JOINING FORCES FOR RESIDENTS

Citizen Advocates and Long Term Care Ombudsmen

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JOINING FORCES FOR RESIDENTS:
Citizen Advocates And Long Term Care Ombudsmen

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Purpose

The purpose of this paper is to assist citizen advocates and long term care ombudsmen in working together on behalf of residents. A session at the 2000 Annual Meeting of the National Citizens' Coalition for Nursing Home Reform focused on ways citizen advocacy groups (CAGs) and Long Term Care Ombudsman Programs (LTCOPs) have worked together to achieve a common goal. Concrete examples of the results of collaboration were given. This paper provides a summary of the session entitled *Joining Forces for Residents: Citizen Advocates and Long Term Care Ombudsmen.*[1]

This paper contains the following sections:

- Background: a brief overview of the goals of and distinctions between CAGs and LTCOPs.
- Highlights: information and examples from the three states regarding: the formation of the CAG, shared accomplishments, and the keys to working together. This section includes the key points made by the presenters during the Annual Meeting seminar.
- Common Themes: consistent threads in all three states regarding collaborations and respecting differences.

Background

Working to achieve quality care for nursing home residents is a long-standing goal of both citizen advocates and the LTCOP. Citizen advocacy groups have been created in many states, typically in response to care issues. The federal Older Americans Act established the LTCOP to resolve complaints and act on behalf of long term care residents. Other responsibilities of the LTCOP include promoting the development of citizen organizations and of resident and family councils to protect the well-being of residents.[2] Improving care for residents is a common goal of CAGs and the LTCOP.

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[1] This session was convened on October 31, 2000, in Washington, DC. Each of the presenters consented to including their information in this summary.

[2] Older Americans Act of 1965 as amended, Public Law 89-73, §712(a)(3)(H)(ii-iii).

While sharing a common goal, CAGs and LTCOPs have several distinctions. A couple of these are pertinent to the focus of this session on joining forces. The parameters for CAGs are set by their by-laws, articles of incorporation, and/or policy or position statements adopted by their membership. The LTCOP has its responsibilities determined by federal and state laws.

The second distinction is one of placement and allegiance. It is obvious that CAGs are independent of government and thus of the regulatory and enforcement system for nursing homes. Their actions are clearly on behalf of residents. The LTCOP is sometimes perceived as being too sympathetic to regulators and to facilities. This perception is influenced by several factors including: the LTCOP is created by federal and states laws; many programs are located within government agencies; LTCOP mandate is to relate to governmental systems yet speak out when these systems need to change. An example is that the LTCOP is mandated to act on behalf of residents and to maintain the confidentiality of residents. When what a resident wants conflicts with the family's wishes or the family is not contacted because the resident has refused permission, the family might be upset with the ombudsman. The ombudsman's perspective and actions are directed by federal law; yet the LTCOP may be perceived as working against families. These two distinctions—the way parameters are established and placement and allegiance—can either be sources of misunderstanding or complementary sources of strength.

Highlights

Although there are numerous examples of successful joint efforts between CAGs and LTCOPs, time constraints limited the panel of presenters to individuals from three states. These states were North Carolina, Indiana, and Oklahoma. A summary of the presentations from each state describes the formation of the CAG, highlights of shared accomplishments, and keys to working together. The LTCOP in each of these states is located in the State Unit on Aging which is a department within a larger state agency.

North Carolina

Presenters: Carol Teal, Executive Director, Friends of Residents in Long Term Care
Wendy Sause, State Long Term Care Ombudsman, North Carolina Division of Aging

- **Formation of the Citizen Advocacy Group**

Friends of Residents in Long Term Care (FOR) was formed fifteen years ago as a result of a LTCOP in the Winston-Salem area. The Ombudsman Program came together with citizen advocates to establish a non-profit organization to do what the LTCOP could not do. The most important thing FOR does is policy and legislative advocacy. Friends of Residents in Long Term Care get their "wisdom" from a group of folks the ombudsmen who are professionally trained. The LTCOP wisdom helps with the details of bills, policies, and regulations. Several years ago,

FOR made a decision to hire a lobbyist to increase their effectiveness in working with the Legislature.

- **Highlights of Shared Accomplishments**

A Long Term Care Conference was jointly sponsored in 1998. Changes in assisted living rules resulted from this statewide advocacy focus on issues. This conference achieved public visibility and created statewide pressure for change. Although both FOR and the LTCOP worked together in developing this conference, FOR took the credit for applying grassroots pressure and visibility to the issues that needed change. The LTCOP's role was supplying information behind the scenes. It took both types of expertise and resources to make the conference a success. Plans are being discussed for collaborating on another long term care conference or jointly sponsoring another emphasis to be a catalyst for improving life for residents.

Working together on legislative issues has accomplished some positive changes. Although FOR and the LTCOP *do not always agree* on their legislative priorities, they work together as much as possible. FOR considers their lobbyist a resource for the LTCOP. The FOR lobbyist helped ombudsmen learn how to testify and to more effectively work with the legislature. When the LTCOP cannot take a public lead on certain issues due to its position in the state government, FOR taps into its grassroots network to promote and apply political pressure. FOR has the ability to make things happen due to their statewide membership. FOR and the LTCOP work together to ensure that each has a "seat at the table" as much as possible at meetings to discuss policy and regulatory changes in long term care.

- **Keys to Working Together**

Once a month FOR's Executive Director and the State Long Term Care Ombudsman try to carve out time to exchange information and to brainstorm about what needs to be done and how to do it. This regular dialogue significantly contributes to a strong working relationship. FOR has at least two ombudsmen on its Board of Directors which further increases the dialogue and mutual support.

Both groups, FOR and the LTCOP, see themselves as supporting the other to help residents. The LTCOP encloses information about FOR in the information packets it mails, invites FOR to speak at family council meetings and to ombudsman volunteers. They collaborate by proofing each other's letters to the editors of newspapers and information developed addressing long term care issues.

The NC Citizen group and ombudsman program they see themselves as filling in each other's weaknesses, strengthening each other's strong points, and being partners in achieving change for residents.

Indiana

Presenters: Paul Severance, Executive Director, United Senior Action
Arlene Franklin, State Long Term Care Ombudsman, Indiana Division of Disabilities and Rehabilitation Services

➢ Formation of the Citizen Advocacy Group

United Senior Action (USA) was organized in 1978-79. Paul Severance initiated the organizing process as part of a larger citizen organizing process under the auspices of a federation of Indianapolis organizations. Long term care has been at the center of what USA does from the beginning. United Senior Action also addresses other issues such as public utilities.

➢ Highlights of Shared Accomplishments

During the past decade, USA and the LTCOP have worked collaboratively on virtually every major nursing home policy issue. Successful examples include:

- Rewriting the entire state nursing home regulations, with greater enforcement powers and stronger resident rights;
- Forcing the state survey agency to take a more aggressive stance on violations;
- Winning greater transfer/discharge protections for residents;
- Increasing the personal needs allowance;
- Gaining nursing home criminal background check legislation and nursing home staffing disclosure legislation;
- Gaining improvements in the complaint response system;
- Fighting Vencor's discharge of Medicaid residents from an Indianapolis facility; and
- Monthly meetings with the state survey agency, the LTCOP, and USA, in which the LTCOP and USA jointly push for improvements in the system.

United Senior Action has pushed hard to strengthen the Indiana LTCOP. Initially the push was for a significant expansion of the LTCOP into all areas of the state. This was accomplished. More recently, USA led a coalition of consumer organizations in demanding, and obtaining, new state regulations for the LTCOP that expand the authority of the state long term care ombudsman to act independently of the state agency that houses the program. This independence is focused on direct involvement in systems advocacy as well as the ability to direct the functioning of local long term care ombudsmen. United Senior Action is also pushing for an increase in funding for the LTCOP. By strengthening the LTCOP, USA is having a

positive impact on the care residents receive as well as adding to the number of public voices advocating on behalf of residents.

Prior to the new LTCOP regulations, USA and the LTCOP had an understanding about the roles each could play. When the state or local ombudsmen encountered barriers to taking a public advocacy stand, USA was the public voice, collaborating with the LTCOP behind the scenes. United Senior Action decided that residents were entitled to a strong LTCOP and that another public voice speaking for residents was needed. Thus, USA directed attention to strengthening the LTCOP.

- **Keys to Working Together**

Maintaining an on-going dialogue focused on the needs of residents has been a primary key to working collaboratively over the years. Each entity relies on the other for certain types of expertise and activity. United Senior Action taps into the knowledge and expertise of the LTCOP to inform its decisions. The LTCOP gains from the expertise of USA in working with legislators. When demand letters need to be written, USA takes the lead. The USA lobbyist covers long term care issues in the legislature more thoroughly than the LTCOP can; information is shared with the LTCOP. Seeking an increase in the LTCOP's funding is more effective when USA takes the lead because the request is not viewed as self-serving or greedy.

Both USA and the LTCOP acknowledge each other's advocacy role in working on behalf of residents. By joining with USA's efforts, the LTCOP taps into more than 125 member organizations with 17,000+ individuals. This commands more attention than if the LTCOP were the only one voicing a concern or working for a specific change. There is a mutual exchange of information about developments in long term care. United Senior Action and the LTCOP also strongly support having representatives from both present in meetings on long term care issues. A commitment to a unified agenda to achieve better care for residents is the strong bond between these two entities.

Oklahoma

Presenters: Jo Anna Deighton, Oklahomans for the Improvement of Nursing Home Care, Inc. (OK INCH)
Eleanor Kurtz, State Long Term Care Ombudsman Program, Aging Services Division, Oklahoma Department of Human Services

- **Formation of the Citizen Advocacy Group**

Oklahomans for the Improvement of Nursing Home Care (OK INCH) was founded by Jo Anna Deighton. As an ombudsman volunteer, Jo Anna became very frustrated with the lack of positive change in nursing homes. She believed she could get more done outside the LTCOP than she could from within. She resigned as an ombudsman and began OK INCH. All OK INCH

members are family members of nursing home residents. Other advocacy groups exist in Oklahoma but do not focus exclusively on nursing home issues.

➢ **Highlights of Shared Accomplishments**

Communication and working together expands whatever OK INCH or the LTCOP could accomplish by going solo. Each entity has its own mailing list and phone tree. By activating the resources of both whenever an issue needs action, the advocacy network is greatly expanded. Instead of fighting about agendas and strategies, these two choose to focus on the resident. This common focus has led to several accomplishments over the years. A few of these are listed.

- A one day workshop, a manual, and printed materials, on family council development were jointly developed by OK INCH and the LTCOP as a result of an American Association of Retired Persons grant to OK INCH;
- The enforcement system was strengthened in several ways including the addition of ten inspectors;
- An increase in the personal needs allowance was obtained;
- An increase in staffing in nursing homes was enacted;
- Other changes including coverage for eye glasses for certain residents; and
- The LTCOP budget was increased to expand the number of paid ombudsman positions at the local level.

➢ **Keys to Working Together**

The primary key to collaboration is talking with each other and maintaining a common focus on the resident. When questions arise, OK INCH and the LTCOP are willing to reach out to the other seeking an explanation. They acknowledge that each has a role to play in moving issues forward and have different strengths in addressing policy and legislative changes. Both believe that joining together with a unified message accomplishes more than either could alone. There is a synergy when tapping into both networks.

COMMON THEMES

Several themes emerged throughout the three presentations and discussion that followed. These themes enable citizen advocates and long term care ombudsmen to work together to benefit residents. In essence, the themes provide guidance for establishing and maintaining cooperative relationships to achieve a common purpose - improving resident care.

➢ Maintain a focus on benefiting residents: The strongest connection between CAGs and LTCOPs is the goal of improving the quality of care and life for residents. Whenever differences arise, both entities return to a resident focus to identify areas agreement. Focusing on common goals instead of focusing on differences leads to accomplishments. CAGs and

LTCOPs avoid criticizing each other by moving forward on issues where a unified front can be established.

- Respect for each other's role: CAGs and LTCOPs understand that each operates under different parameters, which shape their strategies and their advocacy role. Instead of expecting each other to be the same, they respect their differences. LTCOPs work with CAGs to bring the personal experiences of the CAGs to the fore at pivotal times in meetings and hearings, respecting the power of the consumer voice. CAGs work to support a strong LTCOP and LTCOPs promote citizen participation in the CAG.

- Maximize each other's strengths: The differences that exist are viewed as strengths that can be utilized to achieve the common goal. The networks of both are combined to address an issue. The LTCOP often has expertise on regulations and policies and may have a more direct link to meetings with state agencies. CAGs may have more expertise in lobbying, in working with the legislature, and in capturing public attention. CAGs and LTCOPs share their expertise with each other. Decisions regarding which takes the lead role are collaboratively made based on the strengths of each.

- View more than one consumer voice as essential: CAGs and LTCOPs seek to have both entities participating in meetings and working on issues. They believe two voices speaking for residents are more powerful than either one alone.

- Maintaining direct communication with each other: When differences and disappointments arise with each other, the CAG and the LTCOP pick up the phone or meet together to ask for an explanation. They seek to work out issues between them. They may agree to disagree or they may admit there is room for improvement. Regardless of the circumstance, they are committed to continuing to work together and to move past the immediate issue. They are willing to listen to each other and learn from mistakes.

Establishing and maintaining collaborative relationships between CAGs and LTCOPs takes continual time and effort. Both entities must want this type of relationship for it to succeed. The intent of this session was to glean several concrete examples of accomplishments when a common focus exists and to identify some guiding principles from states where these relationships are strong. Although the common themes will be influenced by the dynamics within each state, residents benefit the most when there are strong CAGs and strong LTCOPs working on their behalf.

Joining Forces for Residents:
Citizen Advocates and Long Term Care Ombudsmen

Tuesday, October 31 2:30 B 3:45

Learn what can be accomplished when Citizen Advocacy Organizations and Long Term Care Ombudsman Programs collaborate to improve life for residents. Concrete models of joint advocacy; respecting differences in role and perspective; identifying common goals and complementary strategies.

Presenters

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ABOUT THE AUTHOR

Sara Hunt, MSSW is a consultant for the National Long Term Care Ombudsman Resource Center with expertise in the areas of ombudsman training, policy development and program management. Sara was the State Ombudsman in Louisiana for five years (1981-1986) and has served as a consultant to the Center since 1987.

ABOUT THE REPORT

For more information about this topic, contact the National Long Term Care Ombudsman Resource Center, National Citizens' Coalition for Nursing Home Reform, 1424 16h Street, NW, Suite 202, Washington DC 20036-2211, 202-332-2275.

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