THE NATIONAL ASSOCIATION OF STATE
LONG-TERM CARE OMBUDSMAN PROGRAMS
WHITE PAPER

SYSTEMS ADVOCACY AND THE LONG-TERM CARE OMBUDSMAN PROGRAM

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Frequently Used Acronyms

AoA	Administration on Aging
IOM	Institute of Medicine
LTCOP	Long-Term Care Ombudsman Program
LTCOPs	Long-Term Care Ombudsman Programs
NASOP	National Association of State Long-Term Care Ombudsman Programs
OAA	Older Americans Act
SUA	State Unit on Aging

EXECUTIVE SUMMARY

Almost four million individuals live in long-term care facilities in the United States. When problems related to their rights and care arise, residents can turn to the Long-Term Care Ombudsman Program for assistance. This program also is charged with representing the needs of residents to public officials and working to change systems on behalf of residents. In some states, this public advocacy voice for residents is limited by restrictions imposed on the program. Residents lose when this happens.

A study conducted by the National Association of State Long-Term Care Ombudsman Programs in 2005–2006 found current evidence of state imposed limitations on systems advocacy. The data suggest that in many states significant interference with one of the core federal mandates of the long-term care ombudsman program exists. Evidence of interference includes:

- 36% of state ombudsmen need prior approval before testifying to legislators on issues related to long-term care facility residents;
- 21% of state ombudsmen are not allowed to initiate contact with legislators;
- 12% of state ombudsmen have never provided written or oral testimony to lawmakers regarding the interests of long-term care residents;
- 6% of state ombudsmen were unwilling to respond to this survey during office hours.

The Older Americans Act clearly mandates that long-term care ombudsman programs provide systems-level advocacy on behalf of long-term care residents. The language of this mandate has remained consistent since the 1978 amendments to the Act required that each state establish a long-term care ombudsman program. Since 1995, national studies have documented restrictions on systems advocacy, limiting the program's ability to effect change on behalf of residents.[1] Furthermore, inadequate resources and restrictions continue to hamper this critical effort.

The program designed to empower others must be empowered to fulfill its federal mandate to be the voice of residents.

It is time for the program that was intentionally designed to empower others, to be empowered to carry out its statutory mandate. The long-term care ombudsman must provide, in every state, both individual and systems advocacy services on behalf of older residents of long-term care facilities. Twenty-eight years after the enactment of the program mandate, the Administration on Aging must move from data collection to action, intervening so that the ombudsman program's fundamental services are consistently available to elders nationwide.

[1] Several seminal studies are listed in the references sections of this paper.

Recommendations

In order to fulfill the federal mandate that state ombudsmen serve long-term care residents through systems advocacy, the National Association of State Long-Term Care Ombudsman Programs (NASOP) makes the following recommendations.

Recommendation 1

Congress

- The Senate Special Committee on Aging should expand its oversight over the Older Americans Act (OAA) by examining barriers to full implementation of the act, pertaining to the long-term care ombudsman program.

- NASOP should provide relevant data and anecdotal information to the Senate Special Committee on Aging.

- Congress should review the findings and recommendations of the 1995 Institute of Medicine (IOM) report related to the ability of the state long-term care ombudsman programs to carry out systems advocacy activities.

- Congress should provide appropriate oversight of the OAA, including consideration of the effectiveness of the long-term care ombudsman program and how performance is measured by the Administration on Aging.

Recommendation 2

Administration on Aging

- The Administration on Aging (AoA) should use an objective method, such as the IOM Committee's practice standards, to conduct annual assessments of each states' office of the long-term care ombudsman.

- AoA should use its authority under federal law to enforce compliance with the OAA requirements for ombudsman services, and bi-annually, publicly report to Congress their findings and resolution plans.

- Regardless of the placement of the LTCOP, every non-compliant state must be assessed penalties and caused to correct those practices that willfully interfere with the operation of the ombudsman program.

Recommendation 3

State Unit on Aging

- Each State Unit on Aging Director, and its governing board, should review the OAA mandate for operation of the SLTCOP. If deficiencies are found in the practices or policies of the agency housing the program or in the operation of the program itself, immediate steps should be taken to correct the areas of concern. Correction plans should then be reported to AoA for their review.

Recommendation 4

State Long-Term Care Ombudsman Program

- Each State Long-Term Care Ombudsman Program, and its governing board, should review the OAA mandate for operation of the LTCOP. If deficiencies are found in the practices or policies of the state or local program(s) or in the systems advocacy operations, immediate steps should be taken to correct the areas of concern. Correction plans should then be reported to the state unit on aging for their review.

INTRODUCTION

The fifty-three state long-term care ombudsman programs (LTCOPs) serve approximately 3 million residents of licensed nursing facilities, more than 400,000 residents of board and care facilities, and 530,000 residents in assisted living facilities throughout the nation. The Older Americans Act (OAA) clearly mandates that LTCOPs provide systems-level advocacy to assure that the needs of long-term care residents are fully represented. In particular, the LTC ombudsman is to:

- Represent the interests of residents before governmental agencies and seek administrative, legal, and other remedies to protect the health, safety, welfare, and rights of residents;

- 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 long-term care facilities and services in the state;

- Facilitate public comment on laws, regulations, policies, and actions related to residents of long-term care facilities and the ombudsman program;

- Recommend any changes in laws, regulations, policies, and actions that will further promote the interests, well-being and rights of residents; and

- Provide such information as the State Ombudsman Office determines to be necessary to public and private agencies, legislators, and other persons, regarding: (1) the problems and concerns of individuals residing in long-term care facilities; (2) and recommendations related to these problems and concerns (Older Americans Act of 1965, Sec. 712(a)(3), 42 U.S.C. §3058g).

The language of this mandate has remained consistent since the 1978 OAA reauthorization, which provided the original requirement that each state establish a LTCOP. The statute has been strengthened repeatedly to facilitate such activities. These changes included requiring each state to:

One of the main duties of LTCO is to represent the needs of residents before governmental agencies and seek administrative, legal, and other remedies to protect the health, safety, welfare and rights of the residents.

- Increase the visibility of the LTCOP by creating an Office of the State Long-Term Care Ombudsman (OSLTCO);
- Protect from liability ombudsmen who properly carry out the functions of the Office; and
- Make unlawful the willful interference with representatives of the OSLTCO in the performance of their official duties.

To be effective in systems advocacy as described above, the state LTCOP must have available the full resources[2] and authority to function given it by the OAA:

- ⇨ Access to long-term care facilities and residents;
- ⇨ Access to decision-makers within state agencies;
- ⇨ Adequate legal counsel; authority to personally make recommendations to legislators without interference; and
- ⇨ Freedom to discuss non-confidential information with the media.

These are all minimum requirements of the federal law. Yet LTCOPs positioned in various settings still report being prohibited from contact with legislators and media, as well as being prohibited from direct interaction with policy-makers, and other problems.[3] Data from as long ago as 1995 and reiterated in 2001, show consistent obstacles to LTCO exercising their duties in the area of systems advocacy. Systems advocacy should flow in a natural progression from the long-term care ombudsman's advocacy on behalf of individual long-term care residents. Systems advocacy supports individual advocacy activities.

If a LTCOP can bring about changes in policies or laws that affect residents, the program is improving circumstances for many residents instead of just one.

It is time for the program that was intentionally designed to empower others, to be empowered to carry out its statutory mandate. The long-term care ombudsman must provide, in every state, both individual and systems advocacy services on behalf of older residents of long-term care facilities. Twenty-eight years after the enactment of the program mandate, the Administration on Aging must move from data collection to action, intervening so that the ombudsman program's fundamental services.

The mission of the LTCOP goes beyond individual complaint and investigative work. LTCOPs have a mandated duty to represent the interests of long-term care residents before administrative policy makers and legislators, as well as to the media and the general public. When the LTC ombudsman is prevented from being a direct voice for the resident the program loses its effectiveness and credibility.

Background Information

In 2002, with support from the Helen Bader Foundation, the National Association of State Long-Term Care Ombudsman Programs[4] (NASOP) convened a working retreat

[2] e.g.: Sufficient funding and adequate level of support staff, such as: volunteers, office staff, and information technology support to address daily operations and support systems advocacy.

[3] This statement is based on findings reported in previous research specifically, Effectiveness of the State Long Term Care Ombudsman Programs. C. Estes, D. Zulman, S. Goldberg, D. Ogawa. A Report submitted to the Henry J. Kaiser Family Foundation, June, 2001. Further discussion of research findings follows throughout this paper.

[4] The National Association of State Long-Term Care Programs (NASOP) was formed in 1985 as a non-profit organization composed of State Long-Term Care Ombudsmen representing their states. NASOP works to

with the theme, "The Long-Term Care Ombudsman Program: Rethinking and Retooling for the Future." Participants representing a cross section of the aging network thoroughly examined the needs of long-term care ombudsman programs and projected them into the future. A set of recommendations was produced for NASOP to address. Retreat participants agreed that nationally, the long-term care ombudsman program is not consistently able to fulfill its mandate to pursue systems advocacy.

The participants found that barriers to systems advocacy included:

- Insufficient ombudsman training;
- Lack of monitoring and enforcement of systems advocacy responsibilities; and
- Inappropriate restrictions placed on some ombudsman programs that lead to inadequate partnering with other organizations.

A primary recommendation of the retreat was that "[the] National Association of State Long-Term Care Ombudsman Programs should conduct confidential oral interviews with state ombudsmen to get a full sense of attitudes, barriers, and supports to fulfill the mandate for systems advocacy." In this context, systems advocacy is the general term for efforts by ombudsmen to effect change within regulatory and provider entities that will benefit the consumer of long-term care.

In order to fulfill this recommendation, NASOP received a second grant from the Helen Bader Foundation to undertake a systematic, in-depth examination of these matters. A committee of state ombudsmen developed a set of interview questions. NASOP submitted the questions for review and revision to a researcher to improve the validity and consistency of the instrument.[5] NASOP then contracted with an individual to conduct the interviews by telephone with current and former state long-term care ombudsmen. Six former state ombudsmen and all but three current state ombudsmen made themselves available for this lengthy interview**.**

FINDINGS

Extensive information has been gathered about systems advocacy activities across the nation as a result of NASOP's confidential interview project. The findings provide insight into potential and actual barriers that exist in many states. All documents connecting identifiable respondents to their responses will remain protected to honor our promise to state long-term care ombudsmen to protect their confidentiality.

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strengthen State Long-Term Care Ombudsman Programs' effectiveness by providing education and support for the programs, participating in public dialogue and development, and collaborating with other organizations, governmental bodies, and health care providers.

[5] Even though a considerable amount of expertise and time were devoted to the development of the survey tool, it should be noted that the tool is not scientific in nature. The study is the most comprehensive assessment and analysis of LTCOP systems advocacy activities that exists to date.

In order to understand why state ombudsman programs are not exercising, or unable to exercise, their federally mandated authority, NASOP's consultant asked a series of questions of forty-eight state ombudsmen. The information was collected and analyzed from each state ombudsman within the time period of September 2005 through March 2006. The results follow.

Years as a State Long-Term Care Ombudsman

Of the forty-eight state ombudsmen interviewed, forty-three (ninety percent) of the participants had at least one full year of on-the-job experience.

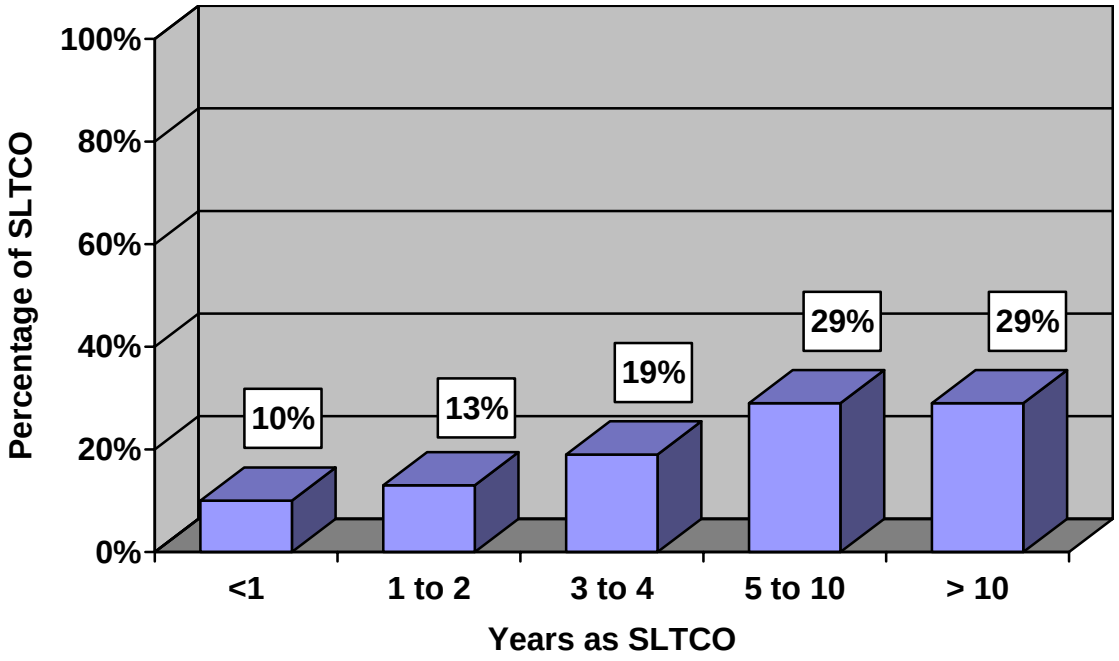

Figure 1: Years as a State Long-Term Care Ombudsman

Support for State and National Systems Level Advocacy

State ombudsman program locations differ by state. Some LTCOPs are located outside of their State Units on Aging (SUAs) and some are housed outside of state government. State ombudsmen located outside of their SUAs were asked about support from both the SUA and from their employer.

State Unit on Aging Support

State Advocacy

All state ombudsmen interviewed, regardless of program placement, were asked how their State Unit on Aging supports them with state specific systems advocacy activities. A ten point scale was used to indicate the level of support received from their State Units on Aging with zero representing no support in conducting systems advocacy and ten meaning being strongly supported. Less than twenty-five percent reported being fully supported in state level advocacy efforts, and an almost equal number reported receiving little to no support.

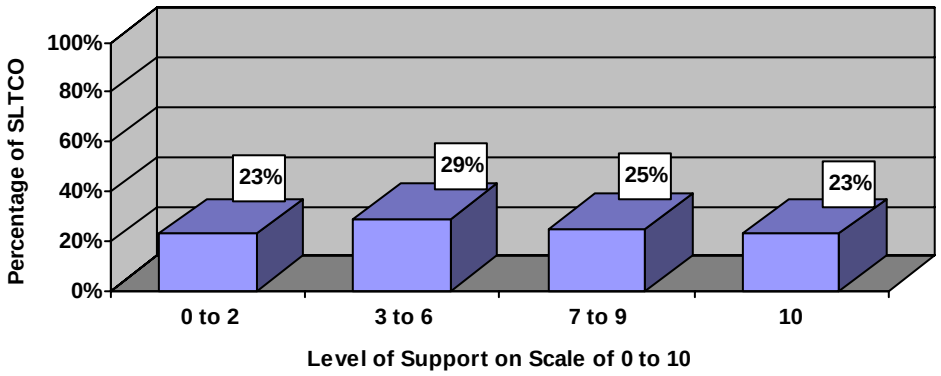

Figure 2 Level of Support by State Unit on Aging for State Level Systems Advocacy

State ombudsmen were then asked whether they are discouraged from conducting systems level advocacy by the SUA. Figure 3 shows their responses. Although this program has existed for almost thirty years, nearly half of the state ombudsmen report being discouraged from systems advocacy activities by their state unit on aging.

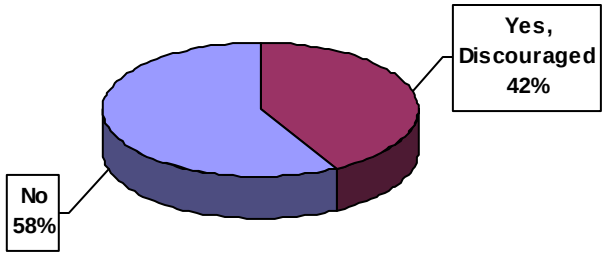

Figure 3 Percent of SLTCO Discouraged by State Unit on Aging in State Level Systems Advocacy

State Unit on Aging Support

National Advocacy

Each state ombudsman was asked if s/he were supported by the SUA to conduct national level systems advocacy. Using the same measuring scale of zero to ten, with ten being the most support, Figure 4 shows their responses.[6]

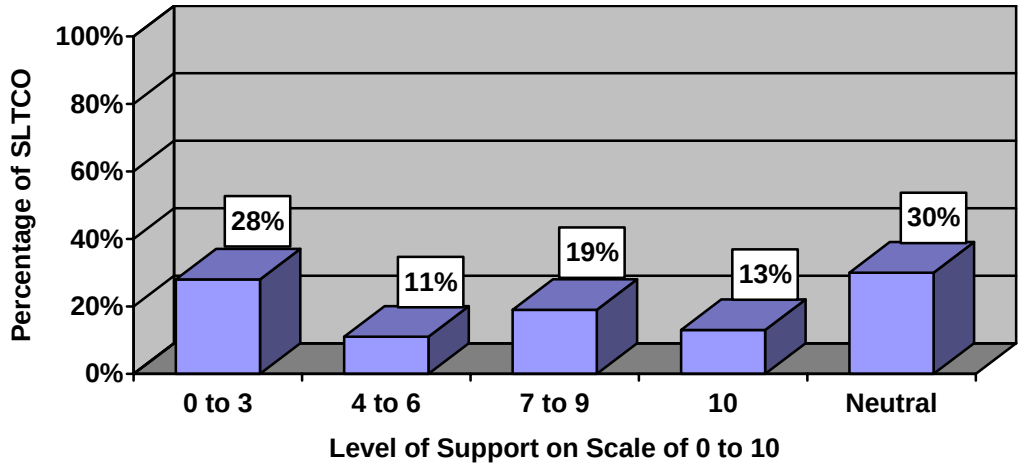

Figure 4 Level of Support by State Unit on Aging for National Level Systems Advocacy

As with state level advocacy, state ombudsmen were asked if they felt the SUA discouraged them from conducting national level systems advocacy. While seventeen percent reported that their SUAs were neutral in their levels of support, twenty-seven percent were discouraged to engage in this critical effort.

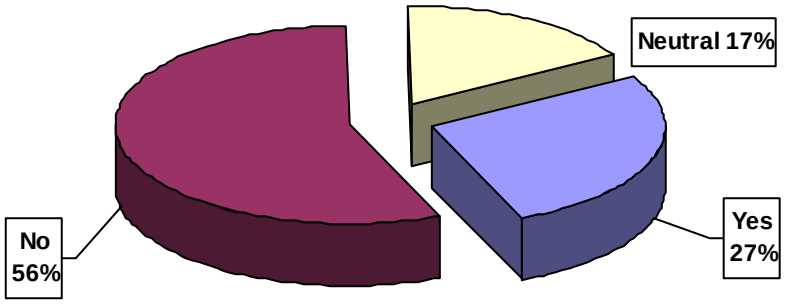

Figure 5 Percent Discouraged by State Units on Aging in National Level Systems Advocacy

[6] Neutral means: state ombudsmen report that SUAs neither support nor discourage state ombudsmen advocacy on the national level.

Employing Agency Outside of State Unit on Aging Support

State Advocacy

State ombudsmen located outside of SUAs (N = thirteen) were also asked to rate their employing agency's support for state specific systems advocacy on a scale of one to ten, with ten being the most support. The results are presented in Figure 6. In contrast to the ratings of the support from SUAs (Figure 2), more than fifty percent of state ombudsmen gave their employing agencies the highest rating.

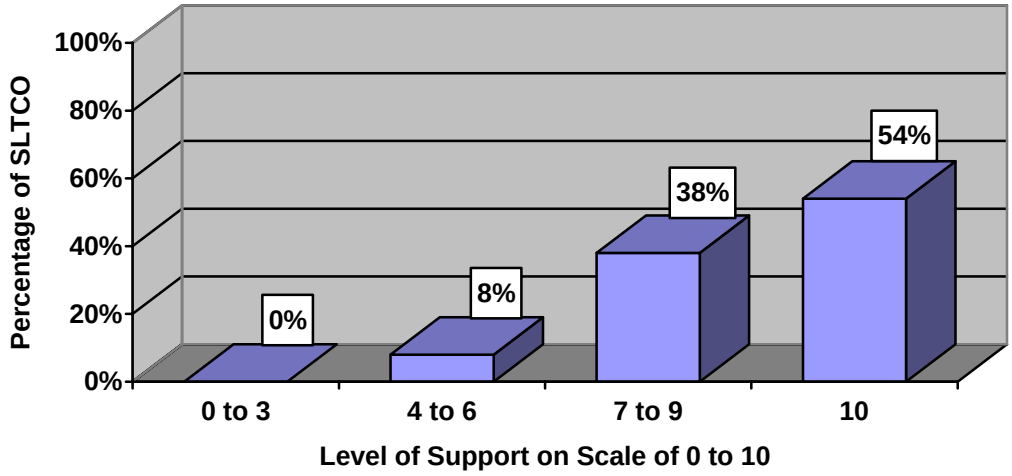

Figure 6 Supported by Employing Agency in State Level Systems Advocacy

Similarly, when asked if the program was discouraged from engaging in systems advocacy by the employing agency, eighty-three percent of state ombudsmen replied in the negative.

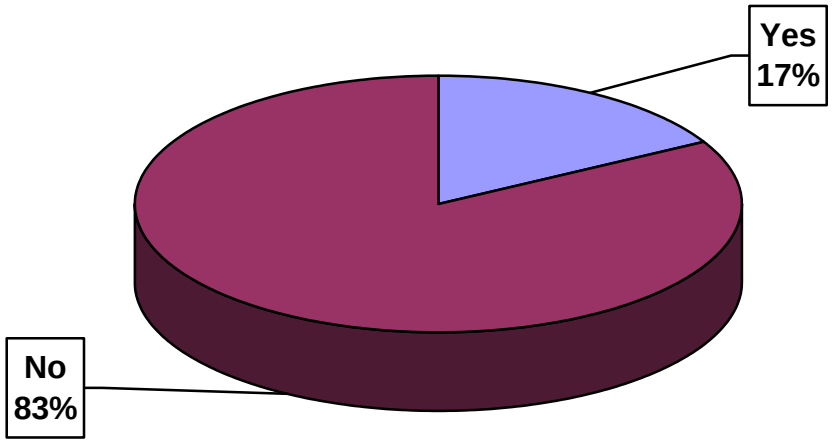

Figure 7 Discouraged by Employing Agency in State Level Systems Advocacy

Legislative Advocacy Activity

In response to questions about ability to engage in legislative advocacy, state ombudsman answers fit into three primary categories:

- State ombudsman decides about legislative activities, frequently keeping others informed, e.g. SUAs, employing agency, policy makers, citizens' advocacy groups, or other stakeholders (forty-nine percent);
- State ombudsman decides but must have prior approval to act (thirty-seven percent); and
- State ombudsman is prevented from initiating legislative contacts and deciding what legislative advocacy actions to take (fourteen percent).

The responses are depicted in Figure 8. The figure shows a further breakdown within the "prior approval" category of those who said obtaining prior approval:

- Is not a problem (four percent);
- Is a problem, e.g., delays that result in missing hearings, and other events, message content being altered, requests being denied (twelve percent); and
- Has not been a problem but that it might be in the future, e.g., a change in policies or perspective with a change in administration or personnel (twenty percent).[7]

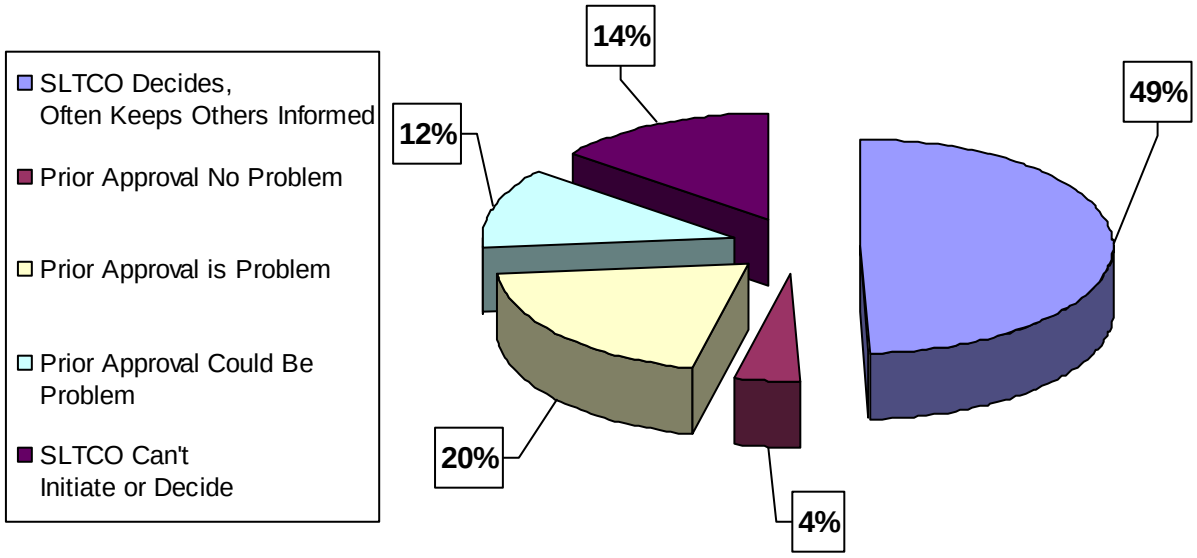

Figure 8 Legislative Advocacy and State Ombudsman Decision Making

[7] One state reported that prior approval is not required but that it could be in the future and could be a problem, depending upon changes in administrative personnel and agency policies.

Of the forty-eight state ombudsmen, twenty-one reported encouraging local ombudsmen (paid or volunteer) to engage in legislative advocacy.[8] While encouraging local ombudsmen to participate in legislative advocacy is an example of appropriate leadership, in some states it is the only way that the ombudsman program can represent residents with legislative issues because the head of the program, the state ombudsman, is prevented from directly engaging in legislative advocacy.

Testimony

The interviewer pursued this topic area and asked if state ombudsmen ever testified on the behalf of residents in front of their state legislature, or in other policy events. Figure 9 shows the responses. Despite the mandate to comment on local, state, and federal laws and regulations, a full twelve percent of the state ombudsmen, representing seven states, have never provided written or oral testimony.

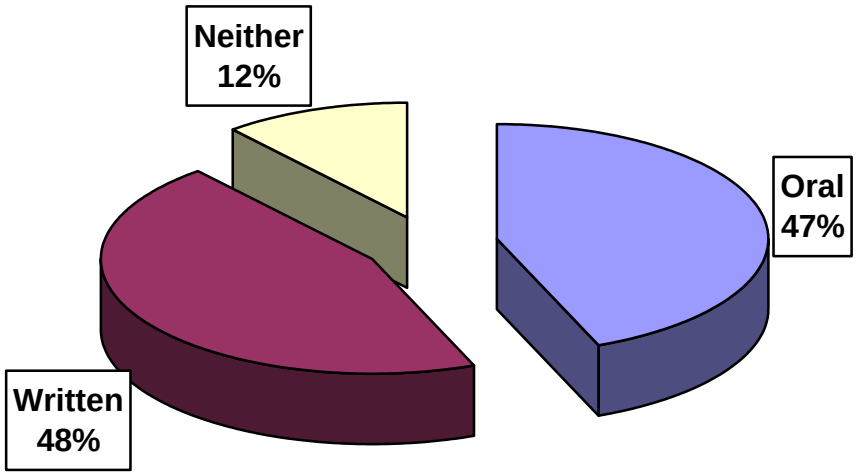

Figure 9 Percent of State Ombudsman Giving Legislative Testimony

[8] Not all State Long-Term Care Ombudsman Programs have local programs.

Partnerships for Systems Advocacy

Working in partnership with others, such as citizens' advocacy groups, advocacy agencies, or resident and family councils, is frequently a preferred systems advocacy strategy. When asked if state ombudsmen partner with outside groups in order to ensure that long-term care facility residents' concerns are voiced within the state legislative sessions, media, or other long-term care arenas, the responses clearly show that ombudsman programs work with others to pursue systems advocacy. (See Figure 10.)

LTCOPs appropriately use many strategies in conducting state or national systems advocacy, including partnering with others in order to represent residents. However, as previously discussed, for some state ombudsmen working with others is the only option available for pursuing some types of systems advocacy. The survey responses also reveal that two of the programs where the state ombudsman is prevented from directly engaging in legislative advocacy activities are states where the state ombudsman does not work on systems advocacy activities in partnership with others.

In Figure 10, the response categories are mutually exclusive. State ombudsmen who responded, "Yes and Do," said that they work in partnership and they also directly engage in systems advocacy when that is an appropriate strategy. State ombudsmen who responded, "Yes," said that they have worked on systems advocacy only in partnership with others. The "No" responses have not worked in partnership and have not directly engaged in systems advocacy activities.

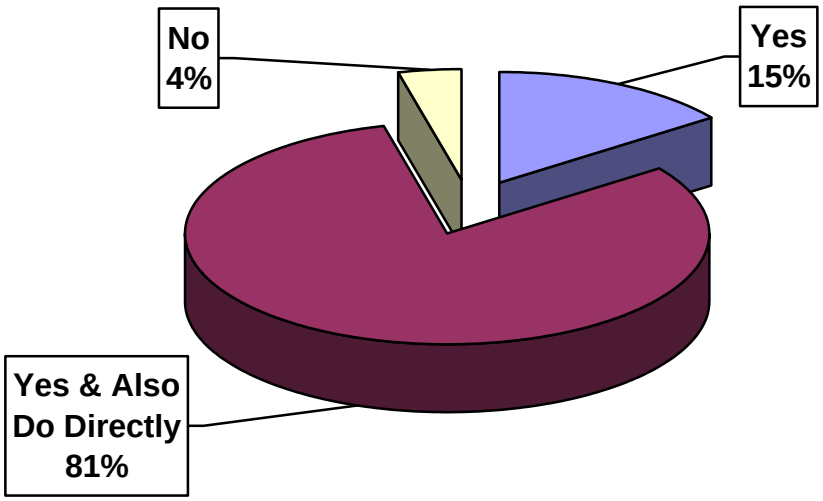

Figure 10 Partner for Systems Advocacy

In order to learn how state ombudsmen work with partners, ombudsmen were asked if they currently serve on any advisory committees or task forces as a spokesperson or representative for long-term care facility residents. Six percent did not engage in even this basic level of systems advocacy.

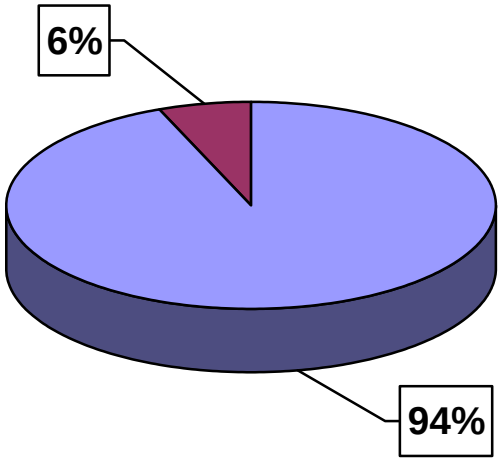

Figure 11 Member of State Level Advisory Committee or Task Force

Communication with Licensing and Certification Agencies

To fulfill the LTCOP's mandated responsibility to monitor the development and implementation of federal and state laws, regulations, and other governmental policies and actions, the program must interact with the state licensing and certification agency for long-term care facilities. When asked about this activity, ninety-eight percent of the state ombudsmen responded that they actively communicate with their licensing and certification agency. However, two percent reported that they do not have a relationship or regular communication with their licensing and certification agency and are therefore unable to engage in what might be argued to be one of the most basic levels of systems advocacy.

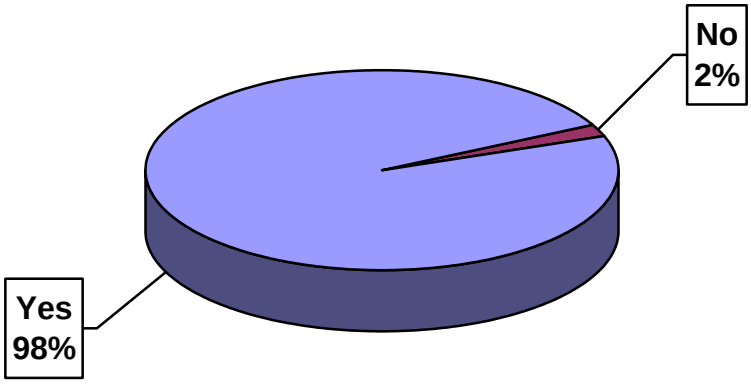

Figure 12 Interact with Regulatory Agency

Other Barriers to Systems Advocacy

Expand systems advocacy with time, funding, and other supports.

When asked an open-ended question about barriers that are experienced when trying to expand systems advocacy activities:

- 27% of state ombudsmen replied that they needed more time;
- 37% replied that they needed funding; and
- 36% gave various responses captured under "Other."

(Figure 13) Responses indicated that several key resources were essential in order for a state ombudsman program to conduct systems advocacy, such as: volunteers, volunteer coordinator, legal staff, funding for travel, resources to conduct training, and supervisory support to obtain the resources they needed to expand the program.

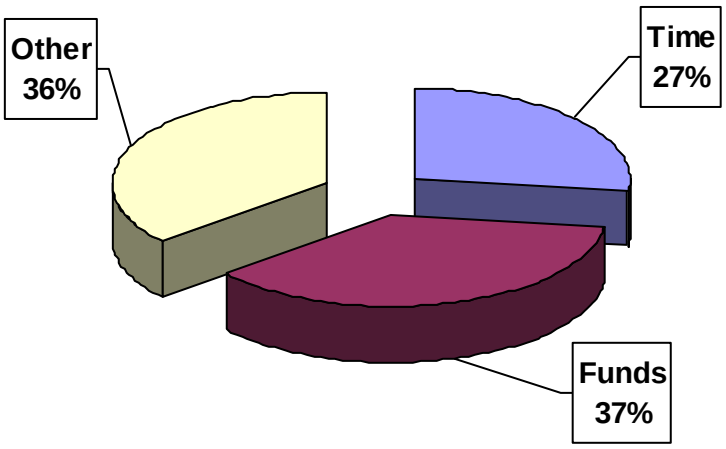

Figure 13 Help to Expand Systems Advocacy

Systems Advocacy Activities Stopped

The interviewer probed to determine if any systems advocacy efforts had been stopped, and if so, why. A majority (seventy-three percent) of the state ombudsmen reported that no systems advocacy activities have been stopped. However, twenty-seven percent reported that some activities had been stopped. (Figure 14) Ombudsmen who responded, "Yes," provided a variety of reasons for terminating some systems advocacy projects. Rarely was the reason positive, the goal of the project was positively achieved and another project would be undertaken shortly. More often, the reason was negative such as: the lack of continuous funding, a lack of staff and office support, a lack of supervisory support.

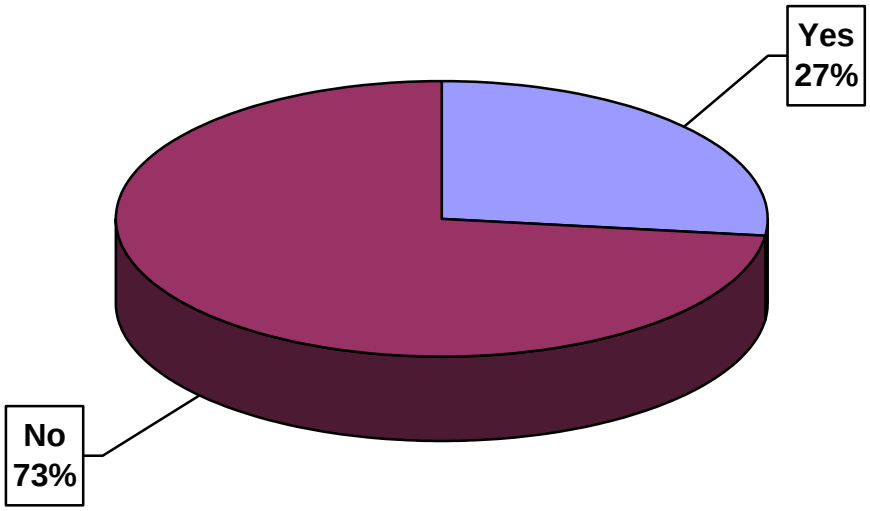

Figure 14 Stopped Systems Advocacy Activities

ANALYSIS OF COLLECTED DATA

The Older Americans Act mandates that states ensure that "willful interference with representatives of the Office [of Long-Term Care Ombudsman] in the performance of the official duties of the representatives…shall be unlawful." (Section 712 (a)(3)(j)) The Act also requires states to provide for appropriate sanctions with respect to the interference, retaliation, and reprisals. However, some State Units on Aging and other host agencies routinely and willfully interfere with the performance of the duties of long-term care ombudsmen.

NASOP's Systems Advocacy Committee found many examples of interference, including examples of what appeared to be willful interference, with a state long-term care ombudsman's duties. For example, three state long-term care ombudsmen refused to answer NASOP's survey unless they were called after hours in the privacy of their own homes. This refusal was motivated by fear of retaliation by supervisors or policy makers. Answering the survey questionnaire frankly was perceived to risk negative repercussions for the ombudsman and the program. This clearly indicates that some state ombudsmen are completely compromised and are unable to fulfill their federal mandates.

Some state ombudsmen are compromised and unable to fulfill their federal mandates.

Furthermore, information gleaned from the interviews, as well as from the data previously presented, suggests that interference is both blatant and subtle. For example: nearly half of the state ombudsmen who wish to conduct systems advocacy have to gain prior approval before participating in systems advocacy activities involving either the state legislature or national events. This includes submitting written or oral testimony. Some state ombudsmen are not even permitted to attend legislative hearings to remain informed about changing legislation, regulations, or policies that affect long-term care residents. Through the interview process it was learned that some states totally restrict the LTCOP from contact with the media or legislators. Although in some of these states legislators can directly request the presence or testimony of an ombudsman at a hearing, such purely reactive advocacy is not sufficient to meet the standard set in the OAA.

A frequently reported example of more subtle interference actions is agency policies requiring prior review or approval by other levels of administration before the ombudsman program distributes reports or press releases. Such policies can create delays that diminish or destroy the effectiveness of an action by the LTCOP. The message content or the opportunity to act on behalf of residents may be lost due to the timing or withholding of approval.

Further examples of subtle interference include not having enough staff to conduct or sustain systems advocacy. When asked why this occurs, the state ombudsmen reported that the program was not a priority; some state officials did not care about or understand the mandates of the program, or simply ignored requests from the state ombudsmen in order to fulfill other state programmatic needs. Thus, crucial resources

were never supplied and consequently limiting each state long-term care ombudsman program to conducting investigative and individual advocacy only. Clearly, many states fail to comply with the Older Americans Act.[9] Only twenty-four state ombudsmen are allowed to exercise their authority to decide about legislative testimony without interference.

Only twenty-four state ombudsmen are allowed to exercise their authority to decide about legislative testimony without interference.

The Region V Office of the General Counsel of the Administration on Aging delineated the public testimony responsibilities of the state ombudsman program in a memo to Larry Brewster, Bi-Regional Administrator, Administration on Aging dated February 2, 2002. An excerpt follows.

> (1) The Ombudsman Must Be Allowed To Independently Determine What Testimony Or Information To Submit To A State Legislature. We have highlighted above the statutory language which bears most directly on the questions you have raised. These statutory provisions make clear that the Ombudsman's Office is authorized to testify before a State legislature on long-term care issues. Moreover, if Congress had intended that the Ombudsman simply report to the State agency on aging, and that it would be the State agency which would report to the State legislature, Congress could easily have said so by providing, for example, that the Office, through the single State agency, would make recommendations and reports. In contrast, the use of the phrases 'as the Office determines to be appropriate,' and 'as the Office determines to be necessary' very strongly suggests that Congress intended the Ombudsman's Office to independently determine what recommendations and information to report to a State legislature. This very specific statutory language thus strongly supports the conclusion that the State agency should not have any veto power or right to approve the communications that the Ombudsman's Office chooses to make to policy makers, including a State legislature.
>
> Moreover, although you have inquired specifically about communications to state legislators, we believe that the very same analysis and conclusion would apply to the Ombudsman's communications with the press or other interested members of the public. This follows from the breadth of the OAA which authorizes the Ombudsman to provide such information "as the Office determines to be necessary" to "public and private agencies, legislators, and other persons[.]" 42 U.S.C. § 3058g(h). The legislative history also clearly expresses the intent that "problems encountered by the Ombudsmen and proposed solutions are made known to policy-makers and the public." H.R. Rep. No. 102-199, 102nd Cong., 2nd Sess., reprinted in 1992 U.S.C.C.A.N. 1056, 1081. " (pp. 3 – 4)

[9] Older Americans Act , Section 712(a)(3) in appendix.

Confirmation of Survey Results

NASOP's most recent survey of LTCOPs reinforces the findings of the major study conducted by Carroll Estes and others, as a follow-up to the Institute of Medicine's evaluation of the ombudsman program.[10] The study's findings revealed that many states still have barriers that prevent the LTCOP from achieving full compliance with federal law, especially related to activities essential for effective systemic advocacy.

> Twenty-eight state ombudsmen (fifty-five percent) state that the placement of their state LTCOP creates difficulties for their ability to fulfill their mandate under the Older Americans Act. Reported difficulties include lack of autonomy to speak to legislators or the media, conflicts of interest, barriers to policy information, bureaucratic red tape, limited access to resources, and budget vulnerability."[11] (Estes, Zulman, Goldberg, & Ogawa, 2003)

These reports highlight the lack of effective monitoring and evaluation of LTCOPs by the Administration on Aging (AoA), and the need for sanctions to be brought against non-compliant states, in order to bring about change.

Oversight and Enforcement Continue to be Needed

State ombudsmen should be able to expect the Administration on Aging to monitor each state's program performance, identify problems, and require correction by the state agency or state ombudsman involved. The 1992 amendments to the Older Americans Act established the Office of Long-Term Care Ombudsman Programs, to be headed by an Associate Commissioner for Ombudsman Programs within the Administration on Aging. The responsibilities of the Associate Commissioner include several oversight functions related to the operation of the ombudsman program within each state.[12]

Quantitative data collection alone is insufficient for proper oversight.

In much the same way, local ombudsmen should be assured that the state LTCOP has quality control measures in place, and will enforce the terms of its contract with a local program's sponsor. Quantitative data collection alone is insufficient for proper oversight, especially related to monitoring of systems advocacy efforts. While no program can guarantee that its systems change efforts will be successful, each program should be expected and permitted to use every tool available for systems change work on behalf of residents. When such work is not done, correction should be required.

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[10] Estes, C., Zulman, D., Goldberg, S., Ogawa, D., "Effectiveness of the State Long-Term Care Ombudsman Programs," June 2001.

[11] "Independence and LTCOP's Ability to Fully Represent Residents." This report contains further analysis and information based on the 2001 Estes study.

[12] Section 201(d).

Looking back at the Institute of Medicine's (IOM) 1995 report, Real People, Real Problems: an Evaluation of the Long-Term Care Ombudsman Programs of the Older Americans Act, (Harris-Wehling, Feasley, & Estes, 1995), it is both remarkable and disheartening to note that the IOM's findings so closely parallel the 2001 evaluation of the program funded by the Kaiser Family Foundation (Estes, et al), described earlier, and the NASOP confidential interviews, completed in 2006. The IOM study reported:

> The committee believes that the individual and systemic successes attributed to the ombudsman program occur despite considerable barriers in most, if not all states…In many states, the program attempts to operate in a structural environment that expressly prohibits or, at least, does not foster its ability to carry out all federally mandated functions. The committee observed such examples as prohibitions on state and local ombudsmen from talking to any state or federal legislators about issues of concern to residents…" (IOM, 1995, p.12)

Based on its findings of wide variation among the states in their implementation of the program's mandate, the IOM committee developed a set of elements describing exemplary, essential, and unacceptable practices. The IOM proposed that the AoA use these elements to develop a method for assessing compliance of state LTCOPs. AoA has not acted on this recommendation.

CONCLUSION

It is time for the program designed and intended to empower others to be, itself, empowered to carry out its statutory mandate.

The Long-Term Care Ombudsman Program has federal mandates to resolve complaints on behalf of individual residents and to represent residents through systems level advocacy. Impediments to LTCOPs' ability to fulfill systems advocacy responsibilities have been documented by national studies since 1995. A basic description of systems advocacy activities was included in the IOM report to guide the Administration on Aging and states toward more effective program practices. (IOM, p. 161)

The IOM described the following as essential systems advocacy practices:

- "The state ombudsman develops a…participatory approach for local programs to analyze their individual resident advocacy service work to identify systems issues."

- "…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 issues."

- "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 operation of state or federal program…"

- "The work demonstrates a willingness to take on vested interests of all kinds and bring to bear persistence, creativity, and multiple constituencies."

- "The Office has regular contact with regulatory agencies…This includes ombudsman participation in committees and work groups related to LTC [long-term care]; and submission of comments on all proposed administrative policies that affect LTC facility residents." (IOM, 1995, pp. 180-181.)

It is time for the program designed and intended to empower others to be, itself, empowered to carry out its statutory mandate. The LTCOP must provide, in every state, both individual and systems advocacy services on behalf of older residents of LTC facilities. Twenty-eight years after the enactment of the program mandate, the AoA must move from data collection to action, intervening so that the LTCOP's fundamental services are consistently available to elders nationwide without restriction.

RECOMMENDATIONS

In order to fulfill the federal mandate that state ombudsmen serve long-term care residents through systems advocacy, the National Association of State Long-Term Care Ombudsman Programs (NASOP) makes the following recommendations.

Recommendation 1

Congress

- The Senate Special Committee on Aging and other relevant committees of jurisdiction should expand its oversight over the Older Americans Act (OAA) by examining barriers to full implementation of the act, pertaining to the long-term care ombudsman program.

- NASOP should provide relevant data and anecdotal information to the Senate Special Committee on Aging.

- Congress should review the findings and recommendations of the 1995 Institute of Medicine (IOM) report related to the ability of the state long-term care ombudsman programs to carry out systems advocacy activities.

- Congress should provide appropriate oversight of the OAA, including consideration of the effectiveness of the long-term care ombudsman program and how performance is measured by the Administration on Aging.

Recommendation 2

Administration on Aging

- The Administration on Aging (AoA) should use an objective method, such as the IOM Committee's practice standards, to conduct annual assessments of each states' office of the long-term care ombudsman.

- AoA should use its authority under federal law to enforce compliance with the OAA requirements for ombudsman services, and bi-annually, publicly report to Congress their findings and resolution plans.

- Regardless of the placement of the LTCOP, every non-compliant state must be assessed penalties and caused to correct those practices that willfully interfere with the operation of the ombudsman program.

Recommendation 3

State Unit on Aging

- Each State Unit on Aging Director, and its governing board, should review the OAA mandate for operation of the SLTCOP. If deficiencies are found in the practices or policies of the agency housing the program or in the operation of the program itself, immediate steps should be taken to correct the areas of concern. Correction plans should then be reported to AoA for their review.

Recommendation 4

State Long-Term Care Ombudsman Program

- Each State Long-Term Care Ombudsman Program, and its governing board, should review the OAA mandate for operation of the LTCOP. If deficiencies are found in the practices or policies of the state or local program(s) or in the systems advocacy operations, immediate steps should be taken to correct the areas of concern. Correction plans should then be reported to the state unit on aging for their review.

Pertinent Sections of the Older Americans Act

As Amended 42 USC 3058g

(a) Establishment.

* * *

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

(A) identify, investigate, and resolve complaints that-

(i) are made by, or on behalf of, residents; and

(ii) relate to action, inaction, or decisions, that may adversely affect the health, safety, welfare, or rights of the residents (including the welfare and rights of the residents with respect to the appointment and activities of guardians and representative payees), of—

(I) providers, or representatives of providers, of long-term care services;

(II) public agencies; or

(III) health and social service agencies;

* * *

(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

* * *

(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, 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--

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

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

* * *

(j) Noninterference. The State shall—

(1) ensure that willful interference with representatives of the Office in the performance of the official duties of the representatives (as defined by the Assistant Secretary) shall be unlawful;

* * *

(3) provide for appropriate sanctions with respect to the interference, retaliation, and reprisals.

References

Administration on Aging. AoA-PI-81-8, Supplemental Guidance in Implementation of Long-Term Care Ombudsman Program Requirement of the Older Americans Act. January, 1981.

Estes, C., Zulman, D. Goldberg, S., and Ogawa, D. Effectiveness of the State Long Term Care Ombudsman Programs. A report submitted to the Henry J. Kaiser Family Foundation, June, 2001.

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