation Out

With Reagan cuts, stayed on point - people came to us

We had the information and became the place people came with info (HCFA)

Consumer Statement of Principles - we needed allies; they needed a place to go with their protest and a success story;

Elma always shared the credit and the center stage

• Don’t Sacrifice Message for Place at the Table

Official listeners - no shows; never again

OBRA negotiations with Waxman



Hindsight is 20-20

- ◆ Capacity
 - ◆ Don't put all your eggs in one basket
 - ◆ Need for Board and leadership development
- ◆ Focus/Scope - What you take on
 - ◆ Stay on focus or tunnel vision? Big picture or diffusion? Incremental change or compromise?
- ◆ Working the Process
 - ◆ Irreconcilable differences come back to bite you
 - ◆ Staying "above" politics or getting blindsided?
- ◆ What happens when you lose leverage? or when the disequilibrium gets too big?