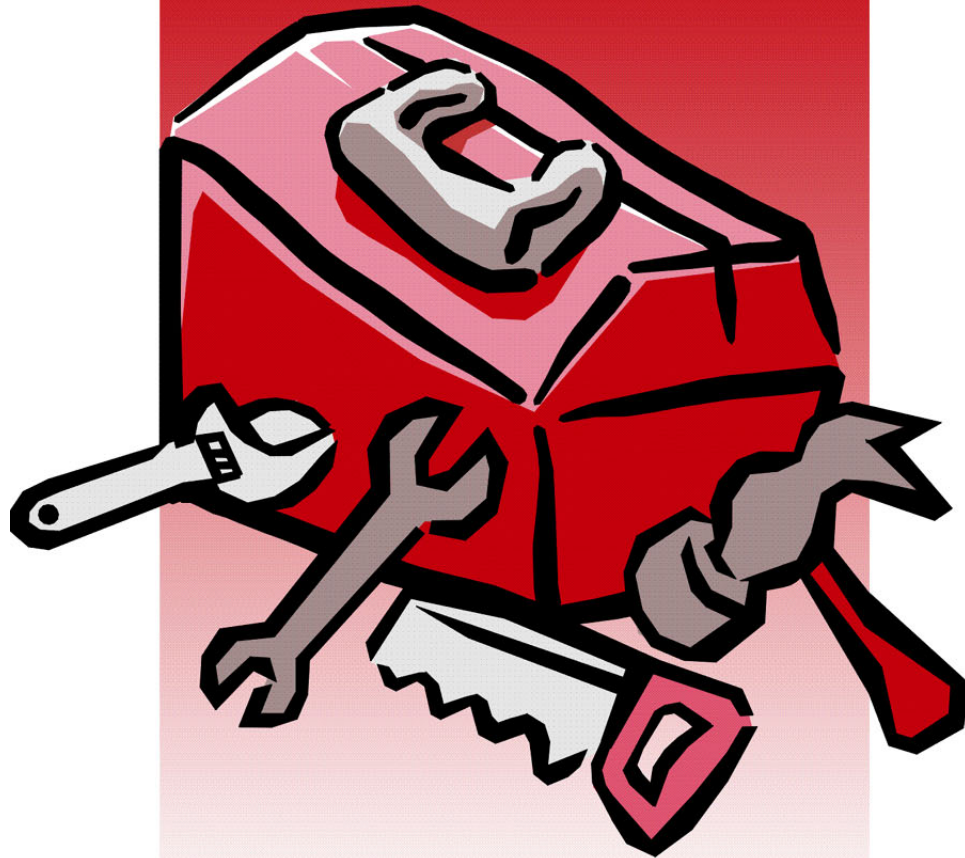


THE LONG-TERM CARE
OMBUDSMAN PROGRAM:
RETHINKING AND
RETOOLING
FOR THE FUTURE

NASOPRETREAT



**Proceedings
and
Recommendations**

APRIL 2003

National Association of State Long-Term Care Ombudsman Programs

The National Association of State Long-Term Care Ombudsman Programs (NASOP) was formed in 1985 and is a nonprofit organization. It is a membership organization made up of 52 state/territory long-term care ombudsman programs. NASOP is dedicated to improving the quality of life and quality of care of long-term care consumers through effective state long-term care ombudsman programs.

NASOP does this by:

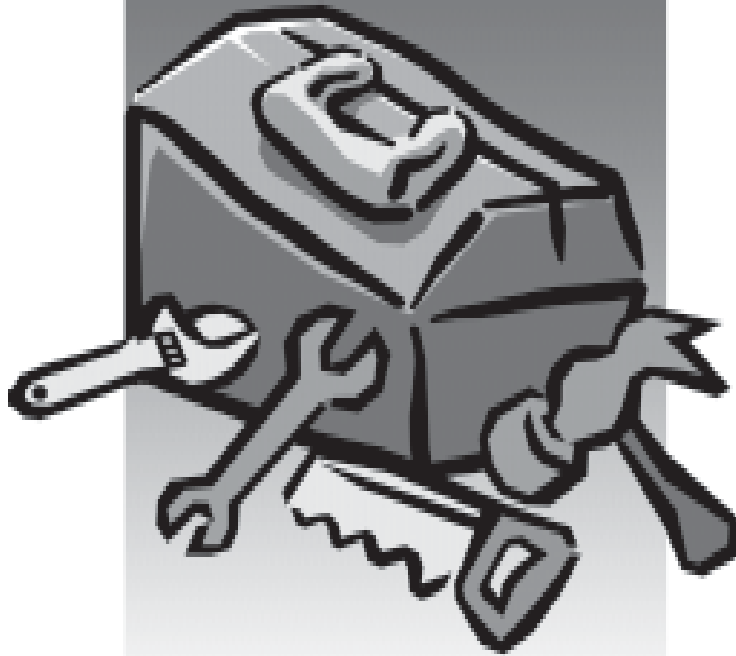
- Holding national education and advocacy training conferences;
- Providing mentors for new ombudsmen;
- Bringing ombudsmen together to exchange information and develop strategies to better serve long-term care residents;
- Developing position papers on long-term care issues;
- Analyzing and commenting on national legislation, regulations, and policies that affect long-term care; and
- Working in conjunction with other organizations to advocate for and make changes that will improve the lives of long-term care residents.

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Carol Scott

President, NASOP, and
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Finally, a special thanks to all the retreat participants. These individuals turned an idea into invaluable dialogue and developed a set of recommendations that will help direct the future of the long-term care ombudsman program and improve the quality of life for long-term care residents.

Foreword

The National Association of State Long-Term Care Ombudsman Programs (NASOP) is proud to publish the proceedings and background materials from our retreat: *The Long-Term Care Ombudsman Program: Rethinking and Retooling for the Future*.

The long-term care ombudsman program has now moved into its fourth decade and faces many challenges, including the aging of the baby boom generation, competition for resources, and a changing long-term care system.

Although the ombudsman concept has been in existence for hundreds of years, it is easily argued that the long-term care ombudsman program is the largest ombudsman program to date. Given its size and longevity, it has received relatively little attention, inadequate resources, and little research or scrutiny. As the members of NASOP look toward the new millennium, we embrace the notion of evaluation and critique from those inside and outside the program.

The questions and issues were numerous, but the mission was to evaluate whether the program is living up to the hopes of its creator, Arthur Fleming, former Commissioner on Aging and the first Secretary of Health, Education, and Welfare. He envisioned making justice and human dignity a reality for all individuals who reside in long-term care facilities. NASOP believes that in order to be viable, the ombudsman program must change as needed and remain contemporary. We must respond to the needs of long-term care residents by rethinking and retooling for the future.

We chose to face these challenges head on with the help of many of our colleagues at our retreat last year. We hope that you will see from this report that NASOP, with help from the Helen Bader Foundation, has carefully looked at the past, analyzed the current challenges, and begun a proactive and thoughtful agenda through the recommendations of the retreat. Our goal is simply to strive for excellence in the ombudsman program to ensure a better quality of life for millions of long-term care residents across America.

Carol Scott
President
NASOP

As the members of NASOP look toward the new millennium, we embrace the notion of evaluation and critique from those inside and outside the program.



Executive Summary

In 2001, the National Association of State Ombudsman Programs (NASOP), a non-profit organization composed of state long-term care ombudsman programs, received a grant from the Helen Bader Foundation to convene a forward-looking conference with a unique format. The retreat became an all-encompassing review of the ombudsman past, reflection on the present program, and consideration of its future. The format, which included commissioned white papers and a series of consensus-building sessions, involved all of the retreat participants in debates and discussions to a degree not commonly seen at a conference. The result was a series of recommendations in six key areas that will help state and local long-term care ombudsmen shape their programs in the years to come.

NASOP set out a number of ambitious goals for the retreat. It wanted a comprehensive review of the current research and knowledge about the long-term care ombudsman program (LTCOP), the characteristics of the long-term care population it serves, and the changing health care climate of the 21st century. It wanted to educate and inform the participants on these topics as well as stimulate discussion around the more controversial issues. Another goal was to consider how better to coordinate services for people with Alzheimer's disease and their families. NASOP also wanted to develop materials that could be used in publications, testimony, speeches, and other public commentary on the program and long-term care in general. Improvement in the ombudsman program and in the care of long-term care residents was the ultimate goal.

In order to accomplish these goals, NASOP asked the Retreat Advisory Committee to bring together a multidisciplinary group of individuals from the aging network, local and state ombudsmen, researchers, health care professionals, residents and their families, state and federal officials, and representatives of the health care and long-term care industries. The committee also commissioned six leading health and aging scholars and policy experts to prepare white papers for the retreat. The papers were sent to the retreat participants in advance of the weekend retreat so they would be fully prepared for the discussions and deliberations.

The Retreat Advisory Committee developed a consensus building format which involved small breakout groups, meetings of consensus committees, and then discussions and conclusions at the plenary session with the full body of participants. The recommendations evolved throughout the series of meetings – not all of the recommendations were accepted at each meeting and some were modified at each step. The result was 46 recommendations supported by the full body of participants.

The retreat evaluations showed that the participants came away with a sense of having accomplished a great deal. In addition to sharing information and expressing ideas, the participants were able to explore their visions of the improvements and successes they wanted to work toward in the coming years. The ombudsmen particularly felt a renewed sense of mission about their work. The NASOP retreat gave

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the participants, the organization, and the field of long-term care some new tools and resources for shaping the LTCOP's future, not the least of which is the resolve to meet obstacles and overcome challenges for the benefit of the long-term care ombudsman program and the population it serves.

NASOP will continue to use the materials created for the retreat and its outcomes to shape NASOP's strategies for the future of the ombudsman program.

Overview of Topics and Recommendations Developed at the Retreat Independence

The ability of the ombudsman program to carry out its responsibilities rests to a large extent on the degree of independence, or program autonomy, the ombudsman experiences. Two major factors that affect ombudsman independence are the organizational placement of the program and actual and perceived conflicts of interest. Other critical factors influencing independence include the degree to which ombudsman programs control their program resources, including budgets and expenditures, as well as the extent to which the program is accountable to residents and the public. Research by Carroll Estes found that program effectiveness is linked to the independence of the ombudsman program.

The retreat participants developed recommendations in several key areas that address independence. One set of recommendations lists in detail potential conflicts of interest and whether the conflicts should be eliminated or merely managed. This is an important concession to necessity, as the retreat participants felt strongly that an ombudsman's credibility rests, in part, on her or his being free of real or apparent conflicts of interest.

Another key area in the Independence section involves the Administration on Aging. In several recommendations, the retreat participants call on AoA to support the ombudsman quest for program autonomy. The LTCOP needs AoA to review and eliminate conflicts of interest, to monitor Older Americans Act (OAA) compliance, and to provide the ombudsmen with a full-time national-level administrator. The participants noted that AoA should receive the resources necessary to allow it to comply with the responsibilities required by the OAA.

Systems Advocacy

The retreat participants agreed that nationally, the long-term care ombudsman program is not consistently fulfilling its mandate to pursue systems advocacy. The participants found that barriers to systems advocacy included insufficient ombudsman education and training, lack of monitoring and enforcement on the state and national level, and inadequate partnering with other appropriate organizations.

Therefore, the recommendations for the topic of systems advocacy focused on training, support, relationships with other organizations, and accountability.

There were three recommendations of particular interest that emerged from the consensus building process. One recommendation calls for conducting oral interviews with state and local ombudsmen to get a full sense of the barriers, attitudes, and approaches to systems advocacy. Another was the belief on the part of the retreat participants that they must police themselves; therefore they recommended that NASOP develop intervention strategies and remedies for programs and states that are not doing a good job of systems advocacy. A third area of importance was a set of recommendations proposing better communication and closer working relationships with the National Association of State Units on Aging (NASUA), the National Association of Area Agencies

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on Aging (N4A), state units and area agencies on aging, as well as the National Association of Legal Services Directors (NALSD), and the National Association of Adult Protective Services Administrators (NAAPSA). It was felt that these organizations have a role in peer education and support of the ombudsman goal of systems advocacy. They also share the ombudsman and NASOP goal of serving older people and improving the long-term care resident's quality of life.

Training and Qualifications

The role of the ombudsman in the long-term care setting is demanding, requiring a wide range of abilities, knowledge, and characteristics. The environment may be unfriendly or even hostile, the residents are typically frail and may suffer from Alzheimer's disease or have other limitations to communication, and the ombudsman works alone. Clearly, an ombudsman must be well trained to solve problems and pursue advocacy in a variety of settings and situations.

By the same token, recruitment strategies and techniques must identify appropriate candidates for the job — paid or volunteer — in terms of skills, values, and temperament, so as not to waste personal or program time and resources. Turnover among ombudsmen, including volunteers, can be exacerbated by inadequate selection procedures and insufficient training, supervision, and support. The consequence of insufficient training and high turnover rates is that LTCOP effectiveness can be compromised, resulting in lost opportunities for advocacy, unsolved or inadequately solved problems, unmet needs, and dissatisfied clients.

The retreat participants were well aware of the challenges facing ombudsmen. The recommendations are appropriately sweeping as well as detailed. The first recommendation suggests the development of a mission statement because training should emanate from the values articulated in such a statement. The primary recommendation of the Training section calls for national training standards developed by a task force consisting of NASOP, the National Association of Local Long-Term Care Ombudsmen (NALLTCO), the National Long-Term Care Ombudsman Resource Center (NORC), and others. It outlines what the standards would address, what the subjects for new and continuing education should be, and specifies various training methods, including on-line learning. Another key recommendation urges NASOP to develop hiring and management tools for use by state and local programs.

Data and Information

Ombudsmen know that data and information, if done well, not only tell the story of how their program works, but also paint an accurate picture of the circumstances in which residents of nursing homes, assisted living, and other residential facilities find themselves. While specific case examples or anecdotal stories illustrate the story and provide emotional context, data provide a more complete picture. Data give a story scope and impact, making it more difficult for bureaucrats, the media, the public, and policy-makers to dismiss individual cases as isolated or “merely anecdotal.” Analysis of data can also assist long-term care ombudsmen in determining topics for training programs.

The recommendations for LTCOP Data and Information reflect three concurrent needs. One is the need to educate program staff and volunteers on the usefulness of data and the importance of complete and reliable data collection, entry, and analysis. The second need for NASOP, in conjunction with AoA and NORC, is to plan and implement a restructured and improved national reporting system. The system would be able to

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incorporate all kinds of data, from many sources, and be useful for comparisons, research, analysis, and education. The third area involves developing a funding strategy to obtain the necessary hardware and software for all LTCOPs to be technically and technologically up-to-date.

Program Effectiveness

The concept of program effectiveness incorporates all of the topics addressed at the NASOP retreat. Retreat participants know that effective advocacy is influenced by the organizational placement of the program and how much independence it has, the training and supervision of the staff and volunteers, the approach to systems advocacy, and the ability to measure and describe success and failure. Part of program effectiveness is dependent on the ombudsman's understanding of the special needs of the long-term care population, the changing nature of the long-term care industry, and knowing current research and best practices.

The recommendations that evolved from the discussions and debates at the retreat focused more specifically on the program operation aspect of program effectiveness. Two of the recommendations relate to the direction, supervision, and monitoring that those who are accountable should provide: from the director of the Office of Long-Term Care Ombudsman Programs in AoA, to the state long-term care ombudsman. Two of the recommendations are specifically prescriptive: one about the proper staffing equivalents and one about the response time for complaints of various priority levels. One recommendation addressed the issue of program placement and structure in order to maximize independence and minimize conflict of interest.

One of the most important recommendations challenged NASOP, NORC, and NALLTCO to develop a tool to measure ombudsman program effectiveness. The ability to evaluate a program's effectiveness has far-reaching implications for the program's future success.

The Changing Long-Term Care Resident Population and its Needs

The author of the white paper on this topic discusses the changes that have taken place in the long-term care field since the long-term care ombudsman program began three decades ago. Paramount is the growth of the elderly population, especially the oldest old and individuals suffering from Alzheimer's disease. This population growth has had an impact on long-term care and, by association, the long-term care ombudsman program. In addition, the long-term care resident no longer resides only in traditional nursing homes. Board and care facilities, assisted living facilities, and community and home based care are common settings for people in need of ombudsman services.

The Changing Population recommendations address a broad range of issues. One of the recommendations suggests independent research to determine the actual cost of the ombudsman program if all of the OAA mandates were fulfilled. Another recommendation urges NASOP to continue its work on national standards of care for assisted living. Training programs for long-term care ombudsmen on Alzheimer's disease, dementia, depression, and delirium are the focus of another recommendation. All of these recommendations are unique and urgent.

This topic contains the only recommendation from the retreat that deals with the LTCOP's public image. It calls upon NASOP to work with other organizations to develop a public awareness campaign to heighten the visibility of the LTCOP and the people it serves.



Introduction

The world of long-term care has changed dramatically since 1971 when the Long-Term Care Ombudsman Program was created. In addition to the growth in the older population, there have been changes in the financial status of the long-term care industry and in the way care is delivered in various settings, including nursing homes, board and care, assisted living, home care, managed care, and other settings. Advances in health care technology, more acutely ill patients, and the growing medicalization and professionalism of community care affect the treatment that long-term care residents receive and the demand for advocacy programs like the long-term care ombudsman program.

The Institute of Medicine conducted a yearlong study of the long-term care ombudsman program in 1995, *Real People Real Problems: An Evaluation of the Long-Term Care Ombudsman Programs of the Older Americans Act*. The IoM concluded that the ombudsman program serves a vital public purpose and contributes uniquely to the well being of long-term care residents and their families. It supported the program's mandate and its continuation. Further, the IoM report found that the program was not adequately funded and made several recommendations intended to build the program and bring it into compliance with law. It also acknowledged the program as a potential model for other health care ombudsman programs.

In order to remain responsive to its constituency, many in the long-term care ombudsman program believe that it must periodically review its mandate, assess its effectiveness, and closely examine the changing face of the population it serves. For example, most ombudsmen now regularly encounter people with Alzheimer's disease on their facility visits. Up to one-third of nursing home residents may have Alzheimer's disease. Ombudsmen need to be trained regarding the best advocacy services that will benefit individuals with Alzheimer's disease and their families. In addition, there is a need to reassess the research of the past and its recommendations and relevance to the long-term care system of the future.

To this end, the National Association of State Long-Term Care Ombudsman Programs (NASOP) received a generous grant from the Helen Bader Foundation to address these programmatic challenges. In February 2002, NASOP convened a consensus-building conference, *The Long-Term Care Ombudsman: Rethinking and Retooling for the Future*. The goal was to assemble a unique and diverse group of leaders to examine the past, present, and future of the long-term care ombudsman program, and to build consensus on recommendations for the next decade. Sixty-five individuals participated in the retreat.

The Retreat Advisory Committee chose policy paper topics and authors for the papers and helped select invitees. Moreover, the committee determined that a consensus format, while unique, was an excellent way to intimately involve many ombudsmen, health care and aging experts, and other advocates and stakeholders in a dialogue that would invest and invigorate them for the work that lies ahead.

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The policy and technical papers were commissioned to inform the retreat participants of the most current analyses of issues regarding the program, the changing long-term care environment, and options for the program's future. The six topic areas were:

- Independence of the ombudsman
- Systems advocacy in the ombudsman program
- Training and qualifications of the long-term care ombudsman
- Program data and information collection, analysis, and dissemination
- Program effectiveness
- Changing population and needs of the long-term care resident

These topics are the critical issues that have manifested themselves over the past years in the ombudsman program. Their interconnectedness is exemplified by the fact that a number of the papers address issues that bear on the program's effectiveness, itself a paper topic.

The papers were distributed to the participants prior to the retreat for review. The papers were designed to form the basis for discussion and recommendations. When possible, the paper authors presented their own papers to the participants. Each paper had a track at the retreat. Each track was divided into two breakout groups so that smaller groups could work concurrently to discuss the issues, propose recommendations, and develop consensus. Facilitators were delegated to stimulate response and discussion in each track's session and recorders were used to take notes and record consensus decisions. Each breakout group sent representatives to meet in smaller settings called conference committee meetings. The conference committees reported a set of no more than ten recommendations for each paper topic to the full body at a plenary session. During the plenary session, the full group discussed, modified, and developed consensus around recommendations in each topic area. Detailed descriptions of the consensus building process, the groups' discussions, and the recommendations are featured in this report.

The retreat participants were fortunate to hear from two very special speakers: Ms. Martha Eaves and Ms. Jean Scher. They provided the perspective of witnesses to the changes in the ombudsman program over the years and of personal contact with the program. Ms. Eaves has followed the program through her work as the Chair of the Georgia Council on Aging and as an advocate. Ms. Scher spoke to the group as a former nursing home resident and family member of a nursing home resident. Their real life lessons in advocacy helped to frame the retreat and inspire its participants.

NASOP would like to thank the Helen Bader Foundation for its support of the retreat, especially Robin Mayrl of the Helen Bader Foundation for her guidance and encouragement. Also, NASOP thanks the members of the Retreat Advisory Committee, and the retreat participants themselves, for making the retreat a success.

NASOP would also like to acknowledge and thank the talented paper authors: Carroll L. Estes, Robyn Grant, Elma L. Holder, Esther Houser, James R. Kautz, and H. Wayne Nelson, Jr. The complete texts of the papers can be found in the Appendices to this report. The National Long-Term Care Ombudsman Resource Center (NORC), directed by Alice Hedt, was extremely helpful to the authors and staff of the retreat.

NASOP would also like to recognize the hard work of the facilitators and recorders as well as Pam Carlson and the other staff of Management Plus for their logistical contributions. NASOP is grateful to the staff that conducted the bulk of the work that a

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project of this magnitude requires: Bill Benson, Kate Hughes, Sara Hunt, and Brian Lindberg. Special appreciation goes to Bill Benson, who ably served as the facilitator for the plenary sessions.

Finally, NASOP is indebted to George Potaracke and Brian Lindberg for having the vision for this endeavor and securing the resources to make it happen.

NASOP will continue to use the materials created for the retreat and the discussions and recommendations of the retreat itself to shape its strategies for the future of the ombudsman program. This manifests itself in programs, publications, testimony, speeches, and other public commentary on the program and long-term care in general. Improvement in the ombudsman program and in the care of long-term care residents is the ultimate goal.



Overview of Paper Topics and Authors

NASOP commissioned papers on six priority topics for exclusive use at the retreat. Leading scholars and experts in the field of aging, ombudsman programs, and long-term care policy wrote the papers. The authors were asked to provide an overview of the current situation, background information as necessary, the most up-to-date research findings, and analysis and recommendations. The retreat participants received the papers in advance so that they could attend ready to discuss, debate, and build consensus on the recommendations. Retreat participants were informed that the authors' views were not necessarily those of NASOP.

Independence: The Long-Term Care Ombudsman Program's Ability to Fully Represent Residents, by Carroll L. Estes, Ph.D.

Dr. Estes is a Professor of Sociology at the University of California, San Francisco. She is a leader in the field of aging, long-term care, and health policy and one of the nation's foremost scholars of gerontology. She is the author of 6 books and more than 100 scientific articles and book chapters. Dr. Estes chaired the 1995 IoM study on the LTCOP. She has been honored with numerous awards for her accomplishments in research, policy making, and education. In 1998, the League of Women Voters named her "A Woman Who Could Be President."

Dr. Estes's paper on independence focuses on the ability of the ombudsman to fully represent the residents of long-term care facilities given the program's mandate and structure under the Older American's Act. During 2000 and 2001, Dr. Estes and colleagues at the Institute for Health and Aging, University of California, San Francisco, conducted a study of state LTCOPs. The researchers found that organizational placement, conflicts of interest, and fiscal control are some of the key elements affecting the ombudsman program's independence. Further, they found that lack of independence or inadequate program autonomy inhibits the effectiveness of the ombudsman program. Dr. Estes provides research findings, analysis, and suggestions for securing program independence and improving program effectiveness.

Systems Advocacy and the Long-Term Care Ombudsman Program, by Esther Houser, M.S.W.

Ms. Houser has served as the State Long-Term Care Ombudsman in the Aging Services Division of the Oklahoma Department of Human Services since 1979. Her area of expertise includes ombudsman practice and long-term care issues, and she has published numerous articles and manuals on these topics. Ms. Houser served two terms as President of NASOP.

Ms. Houser's paper on systems advocacy describes the broad range of advocacy activities that long-term care ombudsmen conduct. While the Older Americans Act has been strengthened over the years to support advocacy work of the ombudsman

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program, Ms. Houser describes how in some cases states still prevent the long-term care ombudsman program from carrying out its full range of systemic advocacy. The mission of the long-term care ombudsman is to represent the interests of long-term care residents, not the state, providers, or even the aging network. As a result, Ms. Houser points out, the vulnerability of the program is obvious. The federal government bears the responsibility to evaluate each state's performance related to the program and to enforce the OAA. Ms. Houser's paper includes several recommendations on improving the ombudsman's ability to advocate effectively, from evaluation of performance and practical training of state and local ombudsmen, to action on the legislative and national level.

Training and Qualifications for the Long-Term Care Ombudsman Program, by H. Wayne Nelson, Jr., Ph.D.

Dr. Nelson is an Assistant Professor in the Department of Health Science at Towson University, MD. He has more than 15 years of experience overseeing Oregon's long-term care system as the Deputy Director of Oregon's state long-term care ombudsman program. Dr. Nelson is a Summer Fellow for the National Institute on Aging, Summer Institute on Aging Research. His academic and professional experience combines theory and practice on aging, advocacy, the ombudsman program, and other aspects of long-term care administration. In addition to publishing numerous articles, Dr. Nelson has served on many state and national task forces, provided training to ombudsman programs, and has been a spokesman in the media and to policy makers on aging issues.

Dr. Nelson's paper addresses the challenges of training and certification in the long-term care ombudsman program. To develop a "standard of best practice," Dr. Nelson points out that a number of concepts, subjects, and issues must be pulled together into a cohesive approach to training, educating, and evaluating ombudsmen. This paper discusses the differences between paid and volunteer ombudsmen, conflicts of interest, inconsistent training, the need for certification exams, the importance of continuing education, the role of performance reviews, and other areas critical to establishing consistently effective long-term care ombudsman programs. Dr. Nelson offers detailed recommendations for addressing the problems in ombudsman program training.

Long-Term Care Ombudsman Program Data and Information, by James R. Kautz, Ph.D.

Dr. Kautz recently completed a 21-year career in state government. In addition to experience in corrections, hospitals, and aging services, Dr. Kautz has served as a state long-term care ombudsman and a state unit on aging director from 1985-1990. His areas of expertise include program performance measures and quality of services. He has worked with NASOP and NASUA, and contributed a paper to the Institute of Medicine's study of ombudsman programs.

Dr. Kautz's paper describes how the use of data has become a valuable tool for many ombudsman programs. Statistics now provide support for advocacy positions, form the basis for priorities, and provide rationales for training programs. The proper use of data also helps ombudsmen inform individuals, legislators, and the media about issues such as quality of care. With the increase in the use and importance of data come problems with its collection and dissemination. Dr. Kautz points out that computerization has raised new issues about confidentiality of records as well as the adequacy of the computer systems themselves. The author describes the features of a useful data system and

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discusses ways that the Administration on Aging and national and state agencies can facilitate improvement in data and information use by long-term care ombudsman programs.

Long-Term Care Ombudsman Program Effectiveness: Building Strong Advocacy, **by Robyn Grant, M.S.W.**

Ms. Grant is a consultant with the National Long-Term Care Ombudsman Resource Center and the Manager of Advocacy Services with an elder law firm in Indianapolis. Ms. Grant served as the Indiana State Long-Term Care Ombudsman for eight years. She has also served two terms as President of NASOP and is currently on the boards of the United Senior Action Foundation and the National Citizens' Coalition for Nursing Home Reform.

Ms. Grant approaches the discussion of program effectiveness by describing an effective ombudsman program as one that pursues individual advocacy (individual resident issues) and systems advocacy (representing the interests of residents in general). She then defines the elements of an effective program, from its accountability and its goals and priorities, to its infrastructure and operation. For example, Ms. Grant points out that the organizational placement of the program must be unencumbered and free of conflicts of interest. She also discusses the financial resources required to support an effective long-term care ombudsman program, as well as the influence of relationships with other agencies, programs, and groups. Recommendations are offered for improving each element of program effectiveness.

The Changing Long-Term Care Resident Population and Its Needs, **by Elma Holder, M.S.P.H.**

Elma Holder founded the National Citizens' Coalition for Nursing Home Reform and served as the organization's executive director from 1975-1995. Prior to that role, Ms. Holder worked as a gerontology and health consultant for state and national agencies. Ms. Holder has received numerous awards for her groundbreaking work serving nursing home residents and improving nursing home care. Among those honoring her have been the Consumer Federation of America with the Esther Peterson Advocacy Award, Allied Signal with the Achievement Award in Aging, the Health Care Financing Administration (now "CMS") with the Administrator's Award, and the National Academy of Sciences with the Institute of Medicine "Gustave Leinhard" award. In 1998, *Contemporary Long Term Care*, a nursing home industry trade magazine, named Ms. Holder one of "20 Who Make a Difference."

Ms. Holder's paper describes how the composition of the long-term care population has changed over the years. Long-term care residents are likely to be older, with greater health care needs, especially those with Alzheimer's disease and other dementias. There is more diversity among the residents. Veterans and various ethnic and cultural groups are often underserved and need special assistance. People with disabilities who live in the community need specialized advocates to help them maintain their quality of life. Managed care presents new complexities and problems for consumers. Ms. Holder shows how these and other factors have a tremendous impact on long-term care facilities and on the ombudsman program. She enumerates the considerations that must be addressed when program expansion is discussed, as well as suggests how the ombudsman program can better serve a diverse population of home- and community-based long-term care clients.



Retreat Design: The Consensus Building Process

The goal of this retreat was to arrive at a set of conclusions and recommendations that would help steer the course of state long-term care ombudsman programs. The Retreat Advisory Committee designed the retreat specifically to ensure that the conclusions and recommendations reached would be based on the consensus of the participants. The retreat design included the following elements:

- Commissioned white papers written by leaders in the field of aging and ombudsman programs
- Discussion questions at the end of each paper
- Breakout groups corresponding to each paper topic
- Facilitators and recorders in each breakout group
- Conference committee meetings to select and prioritize recommendations from the breakout groups
- Plenary sessions.

Each conferee participated in two different breakout sessions on different topics. The breakout sessions corresponded to the six papers each participant received prior to the retreat: Independence, Systems Advocacy, Training and Qualifications, Data and Information, Program Effectiveness, and Resident Population. There were two breakout sessions offered at different times for each of the six topics.

Each breakout group was asked to reach agreement on five to ten specific recommendations directly relevant to its assigned topic. Discussion questions were provided. The exact process used for reaching consensus on the recommendations was left to each breakout group. Groups typically chose to discuss key topics from the papers, modify or draft recommendations, and take a poll of those who supported the recommendations. The authors of the topic papers participated and served as sources of information and analysis. Each breakout session had a facilitator who helped move the discussion toward consensus on the different recommendations and conclusions. A recorder captured the discussions. The breakout sessions lasted two hours and fifteen minutes with approximately ten people in each group.

Since there were two breakout groups addressing each of the topics, the retreat planners knew that the groups might arrive at different or even conflicting recommendations. Therefore, a process for reconciling differences or compromising on differences was included in the retreat design. These “conference committee” meetings were held between representatives of each of the breakout groups to reach agreement on the recommendations that would be presented in the plenary sessions. For example, representatives of the two breakout groups addressing “Independence” met in a “conference” session to decide which recommendations to offer on behalf of

Retreat Design: The Consensus Building Process

the two “Independence” groups and which would be the priority recommendations. Ninety minutes were available for the conferencing process. Conference committees were asked to bring no more than ten recommendations to the full group.

Two plenary sessions were held to discuss and consider each of the recommendations developed during the conference meetings. The conference meeting representatives presented their recommendations for up to 15 minutes, with 45 minutes for discussion and reaching consensus among the full body. A total of six hours was dedicated to this part of the process (one hour per topic). The first plenary session considered three retreat topics (Independence, Systems Advocacy, and Training and Qualifications) and the second addressed the remaining three topics (Data and Information, Program Effectiveness, and the Changing Resident Population).

The consensus building process during the plenary session did *not* include vote taking or prioritizing recommendations. However, the facilitators attempted to come to an understanding of where the full group of retreat participants stood on the recommendations and issues. For example, the facilitators considered whether the participants gave the recommendation: 1) strong support – “a thumbs up,” 2) moderate support – “it isn’t perfect, but I can live with it,” or 3) little support – “this is unacceptable.”

When the consensus building process was completed for the six topics, the full body discussed implementation strategies for the recommendations, as time allowed.

All of the work at each stage of this consensus building process was important to the success of the retreat and the sharing of ideas and information with NASOP.



Independence: The LTCOP's Ability To Fully Represent Residents

Retreat Recommendations and Analysis

The ability of long-term care ombudsmen to fulfill the promise to long-term care facility residents and the public, as contained in the Older Americans Act rests, to a large degree, on the independence of the individual ombudsman and program. A host of factors can influence the extent to which an ombudsman can perform her or his duties freely and fully – that is, without constraint. Two major factors that can have a profound effect on ombudsman independence are the organizational placement of the program and actual and perceived conflicts of interest. If the organizational location of the LTCOP is such that there are impediments to the ombudsman freely representing the needs and interests of residents, then the ability of the LTCOP to serve as an independent voice and advocate for residents is impaired if not destroyed. The impediment may be because the ombudsman is constrained from representing residents without the approval – explicit or implicit — of his or her superiors, or because the organization engages in activities that conflict with or are perceived as conflicting with the ombudsman's role. Ombudsmen may face impediments within their own organizations by restraints placed upon them by their superiors. Such restraints may include limiting or prohibiting ombudsmen from directly participating in activities that address policy matters related to residents and LTC facilities (e.g., committees, meetings, providing information).

Other critical factors influencing independence include the degree to which ombudsman programs control their program resources including budgets and expenditures, as well as the extent to which the program is accountable to residents and the public.

Carroll L. Estes conducted research to examine the LTCOP with particular emphasis on issues related to the program's effectiveness, independence, and its ability to engage in systemic advocacy. Selected results from Dr. Estes's research are found in the paper that she prepared for the retreat (see Appendix IV of this report). Dr. Estes found that more than half of the state long-term care ombudsmen (55%) stated that the organizational placement of their program creates difficulties for fulfilling their OAA responsibilities. Reported difficulties included "lack of autonomy to speak to legislators or the media, conflicts of interest, bureaucracy, limited access to resources; and budget vulnerability" (Appendix IV, Estes, p. 4). LTCOPs located within state agencies (both SUA and non-SUA) are much more likely (63% and 60%, respectively) than state LTCOPs located within legal services offices or nonprofit agencies (22%) to report difficulties in carrying out their responsibilities and providing services to facility residents (Appendix IV, Estes, p.4).

In her paper, Dr. Estes emphasizes that the extent of reported program autonomy is statistically significantly associated with state ombudsmen being able to carry out

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successfully their federally mandated duties on behalf of long-term care residents (Appendix IV, Estes, p. 7).

The retreat included specific discussion about whether the LTCOP could function effectively located in an entity of government, including state units on aging. Although there was not unanimous agreement on this issue, retreat participants did not recommend or intend to imply that LTCOPs should be moved outside of government.

Conflict of Interest

1.1) A LTCOP located in an entity of government (state or local) or agency outside government whose head is responsible for the following faces potential conflicts of interest that must be prohibited:

- **Licensure, certification, registration, or accreditation of long term care residential facilities;**
- **Provision of long-term care services, including Medicaid waiver programs;***
- **Long-term care case management; ***
- **Reimbursement rate setting for long-term care services;**
- **Adult protective services; ***
- **Medicaid eligibility determination;**
- **Preadmission screening for long-term care residential placements;**
- **Decisions regarding admission of elderly individuals to residential facilities (Harris-Wehling, Feasley & Estes, 1995; Recommendation 4.1, pg. 124);**
- **Guardianship services;**
- **Management or ownership of a long-term care facility.**

*** *Conflict of interest may be managed rather than prohibited***

Both breakout groups included this recommendation in their proposed recommendations. Concerns about actual and perceived conflicts of interest are especially significant for ombudsmen; hence the detailed list of situations where conflicts tend to arise. Participants recognize that the ombudsman's "stock-in-trade" is his or her credibility or word. Since ombudsmen have no enforcement power, they can neither compel action by any parties nor sanction them for failure to act in some way. The ombudsman's only power is the power to convince others to "do right" for the complainant or residents in general. Thus, it is imperative that the ombudsman and the program be perceived as free of conflicts of interest.

The conference committee discussed whether management of a conflict of interest is sufficient rather than to require a strict prohibition on every form of potential conflict of interest, and agreed that in some cases it is. Nevertheless, the overall feeling of the participants was that it is preferable to prohibit rather than manage conflicts of interest. Yet, there was clear recognition among the participants that this may not always be possible or may be too difficult to implement in some circumstances.

1.2) States must identify and propose remedies to conflicts of interest and report to the Administration on Aging. The AoA Office of Long-Term Care

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Ombudsman Programs should review, for the purpose of approval or disapproval, states' proposed remedies to conflicts of interest.

1.3) In collaboration with stakeholders, AoA's Office of Long-Term Care Ombudsman Programs must identify conflicts that must be eliminated.

These recommendations reflect in large part the desire of participants that AoA play a more active role in oversight, guidance, and monitoring of the LTCOP. Not only is this perceived as an appropriate role for the federal agency responsible for overseeing the OAA on a national basis, but is also consistent with AoA's statutorily based advocacy role. The organizational placement of individual LTCOPs, and the circumstances under which they operate, may well require that AoA perform its oversight responsibilities to rectify situations involving actual or perceived conflicts of interest, and to ensure that older Americans and their families receive the assistance of ombudsmen that best reflects the letter and spirit of the OAA.

Independence and Authority

1.4) LTCOP autonomy is essential to program effectiveness. State LTCOPs should have sufficient organizational autonomy from the state to ensure that ombudsmen may advocate for residents (in accord with their responsibilities as defined by law) without fear of political ramifications. As advised by the 1995 IoM Report: "Ombudsmen must be able to pursue independently all reasonable courses of action that are in the best interest of residents." (Harris-Wehling, Feasley & Estes, 1995; pg. 125). Therefore, NASOP should work to ensure that in order to comply with the Older Americans Act, Section 201, the Administration on Aging should include a position responsible for the administration of the ombudsman program. A full-time dedicated position (Director of the Office of the Long-Term Care Ombudsman Programs) should report directly to the Assistant Secretary on Aging.

The conference committee reached consensus on this recommendation, but no consensus was reached during the plenary session. While there is a clear sense among ombudsmen that the position of Director of the Office of LTCOPs at AoA should be full-time, there is recognition that even a part-time position is desirable in the absence of a full-time position. NASOP is grateful that the Assistant Secretary for Aging has named a senior staff member to serve as Director of this office despite the fact that the incumbent has many other demanding responsibilities within AoA. Nonetheless, NASOP believes that a part-time position is a positive step forward.

The following language was deleted during the final discussions: *The ombudsman position at the state and local levels should be elevated to report directly to the director of the respective agency (if the ombudsman is not the director), for the purposed of maximizing independence.* In part, this reflects participants' recognition that such a requirement would be exceptionally difficult and disruptive to the program in a number of states.

Accountability

1.5) The Administration on Aging should monitor the LTCOP compliance with the Older Americans Act. AoA's Office of Long-Term Care Ombudsman Programs

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should be provided adequate resources to fulfill the responsibilities required by law.

This recommendation is similar to a recommendation that emerged from the Effectiveness group, reflecting the overall importance of this activity. The provision in Title II of the OAA requiring that the Administration on Aging establish an Office of State Long-Term Care Ombudsman Programs and that a "Director head it" was created for several key purposes. These include providing a focal point within the federal government for the states' LTCOPs, monitoring the overall effectiveness of LTCOPs, and responding to complaints and concerns that the individual states' LTCOPs are not in compliance with OAA provisions. The participants agreed that given the statutory array of roles and responsibilities delineated in the OAA for this position, it couldn't be effectively implemented without adequate resources.

1.6) Mechanisms should be developed to hold the program accountable to fulfill the public trust, including:

- **Ensuring that state long-term care ombudsman programs have their own independent advisory boards;**
- **Dealing with potential or actual conflicts of interest;**
- **Hearing disputes around program independence and autonomy and working to resolve them.**

Whereas the LTCOP endeavors to hold the various parties of long-term care accountable for the performance and behavior from the perspective of the wishes and needs of residents, the program must also be accountable as a matter of public trust, especially to long-term care facility residents and to the public. The retreat participants believe that achieving these recommendations would represent major steps in ensuring the LTCOP is indeed accountable for its work. Participants also believe that all stakeholders in the LTCOP especially AoA, the SUAs, state and local LTCOPs, and NASOP must be committed collectively and individually to fulfilling this recommendation.

1.7) Research and evaluation should be conducted on the issues of the autonomy and independence of the program including the organizational structure and placement of the LTCOP that will allow ombudsmen best to meet statutorily mandated requirements, including complaint investigation; resident, family, and community education; and systems level advocacy. Issues of conflicts of interest also need to be investigated.

Dr. Estes's recent research about the LTCOP has contributed a great deal of new knowledge and understanding regarding the extent of autonomy in long-term care ombudsman programs and the consequences of its presence or absence. This work, coupled with the landmark IoM study of the LTCOP, chaired by Dr. Estes, and limited research by others have been essential to improvements in the program. It is clear from the deliberations during the retreat that the participants and NASOP believe that continuing research and evaluation that examines the program at the national, state, and local levels is essential for the following: continuous improvement in the LTCOP; ensuring that, in every state, it fulfills the promises of the OAA and that all residents can expect a consistent level of service regardless of where they reside; and ensuring that the program adapts appropriately to the changing world of long-term care.



Systems Advocacy in the LTCOP

Retreat Recommendations and Analysis

Systems advocacy is central to the roles and purpose of the long-term care ombudsman program. The Older Americans Act has long been clear on the importance of systems advocacy by ombudsmen: that it is an integral part of the LTCOP. From its earliest days, the LTCOP's mandate has been to "recommend changes in the long-term care system which will benefit institutional residents as a class" (AoA Program Instruction, 1981) (Appendix V, Houser, p.3). From the program's inception, it has been recognized that to focus solely on responding to individual complaints by individual residents would mean not only that ombudsmen address the same or similar matter over and over, but also that much larger numbers of residents with a similar problem would not be helped if all matters were handled on a case-by-case basis. Not only would that undermine program efficiency, but time and resource limits would dictate that large numbers of individuals would not receive help.

Esther Houser, the author of the paper on systems advocacy, observes that the range of activities constituting systems advocacy is very broad. Such activities can be focused on a single facility, all the facilities owned by one large provider or an entire chain, the industry as a whole, or other elements of the long-term care system, such as the regulatory and reimbursement systems. The goal driving ombudsman advocacy on any level is improving the lives and circumstances of long-term care clients individually and collectively.

In order to engage in systems advocacy in a meaningful way, state and local long-term care ombudsmen must have the resources and the autonomy to communicate on behalf of residents to providers, regulators, lawmakers, the media, and others in a position to influence or create change in practice and policy. Despite the statutory underpinnings of and the need for systems advocacy, there remains wide variation among states in the ability of the LTCOP to engage in systems advocacy. Some states' LTCOPs do not engage in advocacy activities at all beyond helping individual residents resolve their individual complaints (Appendix V, Houser, p.4). Others work indirectly through state and local citizen advocacy groups. Some state programs are not allowed to contact directly the media or policymakers. Moreover, many ombudsmen are hampered in their work by lack of independence related to their organizational placement. Severe limits in funds and personnel will likely mean that ombudsmen may have only the wherewithal to respond to individuals and be unable to address matters on a more systemic basis.

Inattention to or deliberate constraints on the ability of ombudsmen to do systems advocacy has been compounded by the lack of performance evaluation related to systems advocacy and outcomes and the lack of oversight of states' LTCOPs. Reports by the Office of the Inspector General, the General Accounting Office, and the Institute

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of Medicine have found that states need more guidance from the federal government in general and specifically with regard to systems advocacy (Appendix V, Houser, p.4).

2.1) NASOP should work on the following recommendations because nationally, the ombudsman program is not consistently fulfilling the federal mandate to pursue systems advocacy.

As the retreat participants deliberated about the potential for and realities among LTCOPs related to systems advocacy, a clear consensus emerged that LTCOPs, at both the state and local levels, face numerous impediments to their ability to carry out this fundamental and crucial part of their responsibility. In short, because this mandate under the OAA is simply not met in far too many programs, serious problems affecting residents go unresolved and in some cases are exacerbated. The consensus is that eliminating these impediments must be a high priority by all stakeholders in the LTCOP, from ombudsmen themselves to policy makers to all state and area agencies on aging. Participants offered examples of state and local LTCOPs that are able to conduct effectively systems advocacy without hindrance or other major constraints. Some of these examples could be considered as best practice scenarios that should be emulated in other states and localities.

The members of breakout group one noted that there are a number of reasons why systems advocacy is not being aggressively pursued throughout the nation. The lack of resources, the organizational placement of the programs, and the failure on the part of the ombudsman program itself to understand that systems advocacy is one of their central duties were discussed. Inadequate training and lack of monitoring were also pinpointed.

Breakout group two brought recommendation 2.1 to the conference committee meeting with the terminology, “the ombudsman program is not fulfilling the federal mandate to aggressively pursue systems advocacy.” It was accepted. During the plenary session with the full body of retreat participants in attendance, the word “aggressively” was deleted from the last phrase and “consistently” was inserted. The retreat participants felt that the word “consistently” portrayed the on-going and regular nature of the ombudsman’s duty to systems advocacy. The term “aggressively” was not necessary because of the already important nature of systems advocacy.

First Step:

2.2) NASOP, in cooperation with the National Association of Local Long-Term Care Ombudsmen should conduct confidential oral interviews with all state ombudsmen and some local ombudsman to get a full sense of attitudes, barriers, and supports to fulfilling the mandate for systems advocacy.

The participants noted that local ombudsmen are an integral part of the long-term care ombudsman program. To fail to elicit information from local ombudsmen would create an incomplete picture of the ombudsman experience for they are the very people who carry out the day-to-day duties of the ombudsman program. Systems advocacy at the local level may be quite different from the work the state ombudsmen might accomplish. Local ombudsmen would most likely concentrate more on local entities, media, and legislators than the state ombudsman. Gathering information from local ombudsmen would provide necessary evidence as to the barriers to advocacy,

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the need for training, and other important information.

In addition, one cannot necessarily draw conclusions about a program in one state from information about a neighboring state. It is necessary to collect information from each state.

The question was raised as to whether Carroll Estes had surveyed local ombudsmen in her recent research. Carroll commented that her paper did not cover local ombudsmen. Carroll noted that this portion of her research was the most problematic and needed to be addressed further.

In the conference committee meeting, participants requested that NALLTCO work with NASOP on the interviews. The group thought this was appropriate and helpful, as NALLTCO is the ideal organization to work with NASOP on this recommendation.

Training:

2.3) The National Long-Term Care Ombudsman Resource Center should ensure that orientation of all new state ombudsmen include training in systems advocacy.

NORC is responsible for developing many of the training tools that ombudsmen use, as mandated by the Older Americans Act. So much of long-term care policy is federally developed and nationally applied, such as standards for nursing homes, that for consistency and completeness, training on systems advocacy appropriately would come from NORC.

2.4) The National Long-Term Care Ombudsman Resource Center should develop ongoing systems advocacy training, including community organization skills, for all state and local long-term care ombudsman programs.

The retreat participants felt that community organization skills were particularly valuable for promoting systems advocacy. The elements of organizing residents and their family member councils, and getting to know local policy makers are brought together under community organization skills.

Ongoing training is also necessary in situations of evolving research and changing best practices, as well as when new personnel join the ombudsman program.

2.5) NASOP should establish teams of experts to offer on-site visits to educate their state counterparts and the state unit director on effective systems advocacy. NASOP should work with the National Association of Legal Services Directors, the National Association of Adult Protective Services Administrators, and others as appropriate and necessary.

This strategy was recommended because the retreat participants felt that experienced peers are the best people to convey the intricacies of systems advocacy. In addition to NALSD and NAAPSA members, the “experts” would include individuals from state units on aging, area agencies on aging, as well as ombudsman program staff and citizen activists. It became clear that the retreat participants felt that there was no cookie cutter approach to systems advocacy.

Support:

- 2.6) NASOP should develop intervention strategies and remedies to assist state LTCOPs to fulfill their mandate for systems advocacy. Strategies might include training, mentoring visits, letters of support from residents and citizen groups, and other state and national senior organizations. Remedies might include congressional inquiries, requests for sanctions, writs of mandamus, or private lawsuits.**

Retreat participants endorsed this recommendation because it conveys an important aspect of the long-term care ombudsman philosophy of always seeking to improve the ability to serve residents. The recommendation specifies strategies and remedies to address state and local programs that are not adequately providing systems advocacy. The retreat participants believe that, through NASOP, ombudsmen must take it upon themselves to monitor state and local long-term care ombudsman programs; in essence, ombudsmen must police themselves. This is a logical and appropriate extension of systems advocacy. If states are not doing what they should be doing, i.e., systems advocacy, the entire ombudsman program can be hurt. If systems advocacy is not consistently being pursued throughout the country, the LTCOP mandate is not being fulfilled.

Relation to other Organizations:

- 2.7) NASOP should continue the dialogue with conference participants and other organizations to develop a joint policy statement supporting enforcement of the OAA mandate for systems advocacy.**

This recommendation reflects the importance of involving the many organizations and agencies that work closely with state and local ombudsmen in promoting more effective systems advocacy.

- 2.8) NASOP should contact the National Association of State Units on Aging and reconvene the joint work group to address areas of concern and collaboration.**

The participants felt that NASUA is pivotal to supporting enforcement of the OAA mandate, statewide and nationally.

- 2.9) NASOP should ask the National Association of State Units on Aging, especially due to its role in the National Long-Term Care Ombudsman Resource Center, to work with NASOP to address the barriers to effective ombudsman programs that exist in some state units on aging.**

NASUA has a unique role to play because it represents the state units on aging. SUAs have special insight and perhaps understanding why some of the barriers to systems advocacy have evolved. NASUA has the ability to help facilitate the kinds of exchange of information and promotion of best practices within the state units. NASUA is also in a position to motivate SUAs that have not performed well with systems advocacy.

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2.10) NASOP should review, and revise if needed, “What’s it All About? Ombudsman Program Primer for State Aging Directors and Executive Staff,” as part of the preparation for meeting with the National Association of State Units on Aging.

Participants thought this was a very specific and helpful way to begin information exchange between NASOP and NASUA about systems advocacy.

2.11) NASOP should contact the National Association of Area Agencies on Aging to convene a joint workgroup.

Area Agencies on Aging (AAAs) have a responsibility to be advocates for older people, and AAAs help run most local ombudsman programs. AAAs need to be engaged fully in the effort for effective systems advocacy. Retreat participants identified AAAs and their national association as key players in many aspects of LTCOP systems advocacy. AAAs often work closely with zoning bodies, county commissioners, local media, and other local entities and could be very helpful to local ombudsmen.

Accountability:

2.12) NASOP should assert its influence on the Administration on Aging to fulfill its OAA responsibilities.

Retreat participants feel that given the enormity of OAA responsibilities and its many programs and stakeholders, it falls to NASOP to focus AoA on the LTCOP and to address the critical program issues. Participants recognized that given the lack of a full-time director of the Office of SLTCOP, the enormity of the jurisdiction of AoA, and the limited AoA staff and resources, it is appropriate for NASOP to be the voice of ombudsmen to AoA. NASOP must make sure that AoA is cognizant of the issues around systems advocacy, especially where the OAA mandate is not being fulfilled.

2.13) NASOP should review the findings and recommendations of the 1995 IoM report related to the ability of LTCOPs to carry out systems advocacy activities, and develop and implement a method for assessing the performance of state and local long-term care ombudsman programs.

Retreat participants thought it would be an appropriate role for NASOP to look back at the highly acclaimed IoM report and determine if it offers any further implications for improving systems advocacy.



Training and Qualifications for the LTCOP

Retreat Recommendations and Analysis

The appropriateness of those who serve as ombudsmen, in terms of their qualifications and the training they receive, has been a major focus and challenge for ombudsman programs throughout the LTCOP's history. Arguably, the role of an ombudsman in the long-term care setting is one of the most difficult positions imaginable. This is true for paid ombudsmen and even more so for volunteers. An ombudsman is expected to enter into a setting — the long-term care facility — as an outsider, and is there to accept and respond to complaints voiced by residents and those who voice them on their behalf; complaints are usually about or related to the care and services provided within the facility. The ombudsman may be met with an unpleasant, unfriendly and, on occasion, hostile and defensive reception by facility personnel, especially management.

When an ombudsman accepts a complaint, inherent within that complaint — depending upon its nature and severity — is the potential for serious consequences for the facility, such as complaint-triggered inspections, citations, civil monetary penalties, and even harsher sanctions including potential lawsuits. Potentially serious consequences for facility personnel can result from some complaint investigations including dismissals, sanctions related to their professional licenses, or worse. This is all to say that an ombudsman must be well trained to solve problems and pursue advocacy in various environments and under varying degrees of pressure.

Further, facility residents are typically very frail or disabled. They often suffer from Alzheimer's disease and other dementias or have other limitations in their ability to communicate, making informed consent and care directives very difficult. Consequently, the ombudsman requires specialized and sophisticated training on communication and caregiving for persons with mental health conditions and dementias.

Therefore, it is imperative that ombudsmen be right for the job. Recruitment strategies and techniques must identify appropriate candidates for the job — paid or volunteer — in terms of skills, values and temperament, so as not to waste personal or program time and resources. Turnover among ombudsmen, including volunteers, can be very high especially if ombudsmen are not appropriate for the roles or do not receive adequate training, supervision, and support. Particular attention must be paid to strategies to retain ombudsmen, especially volunteers, so as to minimize attrition within the ranks.

The skills needed to be an ombudsman are diverse and sophisticated, ranging from the ability to communicate effectively with providers and regulators, family members and representatives of community organizations, and, most importantly, residents. Communication skills must include the ability to interview and to effectively elicit facts and then to document the facts and information obtained. The core statutory role of the ombudsman is to investigate complaints, thus investigative skills, including those related

Training and Qualifications for the LTCOP

to evidence, are imperative in the role. The role is much more than to investigate complaints; it is to resolve complaints. Thus, the ombudsman must possess problem resolution skills, from developing problem-solving strategies to negotiating skills. Ombudsman managers must be able to provide solid supervision and direction to the ombudsmen under their jurisdiction to ensure effective and responsible ombudsman services in their states and communities.

Ombudsmen must be well trained. That includes ongoing training or continuing education, not only to refine and hone skills but also to learn new information and develop new skills. The long-term care field is dynamic, especially given the changing nature of the long-term care population (see separate discussion on this topic) and the long-term care field, including its oversight and financing.

Continued preparation for serving effectively as an ombudsman also requires feedback and evaluation. Individual ombudsmen, the programs within which they work, and the clients they represent, deserve to know what is working and what can be improved upon. Programs need the technical support and resources to engage in meaningful evaluation of their recruitment, training, and supervision of ombudsmen.

All of this has created on-going challenges for ombudsman programs throughout the country, from making proven strategies and techniques widely available to obtaining the resources to ensure adequate recruitment, training, supervision, and support of ombudsmen. The recommendations agreed to during the retreat address these challenges.

3.1) NASOP should articulate the values of the ombudsman program through a mission statement for the Long-Term Care Ombudsman Program, grounded in the Older Americans Act. Training should emanate from those values.

The breakout groups discussed the prospect of developing a national training program for state and local long-term care ombudsmen. In doing so, they realized that, over time, different approaches to their roles have evolved (e.g., advocacy vs. mediation). The programs also may have somewhat different goals (e.g., individual complaint resolution vs. systemic change), and emphasize different values (e.g., paternalistic vs. resident directed). Under these circumstances, it would be difficult to develop national training standards. The need for a mission statement became apparent to retreat participants to ensure that ombudsman programs function from a common core set of values and roles based on law. As one participant said, “training begins with values.” All ombudsmen, whether paid or volunteer, whether on the local, state, or national levels, would have a common understanding of the program’s mission, vision, and values. The OAA was considered the appropriate starting place for developing such a mission statement.

The recommendation was accepted in the conference meeting with only the addition of the phrase *for the long-term care ombudsman program*. It was accepted without change in the plenary session.

3.2) NASOP should promote and encourage state long-term care ombudsman programs to view training as a basic management function linked to other management processes, program policies, and procedures. NASOP should call upon all state long-term care ombudsman programs to review and evaluate their training programs to ensure compliance with the OAA and for internal consistency.

Training and Qualifications for the LTCOP

H. Wayne Nelson, the author of the retreat white paper on training and qualifications, points out that although NORC has developed “excellent” training materials, training programs vary widely across the nation. For example, preliminary training may range from 5 to 48 classroom hours. Nelson observed that on local, state, and national levels, concern exists about the inconsistency and inadequacy of LTCO training. The consequence of insufficient training is that LTCOP effectiveness can be compromised, resulting in lost opportunities for advocacy, unsolved or inadequately solved problems, unmet needs, and dissatisfied clients.

In addition, breakout group two pointed out that the state long-term care ombudsman programs should examine and evaluate their training programs to ensure consistency and effectiveness in their content and application.

This recommendation followed from the conference participants’ discussion of national standards. Just as a mission statement is needed to clarify and reinforce the ombudsman program’s vision and values, so too the LTCOP needs to know what training regimens (including curricula and methodologies) currently exist in order to move forward on developing nationwide training protocols. During the conference meeting, the participants combined two recommendations to create the final version of recommendation 3.2.

3.3) National standards for training representatives of the Office of the State Long-Term Care Ombudsman (individual designation or certification of representatives) should be developed by a task force of NASOP, the National Association of Local Long-Term Care Ombudsmen, the National Long-Term Care Ombudsman Resource Center, and others, as appropriate. The standards would address: (a) core competencies for basic certification training; (b) minimum number of hours for training prior to designation and for maintaining designation (on-going training); (c) content topics; and (d) methods. These standards need to be accessible to local ombudsmen via the Internet as well as other means.

The state long-term care ombudsman should direct the training. Topics for initial and continuing in-service training should include subjects such as:

- Investigation and problem resolution skills
- Conflict of interest
- Confidentiality
- Access
- Autonomy
- Systems advocacy
- Reporting system
- Ombudsman values (including resident directed and resident centered)
- Ombudsman ethics
- Protocols for ombudsman work/roles
- OAA and the LTCOP
- Laws as tools, such as resident rights
- Resident direction: for care and also with ombudsman competency (Precedence Protocol for Advocacy)
- People resources and when ombudsmen need to contact them
- Mental health issues
- Alzheimer’s and other dementias.

Training and Qualifications for the LTCOP

Methods for training should include:

- **Looking at web-based tools such as manuals, questions and answers, core competencies, sections of content**
- **Facility visits, mentoring, and internships under the guidance of the LTCOP**
- **Application-based “Formal” evaluation before certification**
- **Conference calls on specific topics for on-going training**
- **Training conferences.**

Many of the retreat participants acknowledged the good work in the area of training by NORC. They conceded, however, that, in general, ombudsman training across the country needed improvement. There was a great deal of discussion and debate about the details of what those improvements should be. Some participants questioned the need for a national program, considering the differences between states and localities. The response was “an ombudsman is an ombudsman, regardless of state or locality.” The issue of values arose, and the fact that values sometimes differ between programs. They agreed that the Precedence Protocol for Advocacy (PPA) should be a prominent part of the core competency curriculum. The author of the paper’s position was that the PPA (*informed consent* first, *substituted judgment* second, and *beneficence* only as a last resort) should be a guiding principle in all ombudsman interactions regarding residents’ rights.

The conference committee members agreed to rank the list of subjects considered for training topics by their order in the OAA provisions. Although the paper specified a training regimen, including format (lectures, role plays, etc.), number of hours of classroom work and home study, and other training aids, the breakout groups declined to be so specific in their recommendation. There was concern about being “over-prescriptive.” Breakout group one wanted the task force to “recognize the complexities and grand scale of the subject.” At the plenary session, the retreat participants added the phrase requiring Internet access to the training standards and they added “Alzheimer’s disease” to the list of topics for continuing in-service training.

The evaluation phase is a key part of training. Only 11 states evaluate their ombudsmen for certification purposes. On-going training and performance appraisals also must be part of a complete management plan.

3.4) NASOP should work with the Administration on Aging, the National Association of Local Long-Term Care Ombudsmen, and the National Long-Term Care Ombudsman Resource Center to develop:

- **Role-appropriate selection criteria for ombudsmen;**
- **Management tools for ombudsman programs using volunteers, including recruitment and retention;**
- **Tools for understanding and minimizing attrition;**
- **Skills and tools for effective training including using new technologies. These products will be developed with an advisory group(s) of state and local ombudsmen.**

This recommendation reflects the retreat participants’ agreement with the author on the subject of recruiting and training newly hired long-term care ombudsmen. The paper author points out that by spending extra time and effort upfront, the “payoff will be more competent and satisfied staff with decreased attrition down the road (Appendix VI, Nelson, p.7).” The paper identifies attributes that a screener would look for in an applicant (such as a sense of justice, which may be more important than empathy) and suggests resources for training effective interviewers. Breakout group one discussed interview

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techniques for identifying a conflict avoider (for example, using an assessment tool called the Thomas-Killman conflict model), someone who is advocacy-oriented, etc. One group member suggested that an interviewer could ask “trick questions” during the screening, such as “how do you punish a patient when they do something wrong?”

The volunteer ombudsman is included in this recommendation. Volunteers can and do play a variety of roles in ombudsman programs, and they deserve appropriate recruitment and training both to enhance their performance outcomes and their own job satisfaction, as well as to contribute to overall program success. Volunteers and the issues of liability and provider relations were raised during the discussion. It was pointed out that some providers do not want to deal with volunteers because they want a trained, accountable, *paid* professional. For some providers, this is driven by the belief that volunteers may lack traditional motivations and incentives for not “stepping out of line” or for being too aggressive in their advocacy – e.g., wanting to keep their job, or pay raises. Of course, with appropriate selection, training, and supervision, a volunteer should be no different than any employee, whether they receive monetary compensation or not – i.e., an accountable, responsible, and valuable resource. It was broadly acknowledged at the retreat that the LTCOP needs resources to implement a successful volunteer program. It takes “money, commitment, and investment.” The notion that volunteers come “free” of cost is absurd on its face, even more so if the expectation is that they are appropriately recruited and screened, trained, evaluated, and supervised; these are all management responsibilities that have program costs associated with each.

This recommendation also specifies the use of “new technologies.” The breakout group participants felt that the LTCOP should take advantage of the growing number of opportunities for on-line learning, from virtual-lectures to topical chat rooms. The author points out that in using on-line forms of learning, “the learner’s direct contact with the program need not be sacrificed, as long as in-service opportunities and continuing education courses are regularly scheduled (Appendix VI, Nelson, p.17).”

3.5) The National Long-Term Care Ombudsman Resource Center, working with NASOP, should expand the orientation for new state ombudsmen, covering the critical aspects of their role.

The Training paper offers a model for training new ombudsmen that covers the core content of the role. Breakout group one recommended that the paper be a resource for developing a tool for orienting new state ombudsmen to their role. In addition to an initial orientation, it points out that new information needs to be followed up with guidance, supervision, and feedback. For example, the new ombudsman may learn in the “classroom,” but the theory must be applied at the facility and through interactions with residents, health care professionals, regulatory personnel, and others. In order to ensure that the program’s values as well as the skills necessary for effective advocacy are instilled in the new ombudsman, on-going supervision or even mentoring should take place.

The participants considered the “critical aspects” to be included in the list of subjects listed under Training recommendation 3.3 (e.g., conflict of interest, confidentiality, systems advocacy, etc.). The other key point of this recommendation is that NORC should work with NASOP in the expansion of the orientation.

Also discussed in the paper was the idea of “facility rotation.” This is an approach that programs embrace for at least two reasons: 1) so that an ombudsman doesn’t get too “comfortable” in a particular facility and develop cozy relations with facility personnel; and 2) to ensure that more facilities have ombudsman coverage when there are not enough ombudsmen to cover the facilities within the jurisdiction. The retreat participants did not agree to a recommendation on this topic.



LTCOP Data and Information

Retreat Recommendations and Analysis

Data can be both the bane and blessing of long-term care ombudsman programs. Ombudsmen are often overwhelmed with their daily work – receiving and investigating complaints, raising funds and managing their programs, and working to improve the quality of care and life for long-term care facility residents, along with other tasks. Recording, analyzing, and managing data can be an immense chore for under-resourced and overworked advocates, especially when the data is thought of in terms of being done for bureaucratic or “bean-counting” purposes.

Yet, ombudsmen know that data and information, if done well, not only tell the story of how their program works or does not work, but also paint an accurate picture of the circumstances in which residents of nursing homes, assisted living, and other residential facilities find themselves. For example, several recent studies suggest that persons with dementia, such as Alzheimer’s disease, are at increased risk of elder abuse. More data and better dissemination of the information could help ombudsmen provide the knowledgeable advocacy that people with Alzheimer’s disease and their families deserve.

Retreat participants endeavored to reach agreement on how data and information related to the ombudsman program can be obtained, analyzed, and used in ways that are not cumbersome and are user-friendly; that are meaningful, useful and timely; that respect and protect confidentiality; and that can be reasonably paid for.

The conference committee members (all from the one breakout group) brought seven recommendations to the plenary session for the full body to consider. The recommendations focus on concerns for confidentiality of information, the usefulness of the data, and the technical integrity of the data and the computer system itself. Concerns related to conflicts of interest are also important. Other important issues include training on data systems, and the purchase and use of appropriate software. Language regarding confidentiality and conflicts of interest was added and approved at the plenary session for this topic.

4.1) NASOP should work with the Administration on Aging and others to plan a national reporting system that will incorporate disaggregated data that can be useful for comparisons, further study and research that supports advocacy, accountability, consumer information, and training through comparisons, further study, and research. The goal will be to implement the restructured system in five years. NASOP should appoint a workgroup to work with the National Long-Term Care Ombudsman Resource Center and the Administration on Aging to develop a plan and timeline, beginning in April 2002.

This recommendation acknowledges the importance of data and information for the ombudsman program, such as for systems advocacy and training. As an example, the

paper's author had pointed out how information about recurring problems in hygiene care and staffing had prompted an ombudsman program to press for the passage of legislation to increase the ratios of nursing assistants and of nurse supervision (Appendix VII, Kautz, p.5). Numbers tell the rational and objective story of what ombudsmen do and what long-term care facility residents face and experience. While specific case examples or anecdotal stories illustrate the story and provide emotional context, data provides a more complete picture, giving it scope and impact, making it more difficult for bureaucrats, the media, the public and policy-makers to dismiss individual cases of ombudsmen as isolated or "merely anecdotal."

Analysis of data can also assist long-term care ombudsmen in determining topics for training programs. If, as an example, ombudsman program data indicate increased complaints and cases related to matters involving disregard for or lack of bona fide advance directives or other expressions of personal choice by residents, this may suggest the need for training for ombudsmen on how to understand, investigate, and resolve complaints related to this matter. Moreover, it may suggest the need for training for long-term care facility personnel, as well as potential policy changes at the facility level or in public policy.

One of the key points about data collection and effective use of data has to do with disaggregated versus aggregated data. Recommendation 4.1 specifies disaggregated data because this type of data is the best kind for flexible use. Ombudsmen and other attendees agreed that it is easier to pull out, categorize, and analyze data that is disaggregated. The conferees said that the optimal data system would be one that is "seamless from local to state to national..." That is to say, data can be meaningful and useful locally but have similar meaning and usefulness at the state and national levels at the same time; data can be understood by a local ombudsman in a similar way that it is understood by the state ombudsman and by those "reading" it from a national perspective.

Breakout group members pointed out, however, that the cost of states' compliance with this national reporting system, including training costs, would be an obstacle to its successful implementation. While not addressed specifically during the retreat, this raises the issue of seeking additional federal funds that could be dedicated to data collection or serve as incentives to state expenditures on data collection, much like what has been done for states through Medicaid (e.g., enhanced matching rates for automation).

4.2) To promote consistency, integrity, and confidentiality of data, the Administration on Aging (AoA) should ensure that the state long-term care ombudsman has regular methods of auditing data. The AoA should provide training, technical assistance, and policy for such audits and on-going use of the National Ombudsman Reporting System. By the 2003 National Ombudsman Training, plans should be in place for training and NASOP should work with the National Long-Term Care Ombudsman Resource Center to plan regional training (AoA regions). NASOP should appoint a workgroup to work with the resource center and the Administration on Aging to develop a plan and timeline, beginning in April 2002.

This recommendation supports the importance of training for effective use of the National Ombudsman Reporting System (NORS). As the breakout group stated, "ongoing training is an essential part of making NORS accurate and useful."

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Completeness, reliability of data, and ease of use are all aspects of data collection and data entry that must be integrated into the daily use of NORS by all ombudsmen, including volunteers. Auditing data is an important aspect of ensuring accuracy of data. The paper's author quoted one ombudsman who uses data frequently for legislative advocacy who said, "I've lost track of how many times a legislator has asked me: 'Are you confident of your data?'" (Appendix VII, Kautz, p.11). Moreover, retreat participants believed that technical assistance related to data and information on an on-going basis would help to ensure that systems remain contemporary and continue to reflect not only improvements in technology but changes in the substantive world of long-term care.

Participants of both the breakout group and the conference committee meeting spent a considerable amount of time discussing the significant variations among programs in their use of technology and data. The need for data verification and consistent standardized collection and recording processes were also discussed. Some states had made available the funds necessary to create systems to assure quality data collection and retrieval and others had not.

4.3) The Administration on Aging should begin immediately a two-step process to improve data collection capacity. The steps are:

- a) AoA will establish baseline minimum standards for state program software.**
- b) AoA will publish and award grants to states to purchase necessary hardware and software to meet standards and assure data integrity and security.**

Implementing NORS in 1995 was a major step toward standardizing ombudsman program data, and the IoM considered NORS a "laudable" achievement (Appendix VII, Kautz, p.7). However, it was pointed out that AoA should continue its work revising and refining the program's data collection capacity. At the conference committee meeting, the concept of *baseline minimum* standards was discussed and added to recommendation 4.3(a). In addition, the paper's author, Dr. Kautz, estimated that the cost per state of purchasing reporting software could be \$16,000 - \$19,785. The cost of purchasing computers, servers, etc., may be \$40,000 - \$50,000 for average states. LTCOPs need financial assistance to enable them to increase their computer capabilities to an acceptable level. Recommendation 4.4 also addresses this issue.

4.4) NASOP should work together with the National Long-Term Care Ombudsman Resource Center and the National Association of State Units on Aging in identifying resources for state ombudsmen to develop or purchase state-of-the-art computer systems and software that assist them in improving services and provide ease of data entry and data analysis. They should promote donations of computers by corporations and government without conflict of interest with the LTCOP.

This recommendation came out of the breakout group session without the second sentence. During the conference committee meeting, a second sentence was added which read, "...identify a [n] NFP [not-for-profit] organization that would promote donations of computers." The need for conflict of interest guidelines was discussed. Participants had concerns that accepting resources or computers from certain entities

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could have the appearance of inappropriate relationships. In the plenary session, the second sentence was changed to specify direct donations of computers by corporations and governments, rather than through a not-for-profit organization, and the conflict of interest caveat was added. See recommendation 4.3 for information on the costs of computer systems.

4.5) States should be accountable for use of data systems to meet the various analytic and reporting requirements of the OAA. NASOP should work to sensitize states to the need to analyze and improve systems advocacy to improve the quality and services in facilities serving special needs populations (e.g., Alzheimer’s disease).

During the breakout group session, participants discussed the need to help program staff and volunteers to appreciate the importance of data collection, entry, and analysis. They introduced the concept of using data to improve systems advocacy for Alzheimer’s disease and other special needs populations. During the conference committee meeting and the plenary session, the wording of the last phrase was modified through several iterations from “...to improve the quality for special needs populations (e.g., Alzheimer’s disease)” to “...to improve the quality and services in facilities serving special needs populations (e.g., Alzheimer’s disease).”

4.6) NASOP should continue to develop standardized national outcome measures based on the work of the 2000-2002 Resource Center project.

Participants discussed the importance of outcomes measures and data. This data will help in program evaluation and training. They did not discuss changing the current outcomes development process.

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

Discussion centered around ways to provide the public with more information on the way that the ombudsman program receives and responds to complaints. Although some participants had concerns about maintaining confidentiality, they felt it would serve the program’s and the public’s best interest to provide access to more information.



LTCOP Effectiveness

Retreat Recommendations and Analysis

What constitutes effectiveness by a long-term care ombudsman program varies with the needs and perspective of the stakeholder. For residents of long-term care facilities and those who voice complaints or raise concerns on behalf of residents, especially family members, an effective ombudsman is one who advocates for the resident and positively influences the outcome of a complaint or dispute. For a citizen advocacy group or senior services agency, an effective ombudsman might work for improvements in the quality of care in long-term care facilities or the long-term care services system. Policymakers and state and national governments may desire to note specific improvements in quality of care measures. Long-term care providers may believe an effective ombudsman is one who helps to resolve disputes with residents or their families without the involvement of regulatory bodies or the imposition of formal sanctions.

Robyn Grant, the author of the paper for the “Effectiveness” topic, points out that LTCOP effectiveness must first be viewed through the lens of the Older Americans Act. An analysis of the OAA language shows that the OAA “requires the program to **advocate** for residents’ interests on both an individual and systems level, but it does not mandate that the program achieve resident quality of care and life (Appendix VIII, Grant, p.7).” Grant also points out that while improving the quality of life for residents is extremely important, having that as the program goal sets up unattainable expectations for the program. It was especially important to the retreat participants that this distinction be kept in mind while developing the recommendations for improving the effectiveness of the LTCOP.

The retreat participants also felt strongly that the ombudsman program’s effectiveness is influenced to a very large degree by the program’s independence. Ombudsman program independence relates to the program’s ability to be free of conflicts of interest and to be able to carry out fully its advocacy activities without fear of unreasonable constraints, reprisal, or other organizational or relationship-related problems. During the plenary session the conferees stressed that the “linkages between independence and effectiveness need specific emphasis and reiteration. They seem to be complementary.”

5.1) NASOP should work for the appointment of the Director of the Office of Long-Term Care Ombudsman Programs in the Administration on Aging. The director should fulfill the Older Americans Act mandate to investigate and resolve complaints about the Long-Term Care Ombudsman Program from citizens, consumers, and others.

This recommendation is a blend of a similar recommendation from the conference

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session of the Independence group, a reflection of the overall importance of this recommendation. The retreat participants believe that the OAA provision adopted in the 1992 reauthorization is of immense importance to the LTCOP nationally. The provision in Title II of the OAA requiring that the Administration on Aging establish an Office of Long-Term Care Ombudsman Programs and that it be headed by a “Director” was established for several reasons. First, it is to provide a focal point and voice within the federal government for the states’ long-term care ombudsman programs. This office is meant to reflect the specific and collective experiences of ombudsmen across the country especially in addressing the needs of facility residents, and to represent those needs with various federal agencies, including the Centers for Medicare & Medicaid Services, the Office of the Secretary of the Department of Health and Human Services, and others. Second, it is to serve as a focal point for the experience and needs of state LTCOPs within AoA. This would include monitoring the overall effectiveness of LTCOPs, and responding to complaints and concerns from individual states in that the LTCOP is perceived as not effective or not in compliance with OAA provisions, or in which complaints are raised about the LTCOP.

Subsequent to the retreat the Assistant Secretary for Aging appointed a respected senior AoA official as the Director of the Office of State LTCOPs. NASOP and the individual ombudsmen view this as a positive development. NASOP recognizes, however, that the official currently holding this position has many other responsibilities, thus his time spent on activities related to the position of Director of the Office of State LTCOPs is curtailed. The result is that the statutory array of roles and responsibilities delineated in the OAA for this position cannot be effectively implemented.

Breakout group one did not include this recommendation in its list. Breakout group two suggested that the Office of the LTCOP become “real.” During the retreat there was discussion about including a requirement that the position be full-time and that additional language be adopted concerning the position’s guidance and monitoring of the ombudsman program. The discussion made clear NASOP’s belief that the authority and obligation for this role is already explicit in the law.

Following considerable discussion and several iterations during the conference meeting, this recommendation emerged as the number one recommendation with the addition that the “OAA be amended to resolve allegations and complaints about LTCOPs from citizens, consumers, and others.” There was also considerable debate as to whether the OAA should be amended to require the AoA Office to “investigate and resolve” allegations and complaints, and whether “state and local ombudsmen” should be included in the list of complainants. While there was overall consensus that AoA must perform this role, there was agreement that it is not necessary to amend further the OAA with regard to this responsibility; that the law is sufficiently clear in its intent. During the plenary session, there was agreement that state and local ombudsmen are among those included in the “others” category of complainants to whom the AoA Office of LTCOPs is obligated to respond, and that this must be reflected in the final report from the retreat. This was also accompanied by discussion and agreement that AoA must be committed to confidentiality for complainants about the effectiveness of state LTCOPs.

Effectiveness breakout group two offered a recommendation that there be consideration of a “Residents’ Rights Czar” at the federal level. Time constraints and other priority recommendations precluded this recommendation from being discussed in both the conference meeting and the plenary session.

5.2) In each state, the program shall be under the direction of one state long-term care ombudsman who is responsible for designating or certifying any local programs, supervising the work of program representatives, guiding program operations, training and designating or certifying ombudsman representatives, and participating in the hiring and firing of ombudsmen. Each state long-term care ombudsman program should be required to develop, implement, and enforce statewide policies for program operation.

This recommendation addresses the need for clear lines of authority and accountability. As provided for in the OAA, the state ombudsman should be the head of the program and direct all aspects of program operation. The OAA requires that the Office of the State Long-Term Care Ombudsman “shall be headed by an individual, to be known as the State Long-Term Care Ombudsman...” (Sec. 712(a)(2)) and that “The Ombudsman shall serve on a full-time basis” (Sec. 712(a)(3)). Both breakout groups included this recommendation in their priority recommendations and few changes were made to the language in the conference meeting. The conferees added language recommending that there shall be “one” state ombudsman (as opposed to more than one individual bearing this title at the same time), both because the OAA speaks to one individual in each state designated as “the State Long-Term Care Ombudsman,” and for purposes of clear authority and accountability, recognizing that multiple individuals bearing the title as “the State Long-Term Care Ombudsman” increases the likelihood of confusion as to roles and authorities. The conferees also added the word “designating” to the recommendation agreeing that this is consistent with the OAA and more fully clarifies the authority of the state long-term care ombudsman. There was clear consensus during the plenary session with both additions.

Conferees and plenary participants also discussed the need to address, on a state-by-state basis, circumstances in which the state ombudsman lacks authority or a clear role in decisions related to the “hiring and firing” of local ombudsmen, especially when hiring and firing is done at the substate level, either by sponsoring area agencies on aging or other entities. There is clear recognition that it can create especially difficult circumstances for state ombudsmen when a local ombudsman is not appropriate for the role or is not performing effectively, or when the local hiring entity wants to terminate a local ombudsman who in the state ombudsman’s judgment is performing effectively. State ombudsmen report experiences in which an AAA or other local hiring entity chooses to terminate an effective local ombudsman for cost reasons or because of her or his strong advocacy on behalf of residents or other local political reasons. These circumstances frequently result in the loss of seasoned and effective ombudsmen, trigger a lengthy learning period for replacement ombudsmen, and reduce at least for temporary periods effective response to residents’ complaints. In addition, this personnel turnover requires additional costs for recruitment, training, and support for new ombudsmen.

Moreover, state ombudsmen report the frequent loss of local ombudsmen due to such reasons as inadequate wages, less than full-time positions and considerable inequities in working conditions among local programs, with the same outcomes as the loss of seasoned and effective ombudsman previously described. Participants stated that program effectiveness is enhanced when the state ombudsman has greater authority over the duties, working conditions, and benefits of local ombudsmen performing under the authority of the state’s Office of the State Long-Term Care Ombudsman.

5.3) The state long-term care ombudsman and ombudsman program representatives should be housed in a setting where they are free of conflict of

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interest and where independence is maximized. * The state long-term care ombudsman and ombudsman program representatives, at the direction of the state long-term care ombudsman, shall have the ability to advocate on behalf of residents in the following nonexclusive ways:

- **Represent the interests of residents before governmental agencies, legislative committees, individual legislators and other individuals, groups or entities where issues that affect residents are addressed;**
- **Communicate directly with directors of government entities, legislators, policy makers, and the media about issues affecting residents; and**
- **Provide uncensored public testimony.**

*** A minority of participants strongly believed that the LTCOP must be outside of government in order to fully represent residents.**

The topic of the organizational location of the state LTCOP was the subject of extensive discussion throughout the retreat especially in the context of both the topics of “Effectiveness” and “Independence.” Although there is clear recognition that the current location of the LTCOP varies from state to state and that there may be significant weaknesses and shortcomings associated with certain organizational settings, the overarching sense of the group is that the most important goal for the LTCOP in terms of its effectiveness is to perform to the greatest extent possible the tasks listed in this recommendation. The consensus was that these roles were more important to focus upon than the minority view that the LTCOP must be fully independent in terms of its organizational setting; that effectiveness is best measured by the program’s ability to fully represent and advance the interests and needs of facility residents. Nevertheless, the conferees did agree to include a note that some participants strongly believe that the LTCOP should be outside of government in order to represent residents fully.

The recommendation’s use of the word “nonexclusive” indicates that despite the importance of the three referenced critical ombudsman tasks, they are not the only tasks ombudsmen perform; rather, they are major indicators of effective ombudsman services.

Discussion of this recommendation emphasized that the independence of the LTCOP, or the lack thereof, affects the ability of the ombudsman to fulfill her or his role. The placement of the program within, for example, a state agency, a not-for-profit social service agency, or a health care organization, likely influences the extent of its independence. In a 2001 report on effectiveness by Estes, et al., “more than one-half of state ombudsman programs reported that their organizational placement creates difficulties for service provision, with conflict of interest and lack of program autonomy identified most frequently as concerns (Appendix VIII, Grant, p.9).” The author of the Effectiveness paper also points out that the 1995 IoM report noted the “prevalence of conflicts of interest, both real and perceived, that arise from the structural location of many of the offices of the SLTCOP,” a “disadvantage to the vulnerable client (Ibid, p.10).”

It is clear that a requirement that the long-term care ombudsman program be located in an independent, freestanding non-profit organization outside of government would need to be accomplished through an amendment to the OAA. If the program were starting from scratch this may be an important program requirement, but after three decades of LTCOP development with most state LTCOPs located in settings that do not

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meet these criteria, it would be exceptionally difficult and disruptive to force a change in location in most states. Moreover, most participants believe requiring such a change would be unnecessary and perhaps counterproductive in many states. Participants recognized that there are state government-based LTCOPs that are notably effective and operating with considerable independence. Examples of such programs located in state units on aging include Oklahoma and Georgia, among others.

The conferees considered including a section from the Independence recommendation 1.4 in Effectiveness recommendation 5.3, which reads: *“to enhance independence and autonomy in representing residents, the state ombudsman and the local ombudsman program representative responsible for the operation of each local program (e.g., the LTCOP coordinator, the lead ombudsman) should be elevated to either be directly under the director of the agency or organization housing the program or be the director of the respective agency.”*

While this section was not included as part of the final Effectiveness recommendation 5.3, there was general agreement among the retreat participants that the best situation for an ombudsman is to be organizationally located at very senior levels. For state ombudsmen, this would be reporting directly to the agency’s head official. For local ombudsmen, this would either be a direct report to the local sponsoring organization’s director or the organization’s executive director. Participants believe there are several key program considerations that require that ombudsmen have the support, respect and authority that accompanies senior placement within any organization’s hierarchy. These include:

- The scope and importance of authority required of ombudsmen under federal, and in many cases, state law;
- The gravity and potential sensitivity of matters handled by ombudsmen and the level of officials with whom ombudsmen must deal (e.g., regulators, trade association officials, corporate executives, law enforcement, and legislators); and
- The need for decision-making authority over use of resources, hiring and firing of ombudsman staff, and deployment of ombudsman staff (e.g., priority-setting as to which long-term care facilities will receive services).

5.4) The loM-recommended minimum ratio of 1 paid designated ombudsman FTE to 2000 beds and 1 full-time staff ombudsman to 40 volunteers must be implemented in every state. The state long-term care ombudsman and SLTCO office staff should not be included in calculating this ratio (unless they personally investigate complaints in facilities). An ombudsman program staffing study is recommended to evaluate and recommend the staffing necessary to comply fully with the OAA requirements. Each local program should have at least one full-time paid ombudsman (not FTE). Additional paid program staff may be part-time, but shall have no duties conflicting with their role as ombudsmen.

This recommendation underscores the importance of adequate staffing for an effective and successful ombudsman program. The author of the Effectiveness paper pointed out that the work of the long-term care ombudsman has become increasingly complex over the years. Ombudsmen address complicated problems such as issues related to behavioral symptoms, transfers and discharges, and the ins and outs of managed care. A minimum number of paid, trained staff devoted to ombudsman

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activities is critical to address and resolve issues effectively and promptly, and to ensure that all long-term care facility residents have equal access to ombudsman services.

The conferees discussed the role of part-time staff. While it is preferable to have full-time staff generally (for ease of training, management, and supervision, for example), part-time staff is helpful, especially if the resources are not available to support full-time staff. The conferees felt that the conflict of interest issue was important to reiterate in this recommendation thus they added the phrase *“but shall have no duties conflicting with their role as ombudsmen”* to the recommendation.

An early version of this recommendation included language calling for the OAA to be amended to require a staffing study, but this was changed to recommending that a staffing study be conducted — without relying upon a change in law to make such a study happen. The participants believe that such a study is not only important but is needed now and recognize that basing a study on a future amendment to the statute is unnecessary and possibly unwise. Given the vagaries of the legislative process such a study may never make it into the statute, may take years to occur, or be structured in a way that does not address the concerns of the retreat participants. Instead, the participants believe that such a study could be undertaken in the very near future through other means, such as from discretionary funding from AoA.

Both of the breakout groups included a recommendation that each state ombudsman program should have a volunteer program in place. However, such a recommendation did not emerge from the conference meeting among the top five recommendations. Due to time constraints, the full group in the plenary session did not take up all of the conference committee recommendations, including the recommendation concerning volunteer programs. Most retreat participants believe, however, that the role of volunteers in the ombudsman program is essential to providing individual ombudsman services to residents. Not only are complaint resolution rates higher in states with more active volunteers, but also in most states it is impossible to provide the routine presence of ombudsmen in long-term care facilities without volunteer ombudsmen. Moreover, even with generous funding, few states could ever ensure routine ombudsman visits to all covered facilities without a large corps of volunteers. Although this recommendation was not considered in the full session and as a result it cannot be said that all participants agree with it, it was offered by the Effectiveness conference committee among its top ten recommendations underscoring its importance.

5.5) The National Long-Term Care Ombudsman Resource Center should develop, in conjunction with NASOP and the National Association of Local Long-Term Care Ombudsmen, a tool to measure ombudsman program effectiveness, which shall utilize the IoM report, outcome measures, and recommendations from this conference. Each state and local ombudsman program should utilize this tool to evaluate its respective programs on an ongoing basis. State and local ombudsman programs should use the results of this evaluation to develop an action plan that includes specific, measurable, and scheduled objectives for each area of ombudsman program function required by the OAA.

Evaluating goals and priorities, measuring program effectiveness, monitoring where the program and its services have been and where it is going, are necessary steps for a program’s future success. Indeed, this NASOP-Bader retreat is an example of such an

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evaluation. For the ombudsman program, a critical component of such evaluation and self-examination is to ensure that local and state programs work together to develop measurement tools including both process and outcomes measures and to analyze program effectiveness, as specified in this recommendation. The author of the Effectiveness paper emphasizes that “the local program goals and priorities must stem from state goals and priorities so that the entire program is moving forward in a unified, integrated manner (Appendix VIII, Grant, p.18).”

In breakout group two, local ombudsmen said that funders want effectiveness and achievement outcomes that show “how/what have you done to change a life.” Resolving complaints is not the fullest measure of what ombudsmen accomplish. A “resolved case” may not always be a good or complete measure of program effectiveness; there are many complaints that are “resolved” in the eyes of the complainant or others that may not have been handled in the best or fullest way possible. NASOP recognizes the importance of process measures as indicators of a program’s effectiveness in addition to outcome measures. An example of a “process” measure might be timely investigation of complaints. While the timeliness of complaint investigation may not provide a measurement of successful outcomes it certainly bears upon program effectiveness (note Effectiveness recommendation 5.6). The implications of untimely response to complaints seem self-evident including: continued harm or other adverse consequences to the resident or others on untimely or delayed complaint investigation; diminished or lost evidence – a “colder trail;” and diminished respect for or reliance on the LTCOP. Even if the ombudsman is unable to provide a satisfactory resolution for the resident or complainant to a particular matter, the complainant may feel some satisfaction if she or he believes the ombudsman acted in a responsive and timely manner. No doubt an unsatisfactory outcome is exacerbated by delays in responding to a complaint.

5.6) Ombudsmen should prioritize and respond to complaints in the following manner:

COMPLAINT PRIORITIZATION AND RESPONSE TIME

PRIORITY LEVEL(From most urgent to least urgent)	TYPE OF COMPLAINT	RESPONSE TIME
Priority 1	§ Abuse or gross neglect and the ombudsman has reason to believe that a resident may be at risk § Actual or threatened transfer or discharge from a facility and the ombudsman has reason to believe the transfer or discharge will occur immediately § Action requiring a time-certain action	Within the next working day
Priority 2	Abuse or gross neglect and the ombudsman has no reason to believe that a resident is at risk	Within 3 working days
Priority 3	Actual or threatened transfer or discharge from a facility, and the ombudsman has no reason to believe that the transfer/discharge will occur immediately	Whichever occurs first: § 5 working days § last day of bed hold period if resident is hospitalized § last day for filing a transfer/ discharge appeal
Priority 4	Other types of complaints	Within 7 working days

This table was developed by the paper author and agreed to by the conferees with few changes.

Additional Recommendations

The Effectiveness conferees agreed upon four additional recommendations that due to time constraints were not taken up in the final plenary session. Therefore, it cannot be said that there was consensus among all the participants about the additional recommendations (breakout group one proposed all four, while breakout group two proposed the third and fourth ones). Nonetheless, since they were among the top ten agreed upon recommendations of the Effectiveness conference and because NASOP believes they are significant, they are included in this report.

- The state ombudsman shall have responsibility for making decisions about the use of the fiscal resources of the Office of State Long-Term Care Ombudsman and the OAA should be amended to require that the state ombudsman manage all fiscal resources related to the program. Local programs should be involved in fiscal management of their programs.

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- The Office of the State Long-Term Care Ombudsman should directly employ, contract, or otherwise have a formal agreement with an attorney who has relevant experience and expertise and who is free of conflicts of interest.
- Each state ombudsman program should have a volunteer component in place including, but not limited to, volunteers who go to facilities to ensure that residents have direct access to ombudsman services.
- Ombudsman programs should organize staff and resources to maximize the potential that every resident has weekly access to an ombudsman program representative.



The Changing Long-Term Care Resident Population And Its Needs

Retreat Recommendations and Analysis

The overarching theme of this set of recommendations is the desire to ensure that all persons in need of long-term care services have access to ombudsman advocacy services. Specific populations with special needs are targeted, including residents with Alzheimer's disease and various underserved populations. Assisted living facilities residents are targeted for increased and improved advocacy and standards because of the vulnerability of this population and because ombudsman services are not as available in assisted living as they are in nursing facilities. Discussion also focused on funding for the ombudsman program, i.e., what the actual costs of the program would be if the residents of all nursing homes and other long-term care facilities were adequately served, as well as if the program were expanded or altered to respond better to contemporary long-term care facility residents. Finally, specific suggestions are made for NASOP to work collaboratively with other groups to increase public awareness about the ombudsman program and advocacy for special needs populations.

The author of the Changing Populations paper, Elma Holder, underscores the implications for the ombudsman program of the projected growth of the older population. The oldest old, those age 85 and over, for example, will double by the year 2020 to 7 million and double again by 2040 to 14 million (Appendix IX, Holder, p.4). It is among the oldest old population that long-term care needs will be the greatest thus the doubling of this cohort will place greatly increased demands upon long-term care services and therefore upon ombudsman programs. In addition, the needs of certain underserved (e.g., ethnic and cultural minorities) and special populations (e.g., disabled, mentally impaired) will increase as well, adding new demands and challenges for ombudsmen. For example, the paper author points out that about four million Americans have Alzheimer's disease, and the prevalence of the disease doubles every five years beyond the age of 65. The number of victims will grow to 14.3 million in the next 50 years, creating a challenge for both care providers and the ombudsmen monitoring the quality of their care.

The stark reality is that funding for the LTCOP remains "completely insufficient," as the 1995 IoM study found (Appendix IX, Holder, p.19). The scope of the ombudsman program initially was on nursing home residents. While board and care homes and other similar long-term care facilities were added to the LTCOP's scope and responsibility as an amendment to the OAA in 1981, the focus in terms of attention and resources has remained largely on the nursing home population. Now, other types of long-term care facilities, such as assisted living, as well as other forms of home and community-based care, are increasingly common and are expected to continue to grow

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as options. Increased use of these long-term care options is not only due to resident and family preference but can be expected to receive increasing attention from cost-conscious policy-makers and providers. As an example, it is likely that expanded use of Medicaid waivers will continue and will increasingly be used for services in assisted living and other similar settings. Reports of quality of care problems are surfacing in assisted living and other facilities. Residents in all types of facility-based long-term care are in need of ombudsman advocacy services.

The recommendations for this Changing Populations topic reflect the current and projected demographics and conditions of the populations in need of long-term care services, and the current realities and projected needs of the ombudsman program. For example, recommendation 6.6 is consistent with the work of the nationally based Assisted Living Work Group, which was established after hearings by the Senate Special Committee on Aging aired consumers' problems in the nation's assisted living facilities. NASOP is a member of this work group.

The two breakout groups for this topic shared the conclusion, which formed the first recommendation, that persons receiving all forms of long-term care services deserve access to advocacy services and that such services should not be limited to those who reside in facility-based long-term care. Both groups also supported the need to determine the actual cost of the LTCOP if current federal mandates were fulfilled. Both groups also came up with recommendations for NASOP to implement a public awareness campaign and to adopt a strategy of working with other organizations, advocacy and disease-oriented, to further the goals of the ombudsman program.

Breakout group one recommended a five-year, five-state demonstration program of an optimal ombudsman program and proposed establishing an expert advisory panel to "examine and inform" the ombudsman program. Breakout group two recommended creating assisted living standards of care and a training program for ombudsmen in mental health conditions among their client population (e.g., dementia, depression, delirium).

The recommendations of the two groups were combined during the conference committee meeting. Group two's recommendation that "any expansion of the program into new arenas will not be undertaken unless the program is adequately funded" was incorporated into recommendation 6.2 and the wording modified to state that "any expansion.... must be accompanied by adequate resources..." Group two's language that, "NASOP will approach other health care organizations to motivate them to advocate for their communities/clients" became recommendation 6.7 calling for NASOP to "develop a plan to explore cooperative activities with national organizations that focus on persons with specific diseases."

Otherwise, there was little difference or disagreement between the two breakout groups and the full plenary session. The recommendations agreed to on a consensus basis by the retreat participants included:

- 6.1) NASOP should work to ensure that all persons in need of long-term care services have access to advocacy services.**
- 6.2) NASOP will join with the National Association of Local Long-Term Care Ombudsmen, the National Long-Term Care Ombudsman Resource Center, and other allies to facilitate independent research to determine actual program costs if the current federal mandates were fulfilled. They will also**

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advocate that adequate resources for program success must accompany any adaptation or expansion of the program into new arenas.

- 6.3) NASOP will work with the Administration on Aging and the National Long-Term Care Ombudsman Resource Center to identify public and private funding sources for a five-year, five-state demonstration program to provide effective high quality “person-centered,” independent, coordinated advocacy services to older persons in need of long-term care regardless of where they reside. An advisory panel of practitioners and scholars, whose work has demonstrated a command of the program’s unique challenges, will oversee the evaluation of the demonstration.
- 6.4) NASOP will join with others to develop a public awareness campaign to heighten the visibility of the LTCOP and the people it serves. Further, NASOP will gather support for the program through coalition strategies with other senior advocacy organizations, direct care workers’ organizations, and other public interest organizations.
- 6.5) NASOP will develop a position on access to long-term care ombudsmen in assisted living, a definition for assisted living, and national* standards for assisted living that are enforceable. (* “National” should not be mistaken for “federal.”)
- 6.6) NASOP should continue its work with others on national standards of care for people in need of facility-based or residential assisted living.
- 6.7) NASOP will develop a plan to explore cooperative activities with national organizations that focus on persons with specific diseases. Activities will focus on advocacy to assist individuals and advocacy for systems change.
- 6.8) NASOP will promote, and develop as necessary, training programs for long-term care ombudsmen that focus on mental health conditions and conditions that affect decision-making capacity (e.g., Alzheimer’s disease, dementia, depression, and delirium).



Afterword

Under the direction of the president of the organization, the National Association of State Ombudsman Programs has met a number of times since the completion of this retreat in the winter of 2002. Individual members and groupings of members have been assigned to explore the options available to the association to pursue activities that will advance the concepts contained within the various recommendations emanating from the retreat. Collectively the organization recognizes that much work is needed to support and shore up individual state programs in order for all member states to carry out the mandates embodied within the Older Americans Act.

As an affiliation of peers, NASOP is well positioned to provide quality training and technical assistance to each of its members. The recommendations contained in this report are already serving as the basis for revising much of this activity. Existing approaches are being evaluated and measured against specific needs that have been articulated by this retreat's report.

Management of the volumes of data that the nation's ombudsman programs generate must be harnessed to positively guide the development of national and state long-term care laws and policies. NASOP is prepared to do just that.

Long-term care is evolving from its very early beginnings of "rest homes" into a much more complex array of services ranging from highly technical supports to the most simple offerings to maximize the independence of frail, older persons. To meet the changing needs of these consumers, ombudsman programs must re-evaluate their focus and continually measure effectiveness in order to truly protect citizens' rights within this system. NASOP accepts and embraces this challenge.

NASOP also knows full well that in order for its members to be successful in this important work, additional resources will be needed to match the increasing demand for services from a widening audience. The organization is committed to that effort.

Early in 2002, five committees were constituted specifically to take up the major recommendations contained within this report. Each has been meeting to identify the necessary steps to be taken by NASOP and/or its affiliated organizations to implement fully the requirements of the Older Americans Act.

Specific committee activities to date include:

Training. A survey of all member states to determine training practices and curriculum of paid and volunteer ombudsmen has been conducted. The committee has recommended to NASOP that the National Long-Term Care Ombudsman Resource Center (NORC) dedicate part of its work-plan for the next grant cycle to include development of minimum training standards, evaluation instruments, and core competencies. The committee, along with the National Association of Local Long-Term Care Ombudsmen, will work with NORC to develop a voluntary certification of

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ombudsmen, and create a model screening instrument for prospective ombudsmen. The committee will also lead NASOP's efforts to develop or identify training materials for special populations, i.e., Alzheimer's disease, etc.

Effectiveness. This committee is tackling structural issues and important relational concerns with other organizations to maximize the effectiveness of each of the state ombudsman programs. Of top priority is raising the visibility of the program within the Administration on Aging and to enhance the independent action of all state ombudsmen. Dialogue with the National Association of State Units on Aging will focus on improved understanding of the unique role of the ombudsman and its basic mandate. The committee is examining structures that will improve the independent operations of local ombudsman programs as well, which will draw upon discussions with the National Association of Area Agencies on Aging. On a separate track, the committee is working with the NORC to create a tool to objectively measure the effectiveness of each ombudsman program, including the ability of the program to advocate effectively for changing populations in long-term care facilities.

Data. This committee is undertaking a review of the status of the technological condition of ombudsman programs around the country to determine what basic computer supports, including hardware and software, will be needed to actualize the value of a sophisticated databank. Ultimately the goal is to create consistent collection of program data, leading to analysis that is defensible in both the public and private arena. These sources of data would form the basis for advocacy efforts within larger systems both at the state and national levels.

Systems Advocacy. To fully achieve the congressional mandate for the ombudsman concept, each program must be positioned to go well beyond individual complaint resolutions and into the sphere of altering public policy that improves the well-being of the long-term care consumer. This committee is drawing upon the findings of other NASOP committees with a goal of providing the tools each state program will need in order to speak openly and effectively about the unacceptable conditions found in many sectors of the long-term care system. The chair of this committee has begun working with the NORC to train new state ombudsmen in systems advocacy.

Appropriations. This long-standing committee of NASOP will continue its work with Congress, educating legislators and their staffs of the needs faced by ombudsman programs around the country. The federal government remains a critically important source of funding. Increased funds will be needed to support programs as they answer the call to expand their advocacy services beyond the more traditional nursing home. The committee will continue to raise these issues with members of Congress. In addition the committee is preparing to find other resources to match specific projects that are prioritized by the NASOP membership.

NASOP is prepared to take on a pivotal role among other players on the national scene to design a long-term care system that is fair and equitable and that honors the very basic dignity of each person who enters that system.

In conclusion, this is the beginning of a process for NASOP, not the end. We thank all of those individuals who helped to make the retreat a success for NASOP and for getting us started on the next stage of our journey on behalf of long-term care residents.

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National Association of State Long-Term Ombudsman Programs
***The Long-Term Care Ombudsman Program:
Rethinking and Retooling for the Future***

Appendix III
Schedule of Events

Thursday, January 31, 2002

3:00 p.m.	Check-in and Retreat Registration
4:00 p.m. - 4:35 p.m. Room 223	Opening Session Welcome: <i>Carol Scott</i>
	Statement of Conference Goals Work Plan: <i>George Potaracke</i>
	The Consensus Process: <i>Bill Benson</i>
4:45 p.m. - 6:00 p.m.	Breakout Session #1
Group One: Room 223	<i>Independence: The Long-Term Care Ombudsman Program's Ability To Fully Represent Residents</i>
Group Two: Room 230	<i>Systems Advocacy in the Long-Term Care Ombudsman Program</i>
Group Three: Room 231	<i>Training and Qualifications for the Long-Term Care Ombudsman Program</i>
Group Four: Room 233	<i>Long-Term Care Ombudsman Program Data and Information</i>
Group Five: Room 237	<i>Long-Term Care Ombudsman Program Effectiveness</i>
Group Six: Room 238	<i>The Changing Long-Term Care Resident Population and Its Needs</i>

Schedule of Events

6:30 p.m. - 8:00 p.m. **Reception and Dinner**
Location: TBA **Keynote Speaker**

Friday, February 1, 2002

7:15 a.m. - 8:15 a.m. **Breakfast on Your Own in Lakeside Dining Building**

8:15 a.m. - 9:15 a.m. **Breakout Session #1 - Continued**

9:15 a.m. - 9:30 a.m. **Refreshment Break**

9:30 a.m. - 11:45 a.m. **Breakout Session #2**

Group One: *Independence: The Long-Term Care Ombudsman
Room 223 Program's Ability To Fully Represent Residents*

Group Two: *Systems Advocacy in the Long-Term Care Ombudsman
Room 230 Program*

Group Three: *Training and Qualifications for the Long-Term Care
Room 231 Ombudsman Program*

Group Four: *Long-Term Care Ombudsman Program Data and
Room 233 Information*

Group Five: *Long-Term Care Ombudsman Program Effectiveness
Room 237*

Group Six: *The Changing Long-Term Care Resident Population and Its
Room 238 Needs*

12:00 p.m. - 1:00 p.m. **Lunch**
Lakeside Dining Bldg. **Speaker: Ms. Jean Scher, Advocate**

1:15 p.m. - 2:45 p.m. **"Conference Meetings" for Breakout Session
Representatives** (*For example: Representatives from
independent breakout sessions #1 & #2 meet*)

Group One: *Independence: The Long-Term Care Ombudsman
Room 223 Program's Ability Fully Represent Residents*

Schedule of Events

- Group Two:** *Systems Advocacy in the Long-Term Care Ombudsman Program*
Room 230
- Group Three:** *Training and Qualifications for the Long-Term Care Ombudsman Program*
Room 231
- Group Four:** *Long-Term Care Ombudsman Program Data and Information*
Room 233
- Group Five:** *Long-Term Care Ombudsman Program Effectiveness*
Room 237
- Group Six:** *The Changing Long-Term Care Resident Population and Its Needs*
Room 238
- 3:00 p.m. - 6:00 p.m.** **Breakout Group Reports and Consensus Building**
Room 223 *Facilitators: Bill Benson, Sara Hunt, and Brian Lindberg*
- 6:30 p.m. - 8:30 p.m.** **Dinner On Your Own in Lakeside Dining Building**

Saturday, February 2, 2002

- 7:30 a.m. - 8:30 a.m.** **Breakfast On Your Own in Lakeside Dining Building**
- 8:30 a.m. - 11:30 a.m.** **Breakout Group Reports and Consensus Building – Ct'd**
Room 223 *Facilitators: Bill Benson, Sara Hunt, and Brian Lindberg*
- 11:30 a.m. - 12:00 p.m.** **Summary of Consensus and Next Steps**
Room 223 *George Potaracke*
- 12:00 p.m. - 12:15 p.m.** **Closing Remarks**
Room 223 *Carol Scott*
- 12:15 p.m. - 1:30 p.m.** **Buffet Lunch in Lakeside Dining Building**



Appendix IV

Independence and LTCOP's Ability to Fully Represent Residents

By Carroll L. Estes, Donna Zulman, Sheryl Goldberg and Dawn Ogawa
Institute for Health & Aging, University of California, San Francisco

Executive Summary

This paper is concerned with the ability of the Ombudsman Program to fully represent residents through the performance of all of the duties assigned to ombudsmen under the Older Americans Act (OAA). The issue of Ombudsman Program independence is important because of its relationship to the ability of ombudsmen to fully represent the residents of long term care facilities. Throughout this Executive Summary and the longer paper, the term, program autonomy, is used interchangeably with that of program independence. Program autonomy (independence) is a characteristic that was examined and deemed crucial to the performance of Ombudsman Programs in the landmark study of the Ombudsman Program conducted by the Institute of Medicine (IOM) of the National Academy of Sciences in 1995 (IOM, Harris-Wehling, Feasley, and Estes, 1995). Issues of conflict of interest and organizational placement were examined at length in the IOM report because they are linked to questions of Ombudsman Program autonomy/independence inasmuch as these characteristics of the program may facilitate or impede the ability of ombudsmen to fulfill OAA mandates. Thus the effectiveness of the Ombudsman Program may be said to hinge to a significant degree on the ability of the program to fully and freely represent residents without impediments and prohibitions upon doing so. Both organizational placement and conflicts of interest are relevant to program independence/autonomy. The reader is urged to read the most relevant sections of the 1995 IOM report that are contained in Appendix A.

Current information on the related issues of program independence/autonomy, conflicts of interest, and organizational placement of the Ombudsman Program has been developed as part of a study by the Chair of the 1995 IOM study committee, Carroll L. Estes, and her colleagues at the Institute for Health & Aging, University of California, San Francisco (IHA/UCSF) (Estes, Zulman, Goldberg, and Ogawa, 2001). This recent work corroborates the findings of the IOM Committee and again underscores the import

of the autonomy/independence of the Ombudsman Program, its organizational placement, and the resolution of conflict of interest issues for the ability of the ombudsman to carry out his/her duties as mandated by law. Other crucial elements of effective performance of the ombudsman program are identified in both studies and their recommendations, including the Ombudsman Program's ability to have and control its own fiscal resources, and for there to be a unified coherent state program that incorporates accountability and direct reporting of the local Ombudsmen Programs to the state Ombudsman Program.

This Executive Summary and the paper draw upon multiple sources of information: (1) the original 1995 IOM study that was funded by the Administration on Aging, (2) the Estes study conducted in 2000-2001 under a grant from the Kaiser Family Foundation, (3) the 1999 national database of the National Ombudsman Reporting System (NORS), (4) a review of recent literature (see Appendix A), and (5) consultation with experts working in the field. The 1995 IOM study and the 2000-2001 Estes/Kaiser Foundation study represent two of the most important sources of information on the Ombudsman Program's ability to represent residents in the varied elements of the OAA legislative mandate for the program. These two studies are among a very limited number of existing efforts to understand what enables (and inhibits) Ombudsman Programs to represent residents, monitor relevant policies, regulations, and laws, and to provide both individual and system level advocacy. Thus, it is not surprising that one consistent recommendation of both studies is for the funding and conduct of more research on this issue.

Both of these projects were designed to broadly understand issues across the nation. Both of these studies identified key elements of the ability to carry out the mandates of the Ombudsman Program as including autonomy/independence of the program, its organizational placement, and the resolution of actual and potential conflicts of interest. Both of these studies relied on interviews and/or written communications (e.g., surveys) with directors of Ombudsman Programs – at both the state and local levels in the IOM study – and at only the state level in the more recent Estes/Kaiser Foundation study (Estes et al, 2001). In addition, in the 1995 IOM study, there were site visits (state and local level) and a major panel of experts was consulted and developed papers. Hence, the information and recommendations presented here come from the reports of the directors of Ombudsman Programs and, in the Estes/Kaiser study, from the state level only—but involving representation from 100% of state Long Term Care Ombudsman Programs (LTCOPs). Nevertheless, the methodology of both projects involved triangulated (multiple) data sources, while both collected data from the directors of the ombudsman program based on the assumption that the ombudsmen, themselves, are in the best position to report on their experiences and ability to do their job as they understand its mandates and requirements. In both cases, the report authors contend that the perspectives of the directors of the Ombudsman Programs are valuable and valid. Corroboration between findings of the two studies (the 1995 IOM study and more recent Estes/Kaiser Foundation study), and the continuity of many of the same issues and concerns across time and the two studies lend credibility to the findings, conclusions, and recommendations that are offered here. Clearly, the views presented are those of the authors alone and are not to be attributed to any of the funding sources or agencies involved.

The 2001 Estes/Kaiser Family Foundation Study Of State Long Term Care Ombudsman Programs

During 2000 and 2001 the Institute for Health & Aging, University of California, San Francisco, under the leadership of Carroll L. Estes, Principal Investigator, conducted a telephone survey of all 50 state Long Term Care Ombudsman Programs, held a focus group of experts, attended and participated in training conferences and web casts with state and local ombudsmen, and surveyed the literature. The objectives of this project, funded by the Henry J. Kaiser Family Foundation, were to follow-up on the 1995 Institute of Medicine (IOM) study (Chaired by Carroll L. Estes), and to shed light on issues of ombudsman program effectiveness and quality of long term care. The Estes/Kaiser Foundation study examined several issues relevant to the ability of the Ombudsman Program to fully represent residents, and particularly issues of organizational independence and autonomy associated with organizational placement and conflicts of interest. The sections of the Executive Summary below are organized to present some of the key findings of the Estes/Kaiser Foundation study in three areas related to the topic: (1) Autonomy and Organizational Placement, (2) Effectiveness of the Long Term Care Ombudsman Program (LTCOP), and (3) Systemic Advocacy and Quality of Care. The Executive Summary concludes with a section on Recommendations. And Questions for discussion. Three important source documents for this paper are: (1) the original IOM report, *Real People, Real Problems* (IOM, Harris-Wehling, Feasley, and Estes, 1995); (2) the current Literature Review (Appendix A) that draws upon Chapter 4 of the IOM report and contemporary literature; and (3) the detailed qualitative responses of state ombudsmen about difficulties with organizational placement and how they deal with them (Appendix B). The full details of the Estes/Kaiser Foundation study findings and recommendations are contained in the DRAFT final report, *The Effectiveness of State Long Term Care Ombudsmen Programs*, by Carroll L. Estes, Donna Zulman, Sheryl Goldberg, & Dawn Ogawa submitted to the Kaiser Family Foundation in May 2001. The Kaiser Foundation will release a shorter version of the Final Report in 2002.

Autonomy and Organizational Placement of the State LTC Ombudsman Program

Program autonomy (independence) and organizational placement are serious issues that create difficulties for the majority of state ombudsmen. The real issue here is how to assure that the Ombudsman Program has sufficient autonomy and independence to fully represent residents. Organizational Placement is reported to be an important issue in the autonomy and independence of the Ombudsman Program.

- While most state LTCOPs (71%) are part of their State Unit on Aging (SUA), 12% are located in another state agency, and 17% are located in a nonprofit agency or legal agency. [Figure 1] [Q2]
- *More than half of state ombudsmen (55%) report 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

Appendix IV

or the media, conflicts of interest, barriers to policy information, bureaucracy, limited access to resources, and budget vulnerability. [Table 1] [Q3]

- *LTCOPs in state agencies (both SUA and non SUA) are much more likely (63% and 60%, respectively) than state LTCOPs in legal or nonprofit agencies (22%) to report difficulties in carrying out their responsibilities and providing services.*
- *Lack of autonomy is most frequently cited as a problem stemming from organizational placement of the state LTCOP. Eleven (11) of 37 LTCOPS in SUAs report their placement limits their freedom to speak with legislators and/or the media. In contrast, only one (1) of 15 LTCOPs in independent nonprofit or legal agencies, or non-SUA state agencies report experiencing limitations on autonomy due LTCOP placement. [Q3a]*
- *All of the 9 state LTCOPs reporting conflicts of interest (see full discussion of this concept in Appendix A) due to program placement are located in SUAs. [Q3]*
- *State LTCOPs located in independent legal or nonprofit agencies are much more likely to report sufficient autonomy (89%) than are programs located in SUAs (54%) or other non-SUA state agencies (60%). (NSS) [Figure 3] [Q5]*
- *Ombudsman program autonomy as reported by state LTCOPs is statistically significantly associated with: (1) ability to carry out federal mandates independently from other state agencies; (2) supportive political and social climate, (3) effectiveness of advocacy efforts, (4) freedom from excessive legislative/regulatory restrictions, and (5) clearly defined lines of authority/accountability for state and local ombudsmen. [Table 1, Appendix C] [Q5]*
- *Ombudsmen report pros and cons to organizational placement within SUAs. “Pros” include resources and support and “Cons” include conflicts of interest and limited autonomy. [Q3b]*
- *The most common types of assistance that state ombudsmen receive from their SUA include financial support (33%), administrative support (19%), moral support and belief in the program (19%), technical assistance (17%), legal assistance (17%), supervisory support (15%), training and conferences (14%), use of facilities (14%), advocacy for the program (12%), and supplies, resources, and clerical support (10%). Eight state ombudsmen report receiving no assistance from their SUA. [Q16]*

Effectiveness of LTCOPs

Autonomy (independence) of the Ombudsman Program and their organizational placement are key factors in effectiveness of the ombudsman program at both the state and local levels.

- The program autonomy and *organizational placement* are among the most prominent factors influencing the effectiveness of LTCOPs as reported by state

ombudsmen programs. (The adequacy of resources and relationships with other agencies are two other major factors.) [Q5]

- *Inadequate autonomy due to the organizational placement of the state LTCOP (39%) is one of the factors that inhibits the effectiveness of LTCOPs.*[Q5]
- When asked if there are any *barriers or impediments at the state or federal level that keep them from carrying out their jobs*, 39% of state ombudsmen report that barriers exist at the state level, 12% of ombudsmen report that barriers exist at the federal level, and 22% of ombudsmen report that barriers exist at both the state and federal level. [Q40]
- More than one-fourth (28%) of state ombudsmen report that they *cannot carry out federal mandates independently from other state agencies and parties*; and 24.5% report their state political and social climate is not supportive of their LTCOP. [Q6]
- Factors that contribute most to the effectiveness of *state* LTCOPs are: *ability to represent interests of residents to most state agencies* (100%); good relationships with licensing & certification (96%), HCFA (93%), the LTC industry (88%); and (among others) several *factors directly related to autonomy and organizational location: freedom of the state LTCOP's activities from excessive legislative or regulatory restrictions* (85%), *clearly defined lines of authority and accountability for state and local ombudsman* (82%), *supportive political and social climate* (76%), *ability to carry out federal mandates independently from other state agencies and parties* (72%), and *sufficient autonomy due to organizational placement* (61%).[Table 2] [Q5]
- Factors that contribute most prominently to the effectiveness of *local* LTCOPs are: staff and volunteer training (98%); response time to complaints (98%); degree of collaboration/cooperation with local nursing home providers (96%); amount of funding (94%); the number of paid staff (94%); ability to obtain needed assistance to deal with complaints (94%); number of visits to nursing homes (94%); quality of working relationship with other local programs dealing with LTC (94%); number of volunteers (92%); and *organizational placement of local LTCOPs* (91%).[Table 3] [Q11]

Systemic Advocacy and Quality of Care Issues

Effective advocacy by the ombudsman program is associated with “sufficient autonomy” of the program.

- The effectiveness of state LTCOP advocacy efforts are influenced most by strong nursing home industry lobbying (78%), *the relationship between ombudsmen and representatives from their SUA or AAAs* (47%), and difficulties with regulatory agencies (42%).[Q41]

- *Lack of autonomy is most frequently cited as a problem stemming from organizational placement of the state LTCOP. Eleven (11) of 37 LTCOPS in SUAs report their placement limits their freedom to speak with legislators and/or the media. In contrast, only one (1) of 15 LTCOPs in independent nonprofit or legal agencies, or non-SUA state agencies report experiencing limitations on autonomy due LTCOP placement. [Q3a]*
- *All of the 9 state LTCOPs reporting conflicts of interest due to program placement are located in SUAs. [Q3]*
- *State LTCOP effectiveness in legislative and administrative policy activity is statistically significantly associated with: (1) sufficient LTCOP autonomy, (2) effectiveness of LTCOP at the state level, (3) effectiveness of LTCOP at the local level, (4) effectiveness in monitoring laws, regulations, policies and actions at all governmental levels, and (5) effectiveness in relationships with citizen advocacy groups. [Figure 2]*
- *State LTCOPs located in independent legal or nonprofit agencies are much more likely to report sufficient autonomy (89%) than are programs located in SUAs (54%) or other non-SUA state agencies (60%). (NSS) [Figure 3] [Q5]*
- *Most state ombudsmen (83%) report that their relationships with citizen's advocacy groups are "very effective" or "somewhat effective." Effective relationships are significantly associated with effective legislative and administrative policy advocacy ($p < 0.001$).[Q41]*
- *State LTCOPs located in independent legal or nonprofit agencies are much more likely to report being "very effective" at systemic advocacy efforts (56%) than are programs located in SUAs (14%) or other non-SUA state agencies (33%). (NSS) [Figure7] [Q2]*
- *State LTCOPs located in independent legal or nonprofit agencies are much more likely to report ombudsman program expenditures greater than \$20 per LTC Bed (67%) than are programs located in SUAs (46%) or in other non-SUA state agencies (17%). (NSS) [Figure 4] [Q29]*
- *State LTCOPs located in independent legal or nonprofit agencies are about as likely as those within SUAs to meet the IOM recommended minimum ratio of less than 2000 beds per FTE staff: 44% of state LTCOPs in independent agencies compared to 41% of programs located in SUAs meet the minimum IOM ratio of beds to FTE. State LTCOPs in other non-SUA state agencies are much less likely (17%) to meet the IOM minimum ratio than are programs in state agencies (SUA and non-SUA). (NSS) [Figure 5] [Q37]*
- *State LTCOPs located in independent legal or nonprofit agencies are about as likely as those within SUAs to visit 75% to 100% of nursing facilities in 1999 (78% of LTCOPs in independent agencies compared to 73% of programs located in SUAs).*

Programs in other non-SUA state agencies (33%) are much less likely to visit 75% to 100% of facilities. (NSS) [Figure 6] [Q7]

Recommendations

1. Autonomy, Organizational Placement, Structure, and Conflicts of Interest:

1.1 Findings of the Estes/Kaiser Foundation study support the 1995 IOM Report's recommendation that: "No ombudsman program should be located in an entity of government (state or local) or agency outside government whose head is responsible for:

- Licensure, certification, registration, or accreditation of long term care residential facilities;
- Provision of long-term care services, including Medicaid waiver programs;
- Long-term care case management;
- Reimbursement rate setting for long-term care services;
- Adult protective services;
- Medicaid eligibility determination
- Preadmission screening for long-term care residential placements;
- Decisions regarding admission of elderly individuals to residential facilities." (Harris-Wehling, Feasley & Estes, 1995; Recommendation 4.1, pg. 124).

1.2 State LTCOPs should have sufficient organizational autonomy from the state to ensure that ombudsmen may advocate for residents (in accord with their responsibilities as defined by law) without fear of political ramifications. As advised by the 1995 IOM Report: "Ombudsmen must be able to pursue independently all reasonable courses of action that are in the best interest of residents." (Harris-Wehling, Feasley & Estes, 1995; pg. 125).

1.3 Serious consideration should be given to the Recommendation of the 1995 IOM Committee that the Older Americans Act be amended to mandate that no LTCOP be located in any entity (in or outsider of government)

"whose head is responsible for licensure, certification ... of LTC...Facilities; the provision of LTC services ... LTC case management ... adult protective services ... preadmission screening for LTC ... placements..." (IOM, Harris-Wehling et al, 1995, Recommendation #4.1, p. 124).

1.4 LTCOP autonomy is essential to program effectiveness. .Mechanisms need to be developed to ensure that state LTCOPs have their own independent boards to hold the program accountable to fill the public trust. Consideration should be given as to whether such independent boards would be advisory only or policy and governing boards. Some independent mechanisms need to be established to deal with potential or actual conflicts of interest and to, hear disputes around program independence and autonomy and to resolve them. The Protection and Advocacy Model should be examined for its relevance to the LTCOP.

1.5 *Conflicts of Interest should be more clearly defined in the law, regulations, and program guidance from the Administration on Aging. The current OAA's prohibition on placement in a licensing, certification, etc agency should apply to both outside contracts*

Appendix IV Recommendations

and to SUAs inside an umbrella and to SUAs with responsibilities for licensing assisted living and other entities listed in IOM recommendation 4.1 cited above.

2. Relationship Between State LTCOPs, The Administration on Aging, SUAs, and Others

2.1 *The Administration on Aging (AoA) should take a more active role in monitoring LTCOP compliance with the Older Americans Act. Issues of organizational placement and potential or actual conflicts of interest of LTCOPs should be reviewed on a regular and on-going basis.*

2.2 *State Unit on Aging support for the ombudsman program should be strengthened. AoA should actively work with SUAs to increase financial, technical, administrative, and moral support, ensure adequate legal assistance, increase visibility, and support the mission and autonomy of the LTCOP.*

2.3 *State LTCOPs should continue to work to improve relationships with state agencies that have authority to enforce regulations.*

2.4 *State LTCOPs should increase communication between parties (e.g. SUA administration, licensing agencies, and CAGs) by setting up work groups and negotiating memoranda of understanding that clarify and delineate respective roles and responsibilities in order to ensure that all parties are aware of the designated roles, responsibilities, and capabilities of ombudsmen.*

2.5 *The LTC Ombudsman Program should be a coherent unified program with continuity in the state system and the local Ombudsman Programs clearly designated as reporting to the State Ombudsman Program director on all matters related to the Ombudsman Program. Relationships between state and local LTCOPs should be enhanced through increased training, supervision and technical assistance, provision of educational materials, and timely information on legislative and advocacy issues.*

2.6 *Clearly specified policies and mechanisms are required to ensure autonomy and independence of the state Ombudsman Program, its ability to independently have and to manage its financial resources, and its independent accountability to the public trust.*

2.7 *LTCOPs at both the state and local levels should enhance relationships with citizen's advocacy groups by collaborating on legislative agendas, taking part in each others meetings and conferences, co-sponsoring joint training, and forming coalitions with resident and family councils.*

2.8AoA funded research should be conducted on the issues of the autonomy and independence of the program including the organizational structure and placement of the LTCOP that will allow ombudsmen to best meet statutorily mandated requirements, including complaint investigation; resident, family, and community education; and systems level advocacy. Issues of conflicts of interest also need to be investigated.

Independence: Ability to Fully Represent Residents

Questions

1. What are the elements that assure Ombudsman Program independence and autonomy? How does the OAA or any organization (state or local LTCOP or host agency of any kind) assure the elements that provide Ombudsman Program independence and autonomy?
2. How does the State LTCOP control, or manage, the fiscal resources of the program? (This is an important measure of independence and the ability/responsibility of the SLTCOP to create systems responsive to both resident and program needs.) How do we assure that the Ombudsman Program controls and managed the fiscal resources of the program?
3. What is the accountability of the LTCOP? How are the voices of residents and citizens heard and reflected? Who holds the Ombudsman Program accountable? How do we assure accountability?
4. Should the state Ombudsman Program have an independent board (whether it be an advisory or a policy board) to hold the program accountable to fill the public trust?
5. Is there an ideal placement and structure that would work in every state? Should the Ombudsman Program be modeled after protection and advocacy or other models)?
6. Should all Ombudsman Programs be required to have some kind of specified mechanism of consumer feedback?
7. What is the public perception of the LTCOP's ability to freely represent residents? And how important is it to residents that the LTCOP freely represent residents in resolving their problems, questions, and concerns on an individual and systemic basis?
8. Is the placement of the Ombudsman Program within a state agency, by definition, a problem in itself? Even if the potential conflicts of interest and limitations on autonomy are resolved to the satisfaction of all parties? How can the potential conflicts of interest and limitations on autonomy best be removed and resolved?
9. What policies are needed to delineate and implement mechanisms that assure the independence of the Ombudsman Program in systemic advocacy including speaking to legislators, media access, and grass roots organizing?
10. What policies are needed to assure that the state Ombudsman Program is the head of a programmatic unit with the local ombudsman reporting to the state ombudsman with respect to all aspects of their Ombudsman work.

Questions prepared by Carroll Estes with assistance from Sara Hunt and Hollis Turnham.

The Long Term Care Ombudsman Program: Independence and Ability to Fully Represent Residents

Carroll L. Estes, Donna Zulman, Sheryl Goldberg and Dawn Ogawa

This paper concerns the ability of the Ombudsman Program to fully represent residents through the performance of all of the duties assigned to ombudsmen under the Older Americans Act (OAA). The issue of Ombudsman Program independence is important because of its relationship to the ability of ombudsmen to fully represent the residents of long term care facilities. Throughout this Executive Summary and the longer paper, the term, program autonomy, is used interchangeably with that of program independence. Program autonomy (independence) is a characteristic that was examined and deemed crucial to the performance of Ombudsman Programs in the landmark study of the Ombudsman Program conducted by the Institute of Medicine (IOM) of the National Academy of Sciences in 1995 (IOM, Harris-Wehling, Feasley, and Estes, 1995). Issues of conflict of interest and organizational placement were examined at length in the IOM report because they are linked to questions of Ombudsman Program autonomy/independence inasmuch as these characteristics of the program may facilitate or impede the ability of ombudsmen to fulfill OAA mandates. Thus the effectiveness of the Ombudsman Program may be said to hinge to a significant degree on the ability of the program to fully and freely represent residents without impediments and prohibitions upon doing so. Both organizational placement and conflicts of interest are relevant to program independence/autonomy. The reader is urged to read the most relevant sections of the 1995 IOM report that are contained in Appendix A.

Current information on the related issues of program independence/autonomy, conflicts of interest, and organizational placement of the Ombudsman Program has been developed as part of a study by the Chair of the 1995 IOM study committee, Carroll L. Estes, and her colleagues at the Institute for Health & Aging, University of California, San Francisco (IHA/UCSF) (Estes, Zulman, Goldberg, and Ogawa, 2001). This recent work corroborates the findings of the IOM Committee and again underscores the import of the autonomy/independence of the Ombudsman Program, its organizational placement, and the resolution of conflict of interest issues for the ability of the ombudsman to carry out his/her duties as mandated by law. Other crucial elements of effective performance of the ombudsman program are identified in both studies and their recommendations, including the Ombudsman Program's ability to have and control its own fiscal resources, and for there to be a unified coherent state program that incorporates accountability and direct reporting of the local Ombudsmen Programs to the state Ombudsman Program.

This paper draws upon multiple sources of information: (1) the original 1995 IOM study that was funded by the Administration on Aging, (2) the Estes study conducted in 2000-2001 under a grant from the Kaiser Family Foundation, (3) the 1999 national database of the National Ombudsman Reporting System (NORS), (4) a review of recent literature (see the Appendix A), and (5) consultation with experts working in the field. The 1995 IOM study and the 2000-2001 Estes/Kaiser Foundation study represent two of the most

important sources of information on the Ombudsman Program's ability to represent residents in the varied elements of the OAA legislative mandate for the program.

These two studies are among a very limited number of existing efforts to understand what enables (and inhibits) Ombudsman Programs to represent residents, monitor relevant policies, regulations, and laws, and to provide both individual and system level advocacy. Thus, it is not surprising that one consistent recommendation of both studies is for the funding and conduct of more research on this issue.

Both of these projects were designed to broadly understand issues across the nation. Both of these studies identified key elements of the ability to carry out the mandates of the Ombudsman Program as including autonomy/independence of the program, its organizational placement, and the resolution of actual and potential conflicts of interest. Both of these studies relied on interviews and/or written communications (e.g., surveys) with directors of Ombudsman Programs – at both the state and local levels in the IOM study – and at only the state level in the more recent Estes/Kaiser Foundation study (Estes et al, 2001). In addition, in the 1995 IOM study, there were site visits (state and local level) and a major panel of experts was consulted and developed papers. Hence, the information and recommendations presented here come from the reports of the directors of Ombudsman Programs and, in the Estes/Kaiser study, from the state level only – but involving representation from 100% of state Long Term Care Ombudsman Programs (LTCOPs). Nevertheless, the methodology of both projects involved triangulated (multiple) data sources, while both collected data from the directors of the ombudsman program based on the assumption that the ombudsmen, themselves, are in the best position to report on their experiences and ability to do their job as they understand its mandates and requirements. In both cases, the report authors contend that the perspectives of the directors of the Ombudsman Programs are valuable and valid. Corroboration between findings of the two studies (the 1995 IOM study and more recent Estes/Kaiser Foundation study), and the continuity of many of the same issues and concerns across time and the two studies lend credibility to the findings, conclusions, and recommendations that are offered here. Clearly, the views presented are those of the authors alone and are not to be attributed to any of the funding sources or agencies involved.

Key Findings Related to the Kaiser Family Foundation Study

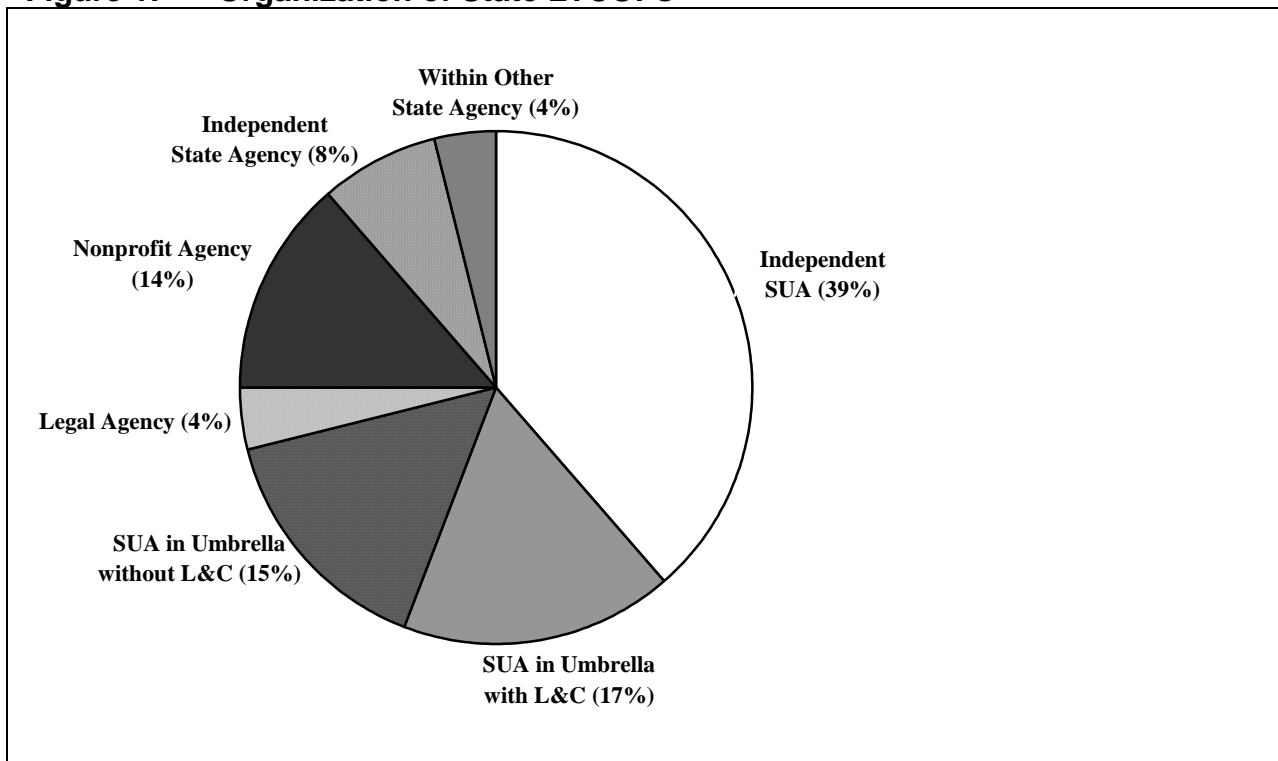
During 2000 and 2001 the Institute for Health & Aging, University of California, San Francisco under the leadership of Carroll L. Estes, Principal Investigator, conducted a telephone survey of all 50 state Long Term Care Ombudsman Programs, held a focus group of experts, attended training conferences of state and local ombudsmen, and surveyed the literature. The objectives of this project, funded by the Henry J. Kaiser Family Foundation, were to follow up on the 1995 Institute of Medicine (IOM) study (Chaired by Carroll L. Estes), and to shed light on issues of effectiveness and quality of long term care. The Estes/Kaiser Foundation study examined several issues that are relevant to the question of the ability of the Ombudsman Program to fully represent residents, particularly issues of program independence and autonomy, organizational placement and conflict of interest in the Long Term Care Ombudsman Program funded under the Older Americans Act. This paper presents selected key findings of the Estes/Kaiser Foundation project in three areas related to the topic: (1) Autonomy and

Organizational Placement, (2) Effectiveness of the Long Term Care Ombudsman Program (LTCOP), and (3) Systemic Advocacy and Quality of Care. Recommendations and Key Questions are presented in the Executive Summary only. Five important source documents for this paper are: (1) the original IOM report, *Real People, Real Problems* (IOM, Harris-Wehling, Feasley, and Estes, 1995); (2) the Literature Review (Appendix A) that draws upon Chapter 4 of the IOM report and other contemporary literature; (3) the DRAFT final report of the 2000-2001 Estes/Kaiser Foundation study (Estes 35 al, 2001); (4) the detailed qualitative responses of state ombudsmen about difficulties with organizational placement and how they deal with them (Appendix B); and the database for the 1999 National Ombudsman Reporting System (NORS) from the Administration on Aging. The full details of the study and recommendations are contained in the DRAFT final report, *The Effectiveness of State Long Term Care Ombudsmen Programs*, by Carroll L. Estes, Donna Zulman, Sheryl Goldberg, & Dawn Ogawa submitted to the Kaiser Family Foundation in May 2001. The Kaiser Foundation will release a shorter version of the report in 2002.

Organizational Structure of State LTCOPs

Thirty-seven (71%) of the state LTCOPs are part of their State Unit on Aging (SUA). Of these, 39% are in an independent SUA and the remainder is in SUAs within umbrella agencies that either include a licensing and certification agency (17%) or do not (15%). In addition, seven (14%) are located in a nonprofit agency, four (8%) in an independent state agency, two (4%) in another umbrella state agency, and two (4%) in a legal agency (See Figure 1).

Figure 1: Organization of State LTCOPs



State LTCOP Survey, Institute for Health & Aging, UCSF, 2001, Q 2

Thirteen (25%) of the state LTCOPs have experienced a change in their organizational placement in the last five years. Five state ombudsmen report that their LTCOP became independent from their SUA and moved into another state or independent agency, with reasons including the need to avoid a conflict of interest with the state agency, a structural change that placed the ombudsman in a less advocacy-oriented role, and a budget change that transferred funds in order to make the program more effective. Three of the 13 state LTCOPs experienced a placement change whereby their program was incorporated into aging services due to consolidation of resources or senior services, or to the creation of a new department. Three different state LTCOPs were elevated within their departments because the ombudsman program became a higher priority in the agency. Other changes in organizational placement include a LTCOP moving from the agency or department for families and children to the health agency or department, and a LTCOP advocating for and gaining increased independence within its SUA.

Twenty-eight state ombudsmen (55%) 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.

When examined by organizational placement, almost two-thirds of state LTCOPs that were located in SUAS (62%) and in other state agencies (60%) reported difficulties in providing their Ombudsmen services due to their placement. This contrasts with 22% of state LTCOPs in legal or nonprofit agencies that reported difficulties in service provision due to organizational placement. Table 1 contains information on the types of difficulties that were reported by state LTCOPs due to their placement, organized by their type of organizational placement (even though some of these problems might be found in any placement).

Table 1: Reported Difficulties in Service Provision Due to Organizational Placement of State LTCOP

State LTCOPs in an independent SUA (39%)

- Lack of autonomy to speak to legislators and the media
- Conflicts of interest with SUA
 - Advocacy efforts hindered
 - Ombudsmen prohibited from criticizing state agencies
 - SUA is also responsible for Adult Protective Services
- No direct access to information about policy issues
- Executive director is appointed by governor

State LTCOPs in SUA within an Umbrella Agency with a Licensing & Certification Agency (17%)

- Lack of autonomy to speak to legislators and the media
- LTCOP is not considered or contacted about policy issues
- Conflicts of interest with SUA and/or umbrella organization
 - SUA also makes recommendations to state agency regarding licensing of facilities
 - SUA is also responsible for Adult Protective Services, administers Medicaid choice, determines nursing home eligibility, and owns and operates LTC beds
- Consumers confused because they think ombudsmen are licensing regulators
- LTCOP must compete for the attention and interest of the director of the umbrella agency
- Cumbersome bureaucracy in terms of budget management and lines of authority

State LTCOPs in a SUA within an Umbrella Agency without a Licensing/Certification Agency (15%)

- State ombudsman is required to keep the entire hierarchy informed of LTCOP activities
- Lack of autonomy to speak to legislators and the media
- Gap in legal services because LTCOP's legal advisor cannot represent residents

State LTCOPs in a Nonprofit Agency (14%)

- Autonomy limited by parent organization
- No access to state amenities due to tight budget

State LTCOPs in an Independent State Agency (8%)

- Lack of protective umbrella agency allows for budget vulnerability

State LTCOPs in Another State Agency (4%)

- Unable to advocate at state level
- Conflict of interest as part of state government

State LTCOPs in a Legal Agency (4%)

- *No specific difficulties due to placement were reported*

State LTCOP Survey, Institute for Health & Aging, UCSF, 2001 (Qs 2 & 3)

State ombudsmen utilize a number of strategies to deal with the difficulties associated with their organizational placement (See Appendix B, Qualitative Response Detail for Q3a and Q3b, Estes/Kaiser Foundation study). In the event of conflicts of interest, one strategy is to work with individuals who have more autonomy to advocate for residents and communicate with legislators and the media, such as volunteer ombudsmen, local ombudsmen, and representatives from citizen's advocacy groups. Communication between parties, including the SUA administration and licensing and certification agencies is essential, and several state ombudsmen have set up workgroups or negotiated contracts of understanding. Some ombudsmen have attempted to work with the media to expose conflict of interest issues. Others report that focusing on education of state agency directors, as well as legislators, has proven effective.

Effectiveness of State LTCOPs

Factors that contribute most to the effectiveness of state LTCOPs are: ability to represent interests of residents to most state agencies (100%); good relationships with licensing & certification (96%), HCFA (93%), the LTC industry (88%); and (among others) several factors directly related to organizational location and autonomy: freedom of the state LTCOP's activities from excessive legislative or regulatory restrictions (85%), clearly defined lines of authority and accountability for state and local ombudsman (82%), supportive political and social climate (76%), ability to carry out federal mandates independently from other state agencies and parties (72%), and sufficient autonomy due to organizational placement (61%).[Table 2] [Q5]

Table 2: Factors Contributing to Effectiveness of State LTCOPs

	Yes (%)	Respondents (N)
Ability to represent interests of residents to most state agencies	100	52
Good relationship with Licensing & Certification	96	51
Good working relationships with HCFA	93	44
Uniform database	86	51
Good working relationship with LTC industry	88	51
Freedom of LTCOP's activities from excessive legislative or regulatory restrictions	85	52
Agreement with position of employees' unions regarding staffing practices	85	26
Clearly defined lines of authority and accountability for state and local ombudsmen	82	51
Supportive political and social climate	76	49
Ability to carry out federal mandates independently from other state agencies/parties	72	50
Adequate communication methods to share information with local programs	69	48
Sufficient legal service available	67	51
Sufficient autonomy due to organizational placement	61	51
Sufficient number of volunteers	22	45
Sufficient funding	22	50
Sufficient number of paid staff	21	52

State LTCOP Survey, Institute for Health & Aging, UCSF, 2001, Q 5

Thus, issues of autonomy due to organizational placement was reported as contributing to the effectiveness of state LTCOPS by nearly two-thirds of ombudsmen. Further, the concepts of independence and autonomy are likely to be embedded in the first ranked factor that is related to effectiveness according to all (100%) of all state Ombudsmen Programs. That first ranked factor is the “ability to represent interests of residents to most state agencies”, as well as other factors (e.g., freedom from excessive legislative or regulatory restrictions” reported by 85%). The key point is that organizational placement may be a marker for issues associated with program autonomy and/or independence that are essential to the ability of the Ombudsman Program to fully represent residents in accord with the OAA. Lack of autonomy is mentioned most frequently as one of the problems stemming from organizational placement of the program..

A key element in the Ombudsman Program’s ability to represent residents is its mandate to conduct legislative and administrative advocacy on the systemic level. From the Estes/Kaiser Foundation project we know that *systemic advocacy* is one area in which *state ombudsmen are least likely to report effectiveness*. Figure 2 illustrates the import of a state Ombudsman Program’s reporting that they have “sufficient autonomy”.

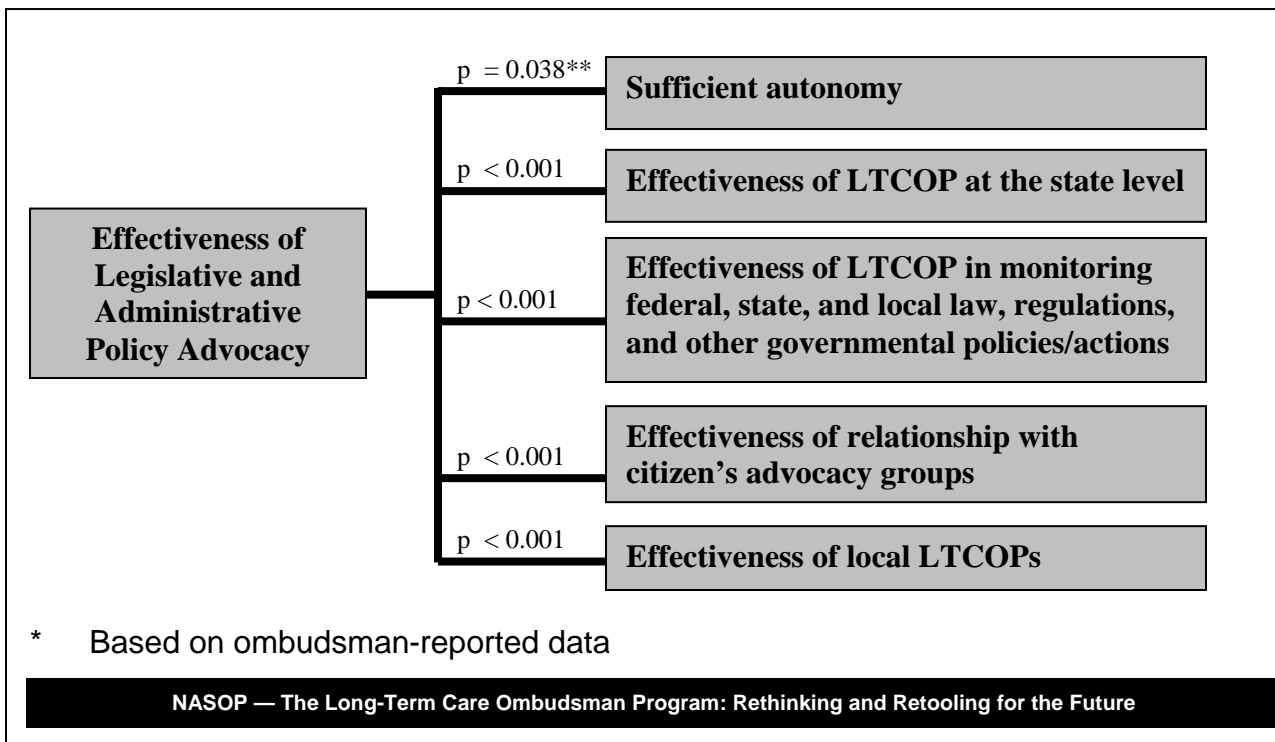
It is significantly and statistically associated with the reported effectiveness of legislative and administrative policy advocacy. In Figure 1, four other factors are shown to be significantly (statistically) associated with a State Ombudsman Program’s ability to be effective at the systemic policy level: (1) effectiveness of the state LTCOP; (2) Effectiveness of the state LTCOP in monitoring federal, state, and local law, regulations, and other governmental policies/actions; (3) effectiveness of local LTCOPs, and (4) effectiveness of relationships with citizen advocacy groups.

State LTCOPs located in independent legal or nonprofit agencies are much more likely to report “sufficient autonomy” (89%) than are state ombudsman programs located in SUAs (54%) or other non-SUA state agencies (60%). (NSS) [Figure 3] [Q5].

As noted above, the lack of autonomy is most frequently cited as a problem stemming from organizational placement of the state LTCOP. Eleven (11) of 37 state LTCOPS in SUAs report their placement limits their freedom to speak with legislators and/or the media. In contrast, only one (1) of 15 stated LTCOPs in independent nonprofit or legal agencies, or non-SUA state agencies report experiencing limitations on autonomy due LTCOP placement. [Q3a] Also notable is the fact that of the nine state ombudsmen reporting conflicts of interest due to program placement, all are located in SUAs.

It is very important to note that Ombudsman *program autonomy* is statistically significantly associated with reports by state ombudsmen of: (1) the ability of the ombudsman program to carry out federal mandates independently from other state agencies; (2) a supportive political and social climate, (3) the effectiveness of the LTCOP in advocacy efforts, (4) LTCOP freedom from excessive legislative/regulatory restrictions, and (5) clearly defined lines of authority/accountability for state and local ombudsmen (See Table 1, Appendix C).

Figure 2: Factors Significantly Associated with LTCOPs’ Effective Advocacy Efforts*



** See Appendix C for statistical tests

State LTCOP Survey (Qs 4, 5g, 6d, 6e, 10, 42; Appendix 1) Institute for Health & Aging, UCSF, 2001

Organizational Placement and Effectiveness of Local LTCOPs

Fifteen (33%) state ombudsmen report that changes have taken place in the organizational placement of their local ombudsman programs in the past five years. Of these, six report an increase in local ombudsmen or the creation of new local programs (due to an increase in state funding, a need for greater coverage and accessibility, or to shift the program from the state to the community level). Four state ombudsmen report that local ombudsman programs previously under an AAA were subcontracted out by the AAA. Reasons for this change include a conflict of interest because the AAA was also administering the Medicaid home care program, and trouble finding qualified workers in a rural community. In two states subcontracted programs were brought back under the AAA umbrella due to poor performance with contractors and administrative problems. Other placement changes include three local programs moving from one agency to another (e.g., AAA to AAA, or AAA to another contract service agency).

When asked to rate the effectiveness of their local LTCOPs, 41% of state ombudsmen rate their local programs as “very effective” and 55% as “somewhat effective.” Effectiveness ratings for local LTCOPs are significantly associated with effectiveness ratings for work with nursing facilities ($p = 0.009$), legislative and administrative policy advocacy ($p < 0.001$) and monitoring of laws and regulations ($p < 0.001$; Table 1, Appendix C).

Factors contributing most prominently to the effectiveness of local LTCOPs are listed in Table 3 and include: staff and volunteer training (98%), response time to complaints (98%), degree of collaboration/cooperation with the local nursing home providers (96%), amount of funding (94%) and number of paid staff (94%), ability to obtain needed assistance to deal with complaints (94%), number of visits to nursing homes (94%), the quality of working relationship with other local programs dealing with LTC (94%), the number of volunteers (92%), and organizational placement of local LTCOPs (91%). Each of these characteristics is extremely important in contributing to the effectiveness of the local Ombudsman Program according to the state LTCOPs.

Table 3: Factors that Contribute to the Effectiveness of Local LTCOPs

	Factor contributes to effectiveness (%)	Respondents (N)
Staff and volunteer training	98	48
Response time to complaints	98	47
Degree of collaboration/cooperation with the local nursing home providers	96	47
Amount of funding	94	50
Number of paid staff	94	50

Ability to obtain needed assistance to deal with complaints	94	49
Quality of working relationship with other local programs dealing with LTC	94	47
Number of visits to nursing home residents	94	47
Number of volunteers	92	47
Organizational placement of local LTCOPs.	91	45
Quality of working relationship with L&C agency and/or survey agency	90	48
Employee consistency (rate of turnover)	88	49
Ability to obtain legal services	79	47
Convenience of travel to facilities	76	46
Agency policies or protocol that allow for contact with the media or legislators	74	46
Quality of working relationship with HCFA	54	39

State LTCOP Survey (Question 11), Institute for Health & Aging, UCSF, 2001

Political Influences and Relationships with Other Organizations

The majority (76%) of state ombudsmen report that the political and social climate in their state is supportive of the mission of the ombudsman program. Ombudsman reports of a supportive political and social climate are significantly associated with reports of sufficient program autonomy ($p = 0.004$) and ability to carry out federal mandates independently from other state agencies and parties ($p = 0.001$; Table 1, Appendix C).

Twenty-two (43%) state ombudsmen report that there is legislation currently being proposed in their state that will affect their state LTCOP. Six ombudsmen report a possible increase in funding for their program, which could allow them to develop or expand their volunteer programs and will help them better meet mandates, but may also require that they address the needs of new populations (such as home care and managed care clients).

When asked if there are any barriers or impediments at the state or federal level that keep them from carrying out their jobs, twenty (39%) state ombudsmen say barriers exist at the state level, six (12%) ombudsmen report that barriers exist at the federal level, and eleven (22%) state ombudsmen report that barriers exist at both the state and federal level. Barriers at the state level include conflicts of interest with umbrella agencies at the state level, a strong nursing home industry lobby, lack of cooperation with other agencies, lack of autonomy in advocacy efforts and in legislative and media contacts, resource and funding issues, hierarchical and bureaucratic structure of state agencies, state mandates that require broad coverage, and a conservative political climate. Barriers at the federal level include inadequate monitoring and enforcement of laws by the AoA, budgetary issues, and inadequate notification about survey scheduling. It is important to note that, because there is no current data source for the local ombudsman perspective and issues, the reports of state ombudsmen in the Estes/Kaiser Foundation study provide the only information available on this topic. Based on the 1995 IOM report and the scant data available here we know that program

autonomy and independence at the local level are just as important in terms of the effectiveness and ability to represent residents as they are at the state level.

According to thirty-nine (78%) state ombudsmen, the strong nursing home industry lobby in their state influences the effectiveness of their political advocacy efforts. When asked to explain, ombudsmen state that the nursing home industry is very powerful due to large contributions to legislators' campaigns and full-time lobbying efforts. In some states the industry has blocked nursing home staffing legislation from passing. A number of ombudsmen report that they do not have the time, money, or autonomy to speak out and counter the actions of the nursing home industry.

Another factor that influences advocacy efforts is the relationship between LTC ombudsmen and representatives of the SUA and AAA (47%). Strained relationships often relate to conflicts of interest and lack of autonomy within the SUA. Some ombudsmen report interference by SUAs and AAAs in both systemic advocacy efforts and at an individual case level. Other related problems include lack of support from AAAs for the program, lack of continuity due to changes in the SUA director's position, lack of control or influence regarding contracts, and conflicts between the SUA and regional units. It should be noted that during the course of this study one state ombudsman chose to resign due to feelings that conditions imposed by the State Unit on Aging limited the ombudsman's ability to act in the best interest of residents.

Difficulties with regulatory agencies (42%) also affect the ability of the ombudsman to fulfill its mandate of advocacy. Problematic aspects concern delayed responses to calls, collaboration with the provider industry, neglecting to notify ombudsmen about surveys, and general communication problems. Each of these problems impairs the ability of ombudsmen, whether they be at the state or local levels, to fully represent residents. Another important finding is the report of state ombudsmen of their perception that the aging network is apathetic to the plight of the institutionalized aged (27%), and that this is another barrier to political advocacy efforts, mostly because community-based services are replacing institutionalized long term care as the current priority of the aging network in many states.

In terms of their program's relationship with citizen's advocacy groups (CAGs), 83% of state ombudsmen report that their relationship with CAGs in their state is "very effective" or "somewhat effective." Effective relationships with CAGs are significantly associated with effective legislative and administrative policy advocacy as reported by state ombudsmen ($p < 0.001$, Appendix C).

Factors that contribute to an effective relationship include regular communication, common goals, attendance at each other's meetings, the ability for CAGs to advocate when ombudsmen cannot speak out, working on legislative agendas together, sharing information, and mutual respect and support. State ombudsmen attribute ineffective relationships with CAGs to different priorities and focus, the need to build awareness among CAGs that ombudsmen are also advocates for LTC residents, turnover within CAGs, a lack of regular meetings among CAGs, and the need to spend more time building a relationship based on common goals.

Discussion of Key Issues

This nationwide survey of state LTCOPs reveals that the majority of state ombudsmen rate their programs as effectively meeting the mandates specified in the Older Americans Act (Estes et al., 2001). A detailed analysis of survey responses, however, suggests that a number of barriers currently exist that limit the ability of LTCOPs to carry out their responsibilities as well as their effectiveness—and particularly concerning issues of organizational placement and autonomy of ombudsman programs.

Organizational Placement and Autonomy of the State LTCOP

More than half of the state LTCOPs report that their organizational placement creates difficulties for service provision, including impaired ability to objectively and independently investigate and resolve complaints, and lack of autonomy to speak to legislators and the media. In some instances, constraints around organizational placement impede the efforts of ombudsmen to fulfill the requirements of legislative and administrative policy advocacy.

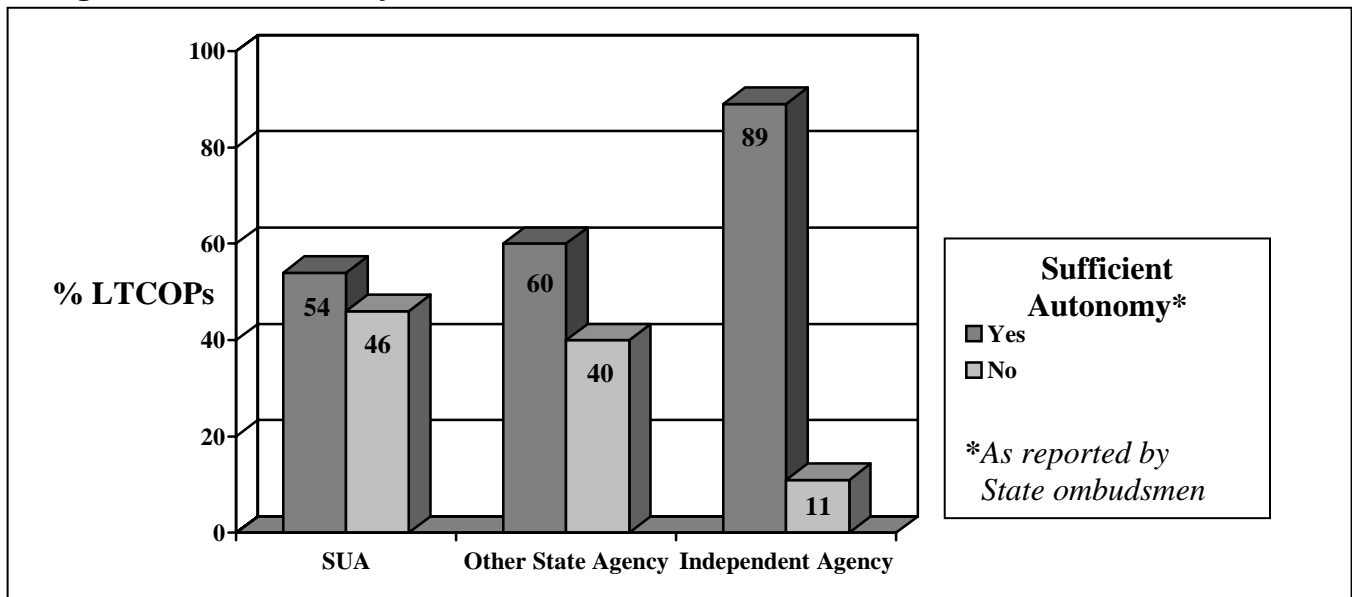
One of the primary concerns with the organizational placement of state LTCOPs is the potential for conflicts of interest. The 1995 IOM Report recommended that by FY 1998 no ombudsman program should be located in an entity of government or agency outside the government whose head is responsible for licensing and certification, provision of long-term care services, adult protective services, and Medicaid eligibility determination. (Harris-Wehling *et al.*, 1995) (See recommendations in the Executive Summary regarding the import of clearly delineating and resolving conflicts of interest.) According to state ombudsmen, however, a number of programs remain in an umbrella agency with their state's licensing and certification agency, adult protective services and/or the programs administering Medicaid. It should be observed here that these placement issues are in many states more worrisome at the local LTCOP level. These issues concern conflicts of issues and lack of autonomy and independence for the local LTCOP associated with guardianship, case management, waiver services, and screening. This is a very important area for investigation and legislative consideration.

A second concern raised repeatedly in discussions with state ombudsmen is the issue of program autonomy. There is a significant association between ombudsman responses to the question of whether their program's placement allows for sufficient autonomy, and their responses to questions about: 1) freedom from excessive legislative or regulatory restrictions ($p = 0.002$), and 2) ability to carry out federal mandates independently from other state agencies and parties ($p < 0.001$). In addition, there is a significant association between ombudsman reports of "sufficient program autonomy" and ombudsman reports of effective legislative and administrative policy advocacy ($p = 0.038$; Appendix C, Table 1), but no association with any other statutorily mandated requirements (including complaint investigation, and community, family, and resident education).

State ombudsmen from programs within SUAs report several other problems stemming from their organizational placement. For example, of the twenty ombudsmen who state that their LTCOP's organizational placement does not allow for sufficient autonomy, seventeen are located in SUAs. Figure 3 displays the association between organizational placement of LTCOPs and ombudsman responses to a question regarding sufficient program autonomy. In addition, when asked about the effectiveness of their LTCOPs in meeting the statutorily mandated requirement to monitor federal, state, and local law, regulations, and other government policies and actions, all except seven ombudsmen rate their program as "very" or "somewhat effective," and these seven are all located in SUAs. Similarly, when asked about their effectiveness in meeting the requirement of legislative and administrative policy advocacy, all except fourteen respond "very" or "somewhat effective," and of the fourteen, twelve are in SUAs.

Interestingly, state LTCOPs located in independent legal or nonprofit agencies are much more likely to report sufficient autonomy (89%) than are state ombudsman programs located in SUAs (54%) or other non-SUA state agencies (60%). (NSS) [Figure 3] [Q5]

Figure 3: Autonomy Associated with Placement of State LTCOPs



State LTCOP Survey (Questions 2 & 5g), Institute for Health & Aging, UCSF, 2001

These findings suggest that being located in an SUA may hinder advocacy efforts and impede autonomy. Some ombudsmen who are in SUAs and are therefore state employees find that even though they are ostensibly free to speak to legislators and the media, the structure of their SUA imposes bureaucratic barriers (such as requiring that communication be pre-approved). SUAs can provide valuable support to ombudsman programs, including financial support, administrative and technical assistance, legal services, advocacy for the program, and the use of facilities and supplies. Being housed outside an SUA can diminish these types of support.

Several ombudsmen in programs located outside SUAs report encountering their own difficulties due to placement, including a lack of access to state amenities (such as travel resources and supplies), budget vulnerability due to the lack of a protective umbrella agency, and limitations on autonomy by the umbrella nonprofit agency. In addition, thirteen ombudsmen in programs within SUAs report having no difficulties due to their placement. Statistical analysis of program placement, resources, and effectiveness did not demonstrate a significant relationship between the organizational placement of state LTCOPs and their funding or staffing levels or self-reported ratings for effectiveness. This indicates that placement within a SUA does not necessarily have to be a problem in itself, if the potential conflicts of interest and limitations on autonomy are resolved to the satisfaction of all parties.

This paper underscores the crucial relationship between ombudsman program independence and autonomy and the ability of state ombudsmen to carry out the first and most important of their duties under their federal mandate: to fully represent long term care residents. A number of questions are developed and several recommendations are offered based on the authors work on both the 1995 IOM study of the Ombudsman Program and our work on the Estes/Kaiser Foundation study completed in 2001.

Note: In Appendix D, Figures 4 through 7 display the relationship between organizational placement of state LTCOPs and funding and staffing levels, as well as facility visitation and other dimensions that have important implications for the ability of the ombudsman to contribute to improving the quality of long term care.

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APPENDIX A

REVIEW OF RECENT LITERATURE

Key Issues Explored in Recent Literature

Issues Related to Effectiveness: Structure/Placement/Autonomy

Currently there are LTCOPs operating in all 50 states, the District of Columbia, and Puerto Rico. In FY 1998 there were 587 local and regional ombudsman programs (AoA, 2000). Most state programs utilize volunteers in addition to paid staff. The majority of programs operate within the State Units on Aging, which are either independent or part of a larger state umbrella agency. In addition several programs are operated by other state agencies, legal services agencies, or nonprofit organizations.

Few studies have investigated the effectiveness of LTCOPs based on their organizational structure and location. One analysis of local ombudsman programs in Kentucky compares the effectiveness of programs situated within an Area Agency on Aging (AAA) with programs that are subcontracted out. The study finds that programs not in AAAs verified a significantly higher percentage of complaints and fully or partially resolved a significantly greater percentage of complaints to the satisfaction of the resident or complainant. Huber *et al.* (1996) comment that one possible explanation for this discrepancy is the different emphases of the two types of programs. While both types of agencies address a wide range of complaints, the programs within AAAs (which are planning and coordination agencies focused heavily upon systems development) emphasize resident rights and administrative/systemic issues, while non-AAA programs emphasize resident care and quality of life issues.

Conflicts of Interest

Conflicts of interest undoubtedly arise due to the OAA's mandate that ombudsmen work toward improving LTC facilities for residents even if this involves challenging, recommending, and facilitating public comment on government policies, laws, and regulations (U.S. Code: Title 42, Section 3058g). The National Association of State Long-Term Care Ombudsman Programs reports that the following circumstances create conflicts of interest:

- The LTCOP is part of an entity that is responsible for licensing or certifying LTC facilities
- The LTCOP is located within an organization that may impair the ability of the ombudsman to objectively and independently investigate and resolve complaints
- The ombudsman role is not seen as independent. (The ombudsman must be free to take action on behalf of residents, to publicly represent the concerns of residents, to bring together individuals who have the authority to solve problems, and to make recommendations to boards, committees, and task forces in developing LTC policy).
- The contract (sponsoring) agency does not understand the ombudsman function. (There must be the recognition that there are inherent conflicts in the job, and a need to support the role and goals of the ombudsman through any conflict) (NASOP, 1989).

To protect against conflicts of interest, the OAA prohibits conflicts of interest with state agencies and legal counsel. State programs are required to establish mechanisms to identify and remove conflicts, and to ensure that the ombudsman:

- Does not have a direct involvement in the licensing or certification of a LTC facility or of a provider of a LTC service
- Does not have an ownership or investment interest in a LTC facility or a LTC service
- Is not employed by, or participating in the management of, a LTC facility
- Does not receive or have the right to receive remuneration under a compensation arrangement with an owner or operator of a LTC facility (§712(f)(3)).

The 1995 IOM report recognizes that “ombudsman programs and individual ombudsmen are particularly vulnerable to actual or perceived conflicts of interest that arise through governance boards” and recommends that the OAA be amended to assert that no ombudsman program should be located in an entity of government (state or local) or agency outside government whose head is responsible for: licensure, certification, registration, or accreditation of LTC residential facilities; provision of LTC services, including Medicaid waiver programs; LTC case management; reimbursement rate setting for LTC services; Adult Protective Services; Medicaid eligibility determination; pre-admission screening for LTC residential placements; or decisions regarding admission of elderly individuals to residential facilities (IOM, Harris-Wehling *et al.*, 1995).

Three dimensions of conflict of interest were identified in the IOM report based on work by Roland Hombostel (1994; IOM, Harris-Wehling *et al.*, 1995, p. 107): (1) *Conflicts of loyalty*, which involve issues of judgment and objectivity, often related to financial and employment issues; (2) *Conflicts of commitment* involving issues of time and attention and relating to the OAA mandate that each state employ a “full time” state ombudsman; and (3) *Conflicts of control* involving issues of independence that raise such questions as “Do other interests, priorities or obligations of the agency that houses the ombudsman materially interface with the ombudsman’s advocacy on behalf of residents? Do administrative or political forces materially interfere with the professional judgment of the ombudsman? Is the ombudsman able to act responsibly without fear of retaliation by superiors?” (IOM, Harris-Wehling *et al.*, 1995, p. 107).

“Conflicts of interest may arise from the structure in which the ombudsman program exists, from situations faced by the ombudsman, and from individual ombudsman relationships or conduct” (IOM, Harris-Wehling *et al.*, 1995, p. 108). As the participation and work of SUAs and AAAs expand in health and LTC, the potential for conflicts of interest increases, particularly where such entities provide or manage LTC or related services (e.g., case management).

One of the current conflict of interest debates involves the issue of placement of the ombudsman program; specifically whether the LTCOP is made more effective or is compromised when it is situated within a state agency as compared to when the program is fully independent from the state. Autonomy of the LTCOP requires that both state and regional ombudsmen are able to freely speak with media, policy makers, and legislators and that ombudsmen may participate in policy and operational discussions with other agencies.

Conflicts relevant to the provision of legal counsel were highlighted in the IOM report (see pp. 117-118), given that the OAA mandates that ombudsmen “represent the interest of the residents before governmental agencies”, which, by definition, requires independent legal

counsel. Conflicts may arise “in circumstances in which the same government attorneys advise the ombudsman program on matters relevant to the rights of LTC residents or ombudsman responsibilities” (IOM, Harris-Wehling *et al.*, 1995, p. 117). Also, the unavailability of independent legal counsel (for any reason) may impede the program’s ability to identify and remedy a range of conflicts of interest.

The key point made by the IOM Committee is that “All conflicts of interest work to the disadvantage of the vulnerable client” (IOM, Harris-Wehling *et al.*, 1995, p. 122). Further,

“In the committee’s judgment, states can comply fully with the OAA goal of avoiding conflict of interest only if the ombudsman program is located outside state government in a freestanding organization that has a commitment to an advocacy mission. If the program is located within state government, then the only acceptable structural alternatives that may sufficiently constrain conflicts of interest are to place the program in an independent government entity without LTC regulatory responsibilities that is directly accountable to the governor or that resides in a independent state commission” (IOM, Harris-Wehling *et al.*, 1995, p. 123).

The IOM committee recommended amending the OAA to mandate that no LTCOP could be located in any entity (in or outside government)

“whose head is responsible for licensure, certification ... of LTC ... facilities; the provision of LTC services; ...LTC case management; ... adult protective services; ... preadmission screening for LTC ... placements...” (IOM, Harris-Wehling *et al.*, 1995, p. 124).

Collaboration and Coordination with Other Agencies Including Licensing and Certification

Ombudsmen frequently interact with other advocates and various representatives of the state and outside agencies within the LTC and health sector. Ombudsmen often work closely with their state surveying agency and the Health Care Financing Administration (HCFA), as well as citizen’s advocacy groups, Medicaid and Medicare program representatives, and the Attorney General’s office. Some ombudsman programs also work closely with Adult Protective Services (APS).

The 1999 OIG study investigates the coordination between ombudsman programs and state surveying and certification agencies and finds that in 1997 ombudsmen accompanied surveyors only 61% of the time, despite the requirement that they be notified of inspection dates (OIG, 1999; OEI-02-98-00351). The study also reports that only 13% of the total ombudsman abuse complaints ultimately reached the survey agency in 1997, and only 5% of all complaints to the state survey and certification agency originated from ombudsmen (OIG, 1999; OEI-02-98-00330). Based on these findings the OIG recommends that the HCFA facilitate better coordination with the ombudsman program.¹

¹ It is important to note that the low numbers reported in the OIG Report do not necessarily indicate a lack of attention by LTCOPs to abuse complaints. For example, ombudsman programs often investigate and resolve complaints brought to their attention without involving the licensing agency, and some states have outside agencies other than the survey and certification agency that are responsible for investigating abuse complaints. In addition, some ombudsmen may refer complaints related to abuse directly to the licensing agency or may urge

While the degree of coordination with surveying agencies is sometimes low when it comes to complaint investigation, many state ombudsmen work closely with HCFA to strive for common goals in nursing home reform. In 1999, representatives from HCFA met with state ombudsmen at the Annual State LTC Ombudsman Spring Training Conference. The meeting was convened to discuss HCFA's response to former President Clinton's 1998 Nursing Home Initiatives. The goal of this collaboration was to inform ombudsmen of HCFA's activities, generate ideas for the role of the ombudsman and the relationship between ombudsmen and HCFA in these activities, shape the advocacy agenda for state LTCOPs, and determine if progress had been made in key arenas essential to improving resident care. Topics discussed include abuse prevention, nutrition/hydration, staffing, the impact of a prospective payment system on residents, restraint use, complaint investigation and follow-up, facility closing, and appeals of survey findings (Hunt, 1999).

In a 1993 meeting arranged by AoA, ombudsmen met with representatives from APS and elder legal services networks to discuss and make recommendations about coordination between LTCOPs and APS programs. Participants at the meeting determined that while the two programs must work together to better serve their clients, there are important distinctions in their philosophy, functions, mandates, and authorities. For example, while the roles of ombudsmen and APS workers may overlap upon receipt of an abuse complaint, their roles in resolving complaints differ in that APS workers act as agents of the state, whereas LTC ombudsmen act as agents of the resident. The participants recommend that AoA issue a regulation that prohibits an ombudsman from also being an APS worker. In addition, the advantages and disadvantages of APS and the LTCOP being in the same agency were discussed. Advantages include an increased potential for the agency to see the "big picture," joint training, and equal access to resources and decision-makers. Disadvantages include potential conflicts of interest, lack of opportunity for both programs to assess and critique the other, and potential breaches of confidentiality (AoA, 1993).

Systems-Level Advocacy

In addition to investigating complaints, ombudsmen are responsible for monitoring and evaluating policy changes. Many ombudsmen work directly with legislators to advocate on behalf of residents, and as a group the National Association of State LTC Ombudsman Programs (NASOP) advocates for positions that benefit residents and responds to requests for information at the federal level.

Ombudsmen are also responsible for informing the public about LTC issues and educating facility staff and the greater community about the ombudsman program and laws and regulations. Ombudsmen disseminate information through the use of posters, brochures, media spots and public forums, toll-free numbers, community outreach efforts, telephone hotlines, and in-service training for facility staff. By taking part in training at nursing facilities, ombudsmen raise staff awareness about residents' rights and quality of care issues. Ombudsmen also promote the development of resident and family councils, which serve to

and assist the resident to register a complaint directly with the licensing agency, thus not including the complaint record in NORS.

support, educate, and inform residents and their family members, and also provide a vehicle for action on concerns and complaints (IOM, Harris-Wehling *et al.*, 1995).

In 1998, NASOP adopted a position paper regarding the representation of LTC residents. One of the core principles is the independence of the ombudsman program:

Program independence is the vehicle that enables ombudsmen to carry the message of residents, to ensure that the laws and regulations are being applied. A LTCOP that functions with independence can effectively give voice to residents' concerns within individual facilities and at local, state, and federal government levels and fulfill the advocacy responsibility called for in the OAA.

According to NASOP's position paper, criteria that enable ombudsmen to most effectively advocate for LTC residents include:

- The LTCOP is unencumbered in its response to complaints made by or on behalf of individual residents. This includes working within facilities to resolve problems, representing residents in administrative hearings, public hearings, and seeking appropriate intervention from other agencies or organizations.
- The LTCOP is unencumbered in its ability to responsibly represent the concerns and interests of LTC consumers through ombudsman program public reports, forums, printed information, and media contacts.
- The LTCOP is unencumbered in making public recommendations and providing educational material to legislators, policy makers and the media to effect positive change for LTC residents (NASOP, 1998).

APPENDIX B

STATE OMBUDSMAN TELEPHONE SURVEY

Qualitative Survey Response Detail to Survey Questions on Organizational Placement

Q 3. Does the placement of your state LTCOP create any difficulties for your service provision (e.g. any conflicts or potential conflicts of interest; perception problems with local ombudsmen, nursing homes, residents, families)?

Yes	28
No	23
DK	0
Refuse To Answer	1

Q3a. What kind of difficulties does it create?

AND

Q3b. How have you dealt with these situations?

Q3a. What kind of difficulties does your placement create?	Q 3b. How have you dealt with these situations?
Our SUA is a branch within the department that licenses and certifies assisted living, performs adult protective services, administers Medicaid, and determines nursing home eligibility. This department also operates long term care beds, so the ombudsmen are in a position where they have to investigate the activities of their own department. Our SUA also discourages ombudsman participation in legislation and the media, and systemic issues for the elderly... we have to go through a series of screens and filters and roadblocks.	Every way possible- telling SUA that this is a conflict, working with media to expose this conflict, working with citizen's groups behind the scenes... in order to have either the ombudsman or LTC beds moved. We've participated in a legislative audit, and we've conducted investigations of our own.
Our executive director is appointed by the governor, and we have to go through the director to send information and advocacy pieces out. Sometimes the state won't let us send something out. So in other words we're not allowed to do our job all the time.	We just quietly work with other groups.
There is a perception of conflict of interest. We are in a very cautious	I've tried to be a neutral force with all the agencies co-mingled together.

<p>position because all the agencies are under one umbrella. We lack autonomy because we're part of state- our biggest problem is that we are competing for the attention and interest of the director and our program is often not contacted or considered. I believe if we were in a more autonomous setting we would be more effective, people would pay more attention to us, our outcomes would matter more. Right now we are a teeny-tiny program- our department is mismanaged and poorly thought of- so overall we take a backseat to all the other agencies wanting attention.</p>	
<p>I am unable to advocate at the state level because I am a state employee</p>	<p>I try to get others to advocate for issues that I can't address.</p>

<p>Q3a. What kind of difficulties does your placement create?</p>	<p>Q3b. How have you dealt with these situations?</p>
<p>We are employees of the government so we have to take things into consideration.</p>	
<p>If I wasn't in the state agency I could be a more outspoken advocate, but we're supposed to be neutral advocates (according to the Older Americans Act).</p>	
<p>There are four issues at stake: 1) potential conflicts of interest with Licensing and Certification, Medicaid, and other departments in our umbrella agency, 2) limitations when it comes to legislative advocacy and addressing the media, 3) confusion among our consumers because we are in the same agency as Licensing and Certification (so some people think we are regulators), and 4) cumbersome bureaucracy when it comes to budget management and general authority.</p>	<p>We pulled together a work group to look at potential placements and whether we're in the best placement to be effective. Also we have worked on educating the leaders of our agency about the role of the ombudsman program and we've been pretty successful with their support for our need to be independent and speak out on legislative issues and to the media.</p>
<p>Our director is very supportive, but we would still have more freedom criticizing state government if we were independent.</p>	<p>I would rather be independent because our director is appointed by the governor, and the governor may be pressured by the nursing home industry and will then ask us to stop working on certain issue. We can't be strong advocates if we are worried</p>

	about our job security.
We have occasional conflicts of interest because our adult protection system is also under the SUA.	We try to keep the two programs separate as much as possible. We did have the ombudsmen doing adult protection in the facilities, but now we keep the workers separate.
We are within a bureau within a division within the department, and we don't have direct access to information. Before we publicly support legislation, we need to clear it because we're an agency within the governor's office.	Our regional programs have an association that carries legislative issues.
Many times we are prohibited from saying what needs to be said, for example we can't criticize new Medicaid regulations.	We have a good relationship with the Licensing agency so we do things quietly- speak to them directly- this has shown to be somewhat effective.
We cannot respond to legislation without the approval of the governor, and some of our media contacts are usually done through public affairs office (as opposed to directly with the ombudsmen). Also we're housed in an agency that is responsible for assisted living and make licensing recommendations to the state agency.	We are supposed to be developing a protocol to address where we have these conflicts to give the ombudsman program more flexibility in dealing with them. We don't know what to do about the fact that we are housed with the individuals involved in licensing.
We have an internal struggle over the issue of independence of the ombudsman program. There is also a problem with public perception.	We have had repeated meetings with the executive director about the need for the ombudsman program to have an independent voice when it comes to legislative and policy issues.
	After the 1995 IOM report, the state moved the ombudsman program into an independent office to make program more visible and make it appear independent. Our state ombudsman reports directly to the SUA director but is not part of any of the teams of the larger umbrella organization. As a result, there has been recognition of independence.
There are problems with perception because the state office is housed in the same agency as Licensing and Certification and there is a perception that I am not as strong or as vocal as I should be.	We try to have written memos of understanding on what info is shared with us, but b/because it's a perception and not a truth it's very hard to overcome that. Our legislature is thinking of moving the ombudsman program to another location.
We're in the same umbrella as	We work with our citizen's advocacy

<p>Licensing and Certification, and there have been times where I've been told I can't speak against that division because two divisions in the same department shouldn't publicly feud. So we meet with them a lot, but when things come up in the legislature or in rules and regulations, it has been very difficult.</p>	<p>group and tell them the situation and they attack it with full force. Also our division director is very supportive so when things come up she does her best to support us. But when an attorney from the state tells us not to talk, we got to the CAG.</p>
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<p>Q3a. What kind of difficulties does your placement create?</p>	<p>Q3b. How have you dealt with these situations?</p>
<p>We don't have autonomy, so everything has levels and a process. I have to answer to [a director], who has to answer to a division director, who has to answer to the executive director [of the umbrella agency]. So that doesn't leave much room for making autonomous decisions (for example when talking to the media). The difficulties include advocating for legislation change. In addition, if I present an agenda for my program, it's out of my control once my director takes it over. In advocacy we don't have latitude to speak to media so we can't ask them to address issues we see in nursing homes..</p>	<p>Occasionally I call the local ombudsman staff because they have more autonomy than we do, and they can get involved with the media. For example, we can call them about information we'd like to see on the legislative agenda, and they call the AARP. So basically we circumvent the system.</p>
<p>We have potential conflicts of interest with Medicaid and adult protective services.</p>	<p>We're currently negotiating a memorandum of understanding to apply in the case of a conflict of interest.</p>
<p>There is a potential conflict of interest simply being in state government, in the department- not necessarily able to speak totally freely on behalf of residents. If the department has a policy that as ombudsmen we feel is detrimental (ie involving Medicaid), the ombudsman may be instructed not to say anything in court. There are also perception problems as there is a perception that we are too objective to act as advocates.</p>	<p>We deal with specific situations as they arise. We also work with grassroots organizations and AARP.</p>
<p>Our agency has raised the priority of the ombudsman program, advocated for increased funding, provided unlimited legal services, and has</p>	<p>I go ahead and say what I want, but there are some times when we choose to keep quiet. Volunteers help because they can do what the state ombudsman</p>

<p>allowed state ombudsmen to talk to the media. However, being in state government still compromises the program.</p>	<p>can't- they can go and advocate in a different way. That's why volunteer programs are necessary. The local ombudsman association was much more effective at getting more funding- I'm an employee, but the volunteers are voters.</p>
<p>Our regional ombudsmen often cite location as a problem</p>	<p>We continue to let people know that the state ombudsman has more autonomy than in previous administrations... Regional ombudsmen meet quarterly with director. Have also put together workgroup and we're using IOM recommendations one-by-one to evaluate our program. We plan to develop recommendations for changes in the program.</p>
<p>Conflict of interest- APS is under the same division and so sometimes ombudsman is advocating for a resident with guardianship that this can get sticky.</p>	<p>We encourage all parties to communicate with each other.</p>
<p>Budget vulnerability- as an independent state agency we have no larger umbrella agency to protect us from legislators that are heavily influenced by the agency.</p>	<p>I just make sure that I run a sound agency that plays by the rules so that I am above reproach in terms of my operation.</p>
<p>I work under the executive director of our SUA so I can't criticize the agency that regulates board and care [which is under the same umbrella].</p>	
<p>We don't have a lot of independence to deal with legislation.</p>	<p>We deal with it by advocating within the department and if they say no we don't do it.</p>
<p>Lobbying is awkward. I'm really not supposed to lobby, but I think the Older Americans Act envisioned that I would lobby the legislators. For me to do that is impossible though because I am a state employee.</p>	

APPENDIX C

Table 1

**STATISTICALLY SIGNIFICANT ASSOCIATIONS
Factors Involved in State LTCOP Effectiveness**

State LTCOP Survey, Institute for Health & Aging, UCSF 2001

AUTONOMY				
Source	Question	Source	Question	P-value
5g	Sufficient Autonomy	6e	Effectiveness of Legislative and Administrative Policy Advocacy	P = 0.038 ^b
		5d	Freedom from Excessive Legislative or Regulatory Restrictions	P = 0.002, df = 1 ^a
		5f	Ability to Carry Out Federal Mandates Independently From Other State Agencies and Parties	P < 0.001, df = 1 ^a
		5o	Supportive Political and Social Climate	P = 0.004, df = 1 ^a
		5e	Clearly Defined Lines of Authority and Accountability for State and Local Ombudsmen	P = 0.001, df = 1 ^a
42	Effectiveness of Relationship with Citizen's Advocacy Groups	6e	Effectiveness of Legislative and Administrative Policy Advocacy	P < 0.001 ^c

Statistical Tests Used to Analyze Associations Between Responses to Five-Point and Yes-No Questions

^a Chi-Squared Test of Association

Analysis of Yes-No x Yes-No (Positive correlations can be extrapolated from contingency tables)

^b Komolgorov-Smirnov Two-Sample Test

Analysis of Five-Point Scale x Yes-No (*Positive correlations can be extrapolated from contingency tables*)

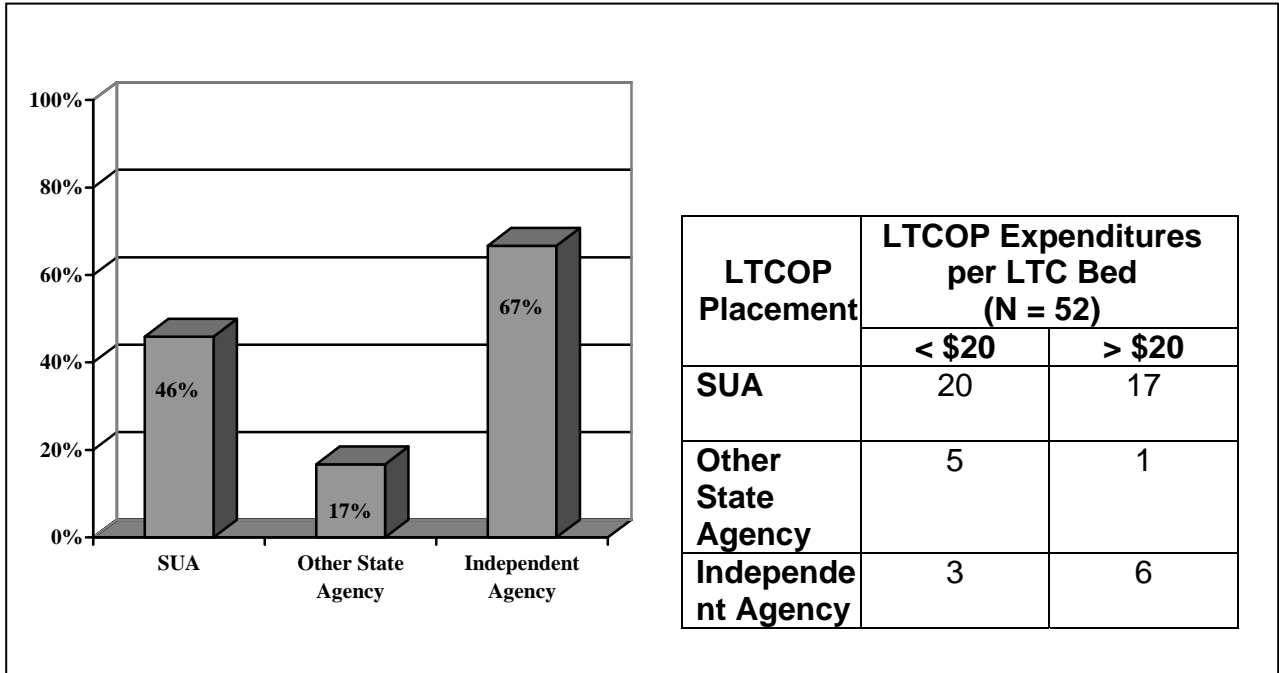
^c Spearman's Test of Rank Correlation

Analysis of Quantitative x Quantitative, Quantitative x Five-Point Scale, and Five-Point Scale x Five-Point Scale

APPENDIX D

Figures 4 - 7

Appendix D Figure 4
Percent State LTCOPs with Expenditures > \$20 per LTC Bed,
By Organizational Placement

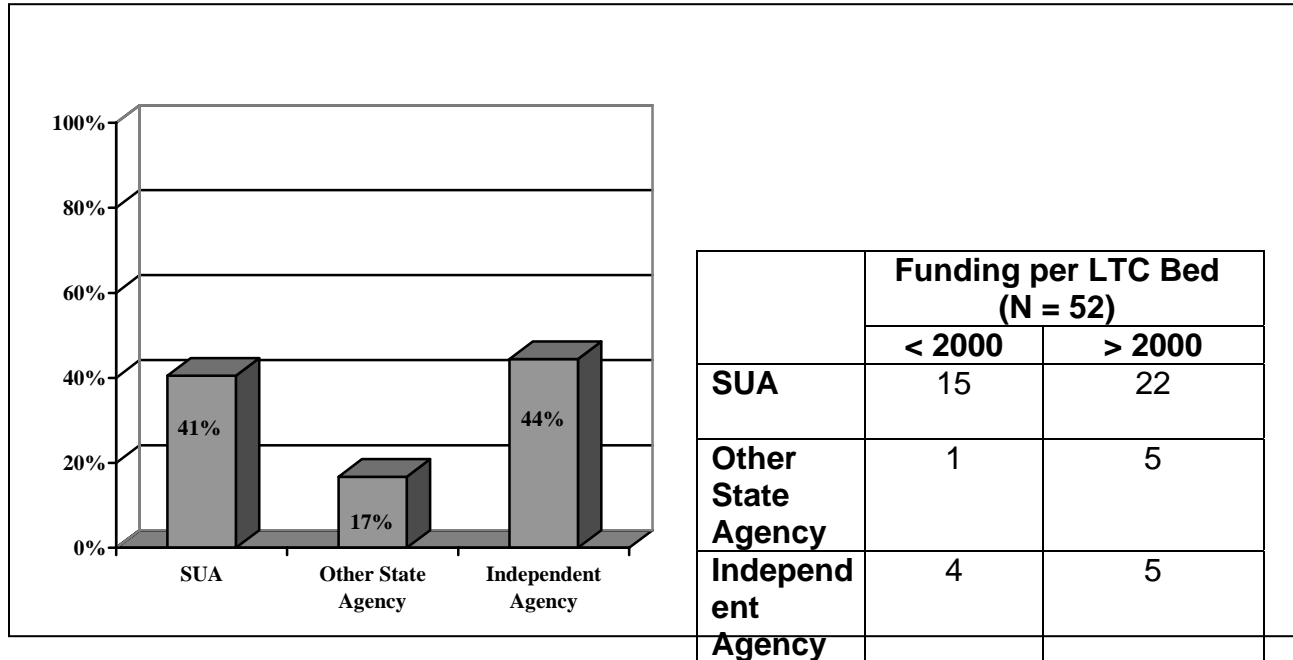


State LTCOP Survey (Question 2), Institute for Health & Aging, UCSF, 2001
Department of Health & Human Services, AoA, National Ombudsman Reporting System, 1999

State LTCOPs located in independent legal or nonprofit agencies are much more likely to report ombudsman program expenditures greater than \$20 per LTC Bed (67%) than are programs located in SUAs (46%) or in other non-SUA state agencies (17%). (NSS) [Figure 4] [Q29]

Appendix D Figure 5

Percent State LTCOPs w/ IOM Recommended Ratio of < 2000 LTC Beds/FTE Staff, By Organizational Placement

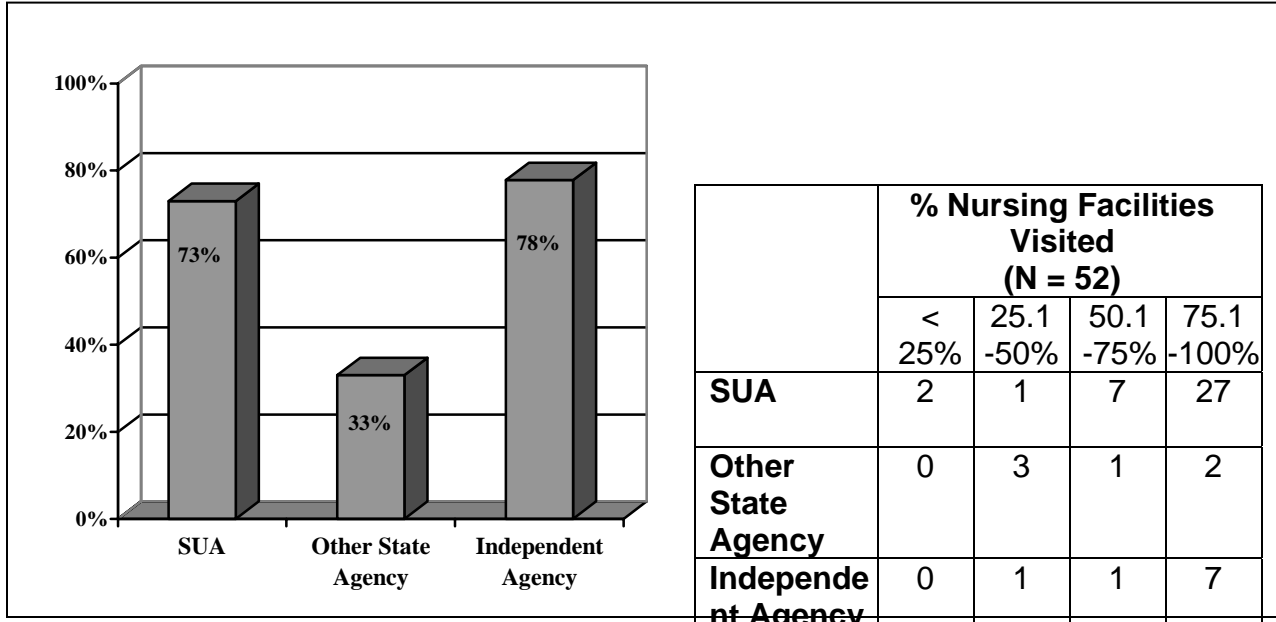


**State LTCOP Survey, Institute for Health & Aging, UCSF, 2001 (Q 2)
Department of Health & Human Services, AoA, National Ombudsman Reporting System, 1999**

State LTCOPs located in independent legal or nonprofit agencies are about as likely as those within SUAs to meet the IOM recommended minimum ratio of less than 2000 beds per FTE staff: 44% of LTCOPs in independent agencies compared to 41% of programs located in SUAs meet the minimum IOM ratio of beds to FTE. LTCOPs in other non-SUA state agencies are much less likely (17%) to meet the IOM minimum ratio than are programs in state agencies (SUA and non-SUA). (NSS) [Figure 5] [Q37].

Appendix D Figure 6

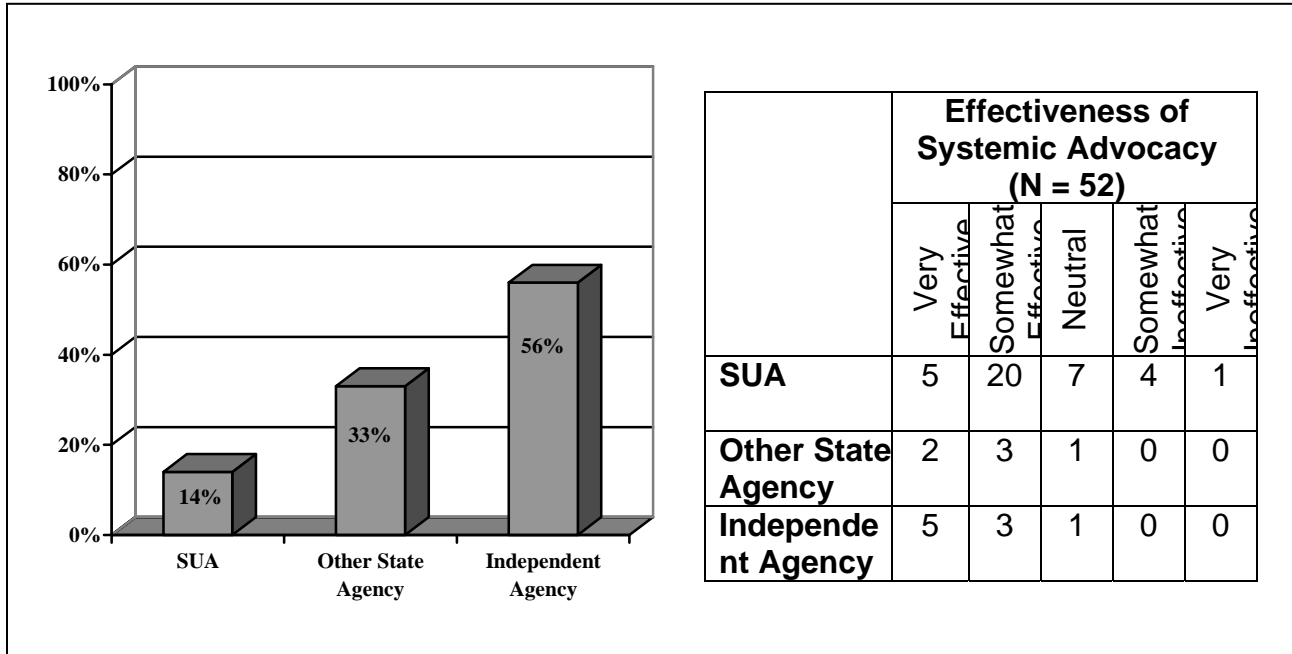
Percent State LTCOPs Visiting 75-100% Nursing Facilities in FY 1999, By Organizational Placement



**State LTCOP Survey, Institute for Health & Aging, UCSF, 2001 (Q 2)
 Department of Health & Human Services, AoA, National Ombudsman Reporting System, 1999**

Figure 6 shows that State LTCOPs located in independent legal or nonprofit agencies are about as likely as state LTCOPs within State Units on Aging (SUAs) to visit 75% to 100% of nursing facilities in 1999 (78% of state LTCOPs in independent agencies compared to 73% of state LTCOPs located in SUAs). Programs in other non-SUA state agencies (33%) are much less likely to visit 75% to 100% of facilities. (NSS) [Figure 6] [Q7]

Appendix D Figure 7
Percent State LTCOPs Rated “Very Effective” at Systemic Advocacy,
By Organizational Placement



State LTCOP Survey, Institute for Health & Aging, UCSF, 2001 (Qs 2 & 6e)

Figure 7 displays the relationship between state LTCOP organizational placement and how state ombudsmen respond to questions regarding the effectiveness of their legislative and administrative policy advocacy. State LTCOPs located in independent legal or nonprofit agencies are much more likely to report being “very effective” at systemic advocacy efforts (56%) than are programs located in other non-SUA state agencies (33%) or SUAs. (NSS)

[Figure 7][Q2]



Appendix V

Systems Advocacy in the Long-Term Care Ombudsman Program

by Esther Houser
Oklahoma State Long Term Care Ombudsman

Supported by a grant from the Helen Bader Foundation

The views expressed in this paper may not represent positions adopted by NASOP.

Executive Summary

The Older Americans Act's clear mandate that Long-Term Care Ombudsman Programs (LTCOP) undertake systems advocacy has undergone no fundamental change since enacted in 1978. Rather, the statute has been strengthened repeatedly to facilitate such activities. This strengthening has included adding protections for Ombudsmen who properly carry out the mandates of the law, directing that willful interference with the program's operation be made unlawful by the states, requiring prohibition of conflicts of interest, and elevating the protection of elders' rights, including the Ombudsman's work on behalf of institutionalized elders, to the status of a separate title in the Act. (Older Americans Act [OAA])

The LTCOP's range of possible and appropriate systemic advocacy activities is very broad. Systems advocacy can be focused on a "system" within a single facility, or all the facilities owned by a particular entity. Such activities often lead the Ombudsman to see broader trends, across a wider system, and to expand the goal of the advocacy effort. As the goal expands, so generally does the need of the LTCOP for allies, or coalition-building. Coordination with citizen advocacy groups can be invaluable to the LTCOP in accomplishing regulatory or legislative changes that benefit residents of many long-term care (LTC) facilities.

Since its beginnings, the National Association of State Long-Term Care Ombudsman Programs (NASOP) has tried to call attention to, and cause improvements in, states

with inadequate Ombudsman programs. These include states in which the LTCOP has been inadequately funded, inadequately staffed, subjected to conflicts of interest that impede the program's ability to advocate effectively for elders in long-term care facilities, or forbidden to conduct activities necessary for systems advocacy. Studies of the Long-Term Care ombudsman Program have been conducted by the Office of Inspector General (OIG), the General Accounting Office (GAO), and the Institute of Medicine (IOM). In each study, problems have been identified and recommendations have been made for their correction.

However, the most recent survey of LTCOPs, conducted by Carroll Estes and others, reveals that quite a few states still prevent their LTCOP from achieving full compliance with Federal law, especially related to activities essential for effective systemic advocacy. This report, as have its predecessors, highlights 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 (Estes, C., Zulman, D., Goldberg, S., Ogawa, D., "Effectiveness of the State Long-Term Care Ombudsman Programs," June 2001, in press).

To be effective in systems advocacy, the state LTCOP must have available the full resources and authority to function given it by the OAA. Access to LTC facilities and residents; sufficient funding to adequately staff the program for timely response to complaints, provision of information to the public, and collection and analysis of data (as well as systems advocacy activities); access to decision-makers within state agencies; adequate legal counsel; authority to make recommendations to legislators; and freedom to discuss non-confidential information with the media 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 limited by insufficient staffing in both program and support positions, being prohibited from direct interaction with policy-makers, and other problems (Estes, et al., in press).

Systemic advocacy should flow in a natural progression from, as well as being supportive of, the LTCOP's personal advocacy activities. The mission of the LTCOP is to represent the interests of LTC facility residents, not the interests of the state, the providers, or even the aging network. As a result, the vulnerability of the program is obvious, and the Federal government bears the weight of responsibility to evaluate each state's performance related to the LTCOP and, using methods including financial sanctions, enforce the OAA and require all states to provide for and permit the lawful functioning of the LTCOP.

Recommendations

Recommendation #1

AoA should review the findings and recommendations of the 1995 IOM report related to the ability of LTCOPs to carry out systemic advocacy activities and the need for AoA to develop and implement a method for assessing the performance of LTCOPs.

AoA should use an objective method, such as the IOM Committee's practice standards, to conduct annual assessments of states' LTCOPs. Further, AoA should use its

authority under federal law to enforce compliance with the OAA requirements for Ombudsman services.

Recommendation #2

The National Ombudsman Resource Center should provide training for State and Local Ombudsmen in community organizing and other fundamental aspects of systems advocacy. This should include theory as well as practical skills, and be conducted in a manner accessible to Ombudsman staff at every level, in all states.

Recommendation #3

NASOP should request that the Senate Select Committee on Aging, expand its inquiry into issues affecting nursing home residents, to address barriers to full implementation of the LTCOP in the states. The inability of many federally funded LTCOPs to represent fully the interests of LTC residents, including through regulatory and legislative advocacy, has caused hardship for residents and placed more responsibility for systems change on citizens' groups.

Recommendation #4

NASOP should contact the National Association of State Units on Aging (NASUA) and ask to reconvene the joint work group established several years ago to address areas of concern and collaboration. NASOP should request NASUA, especially due to its role in the National Ombudsman Resource Center, to work with NASOP to address the barriers to effective ombudsman programs that exist in some SUAs which are members of NASUA.

Recommendation #5

Each State Unit on Aging Director and governing board member 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.

Background Information

Mandate

The Older Americans Act (OAA) clearly mandates that Long-Term Care Ombudsman Programs (LTCOP) provide systems-level advocacy. The language of this mandate has remained consistent since the 1978 OAA Reauthorization, which provided the original requirement that each state establish a LTCOP. In fact, the statute has been strengthened repeatedly to facilitate such activities. These changes included requiring each State to increase the visibility of the LTCOP by creating an Office of the State Long-Term Care Ombudsman (OSLTCO), requiring each state to protect from liability Ombudsmen who properly carry out the functions of the Office, and directing that willful interference with representatives of the OSLTCO in the performance of their official duties be made unlawful by the states. (OAA).

From the earliest days of the LTCOP, its mission has been defined as representing the interests of the residents of long-term care (LTC) facilities. In a 1981 Program

Instruction related to operation of the LTCOP, the Administration on Aging (AoA) listed among the responsibilities and duties of the State Long-Term Care Ombudsman

(SLTCO): “annually report to the State licensing and certifying agency, the Governor, the Commissioner, and the public on the operation of the LTCOP....This report should identify all serious, on-going issues of widespread concern and proposals for corrective action at all relevant levels of government.” The instruction further directed that in the LTCOP “annual report, upon request, and as necessary and appropriate...recommend changes in the long-term care system which will benefit institutional residents as a class.” (AoA-PI-81-8, 1981).

In same Program Instruction, signed by Commissioner on Aging Robert Benedict, the State Unit on Aging is directed to “independently and through coordination between its SLTCOP ... engage in significant activities related to issues on behalf of elderly institutionalized persons.” It describes such activities as “squarely within the State Agency’s responsibilities under... the Act.” It states: “Such efforts consist of the identification of major concerns that affect large numbers of LTC institutionalized older persons...and the aggressive advancement (at all relevant levels of government) of changes necessary in laws, regulations or policies to strengthen the legal position and enforcement of that position for institutionalized older persons.” (emphasis added) (AoA, 1981.)

Lack of Systems Advocacy

However, despite the clear language of the OAA and the energy and focus expected of the LTCOP and State Units on Aging in this early Program Instruction, some states do not carry out systems advocacy activities on behalf of LTC facility residents at all. Others conduct systems change work only indirectly, through LTCOP partnerships with citizen advocacy groups and others, so that Ombudsmen do not make contact with media representatives, legislators, or other policy makers. State Ombudsmen in various states, stretching back well over a decade, have reached out for help to peers and to the Federal government, simply wanting to be freed to carry out the statutory responsibilities of the Office. In fact, the National Association of State Long-Term Care Ombudsman Programs (NASOP), since the late 1980s, has asked various federal entities to conduct evaluations or investigations of the implementation of the OAA Ombudsman mandates by the states, based on reports from many SLTCOs and others that serious barriers to compliance existed.

Since 1990, the Office of Inspector General (OIG), the General Accounting Office (GAO), and the Institute of Medicine (IOM) have all conducted evaluations of the LTCOP. Each has found significant strengths and benefits in the LTCOP’s services. But concerns also have been registered about the lack of direction given to the states, and the absence of objective performance evaluation and effective sanctions by AoA for non-compliance. The most recent such study, “Effectiveness of the State Long-Term Care Ombudsman Programs” (Estes, et al. in press.), states that “many ombudsmen report not having the time, money, or autonomy to speak out and counter actions of the nursing home industry, advocate for key issues in long-term care, or monitor and evaluate policy changes. In addition, lack of autonomy in advocacy efforts and in

legislative and media contacts negatively affects the ombudsman's ability to educate public and facility staff on LTC issues, ombudsman programs, laws and regulations.”

A few states received attention and direction from AoA to remedy certain problems during the mid-1990s. But, in the last few years an alarming trend has developed. At least two states' LTCOPs, which were formerly considered exemplary in their performance of both personal and systems advocacy, have seen dramatic changes, including restrictions being placed by the state unit on aging on the Ombudsman's ability to contact media and legislators, both of which are essential activities in systemic advocacy. While a number of other states have similarly (unlawfully) restricted the SLTCO's activities for years without penalty, some Ombudsmen hope that these more recent acts will finally cause AoA to follow the IOM's 1995 recommendation and take meaningful action to monitor funded programs and enforce the Federal law. (IOM, 1995).

Discussion

The range of systemic advocacy activities appropriate for a LTCOP is very broad. They can be focused on a “system” within a single facility, or all the facilities owned by a particular operator. Such activities often lead the Ombudsman to see broader trends across a wider “system,” and to expand both the goal and the methods used to affect change. In her Ombudsman Best Practices piece entitled “Supporting Culture Change to Promote Individualized Care in Nursing Home,” Barbara Frank points out that the Ombudsman Program has matured to using a range of tools that takes it “beyond complaint processing to problem resolution.” Addressing the root cause of a resident's or system's problems, and “making the residents' interests the driver” describe the transformational work of the ombudsman (Frank, 2000).

When the goal of a systemic advocacy effort expands, so generally does the need for coalition building by the LTCOP to accomplish the goal. Multiple tasks and strategies are generally required in a systems advocacy activity of any scale, making “division of labor” according to various coalition partners' strengths, agendas and constituencies a necessity and a benefit. Success at smaller or more “contained” systems advocacy efforts can help LTCOPs develop the relationships and experience needed when undertaking projects aimed at broader or more complex issues.

An Example from Oklahoma

An example of such a progression might be drawn from an experience of the Oklahoma LTCOP related to the Certificate of Need process. In Oklahoma, nursing facility operators must acquire a Certificate of Need (CON) from the State before acquiring or expanding a facility. Based on many serious care complaints and other concerns, the LTCOP decided to oppose the CON applications of an operator with a very bad performance history, both in and outside Oklahoma.

The LTCOP had joined previously with families from three of this operator's homes to successfully oppose his purchase of three other homes. At the time of the new application, one of his facilities was actually decertified from Medicaid and several others had received penalties from the Medicaid agency. The operator also was under indictment for Medicaid fraud in Texas.

Despite the arguments against approval brought by the LTCOP and others in both written and oral testimony, and in spite of the exposure of the situation in the media which the LTCOP arranged through distribution of press packets, interviews, and other means, the CONs were granted and the operator acquired seven additional facilities across Oklahoma.

That systems advocacy effort failed to achieve its specific goal. However, the heightened public awareness of the issues involved led to intense and prolonged media coverage of the impact on residents and families caused by the poor care in that and certain other operators' nursing homes, and of the obvious failure of the State Health Department to exercise proper judgment or appropriate concern for consumer interests over provider interests. The media coverage caused so much discomfort to the industry that the nursing home association's leadership approached the LTCOP and asked to partner with them in legislative reform of the CON process.

The State Ombudsman Office coordinated collaboration on the legislative advocacy effort with the aging network, area Ombudsman programs, senior advocacy organizations, and nursing home consumer advocacy groups, as well as with the provider associations. The State Ombudsman met weekly with the Strategy Committee of the Alliance on Aging and monthly with the State Council on Aging. The Silver Haired Legislature, AARP, and others agreed to contact legislators at key points in the process, and "Action Alerts" were sent to this coalition by e-mail and regular means. Brief issue summaries and requests for support were distributed by hand to legislators' offices by the State Ombudsman, who participated in both formal and informal discussions and bill drafting on an almost daily basis throughout the four month legislative session.

The result was that specific quality standards were inserted into the CON statute, along with mandatory denial of CON applications if adverse actions "above the level of a deficiency" had been levied against a facility operated by any person with specific roles or business interest in the applicant entity, within the 24 months prior to the application.* In addition, the legislation required that notices be published in newspapers local to facilities whose residents may be affected by an application for CON, and resident council minutes must be included in the CON staff's report.

Systems Advocacy as a Natural Progression

This example shows clearly that systemic advocacy can flow in a natural progression from the LTCOP's personal advocacy activities. Data was generated from complaint documentation and analyzed to identify significant or widespread problems. The situation in this example was translated into an action plan, with the assistance of legal counsel. In the initial stages of this advocacy effort, advice and support from legal counsel was very useful in drafting documents and representing the interests of affected residents before an administrative law judge. Then the initial plan was modified

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* Evidence of continued poor judgment in CON approvals and other matters by the agency's leadership caused a subsequent legislature to extend the "look-back" period to 60 months at the request of the LTCOP.

over time, as legal and practical obstacles, partnership opportunities, and available strategies evolved.

Take Time to Build Relationships

The LTCOP's ability to draw on years of coalition building with statewide senior advocacy groups and nursing home consumer advocates facilitated the establishment of a broad base of support for systems change. In addition, the reputation of the LTCOP for credible (reliable and verifiable) documentation and reporting of conditions in LTC facilities, through its Annual Report and other means, was invaluable. This was evidenced by the willingness of both consumer and provider organizations to partner with the program.

Ongoing efforts by the State Unit on Aging (SUA) to train citizen advocates in legislative advocacy (as part of its own OAA mandate to act as a focal point for advocacy for older persons) made these coalitions more productive. This long-standing requirement for both SUAs and Area Agencies on Aging (AAA) is complimentary to the LTCOP mission, and can support the work of the Ombudsman to promote the development of citizen organizations to participate in the program's activities.

Patience Is Required

One of the most important and difficult aspects of systems advocacy can be the length of time it often takes to achieve systems change. Although some efforts may receive less resistance than others, and systemic advocacy certainly is not always adversarial, the very nature of systems change involves fundamental modification of a broader sort than change which affects only one person. The Oklahoma CON example covered only a couple of years, but benefited from nearly two decades of relationship and reputation building, the LTCOP's familiarity with the systems involved (both administrative and legislative), and its previous successes and failures, which honed skills as well as providing perspective and teaching patience.

Individual Advocacy Must Continue

Systems advocacy can be labor-intensive and time-consuming, and in order to carry out such activities the LTCOP must have the people resources to continue providing personal advocacy services. People living in the substandard provider's facilities continued to be neglected and injured. They needed advocates on-site to help them secure proper care throughout the LTCOP's struggle to change the CON process, and even after the reforms were enacted into law.

Local program staff and volunteers assisted in the CON systems change effort through contacts with legislators, action alerts to local advocates and media, and ongoing reporting to the State Ombudsman Office. But, their responsibility for personal advocacy was supported as their first priority. Each facet of the program plays a role that is interrelated with the others and cannot be neglected without diminishing the effectiveness of the whole.

Appendix V

Program Structure and Data Are Essential

To enable this maintenance of personal advocacy while working on systemic change, an infrastructure must exist within the LTCOP. People must be in place to carry out both program and support functions. These staff and volunteers must produce consistent and timely data and other information, and a process must be in place for communication of that information from the local programs to the SLTCO, from the State Ombudsman Office out to the local programs, between local programs, and out to a larger network as the situation requires.

When the State Ombudsman has no support staff to handle the clerical functions of the Office, or has a complaint caseload due to lack of regional or local staff and volunteers, these systems advocacy activities are likely to sink to the bottom of the priority list. It is legitimate to consider timely response to complaints as the LTCOP's highest priority. However, failure to supplement personal advocacy with systemic advocacy is like putting out fire after fire without ever attempting to identify the root cause or catch a known arsonist. The program's resources are used, instead, to address the same problem over and over again, for different individuals. In this way, systems change can be seen as preventive work. In any event, it certainly is not "optional" under the OAA.

Credibility Must Be Earned

How is the LTCOP able to get citizens, residents, local programs, other agencies and organizations "on board" with systems advocacy? In order to effectively conduct a range of systems advocacy activities, the LTCOP must have both credibility and relationships with other individuals and groups. The OAA foresees this in its mandates, which include a requirement that the Office promote the development of citizen organizations to participate in the program, and to provide technical support for the development of resident and family councils. The program must be free to initiate these contacts and have the time to develop these relationships.

The Act's language related to preparation and distribution of a LTCOP annual report directs that it "provide such information as the Office determines to be necessary" to public and private agencies, legislators, and other persons. The report is to provide insights into the problems and concerns of the program's clients and to also provide recommendations to address them. Distribution of this report to decision makers at the highest level of government is vital to its effectiveness, and lays groundwork for further systemic advocacy activities by providing background information, including complaint data.

A Range of Activities is Needed

Systems advocacy can include a wide variety of activities and methods, ranging from convening work groups to study and address specific issues, to submitting written comments on a proposed regulation, to contacting a policy maker to discuss conditions affecting nursing home residents, to presenting testimony at a legislative hearing.

Generally, none of these activities can stand alone; nor is it as effective for all of the activity on an issue to be generated only by the LTCOP. Sharing information with other individuals and groups who are concerned about the well-being of older persons, is a logical place for the LTCOP to start.

The establishment of respectful relationships and exchange of ideas and information, even with groups whose perspectives may differ from the LTCOP, sets the stage for systems change efforts by creating a network of human resources to focus attention on a specific issue or goal. This requires outreach by both state and local ombudsmen: attending meetings of citizen advocacy groups and resident and family councils, setting up regular sessions with regulatory agencies and law enforcement entities, and joining senior organizations. These relationships, like any other, take care and maintenance. But, they can help the program learn to “agree to disagree” with groups or individuals on some topics or strategies, yet provide a vehicle so that the tasks or goals on which there is agreement can be addressed through the coalition.

Resources Are Essential

Fundamental to the establishment of these relationships and networks is the existence of adequate resources, both financial and human, for the operation of the LTCOP. Each responsibility of the LTCOP supports the other aspects of the program. Adequate funding, personnel, training, data, access, relationships, and freedom from conflicts of interest and willful interference are all required for a program to function optimally.

However, the most recent study of LTCOPs, states that “many ombudsmen report not having the time, money, or autonomy to speak out and counter actions of the nursing home industry, advocate for key issues in long-term care, or monitor and evaluate policy changes. In addition, lack of autonomy in advocacy efforts, and in legislative and media contacts, negatively affects the ombudsman’s ability to educate public and facility staff on LTC issues, ombudsman programs, laws and regulations.” (Estes, et al.)

Formal Rules and Contracts Can Help

The OAA grants authority to the State Ombudsman to designate entities and individuals to represent the Office. This authority should be formalized at the State level into administrative rules, with the assistance of legal counsel for the LTCOP, to assure that certain conditions exist in local entities before contracts are signed and that only appropriate persons are hired to serve as local ombudsmen.

At minimum, designation should hinge upon freedom from conflict of interest and freedom of the designee to carry out the responsibilities of the program as explicitly described by the OAA. Contracts should specify the duties of designated entities and representatives, as provided by law. (OAA). These duties must not be subject to “veto” by the agency in which ombudsmen are housed, or set aside when they conflict with a position taken by the agency. (Of course, these same issues can exist at the State level, too.)

Training Must Be Provided

Another fundamental requirement, which must be met to enable the local programs to engage in systems advocacy, is the State Ombudsman's responsibility to provide for training of representatives of the Office. (OAA) Through this training process, the local Ombudsman staff can gain insights into the full range of responsibilities and activities expected of them and the State Ombudsman Office. This may encourage local ombudsmen to more readily share information with others in the LTCOP about unresolved local issues or individual resident problems, successful strategies and networking opportunities, and needs for supervision, support or additional training.

Information about widespread issues, systems advocacy efforts on the state level, and specific opportunities for local action must likewise flow out of the State Ombudsman Office to local ombudsmen. Feedback and updates on successes, setbacks, and deadlines must also be shared in order to keep local programs engaged in any effort that adds to their workload. Such communication fosters teamwork and increases the likelihood of success.

Barriers and Willful Interference Exist

Barriers to performance of advocacy functions by local Ombudsmen may be erected by sponsoring agencies for local programs and may be subtle or blatant, much as barriers that exist at the state level for some LTCOPs. Routine assessment of local programs, along with frequent contact of other sorts, is vitally important if those barriers are to be identified, let alone remedied. Area Ombudsmen may not feel free to tell the State Ombudsman when they have been forbidden to issue a press release, distribute an action alert, or testify at a meeting. When they likewise are restricted, State Ombudsmen may not do anything to intervene. The result is an ineffective program.

Willful interference is unlawful, and the OAA years ago directed the states to confirm this in state law and establish remedies. However, SUAs and other host agencies routinely and willfully interfere with performance of the duties of State and local Ombudsmen. This interference can be subtle, as with policies requiring reports or press releases to be reviewed or approved by other levels of administration before distribution. Such delays can diminish or destroy the effectiveness of the action due to loss of timing or momentum. What may seem like an innocent management practice is not consistent with the independence of the SLTCOP provided by the OAA.

Interference may be far more direct and intentional. Some states totally restrict the SLTCOP from contact with media or legislators. Although legislators often circumvent such restrictions by directly requesting the presence or testimony of an Ombudsman at a hearing, this is not sufficient to meet the standard set in the OAA. Of course, because SLTCOP are expected by the Act to monitor the development and implementation of laws, rules and policies that affect residents of long-term care facilities, the Ombudsman will find it necessary to comment on the performance or policies of state agencies. Because criticism across agency lines is very uncomfortable in government, it is frequently forbidden; at the very least, it is considered inappropriate

and strongly discouraged. Nonetheless, the OAA clearly expects it from the SLTCOP at all levels, and requires the states to support it.

Oversight Is Needed

State Ombudsmen should be able to expect the federal Administration on Aging to monitor each state's program performance, identify problems, and require correction by the State Agency or State Ombudsman involved. 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. Data collection alone is insufficient for proper oversight, especially related to monitoring of systems advocacy efforts. While no program should be expected to 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.

Looking back at the Institute of Medicine's 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 study committee's findings so closely parallel the 2001 evaluation of the program funded by the Kaiser Family Foundation (Estes, et al., in press), described earlier. 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, and proposed that the AoA use them to develop a method for assessing compliance of state LTCOPs. No such tool has yet been implemented.

Related to systems advocacy, the IOM described as essential practices the following:

"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; and submission of comments on all proposed administrative policies that affect LTC facility residents.”(IOM, 1995, pp. 180-181.)

Many States Fail to Conduct Systems Advocacy

So many states have failed to carry out systems advocacy, or have actively interfered with the State Ombudsman’s performance of this duty, that attention must be paid to the Administration on Aging’s role in monitoring funded programs and enforcing federal law. It is appropriate to inquire why establishment of an assessment of state performance had to be recommended by the IOM, eighteen years after Congress mandated LTCOP implementation nationwide. In fact, the IOM report indicated that “no formal evaluation component was ever built into the program.”

Although assessments were conducted from time to time, at least in some federal regions, using various tools and methods, there seems to have been no uniform application of standards by AoA for program compliance by the states. As a result, it has been “an accident of birth” whether or not older residents of long-term care facilities actually had access to advocacy services. This is unacceptable.

“Taxpayer revolts” of various sorts became commonplace across America during the 1990s. Local, state and national movements were organized to track the use of public moneys by government entities. One of the systems advocacy functions or the SLTCOP, monitoring the development and implementation of laws, rules and policies that affect long-term care facility residents, is intended specifically to include oversight of public agencies whose decisions affect LTC residents. However, few advocates of the proper use of taxpayers’ money are likely to be aware of this, since so many states prevent their LTCOP from carrying out this responsibility. In some cases, the LTCOP conducts monitoring activities, but is prohibited from contacting policy makers or using the media to explain the program’s role, discuss issues, and make recommendations.

It appears to be time, and past time, for the program designed and intended to empower others to be, itself, empowered to carry out its statutory mandate. The LTCOP must provide both personal and systems advocacy services on behalf of older residents of LTC facilities. Regardless of the placement of the LTCOP, every non-compliant state must finally be assessed penalties and caused to correct those practices which, in essence, willfully interfere with the operation of the Ombudsman Program. Twenty-four 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, not just randomly, available to elders nationwide,

Summary

The LTCOP definitely has a statutory mandate to conduct systemic advocacy activities intended to forward the interests of older residents of long-term care facilities. These activities should cover a broad range, be based on reliable data and information, and involve others concerned about the well-being and rights of LTC facility residents.

The actual capacity of a state's LTCOP to engage in systems change depends on a number of factors, including people and financial resources, data, priorities, training, access to decision-makers, and other components. Some states LTCOPs have successfully implemented the full range of advocacy and information services expected by the OAA, proving that it is possible to achieve. Studies of LTCOPs nationwide, however, continue to reveal that systems advocacy responsibilities are not being met in numerous states, and that this can generally be attributed to lack of support, resources, and autonomy for the LTCOP in these states.

Assessment of states' compliance with all of the OAA's requirements for the LTCOP is not being conducted by AoA. Such evaluation, on an ongoing basis, coupled with procedures to require that deficiencies be corrected (including sanctions for failure to correct problems), is vital to the integrity of the program. Due to the highly sensitive nature of the program, the vulnerability of the program's clients, and the political power of the LTC industry in most states, the authority and vigilance of the federal government are needed in support of proper implementation of the federal mandate in every state.

Recommendations

Recommendation #1

AoA should review the findings and recommendations of the 1995 IOM report related to the ability of LTCOPs to carry out systemic advocacy activities and the need for AoA to develop and implement a method for assessing the performance of LTCOPs.

AoA should use an objective method, such as the IOM Committee's practice standards, to conduct annual assessments of states' LTCOPs. Further, AoA should use its authority under federal law to enforce compliance with the OAA requirements for Ombudsman services.

Recommendation #2

The National Ombudsman Resource Center should provide training for State and Local Ombudsmen in community organizing and other aspects of systems advocacy. This should include theory as well as practical skills, and be conducted in a manner accessible to Ombudsman staff at every level, in all states.

Recommendation #3

NASOP should request that the Senate Special Committee on Aging, expand its inquiry into issues affecting nursing home residents, to address barriers to full implementation of the LTCOP in the states. The inability of many federally funded LTCOPs to represent fully the interests of LTC residents, including through regulatory and legislative advocacy, has caused hardship for residents and placed more responsibility for systems change on citizens' groups.

Recommendation #4

NASOP should contact the National Association of State Units on Aging (NASUA) and ask to reconvene the joint work group established several years ago to address areas of concern and collaboration. NASOP should request NASUA, especially due to its role in the National Ombudsman Resource Center, to work with NASOP to address the barriers to effective ombudsman programs that exist in some SUAs which are members of NASUA.

Recommendation #5

Each State Unit on Aging Director and governing board member 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.

Discussion Questions

1. What are the common conditions that exist in many states that cause the lack of systems advocacy to be so widespread?
2. Should State Ombudsmen seek independent legal representation for the SLTCOP if they perceive that willful interference or conflict of interest at the state level of the program is preventing them from carrying out systems advocacy activities? Should the SLTCO notify citizen advocacy groups, AoA, or other entities when such conditions exist? If so, who should be notified?
3. What responsibility does the State Unit on Aging bear for systems advocacy under the OAA, and is this duty being carried out or enforced?
4. If a state is not carrying out systems advocacy activities through the SLTCOP, what sanctions might be proper or effective?

Pertinent Sections of the Older Americans Act

As Amended in 2000

42 USC 3058g

Sec. 712(a)(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 or inaction or decisions that may adversely affect the health, welfare, safety or rights of the residents...of—
 - (I) providers or representatives of providers of long-term care services;
 - (II) public agencies; or
 - (III) health or 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
 - (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--
 - (i) the problems and concerns of older individuals residing in long-term care facilities; and
 - (ii) recommendations related to the problems and concerns;

(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

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Appendix VI

Ombudsman Training and Certification: Toward a Standard of Best Practice

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Executive Summary

The Long Term Care Ombudsman Program (LTCOP) performs a vital resident defense and empowerment role; its residents' rights orientation and grass roots use of volunteers assures it a unique niche among government services. Still, persistent problems of inadequate training and supervision threatens promoting the simultaneous expression of two seemingly incompatible program philosophies operating parallel to each other; one paid, one volunteer, one based on autonomy and patients' rights and the other drifting towards dominant paternalism. The LTCOP must grapple with this possible values dichotomy. Either embrace it and make it work, as some propose, or correct it through training.

Unfortunately, LTCOP training, while valiantly trying to cover too much content, is often practice-deficient and methodologically flawed. LTCOP training regimens are vastly inconsistent between programs. There are no national standards. There appear to be some content deficiencies as well. Provider concerns persist. The future presents other threats that can only be ameliorated through training: advances in healthcare technology, the growing medicalization and professionalization of community care (Harris-Wehling, Feasley, & Estes, 1995); the higher utilization intensity and acuity in nursing facilities, and the development of new long-term care alternatives will collectively push ombudsman training needs to the critical point.

Theories of organizational effectiveness view employee training as an integrated ongoing system's process supported by detailed position descriptions, written policies, regular performance evaluations, intermittent training audits, standardized certification tests and procedures, formal disciplinary and grievance policies as well as other aspects of organizational coordination and communication. It appears that many, perhaps even the majority of LTCOPs are sorely deficient in the various components of this sort of learning infra-structure (due largely to insufficient resources).

Recommendations are presented to move the LTCOP towards the model of a continuously learning organization, one that fully integrates formal and informal learning and is energized by clear program values that motivate across-staff support for program goals. (Note: The following numbered sections are not continuously consecutive as certain background sections in the main document are omitted).

1. The Verdict on Volunteers. Evidence confirms that volunteers are crucial to the LTCOP's visibility, complaint identification, and problem resolution processes. Programs that effectively train and manage volunteers appear to be the best programs (Kusserow, 1991), and state ombudsmen clearly attribute the number of volunteers they field as critical to their overall effectiveness (Estes, Zulman, Goldberg, & Ogawa, 2001).

Recommendation 1 a: *LTCOPs should develop roles for volunteer advocates (only 38 currently use volunteers) as a legitimate part of their grassroots mandate.*

Recommendation 1 b: *LTCOPs should design their volunteer programs to be integrated parts of their organizational structure.*

2. Interview Screening for Staff Selection. The screening process is also a preliminary learning process.

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Recommendation 2 a: *LTCOP should develop detailed position descriptions for all LTCOP staff positions (paid and volunteer—including volunteer screeners). All work roles should be tied to overriding, clearly defined organizational objectives.*

Recommendation 2 b: *Applicants must be thoroughly interviewed via a structured process (Allen, 1997), undertaken by specialized paid or volunteer screeners trained to determine role suitability. They should weigh “negatives more heavily than positives” (Umiker 1998, p. 72). Screeners should use the Thomas-Killman (1974), Nelson (1992) or other conflict/strategy instruments to assess the applicant’s orientation towards advocacy and conflict in long term care (Note :Screeners should avoid general psychological testing; tests must relate directly to job skills or attitude).*

Recommendation 2 c: *LTCOP screening committees must design questions and procedures to select-in qualified applicants with a high probability of meeting role expectations, and to select-out those who do not.*

3. Conflict of Interest. LTCOP screeners must scrupulously assure that all ombudsmen, paid or volunteer, as well as their immediate family members, are free of any conflicts of interest with the resident.

Recommendation 3: *LTCOP leaders should develop policies regarding conflicts of interest including clear explanatory rationales for each issue as part of the agency’s personnel policy handbook.*

4. The Importance of Program Policies. Accountable, programs develop policies to support the staff’s integration of core values. These also serve as valuable training aides.

Recommendation 4 : *LTCOPs should develop personnel policy handbooks that contain the rules, protocols, and conditions under which staff must carry out their duties and possible consequences for failure to do so (Allen, 1997).*

5. Survey of LTCOP Training Program Formats. Ombudsman training remains widely inconsistent across the nation. Variations abound, there is little uniformity of methods, sequencing and in ancillary thematic content.

Recommendation 5 : *The state LTCOPs should form a task force to systematically evaluate LTCOP training practices with the goal of recommending a values-based model of core content and appropriate associative methods and to address the issue of funding.*

6. Toward a Manageable Core Content. LTCOP training is generally inadequate.

Recommendation 6: *LTCOPs should mandate a minimum 60 hours basic certification training covering core concepts and attributes critical to the success of an investigative advocate*. A minimum of 36 hours of this training should be in the*

classroom. Another 24 hours can be home study, including reading assignments and mini-workbook exercises to check understanding. Students should log their home study time.

- 7. Training Methods.** Well-designed training/education program will involve many different, subject-appropriate methods and associated training aids that optimize learning by diverse learners.

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Recommendation 7 a: Lectures should be reduced in length and in terms of the overall percentage of instructional time. Lectures should be reserved for motivational, values based subjects. Substitute lecture content with home study requirements whenever possible.

Recommendation 7 b: Communication based education (including problem resolution) should have strong modeling components (mentor modeling, film) intense practice sessions (role play, triads, simulations) and feedback mechanisms (triads with coaches, video feedback, instructor critiques) and periodic practice refresher courses.

Recommendation 7 c: Problem identification instruction training should rely on case study, prepared film presentations, and practice-based simulations employing mock records checks, mock interviews, and so forth.

- 8. The Need for Service Learning.** Research suggests that in-service training is more important than initial training. However, this training-by-doing must always be supervised by the LTCOP.

Recommendation 8 a: Program directed in-facility service learning opportunities of between 8 and 16 hours should be made available to all ombudsmen following the initial certification training program.

Recommendation 8 b: LTCOPs should provide regular programs of ongoing education comprising day-long seminars offered on a bimonthly or quarterly basis.

Recommendation 8 c: Between six weeks and two months after the newly assigned volunteer has been working alone in the facility, the LTCOP should provide a post-service reflection seminar to assess and validate or redirect volunteer on-the-job-learning.

Recommendation 8 d: LTCOPs should establish regular community support group meetings where local volunteers can discuss and analyze problems encountered in the facilities.

- 9. Certification Exams.** Few LTCOPs assess their training effectiveness. Only 11 states evaluate their ombudsmen for certification purposes (McInnes & Hedt, 1999). This is clearly a material weakness.

Recommendation 9: Ombudsman certification training/education should be based on the satisfactory completion of the instructional program as evidenced by a passing score on an exam comprised of questions that measure the learner's mastery of ombudsman core concepts. The exam should be designed to assess the learner's knowledge and ability to correctly identify problems and to select

situationally appropriate problem resolution techniques. These are key performance indicators. Ombudsmen should not serve in facilities without completing this basic process.

- 10. The Focus of Continuing Education.** To keep ombudsmen connected to program values and procedure, continuing education must provide both back-to-basic refresher courses and advanced training for highly skilled ombudsmen.

Recommendation 10 a: *LTCOPs should perform regular training needs assessments of staff to determine performance discrepancies susceptible to training*

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correction through continuing education workshops. A secondary analysis of identified needs will determine appropriate methods, aids, resources, and training evaluation format.

Recommendation 10 b: *LTCOPs continuing education training should comprise back-to-basics refreshers and practice intensives on subjects identified in the needs analysis, as well advanced training opportunities to meet the diverse needs of all serving ombudsmen. Attendance at two out of three of these programs should be required for continued volunteer certification.*

- 11. Need for Multiple Volunteer Roles-Career Ladders.** Career ladders offer volunteers a chance for growth and recognition and provides incentives to learn new skills and sharpen capabilities

Recommendation 11: *To promote retention, motivation, and personal growth, LTCOPs should develop distinct career tracks with titled grades of advancement within specific volunteer roles. The LTCOP should support these career ladders with continuing service courses, and testing for the highest grade.*

- 12. A Role for Long Distance/On-line Learning** Many LTCOP training programs could be enhanced by a combination of on-line and classroom strategies.

Recommendation 12: *To reduce overall training costs and training labor intensity, and expand recruitment opportunities, LTCOPs should explore developing web-enhanced or fully on-line versions of their basic training programs to serve geographically dispersed areas in order to meet the needs of an increasingly technology tolerant volunteer pool.*

- 13. Performance Appraisals.** Job appraisals identify training needs.

Recommendation 13: *To enhance training audits, LTCOPs that do not regularly evaluate their volunteers should develop and disseminate annual self-appraisal forms soliciting volunteer feedback identifying perceived training needs and “morale slippage” as well as trigger requests for help (Umiker, 1997, p. 151).*

- 14. Discipline and Training.** Another adjunct to program training is a standard progressive disciplinary policy.

Recommendation 14: *LTCOPs should develop clear and comprehensive progressive disciplinary and grievance policies. Data concerning performance*

problems and complaints against ombudsmen are important adjuncts to regular program training audits.

- 17. The Trouble With Guest Trainers.** LTCOPs that delegate training control to others are, in essence, delegating a core management responsibility to outsiders who should not be in a position to interpret policies or procedures.

Recommendation 17: *LTCOPs should severely limit the practice of using facility employees and other non-ombudsman personnel to teach ombudsman roles, values, protocols and procedures. These core management functions require ombudsman expertise.*

- 18. Potential Training Deficiencies I: Problem Resolution Protocols.** Advanced volunteer ombudsmen and paid staff need more training in the rules of evidence and investigation techniques, situational conflict resolution, and argumentation, with less emphasis on bureaucratically weak mediative methods.

Recommendation 18: *Ombudsmen must develop knowledge and skills-based training processes to develop and hone the advocacy skill of persuasion.*

- 19. Advocacy Mediation.** Ombudsmen should develop protocols for activist mediation. In this model, the mediator abandons the principle of neutrality, but otherwise employs the sub-tactics and techniques of mediation.

Recommendation 19: *LTCOPs should develop detailed protocols for advocacy mediation and promote this as a consciously distinct preference to classic mediation in situations of imbalanced power.*

- 21. Looming Crisis: Training Deficiencies II — Ethics & Values: Autonomy, the Key to Being Resident Centered.** Autonomy often loses to paternalism in day-to-day LTC ethical conflicts. This is why the ombudsmen program was developed. Is autonomy now losing in the ombudsman program? Hopefully not, because defending resident autonomy is the essence of being resident-centered. Ombudsmen must follow the autonomy respecting Precedence Protocol for Advocacy (*informed consent* first, *substituted judgement* second, and *beneficence* only as a last resort).

Recommendation 21 a: *LTCOP's should include education on autonomy and paternalism in all introductory sessions.*

Recommendation 21 b: *LTCOP's should teach the Precedence Protocol for Advocacy (PPA) as the foundation for all problem solving.*

- 22. Term Limits and Facility Rotations.** The organizational behavior literature predicts that *role immortality* risks dysfunction, including complacency, conflict aversion, and diffused interests (that is, interests beyond those of the client). At the local, level, evidence supports rotating ombudsman facility assignments on a regular basis to avoid facility co-optation.

Recommendation 22: *Ombudsmen assigned to specific facilities should be rotated every two years, allowing for appeals in rural areas where no alternate assignment may be available.*

OMBUDSMAN TRAINING AND CERTIFICATION: TOWARD A STANDARD OF BEST PRACTICE

Paper Purpose & Perspective

The ombudsman enterprise is vitally important to the future of countless long-term care residents. And few jobs, paid or volunteer are more challenging. To achieve a standard of best practice for ombudsman training/education is to build on a conceptual scheme that systematically pulls together a wide range of subjects from different fields of practice and theory. If “packaged” correctly, these subjects will enable prospective ombudsmen, paid and volunteer, to do their job properly. They will also facilitate an ethical-analytical mindset to help ombudsman–trainees critically contemplate how their roles can influence the lives of residents while helping shape the future of long-term care.

The sections immediately following examine what researchers say about important trends in the implementation and development of LTCOP. A considerable portion of this scholarship relates to volunteers. However, subsequent analysis of LTCOP training problems and this paper’s recommendations relate to paid and volunteer ombudsmen alike unless specifically stipulated otherwise. Finally, this paper treats training as a core program management process that extends beyond the traditional classroom, or in-service environments. It has important ecological ties to a range of organizational processes such as employee recruitment and screening, and performance evaluations that either reinforce or extinguish desirable advocacy behaviors. Thus, this paper assumes a holistic approach to the linked policies and processes of the continuously learning organization.

Research on Ombudsmen, Roles, Focus, and Developing Trends

Despite persistent and considerable capacity issues (Brown, 1999), evidence of long term care ombudsman program (LTCOP) effectiveness is compelling despite lingering uncertainty about the potential of volunteers in a partisan advocacy role (Cherry 1993; Connor, cited in Nelson, 1995; Kahanna, 1994; Netting, Williams, Jones-McClintic, & Warrick, 1989). The latter ambiguity is partially evidenced in suggestions that volunteers are often thwarted by nursing home staff and may not assertively argue the resident’s cause (Connor, 1989; Litwin & Monk, 1984).

Resistance is not uncommon, as providers, like most people, find it hard to give up power (Nelson, 2000). Some resent questioning by “ill-trained volunteers” and see it as impugning their professional standing, or as trespassing into “privileged” patient/client relationships (Nelson, Netting, Huber, & Borders, in progress; Nelson, Netting, Huber, Borders, & Walter, in progress). Experience and reports suggest that friendly visiting and facility helper types of “volunteer ombudsmen” are more welcome than investigative

volunteers, and that volunteers and facility staff often have very different views of the ombudsman's appropriate role (Connor, & Winkelpleck, 1990; Lusky, Friedsam, & Ingman, 1994). It appears that advocacy oriented ombudsmen are less tolerated, not only because they threaten facility power, but because many providers view advocacy as a perversion of the ombudsman's classically neutral stance (Connor, & Winkelpleck, 1990).

Some analysts fear that this opposition strongly undermines volunteer effectiveness. Experience shows that facility resistance can breed conflict avoidance behaviors in some volunteers who, after having been attacked by an irate administrator, shift their focus to merely "getting along." Of course, when "getting-along" supercedes the goal of advocacy, the ombudsman's fundamental role is compromised. This reflects a basic rule of interpersonal conflict: all disputes are regulated by two concerns: concern for one's own goals (or one's client's goals) balanced against a concern for the opponent. Consequently, self, or client advocacy, is invariably limited in proportion to one's concern for the opponent. Now, this does not mean that the advocate's concern for the provider is wrong. In fact, since volunteer ombudsmen typically work beside providers on a regular basis, maintaining a decent relationship (but not too close) is important—cooperative problem solving is highly desirable. However, when residents' rights are violated, or in urgent, high risk situations where the provider is unresponsive or resistant, then the advocate must place the resident's needs above the desire to "get along." Not to do so constitutes an *intra-psychic* conflict of interest with the resident (Bisno, cited in Nelson, 2000), because the ombudsman's job is to maximize client goals, or provide a zealous defense.

That some volunteers may develop slightly friendlier strategic orientations than paid staff is supported by several studies suggesting that volunteers are less likely than paid staff to internalize a strong residents' rights orientation. This is evidenced by their handling far fewer residents' rights complaints than paid staff (Netting, Huber, & Kautz, 1995; Netting, Huber, Borders, Kautz, & Nelson, 2000). Other research suggests that providers prefer volunteers over more "police-like" paid ombudsmen (Lusky, et al., 1994) and that volunteers are more likely to have therapeutic visiting orientation (53%) than an advocate orientation (22%), (Keith, 2000). One study even shows that a minority of volunteers may value their relationships to facility staff over all other relationships or concerns (Nelson & Walter cited in Netting, et al., 2000). These volunteers are probably, in essence, working for the facility. Other evidence suggests that local LTCOPs housed in AAAs may also be more facility friendly (Huber, Netting, & Kautz, 1996.)

Any role/value incongruity between volunteers and their parent agency risks a range of serious organizational dysfunction including the common LTCOP problem of *inappropriate job emphasis*. This occurs when, for instance, investigatory ombudsmen focus on friendly visiting, or even provide direct patient care or other non-ombudsman services to the facility, such as promoting the facility's community relations, or social services functions (Connor & Winkelpleck, 1990b). Research clearly shows how this role incongruity erodes volunteer loyalty and job satisfaction; undermines the volunteer's sense of self-efficacy, and leads to higher turnover and lower productivity in terms of cases handled and number of facility visits (Dehart, 1999; Nelson, Pratt, Carpenter, & Walter, 1995). Consequently, the issue of value-alignment is of over-riding importance to LTCOP program leaders.

Another theory predicting a misalignment between volunteer and paid staff strategic orientations is based on the "capture theory of regulation." This model stipulates that

volunteers, who are often minimally trained in ombudsman values, tend to visit specific facilities, where they risk being sensitized to provider values, problems and concerns. This makes them susceptible to being won over by the facility (Nelson, 2000). The result is the aforementioned *intra-psychic* conflict of interest with their own program and “its resident’s rights ideology” (Bisno, cited in Nelson, p. 2000, p. 51). Some analysts imply that this possibility is so strong that program leaders should simply bow to it, and train volunteers to be collaborators at the local level, and reserve advocacy for state level paid ombudsmen (Cherry, 1993; Kahana, 1994).

Others disagree, and contend that volunteers are capable of strong resident-centered advocacy and conflict surrogacy as long as they are socialized to a resident-centered philosophy through sufficient initial and ongoing training, periodic evaluation, and regular feedback through adequate supervision and support. More importantly, volunteers must understand why rights-based advocacy is crucial. They must see that it is very different from the paternalist sort of “advocacy” that typifies the work of many nurses, administrators, and other caregivers whose “best-interest” efforts often “disempower patients” (Close, Estes, Linkins, & Binney 1994, p. 26; Nelson, 2000). Consequently, they must accept that their roles have little to do with the “passive arbiter” work associated with the neutral classical ombudsman (Monk & Kay, 1982). They should understand that although patients’ rights advocates may situationally employ the social worker’s mediative casework methodologies (Kutchins & Kutchins 1987; Loewenberg & Dolgoff 1988), that there are many circumstances where these collaborative methods are sub-optimal.

It is incontrovertible that training can produce assertive resident-rights based advocates. This is not only theoretically sound, but clearly evidenced in practice. Advocacy oriented volunteers, though a minority, are well documented in the literature (Keith, 2000; Litwin, 1982; Litwin, & Monk, 1987; Litwin, Monk, & Kaye, 1984; Nelson, 1995; Nelson, Pratt, Carpenter, & Walter, 1995;). Research on volunteers in one state that specifically trained volunteers to be strong residents’ rights advocates, showed that advocacy oriented ombudsmen were more loyal, job-involved, and were less confused about their roles than were collaboratively oriented ombudsmen (Nelson, et al, 1995). However, they did experience more role conflict, probably external in nature due to opposition by facility staff—a speculative conclusion, but one that is verified in other research (Litwin & Monk, 1984)

Recent findings by Keith (2000) differentiated advocacy oriented ombudsmen from collaborative ombudsmen by having attended more program sponsored in-service training. Keith speculated that training may have created the advocate, but “even if in-service training did not generate views of advocacy, it may have provided skills to act on the existing ideology” (Keith, 2000, p. 382). Regardless, other studies support advocates as effective when their positions are backed by solid professionally presented evidence (Kutchins & Kutchins 1987) and that advocacy oriented ombudsmen are more effective than mediative ombudsmen in solving problems, promoting change, and protecting residents (Litwin 1982; Nelson, 1995; Nelson, 2000).

Either way, there is strong evidence that training can produce a concrete pay-off in performance. This is supported by broader research which attests that volunteers and paid employees will share job attitudes and values as long as rules, procedures, and training are

the same (Liao-Troth, 2001). Consequently, it is crucial that program trainers be deeply immersed in the LTCOP's core values

The Importance of Shared Values

Unfortunately, research suggests not all programs share these values (Kahana, 1994; Litwin, 1982; Litwin & Monk, 1984; Litwin, & Monk, 1987; Lusky, et al., 1995; Nelson, 1995, Wood & Karp, 1995). Over the years the notion of "advocacy" has blurred in some programs while it has matured and achieved greater clarity in others. Nevertheless, any attempt to clarify LTCOP training needs must begin with a clear focus on the LTCOP's guiding values. Of these, resident autonomy is probably the most important. Autonomy is the key to "resident-centeredness," and is why ombudsmen empower residents (to be self-directed). It is also the indispensable counterbalance to paternalism which otherwise dominates both practice and residents' rights in long-term care. These values are extensively integrated throughout this paper, which aims to provoke thought about how to improve LTCOP training and organizational effectiveness.

Specifically, what follows is an attempt to present an accurate picture of LTCOP training and training related practices and results. It draws attention to potential problems with content, methods, values, and ancillary issues, while offering practical recommendations intended to improve ombudsman productivity within a pro-patient optimization model.

1. The Verdict on Volunteers

Despite the aforementioned concerns about the risks of role misalignment between volunteers and paid staff, the weight of evidence confirms that volunteers are at once the program's greatest strength and its greatest weakness. (If this doesn't make them a priority what does?) Despite the fact that they are difficult to recruit, train, supervise and retain, they are undeniably crucial to the LTCOP's visibility, complaint identification, and problem resolution processes. They provide the community presence that is the grass-roots essence of the LTC ombudsman model.

As was true a decade ago, programs that effectively train and manage volunteers appear to be the best programs (Kusserow, 1991), and state ombudsmen clearly attribute the number of volunteers they field as critical to their overall effectiveness (Estes, Zulman, Goldberg, & Ogawa, 2001). These perceptions seem to be supported by new evidence comparing volunteer ombudsman complaint data to that of multi-agency complaint, survey deficiencies, and adult protective services (APS) sanction data. The research shows that volunteer ombudsmen identify the same essential problems, trouble, and trend-patterns as paid staff in other agencies, despite having very different rules, procedures, and *modus operandi* (Nelson, Netting, Huber, & Borders, in progress).

Recommendation 1 a: *LTCOPs should develop roles for volunteer advocates (only 38 states currently use volunteers) as a legitimate part of their grassroots mandate.*

Recommendation 1 b: *LTCOPs should design their volunteer programs to be integrated parts of their organizational structure.*

2. Interview Screening for Staff Selection

Training begins even before aspiring ombudsmen fill out their application forms. Ideally, applicants will have already read some introductory material sent to them, including a detailed position description and a copy of the National Association of State Long Term Care Ombudsman Programs (NASOP) code of ethics (NASOP, in progress). Next comes the screening process, which is also a learning process. Here is where the applicant and the program begin to seriously assess each other. Of course, adept screeners (comprised of paid staff, volunteers, or both) will do far more listening than talking, but they will still reinforce the program's core values in the course of the interview.

Screeners must systematically seek to fit the right person to the right job, to assess potential role strengths and weaknesses. Pro-social organizations like LTCOPs generally prefer a “selecting in” orientation to staff selection that identifies and fits people to the right volunteer job. Consequently, LTCOP screeners must determine (a) whether applicants identify with the patient autonomy model, (b) if they are good communicators, and (c) if they are assertive, dependable, adaptable, polite, circumspect, unexcitable, and deliberative. Screeners must design questions to determine how applicants handle conflict in different situations, and evaluate the applicant's general “stress resistance” (Umiker, 1998, p. 70). The payoff will be more competent and satisfied staff (paid and volunteer) with decreased attrition down the road.

To screen effectively, screeners must themselves be fully trained in program values and policies, in addition to the art of interviewing. They must understand that investigative ombudsmen should neither be timid, nor primarily motivated by affiliation (social) needs, as the latter will not long swim against the current. They must search for the applicant's sense of justice, which may be as important or even more important than empathy (a subject that demands research) (Nelson, 1995). Screeners must assess the applicants' diagnostic capabilities, communication skills, and their freedom from all conflicts of interests with the resident. Above all, they should look for people who are assertive and caring, but not so emotional as to lose perspective. All these factors should be considered as predictors of ombudsman success.

It is particularly important to determine the applicant's capacity for a strong residents' rights orientation when interviewing potential paid staff. After all, they will be the torchbearers of program values. Failure to do so may dull a program's advocacy bent. Consequently, LTCOP screeners should not be afraid to screen people out. Inappropriate selection will only increase management and training difficulties down the road (Megginson, 1981)—to say nothing of attrition. Finally, state ombudsmen should provide a clear list of expected applicant traits, competencies, and values to regional ombudsman program directors (typically an Area Agency on Aging (AAA)) with a clear proviso that unsatisfactory candidates will not be automatically designated.

Obviously, predictors of success appropriate for investigative ombudsmen are not suitable for other program roles. Standards for friendly visitors will differ markedly. For them, a primary affiliation motive is fine, and empathy is more important than a sense of justice. Warmth and compassion are critical.

Some states have passed legislation requiring criminal record checks for all volunteers working with vulnerable populations. Although procedures vary from state to state, where the burdens of securing record checks are not too onerous (expensive or time consuming), they should be required. There have been scandals recently, where felons serving as ombudsmen have been “outed,” by citizen groups. Integrity is critical to the ombudsman program. It must be protected. At the very least, screeners should not be afraid to ask whether or not an applicant “has been convicted of a crime” related to the ombudsman’s work role (Allen, 1997; Umiker, 1998, p. 62)

Recommendation 2 a: *The LTCOP should develop detailed position descriptions for all LTCOP staff positions (paid and volunteer—including volunteer screeners). All work roles should be tied to overriding, clearly defined organizational objectives.*

Recommendation 2 b: *Applicants must be thoroughly interviewed via a structured process (Allen, 1997), undertaken by specialized paid or volunteer screeners trained to determine role suitability. They should weigh “negatives more heavily than positives ” (Umiker 1998, p. 72). Screeners should use the Thomas-Killman (1974), Nelson (1992) or other conflict/strategy instruments to assess the applicant’s orientation towards advocacy and conflict in long term care (Note: Screeners should avoid general psychological testing; tests must relate directly to job skills or important attitudes).*

Recommendation 2 c: *LTCOP screening committees must design questions and procedures to select-in qualified applicants with a high probability of meeting role expectations, and to select-out those who do not.*

3. Conflict of Interest

Since the long term care ombudsman program is a partisan organization, screeners must scrupulously assure that all ombudsmen, paid or volunteer, as well as their immediate family members, are free of any conflicts of interest with the resident. Even employees of businesses providing services to LTC facilities are ineligible to serve as ombudsmen, as are those involved in certifying or regulating LTC facilities. The law seems clear enough, but program practices vary considerably, and gray areas abound. Conflict of interest is a major healthcare problem generally. Experience, reports, and interviews specifically undertaken for this paper support Darr’s conclusion that: “conflict of interest is an insidious problem into which one can slip almost without realizing what is happening” (Darr, 1991, p. 95).

Consider, for example, the issue of hiring someone who receives a LTC facility retirement bonus. Does this constitute a conflict of interest? One LTCOP attorney argues “yes,” because a bonus is a form of equity income that is dependent on corporate performance. And since ombudsmen who receive such premiums are in a position to influence corporate productivity, they should be selected out. This is consistent with the the Older Americans Act’s (OAA) emphasis that ombudsmen—“be free of conflicts of interests and not stand to gain financially through an action or potential action brought on behalf of individuals the Ombudsman serves” (OAA, 712(a)(5)(C)(ii)).

But, what about regular LTC industry pensioners? Do their fixed annuities create a conflict of interest with residents? The consensus seems to be no, because a pension is a protected source of income unsusceptible to provider control. Thus, since, retirees have no apparent motive to help the facility, they can serve as ombudsmen, as long as they are

assigned to facilities unrelated to their former employment. Of course, the real question is whether or not they can make the paradigm shift to the autonomy based values of LTCOP advocacy—to the far more insidious intra-psychic conflicts of interest discussed before (Bisno, cited in Nelson, 2000).

Some are concerned that they cannot. For example, several paid staff in one state expressed a concern that retired facility nurses in particular, have a hard time shaking old roles. Although they may be adept at identifying nursing problems, they are far less effective in empowering residents. Others disagree, and praise ex-facility staff as superb watchdogs because they really know what's going on—"they know the ins-and-outs." The writer's recollection was that some former facility nurses made excellent ombudsmen, others couldn't abandon their nursing role but were able to provide valuable information on poor nursing care, while a few were hopelessly pro-facility and just couldn't shake an efficiency perspective. The latter unflinchingly valued safety over the residents right to the dignity-of-risk; they were perpetually stalled by liability concerns; and invariably chose protection over autonomy.

Regardless, these cases are prime examples of types of conflicts that State LTC Ombudsmen must resolve. Some take a "strict-constructionist" stance and would even label protected retirement income as an "indirect" revenue disqualifying pensioners from service (Administration on Aging, 2001). Others assume a broader interpretation, and one does not have to look far for other debates.

Consider social workers, nurses and others who also work as paid ombudsmen. Do they face conflicting obligations? This is the problem of revolving hats. Social workers and nurses, for example, are required to mandatorily report abuse in many states. If they are working part-time for the LTCOP, does this put them in direct conflict with the LTCOP's confidentiality requirement, or are they relieved of the mandatory reporting duties if they identify abuse while acting in the immediate capacity of an ombudsmen (Dr. Ellen Netting, Virginia Commonwealth University, personal communication, December 21, 2002)? Which duty predominates: the duty to protect confidentiality over the professional duty to report abuse? Do licensed nurses volunteering as ombudsmen have a higher duty to mandatorily report abuse because of their license? Do they risk losing their licenses if they refuse to breach confidentiality by refusing to report abuse?

One LTCOP attorney sees no conflict of interest in these circumstances because social workers and nurses acting as ombudsmen can always report abuse without revealing the name of the victim or complainant: one merely withholds the victim's/complainant's name or any directly identifying information, while informing regulators that abuse may have occurred in a specific facility. Others are less sure.

What about states in which ombudsmen mandatorily report abuse as a general rule? Many appear to, despite the OAA's (§712(d) stipulation that ombudsmen "may not be required to disclose the identity of a complainant or resident" without their consent, or a court order. Moreover, the federal law clearly supercedes state mandatory reporting statutes requiring ombudsmen to do so. How do states reconcile these apparent contradictions? How does mandatory reporting impact the LTCOP's ability to respect autonomy and confidentiality? Isn't mandatory reporting the height of paternalism?

Some feel that the most pervasive conflict of interest relates to the local LTCOPs that are housed in AAAs: (a) whose boards include directors/owners of facilities, (b) that curtail ombudsman activities and autonomy to such an extent that they can never function at the level of those who are independent, and (c) that by design and intent limit ombudsmen to ¼ or ½ time (Dr. Ruth Huber, University of Louisville, personal communication, December 19th, 2002).

In a different vein, how many LTCOPs take precautions to shield volunteers from possible reproach for having a conflict of interest with the facility? Should volunteers, for example, serve in facilities where they currently have friends or loved ones as staff or residents? Is their credibility potentially impeached by their vulnerability to accusations of partiality, or that they are acting out of a personal motive? Can they fairly mediate disputes between all residents? Does the state LTCOP have any ethical obligations to the facility in these circumstances? What about the common practice of allowing ombudsmen to serve in facilities where a loved one has died? Anecdotal evidence suggests that this can have either a positive or negative impact, depending on the person involved. It is also worth noting that in “rural communities, it is often impossible to have an ombudsmen who does not have family in facilities” (Alice Hedt, National Long Term Care Ombudsman Resource Center Director, personal communication, January 10, 2002).

Although the law restricts ombudsmen from serving as a resident’s “medical decision-maker or surrogate” (AoA, 2001, p. 7) can ombudsmen serve in facilities where they pay a resident’s bills? Should this fiduciary status disqualify them from service in that facility (AoA, 2001)? Aren’t they in a position to unfairly leverage indirect or in-kind gain from the facility through improved attention, care, and better service? I believe my grandmother received much better care after the staff found out I was the Deputy Director of the State LTCOP.

It appears that many state and local ombudsmen avoid these conflicts by assigning volunteers to facilities where they have no friends, relatives, or other apparent conflicts of interest. However, it is unknown how many programs systematically address these and other important issues in clearly written policies. This broaches the question of whether it is ethical for ombudsmen leaders to avoid developing policies in these murky areas, or is it a derogation of duty (Darr, 1991)?

Recommendation 3: *LTCOP leaders should develop policies regarding conflicts of interest including clear explanatory rationales for each issue as part of the agency’s personnel policy handbook.*

4. The Importance of Program Policies

Accountable, *continuously learning organizations* (CLOs) develop policies in these areas as an integral support to the staff’s integration of core values and visionary “mental models.” As such, policies are important adjuncts to teaching. To be effective, they must be fully **integrated** into all aspects of the agency’s daily work-life. Personnel must understand how agency policies relate to the LTCOP’s mission, and that they will be uniformly and scrupulously administered (Herman, 1991). Published policies build LTCOP credibility and accountability by limiting inconsistent and whimsical decision-making. They can also make training easier (just hand out the policies as a reading assignment). Unfortunately, too many policies lie forgotten on dusty shelves.

Recommendation 4 : *LTCOPs should develop personnel policy handbooks that contain the rules, protocols, and conditions under which volunteers must carry out their duties and possible consequences for failure to do so (Allen, 1997).*

Ombudsman Certification Training Overview & Critique

11. Survey of LTCOP Training Program Formats

Despite excellent materials and programs developed by the National Long-Term Care Ombudsman Resource Center (NLTCORC), ombudsman training remains widely inconsistent across the nation. Variations in training and certification protocols abound. Initial training regimens range from 5 to 48 classroom hours (McGinnes & Hedt, 1999). Certification training may be centralized, or decentralized, held at pre-planned dates throughout the year, or organized on an ad-hoc basis when sufficient volunteers are recruited in a given community (Hunt, 2000). There appears to be little uniformity of methods, sequencing and in ancillary thematic content. Some programs require facility visitations (widely varying from 2 to 30 hours), on a weekly, monthly, or some other basis. Other programs arrange facility managed internships that typically invite ombudsman co-optation— this practice should be abandoned generally.

Some ombudsmen programs employ effective post-certification facility visits, or job-shadowing opportunities mentored by veteran volunteers or paid staff (Hunt, 2000). In all, only 16 programs claim to offer some form of in-facility training, however brief (McGinnes & Hedt, 1999). Several programs require post matriculation probationary periods, while others offer progressive levels of volunteer advancement with promotions based on demonstrated capabilities and successful experience (Hunt, 2000).


All this suggests that ombudsman initial training is largely willy-nilly and clearly sub-optimal. Here the LTCOP shares much with many service agencies where the question really boils down to whether the organization really trains its employees or the employees “learn in spite” of the organization (Brown, 1975, p. 150)?

Recommendation 5 : *The state LTCOPs should form a task force to systematically evaluate LTCOP training practices with the goal of recommending a values-based model of core content and appropriate associative methods and address the urgent issue of funding for training..*

Question: Is the average LTCOP initial training program’s content fragmented, unfocused, overstuffed, yet insufficient?

Despite the fact that training is well recognized as crucial to effective volunteer utilization (Schiman, & Lordeman, 1989), and that state ombudsmen rate training as key to local program effectiveness (Estes , Zulman, & Goldberg, 2001; Schiman, & Lordeman, 1989) research has long questioned the adequacy of LTCOP training endeavors (Harris-

Wehling et al., 1995; Institute of Medicine, 1986; Monk, Kay, & Litwin., 1984; Nelson, Netting, Huber, & Borders, (in press); Portland Multnomah Commission on Aging [PMCOA], September 1989). When LTCOP staff were specifically asked to assess the effectiveness of their training programs in 1988, none considered their training to be adequate (Feder, Edwards, & Kidder, 1988, p. 28). Moreover, the long-term care industry has little respect for ombudsman training and has expended some effort to remedy the problem (Lusky, et al., 1994). At the national level, providers are concerned “about the lack of consistent training within and between state programs, the ombudsman’s understanding of how care is delivered by facility staff, and the lack of orientation to the facilities themselves (Alicia Hedt, NLTCORC Director, personal communication, January 10, 2002). An industry leader guest lecturing in one of my graduate classes recently explained that the best that can be said for the outcome of ombudsman training that he observed in three states over ten years, is that the typical ombudsmen ends up “well intended.” These perceptions are widespread and are a threat to the program.

A review of various LTCOP training manuals suggests that the appropriate ingredients of a model ombudsman core-content training are present (see next section). However, it is unclear that subjects are consistently allocated the right amount of time, methods, media or other resources. Concerning emphasis (time per subject)—our present focus, ombudsman training may be (a) overly weighted with aging policy and gerontological issues, (b) too many in-depth sessions on geriatric diseases and (c) special topics such as drug interaction effects and general pharmacology. Although this has undoubtedly changed, in 1988 only eight LTCOPs provided training on resident rights compared to sixteen states that taught extensively about the “aging process,” and six others that offered specialized training in “attitudes towards aging” (Quirck, et al., 1988). 

This “general aging” training, which is still a major section in many LTCOP training manuals, seems of marginal value in the ombudsman’s realm of problem identification and resolution. As it stands now, chapters on general aging are often as long or longer than accompanying sections on complaint investigation and problem resolution. Are program trainers really being efficient or effective when they take up valuable class time involving investigative ombudsmen in *sensory deprivation* training, for example (used to simulate the sensory loss of the aged)? To be sure, such training can engender valuable insights, but are these empathetic discernments crucial to the success of investigative advocates? Might scarce training time be better spent in developing problem identification skills, investigative techniques, or honing skills in the art of persuasion, or in identifying signs of informed choice, or even filling out forms correctly?

As it stands now, no program is allotting enough time to develop mastery in these core subjects. For example, one state’s 20 hour certification program crammed in the following subjects:

“long term care system, life and work in nursing homes, biopsychological aspects of aging, medical vocabulary, empowerment strategies, conflict resolution, . . . verbal and nonverbal communication, active listening, sensitivity to diverse values and impaired mental and physical states, interviewing techniques; using the five senses to detect abuse; substandard care and other problems; documenting complaints, and analyzing evidence and reviewing records. . . proxemics, the study

of cultural differences in interpersonal spacing. . . several sensory limiting and deprivation exercises. . . ” (Vesperi, 1995, p.72).

All this, and no mention of residents’ rights! After 20 hours, which of these subjects could the learners possibly master? Could they even see the relevance of what they were being exposed to, or were they simply overwhelmed? With so little time and so many topics, were there many teachable moments (or “ah, ha” moments when the learner says, “I got it!”). Was there any plan to promote identifiable performance outcomes (behavioral goals) and did lecture dominate methodologically, or was there time for a “mix of methods and media” (Broad & Newstrom, 1992, p. 73).

Regardless, it is apparent that Ombudsman training programs often attempt to cover more knowledge than can possibly be absorbed in the short time allocated most initial training sessions. Ombudsman leaders must reflect whether or not they are making the classic mistake of providing too much content in too short a time. Are they presenting broad overviews of ombudsmen related subjects at the risk of overwhelming trainees? If so, they may be training just for training’s sake. To avoid this common trap, LTCOP leaders must understand how training opportunities that:

“present a smaller amount of knowledge applied well can produce a greater payoff than a larger amount that is never applied. Practice opportunities during training can have tremendous payoffs when transfer of training is measured” (Broad & Newstrom, 1992, p.74).

Finally, critics have another worry about advanced geriatric and other specialized subjects. These topics may be fine for paid staff and veteran volunteers, but may nudge less experienced ombudsmen towards the neutral therapeutic (or lay-practitioner, or service) orientation, which is well documented in the literature (Litwin, 1982; Litwin & Monk, 1984; Nelson, et al, 1995; Keith, 2000). And although no one denies the importance of financial and policy knowledge, realistic performance based training may be more important given the tenuous ties that socialize the volunteer to the ethics, ideology and customs of resident-centered advocacy.

6. Toward a Manageable Core Content

Obviously different volunteer roles demand markedly different preparation. The training for friendly visitors will logically focus on gerontology, aging, and communication barriers to the elderly, the effects of sensory deprivation, and the psychological effects of dependence, isolation, and powerlessness (Nelson, 2000). Conversely, investigative ombudsmen must be immersed in a variety of residents’ rights oriented core concepts and values. These logically include problems of quality eldercare and quality of life, ombudsman ethics; training in relevant law and rules, documentation, problem identification, involved agency overviews, investigation procedures, informed consent, common elder-care problems, Medicaid and Medicare fundamentals, patient abuse, the problems of imbalanced power and dependence, and how to fill out forms correctly.

In this last connection, it is important to train about the importance of LTCOP complaint data generally, and, specifically, how to do the National Ombudsman Reporting System (NORS) reporting. If ombudsman data is to influence public policy through research there

must be some hope of inter-rater reliability. Consequently, volunteers and paid staff must be totally trained in the importance filling out forms in a consistent manner. This would mean that there is agreement on what all the NORS categories mean. Special attention must be paid to disposition: what constitutes resolution of complaint; most importantly, *to whose satisfaction* in a *hierarchy*, i.e. resident, ombudsman, family, etc.(Dr. Ruth Huber, University of Louisville, personal communication, January 11, 2002). Is there an up-to-date code book with all complaint categories defined? This would be important. The NLTCOPRC might consider developing a grant proposal to fund a NORS training and research institute to develop NORS training materials, to help assure training consistency and to evaluate data for consumer education, to influence policy, and to conduct factor analysis to test complaint category grouping validity (for example, contractures, pressure sores, weight loss due to malnutrition, and dehydration *et cetera*, my fit better into a neglect category).

Although most of the foregoing topics appear in most LTCOP training manuals, “any training program worthy of the name should be preceded by a needs assessment” to get the biggest bang for their training buck (Umiker, 1998, p. 290). In terms of initial certification training, this analysis will assess what skills, traits, and attitudes are needed for success in specific volunteer and paid staff roles. In a published large scale needs analysis, Conner and Winkelpleck (1990) assessed the perceptions of about 1,000 volunteers and over 235 nursing facility administrators regarding the training needs of volunteer advocates. The recommended training content is as follows:

Role Definition Module. 1. Responsibility of volunteers

2. Responsibility of facility

3. Residents’ Bill of Rights

Process Module 4. Complaint Investigation and resolution

5. Federal and State regulations

Resident 6. Characteristics of the elderly

Characteristics 7. Characteristics of the mentally retarded or impaired

Module 8. Elder abuse (Connor & Winkelpleck, 1990, p. 8-9)

This model has much to commend itself. It is developed around both knowledge and process modes of training; is manageable in scope, and contains logically essential content, at least in the first five sections. For reasons that shall be discussed later, it could be improved by adding an introductory section on LTCOP values in the “Role Definition Module”(autonomy, resident-centeredness, etc.). One also wonders whether “facility responsibilities” should not be subsumed in section 5. “Federal and State regulations.” Section 6 should focus on the characteristics and common problems of the institutionalized elderly. Regardless, this initial certification program seems to have good face validity, and

is an excellent starting point to develop an adequate yet manageable core orientation program.

Recommendation 6: *LTCOPs should mandate a minimum 60 hours basic certification training covering core concepts and attributes critical to the success of an investigative advocate*. A minimum of 36 hours of this training should be in the classroom. Another 24 hours can be home study, including reading assignments and mini-workbook exercises to check understanding. Student's should log their home study time.*

** More hours would be better yet, but volunteers are often eager to "get to work." The above recommendation is only 12 hours longer than the longest current LTCOP training program. Moreover, basic certification training should be integrated with a pre-training mailing, and a post-certification in-service learning component, and a pass or fail certification exam as shall be discussed later.*

7. Training Methods

The ombudsman role is complex. It embraces widely varying skills and a vast knowledge base. Ombudsmen volunteers are also a complex and diverse group, with different individual learning styles. Given these assumptions, it is clear that a well-designed training/education program will involve many different, subject-appropriate methods and associated training aids that optimize learning by diverse learners. Moreover, these methods should be those shown to be effective for adult learners, which are generally participatory in nature, and learner, as opposed to teacher centered (Knowles, 1990). Assuming also that active learning is more effective than passive learning (Flegg, 1991), then we derive our first methodological question regarding ombudsmen training: is it lecture dominated? Some observers think so.

A lecture has two basic values. It is efficient and can be motivational, but its content can just as well be read at home. Consequently, LTCOP trainers should save lectures for values-based training. Long lectures should also be avoided. Instead, instruction should evolve around shorter, key-concepts based *lecturettes*. These subjects then can be fleshed out through discussion, clarifying questions, impression assessment, active listening/ paraphrase, feelings elicitation, and other forms of exploration and interaction.

One large study of ombudsmen training programs reveals that, in addition to the ubiquitous lecture, training methods were limited to videos, assigned readings, and discussion groups (Quirk, Lordeman, Wood, & Novich, 1988). No mention is made of skills-based training, even though these same programs were clearly teaching communication skills, negotiation, and other forms of problem resolution—subjects not well taught by talking heads. Instead, they require carefully designed simulations, modeled behaviors, and plenty of imitative-practice sessions. They also require substantial visual (via video-replays) and verbal feedback designed to promote "self-awareness, habits of mind, and communication" (Deutsch, 1994; Nelson, et al., in press; Patton, 1995, p. 403).

Other excellent techniques for problem identification include case studies, prepared films (several of which are available through the National Ombudsman Resource Center), simple diagrams, flow charts (the complaint investigation process) and simulations. Values training (autonomy, resident-centeredness) can be enhanced through games, triad-mini-role

plays, self-assessment instruments and other techniques that model critical aspects and attributes associated with specific value orientations.

Training vs. Education: Although the term “training” has been used throughout this paper, the foregoing techniques also promote critical thinking and thus, reflect an educational approach—education being defined as a means to encourage thinking. Conversely, training is merely teaching someone how to do something—like how to fill out a form, how to document properly, how to introduce one’s role, how to follow protocol. But, ombudsmen must be able to critically evaluate complex situations; determine situationally appropriate tactics for problem resolution, and effectively execute selected tactics through the complex art of interpersonal communication. Thus, much ombudsman learning should take place through the formal action and processes of education.

For example some programs teach (educate) prospective ombudsmen about resident-centeredness and autonomy by surveying the learner’s attitudes about these values via a role orientation self-assessment instrument (Nelson, 1992). This instrument has been used in several LTCOPs as a training device to provide feedback to trainees about their personal orientations towards a resident’s rights ideology versus a primarily mediative, neutral therapeutic, or paternalist (facility values) stance. It is currently being revised and updated for use as an instructional aid as well as a valid research tool. The popular Thomas-Killman Conflict mode instrument (1974) has also been used in some LTCOPs to help learners understand their basic conflict orientations and the situational applicability of different problem resolution strategies. There are several other conflict management self-assessment instruments on the market. More broadly, such instruments are an important means to animate “involvement leading to increased participation and personalized learning” (Pfeiffer & Ballew, 1988, p. 5).

These educational methods are sophisticated and time consuming, but impossible to avoid if new volunteers are to be fleeced of their stylistic errors (aggression, avoidance, knee-jerk reactions, wrong-minded paternalism, and so forth) to gain at least minimal competence in the cool-headed skills of resident-centered, case advocacy (Nelson, et al., in press).

Fortunately, LTCOPs have excellent educational and training resources in the staff and consultants, available through of the National Long Term Care Ombudsman Resource Center. There is no reason to present instructional programs with incongruous content—methods formats, inappropriate subject emphasis, impoverished media, technology and so forth. Guidance and support are available. On the other hand, resources are scarce. It would take considerable money for the NLTORC to systematically train the trainers nationally. And although the NLTCORC has some videos, for example, high quality, up-to-date DVDs on subjects requiring modeling are lacking and need to be developed along with other media and state-of-the-art training technologies (Alice Hedt, Director, NLTCORC, personal communication, January 10, 2002). Still, local program trainers need not reinvent the wheel. Some excellent training manuals are on line at the NLTCORC web-site, as well as a variety of other useful documents and training aides. Programs should build on the successes of each other by adapting material as long as the sources are cited (Alice Hedt, Director, NLTOPRC, personal communication, January, 10, 2002).

Recommendation 7 a: *Lectures should be reduced in length and in terms of the overall percentage of instructional time. Lectures should be reserved for motivational,*

values based subjects. Substitute lecture content with home study requirements whenever possible.

Recommendation 7 b: *Communication based education (including problem resolution) should have strong modeling components (mentor modeling, film), intense practice sessions (role play, triads, simulations) and feedback mechanisms (triads with coaches, video feedback, instructor critiques), and periodic practice refresher courses.*

Recommendation 7 c: Problem identification instruction training should rely on case study, prepared film presentations, and practice-based simulations employing mock records checks, mock interviews, and so forth.

8. The Need for Service Learning

Even a well designed initial certification training program of 48 or so hours cannot possibly prepare the neophyte for what lies ahead. Learning for most ombudsmen is probably slow during the first few weeks of initial training— so many subjects, unfamiliar terms and so forth. But, according to the theory of the *learning curve*, towards the end of certification training things probably start coming together. However, this is just when the trainees are cut loose into facilities. For some, this immersion really spikes the learning curve. Mastery improves because the ombudsman is learning by doing.

But this is also a time of great threat as well as opportunity. If totally abandoned to their own devices, some ombudsmen will figure things out incorrectly, developing bad habits and unbecoming roles. Once developed, these will be difficult to undo, especially in the absence of continuing education or close supervision, this is especially true for volunteers and part-time, or isolated paid staff.

To improve the chances of new ombudsmen figuring things out correctly, immersion into the facility should begin only after this orientation training, and under strict LTCOP supervision. It could take the form of an extensive guided tour lasting only several hours, or better yet, two weeks or more of mentoring with a qualified, veteran volunteer, or staff member in what is essentially a program directed internship.

Shortly after new ombudsmen begin visiting the facility alone, in a month or so, the program should provide a post-certification *reflection seminar*. Here the neophytes return to the classroom for a day with their trainer and former classmates. The goals are to: (a) reflect on their independent service learning; to discuss and reconcile perceived discrepancies between learned standards of practice and newly acquired expedients and (b) to reconnect to basic program goals and values.

After several months in the facility, the learning curve may level off. Some volunteers will loose interest and disappear. Others, both paid or volunteer, will be socialized by providers into non-program modalities. Still others will desire to improve and learn new skills. To address all three of these opportunities and threats, LTCOPs should provide regular programs of ongoing education on a bimonthly or quarterly basis. These day-long seminars present periodic opportunities to refresh skills via practice as well as occasions for those who have actually perfected their basic skills to advance in new challenges.

Finally, programs that develop ongoing regular ombudsman community support groups provide important opportunities for serving ombudsmen to meet and discuss problems

encountered in the facilities. These meetings can help prevent skills perishability, while providing psychological support by reducing the volunteer's sense of isolation.

Recommendation 8 a: *Program directed in-facility service learning opportunities of between 8 and 16 hours should be made available to all ombudsmen following the initial certification training program.*

Recommendation 8 b: *LTCOPs should provide regular programs of ongoing education comprising day-long seminars offered on a bimonthly or quarterly basis.*

Recommendation 8 c: *Between six weeks and two months after the newly assigned volunteer has been working alone in the facility, the LTCOP should provide a post-service reflection seminar to assess and validate or redirect volunteer's on-the-job-learning*

Recommendation 8 d: LTCOPs should establish regular community support group meetings where local volunteers can discuss and analyze problems encountered in the facilities.

9. Certification Exams

There is no systematic assessment of how LTCOP certification "training" anticipates job realities, or how this training is assessed. Only 11 states evaluate their ombudsmen for certification purposes (McInnes & Hedt, 1999). This is clearly a material weakness. Moreover, very little is reported about these tests. In one state, the certification exam includes 100 largely knowledge-based items and requires a 70% passing score for certification. Content covers the basic core concepts (discussed above), while problem identification/resolution skills are assessed by written responses to a dozen or so mini-case scenarios. Failure to pass results either in termination, or additional training at the instructor's discretion. Other states use a *pass*, *conditional pass*, and *fail* format. In either case, the goal is not so much to disqualify people, as to assure that matriculants are sufficiently grounded in the basics of their job (Hunt, 2001). Several states have a post-matriculation probationary period, to test the neophyte's suitability. Others offer "entry level" jobs that can be advanced out of by successful time-in-service.

The apparent dearth of formative and summative training evaluations is a major lost opportunity for program quality control. Even haphazardly designed evaluations have some value. Lacking these assessments, program leaders have very little basis to improve volunteer performance or values identification. Finally, assessments end political credibility to the meaning of "certified" ombudsmen.

Recommendation 9: *Ombudsman certification training/education should be based on the satisfactory completion of the instructional program as evidenced by a passing score on an exam comprised of questions that measure the learner's mastery of ombudsman core concepts. The exam should be designed to assess the learner's knowledge and ability to correctly identify problems and to select situationally appropriate problem resolution techniques. These are key performance indicators.*

10. The Focus of Continuing Education

Although addressed earlier (section 8) it is important to point out that ongoing training is also highly variable in states that require it, which are fewer in number than a decade ago. In 1988, for example, 28 states required post-certification training for volunteers with an

average of 27 hours (Schiman & Lordeman, 1989). By 1999, however, only 18 states required continuing education ranging from 6 to 24 hours (McInnes & Hedt, 1999).

Much ongoing training concerns changes in laws and policies as well as in-depth training in specialized topics. This tendency has received some criticism based on the notion that facility-based volunteers often work in isolation from other ombudsmen, and are literally immersed in provider values and goals. Consequently, they need reinforcement in basic ombudsman values and refreshers in back-to-basics investigative techniques, care planning, and advocacy skills *et cetera*, as opposed to heady diets of technical updates (which can be mailed out and read at home) and other specialized subjects of marginal utility. On the other hand, some staff and volunteers will have mastered basic skills and will be looking for new challenges. Consequently, advanced workshops should also be made available for adept veteran ombudsmen. One of the benefits of larger centralized training conferences is the possibility of offering break-out sessions to meet a range of participant needs.

Recommendation 10 a: *LTCOPs should perform regular training needs assessments of staff to determine performance discrepancies susceptible to training correction through continuing education workshops. A secondary analysis of identified needs will determine appropriate methods, aids, resources, and training evaluation format.*

Recommendation 10 b: *LTCOPs continuing education training should comprise back-to-basics refreshers and practice intensives on subjects identified in the needs analysis, as well as advanced training opportunities to meet the diverse needs of all serving ombudsmen. Attendance at two out of three of these programs should be required for continued volunteer certification.*

13. Need for Multiple Volunteer Roles-Career Ladders

Several programs offer at least three basic job opportunities for volunteers: Recruiter/screener, friendly visitor, and investigative ombudsman. Others use volunteers for clerical purposes, compiling data and so forth. Reports suggest that if these roles are clearly differentiated by specific policies, role objectives, position descriptions, and training, each can provide valuable services benefiting the LTC resident.

Beyond this, some LTCOPs understand the motivational value of providing paths of advancement within each volunteer role. Typically, in these scenarios, volunteers will begin their career as a “Certified Ombudsman-Basic,” (COB)—a job status of newly certified ombudsmen hold from the beginning of their in-service training throughout their first year of service. Some states might limit this role to basic problem identification and minor problem solving, requiring that more advanced cases (ethical dilemmas and so forth) be referred to higher grade ombudsmen or paid staff.

The next rank might be comprised of regular “Certified Ombudsmen.” This is the standard service class for most volunteers, where one might serve indefinitely. Finally, those who master additional skills as evidenced by passing an higher level examination may qualify for the advanced grade of “Certified Ombudsmen Mentor” (COM), (Team Leader, District Facilitator, or in one program, District Investigator). This senior grade is reserved for those who have demonstrated records of successful problem solving, reporting, visitation and so forth. In some states, these advanced ombudsmen have assumed quasi-supervisory functions, although one program abandoned this practice,

relegating top volunteers to a lead investigator function. In at least one case, advanced grade ombudsmen are not assigned to specific facilities, but have contractual access to any facility not having a specifically assigned volunteer, thus expanding ombudsman coverage.

Such career ladders offer volunteers a chance for growth and recognition and provides incentives to learn new skills and sharpen capabilities. It is a good way to recognize and re-recruit star personnel. On the other hand, one critic of this process worried that citizens groups might see volunteer career paths is being too bureaucratic. But, politics aside, the “career advancement” model makes good organizational (OB) behavior sense.

Recommendation 11: *To promote retention, motivation, and personal growth, LTCOPs should develop distinct career tracks with titled grades of advancement within specific volunteer roles. The LTCOP should support these career ladders with continuing service courses, and testing for the highest grade.*

12. A Role for Long Distance/On-line Learning

At least one program has delivered a 48 hour minimum home study course, augmented by long distance phone discussions, taped classroom presentations, capped by a certification exam and a post-training, four hour, mentored introductory visit. It may be only a matter of time before LTCOP leaders will invest in interactive on-line training software (*Blackboard 5*, or other packaged, user friendly systems, for example). These distance learning programs still require a good deal of instructor time for initial set up (posting of material; creating learning objectives, training modules, virtual-lectures, quizzes, discussion topics, case study files, posting graphic materials including photos, shelving support documents and articles, responding to emails, monitoring topical chat rooms, informal discussion café’s, and establishing links to external learning web-sites etc.). But, this investment in start-up time can revolutionize training in remote areas, and even improve mass training for new volunteers in urban and suburban areas, especially in centralized programs. The learner’s direct contact with the program need not be sacrificed, as long as in-service opportunities and continuing education courses are regularly scheduled.

The flexibility of “e-learning” is considerable; posted materials are easily updated (eliminating the expense of costly hard-copy manuals that are often out of date as soon as they are printed). Students can receive a great deal of individualized attention because instructors will spend more time in front of the computer than on the road. Unfortunately, distance learning is less than ideal for teaching communication skills which require plenty of modeling, role-playing, repetitive practice and feedback. Still, interactive software could be developed if resources would materialize. The efficiency of any state LTCOP’s training program could be markedly enhanced by a combination of on-line and classroom strategies.

Recommendation 12: *To reduce overall training costs and training labor intensity, and expand recruitment opportunities, LTCOPs should explore developing web-enhanced or fully on-line versions of their basic training programs to serve geographically dispersed areas in order to meet the needs of an increasingly technology tolerant volunteer pool.*

13. Performance Appraisals

Another adjunct to training is the formal job appraisal. It appears that few if any LTCOPs formally appraise their volunteers' job performance. This is understandable given the labor intensity and the other pitfalls associated with performance evaluations. If not done right, they are not worth doing. Still, for LTCOPs with sufficient staff-to-volunteer ratios (of no more than 1 to 20), performance appraisals could be useful in identifying performance discrepancies and, hence, training needs (and assessing whether or not training is the best intervention). It is presumed, but by no means certain, that paid managerial ombudsmen are more routinely subject to regular performance appraisals. If not, why not? Managerial appraisals are important for goal setting, improving performance, planning staff development, and validating the LTCOP's selection process (French, 1978).

Well-designed performance appraisals are based on explicitly written, largely quantifiable, role standards that are directly linked to key organizational objectives. Typically staff are evaluated once or twice a year with the goal to improve performance, motivate change, and set new standards for growth. A well written ombudsman performance appraisal would include, in addition to quantitative job standards (reports filed on time, visitation rates etc.) some personality/behavior based characteristics (assertiveness, judgment, initiative, discernment, etc). However, herein lies a major problem. Most supervisors are ill-prepared and are uncomfortable in making personality/behavior based assessments (McConnell, 1997). This problem is greatly exacerbated in volunteer agencies, where the appraisee's commitment to the program depends on positive self-perceptions about his or her role involvement. Since the volunteer supervisor has considerably less reward power than supervisors of paid employees, they have less leverage to forestall resentment and build a commitment to change. Even in paid organizations, performance appraisal programs have high rates of failure (due to rating errors: central tendency, halo effect, recency, poor supervisor training, lack of consistency, and so forth), (McConnell, 1997).

Still, program leaders might consider the expediency of requesting volunteers to annually rank their perceived effectiveness on a Likert-like check-off scale covering key output standards, including facility visits, complaints resolved, residents visited, residents empowered and so forth, with an open ended question about training needs. This practice is increasingly used in volunteer programs. It invites introspection about the volunteer's commitment to the role and presents a cued opportunity for dead-wood to select out, or re-recruit. It may also identify moral and ethical problems as well as engender some valid training needs and appeals for help, along with some possibly enlightening insights. Although supervisors might receive a few bloated self-ratings, experience shows that most evaluations are refreshingly honest. Annual self appraisals give the program a legitimate opportunity to reward and praise excellent volunteers and helps those in need. It is just one more way to provide and encourage mutual feedback—which must be maximized through multiple methods to build a truly continuously learning organization. Regardless, to encourage honest feedback, the program must make it clear that this process is non-punitive, and will be used for improvement purposes only.


Recommendation 13: *To enhance training audits, LTCOPs that do not regularly evaluate their volunteers should develop and disseminate annual self-appraisal forms*

soliciting volunteer feedback identifying perceived training needs and ‘morale slippage’ as well as trigger requests for help (Umiker, 1997, p. 151).

14. Discipline and Training

Another, oft overlooked adjunct to program training is a standard progressive disciplinary policy— for both paid and volunteer staff. For the trainer, the value of collecting, documenting, and assessing disciplinary actions and complaints against ombudsmen is how this important information augments regular training audits.

In typical progressive discipline policies, minor problems earn a verbal reprimand for misconduct. More serious problems advance through a series of written warnings ultimately leading to suspension or termination for continued misdoing. Performance discrepancies involving poor job knowledge, should not, however, be treated as disciplinary problems, but as training issues. These are first handled by counseling (a form of *dialogue-training* in continuously learning organizations [CLOs] with subsequent errors corrected through formal re-training with the goal of turning poor performers into good ombudsmen (Nelson et al., in progress). Proven inability to learn should result in the volunteer’s transfer to another role, or firing if no alternative role is available (Umiker, 1997).

Analysis of one state’s LTCOP’s  complaints lodged against ombudsman for two years revealed 98 complaints (with multiple sub-issues) of which 64 were categorized as demeanor problems indicating training needs in communication style issues. Another 40 issues concerned various alleged ombudsman access infractions, but most of these, along with a majority of all complaints, were found to be *prima facie* invalid, indicating the provider’s lack of understanding about the ombudsman’s role. Examples include complaints that the: “ombudsman sided with the resident;” “was investigating complaints;” or failed to tell provider “the name of the complainant,” and so forth. Confidentiality infractions emerged as a small, but significant problem suggesting that there’s never enough training about this key subject (Nelson, et al., in progress).

Recommendation 14: *LTCOPs should develop clear and comprehensive progressive disciplinary and grievance policies. Data concerning performance problems and complaints against ombudsmen are important adjuncts to regular program training audits.*

15. Exit Interview

Another important aid to a training coordinator is the exit interview. Well-designed exit interviews can help trainers identify the perceived, reflective perceptions of terminating ombudsmen including morale problems, training needs, and policy conflicts. They can also validate what works. Unfortunately, exit interviews are often unreliable. This is because interviewees often hide valuable facts when interviewed by former supervisors. Wishing not to hurt feelings or burn bridges, they often sidestep potentially embarrassing, controversial, or otherwise sensitive issues.

Trained volunteers have a better chance of conducting candid exit interviews because they are the departing ombudsman’s non-threatening peers. Trust is more easily achieved, and ensuing “discussions” are likely to be more broadly informative.

16. The LTCOP as a Learning Organization

The theory of “continuously learning organizations” (CLO) predicts that LTCOPs that continuously promote their core values throughout their entire organizations will be more energized and effective than those that do not. In effective CLOs “mental models” are continuously reinforced not just through training, but through policies, position-descriptions, and routine practices, as well as multiple means of coaching, coordination, communication. All these are means of learning and all are combined in “a continuous strategically used process—integrated and running parallel to work” (Marquardt, 1996, p. 20) Thus, everybody’s work behaviors, from the secretary’s to state ombudsman’s are energized by the “mental models” that comprise the organization’s guiding values— residents’ rights, empowerment, and resident-centeredness, and so forth. These basic values and their derivative “core competencies . . . serve as a taking off point” for the inevitable task specialization that marks any agencies work force (Marquardt, 1996, p. 20).

Although a LTCOP’s placement in an umbrella organization with diffuse interests and varied and even competing values may undermine the agency-wide commitment necessary to optimize the synergistic effects of a values driven CLO, state ombudsmen should, nevertheless strive to create their own departmental culture by employing “policies, strategies, and models” that reflect the LTCO’s unique, resident empowerment, watchdog, and change-oriented goals (Marquardt, 1996, p. 22). Here, *systems thinking* is especially important as the state LTCO helps employees understand how ombudsman mental models are mediated by the “full patterns” and influences of the parent organization (Marquardt, 1996, p. 23). Although LTCOPs unit goals may not be fully synchronous with the parent organization’s broader goals, the LTCOP unit team will have an inspiring vision that moves them towards common LTCOP objectives.

17. The Trouble With Guest Trainers

Many programs rely heavily on non-ombudsman guest trainers/educators from facilities, or other involved agencies (Kidd, 1991). At one time 25 states used facility staff to train ombudsmen; thirty one states used regulators, and thirty two states utilized other agency conferences to provide some instruction, to nearly all their training for volunteers (Quirk, et al., 1988).

This practice should be re-examined. This is because LTCOPs that delegate training control to others are, in essence, delegating a core management responsibility to outsiders. This may even present a conflict of interest if outsiders have a conflict of loyalty with the resident due to a responsibility owed to the facility. Such people should not be in a position to interpret policies or procedures, which, after all, is what training is all about.

Guest speakers are suitable for training in specialized geriatric subjects, or training about their own agency’s roles and procedures, but not for training on ombudsman program roles, values, protocols, or even on facility responsibilities. This sort of information should be imparted from the LTCOP’s perspective.

Experience shows that guest instructors often try to shape the trainees’ values according to their misunderstanding of the program. Research suggests, for example, that nursing home administrators prefer volunteers who appreciate business realities (Lusky, et al., 1994)—a perception I have seen them share with trainees on many occasions. Other guest trainers insist that ombudsmen should be neutral, and offer detailed definitions of the

classical ombudsman model—which has nothing to do with today’s LTC ombudsmen. Regardless, the breadth and depth of provider misconceptions about the ombudsman program are well supported in the literature (Harris-Whelling, et al., 1995; Nelson, 1995; Connor & Winkelpleck, 1990).


Finally, consider what happens when guest lecturing directors of nursing services or administrators assure new trainees that “they are advocates too,” or, remind them that “after all, we all want the same thing.” Is this really true? Are they really referring to resident empowerment and autonomy in decision making? Probably not. They are more likely referencing the promotion health and safety needs—a beneficence orientation (Gates, 1995), as mediated by realistic facility needs- factors for which they are accountable.

Regardless, it is imperative that LTCOP trainers understand that words are codes, and guest speakers often use words in common with ombudsmen, but that are encoded with an entirely different meaning. Ombudsmen leaders can neither expect their volunteers to act as advocates, nor expect others to see them as advocates if the program itself does not define the tactical and strategic implications of the language they use to describe their own role (Broadwell, 1995).

Recommendation 17: *LTCOPs should severely limit the practice of using facility employees and other non-ombudsman personnel to teach ombudsman roles, values, protocols and procedures. These core management functions require ombudsman expertise.*

18. Potential Training Deficiencies I: Problem Resolution Protocols

Some are concerned that both the methods and content of the ombudsman complaint investigation and problem resolution training undergo careful re-evaluation and possible refinement (Nelson, Netting, Huber and Borders, in press). Many program-training manuals miss much in their usually single chapters on these key subjects. They often avoid the word “conflict” altogether, and their discussion of resolution strategies (conflict tactics) is often imprecise and lacking sufficient contextual cues to indicate appropriate situational application. Moreover, the discussion of tactics is often limited to *mediation* and *negotiation*, which may be less useful than *persuasion* in heavily regulated settings, as shall be discussed shortly.

Although ombudsmen are neither regulators nor police, certain investigative techniques used by these enforcement agencies are also useful to ombudsmen in some situations.  instance, it is often wise to interview alleged perpetrators first before they are tipped-off by a background investigation. And what excuse is there for an ombudsman to be out in the field without a tape recorder? Do ombudsmen ever secure affidavits (Bill Benson, personal communication, November, 18, 2001)? Why not? Have they completely abandoned the practice of becoming notaries so that they can take sworn testimony (which cannot be changed later without implicating a lie)? Do ombudsmen understand the implications of accepting evidence “off the record?”

Advanced volunteer ombudsmen and paid staff need more training in the *rules of evidence*—the sole goal of any investigation. They should understand why they are not required to meet the same standards of evidence as other agencies—their role is more flexible and less restrained. As such, ombudsmen can ask for help or gently warn based on an informed hunch. This is an important means to help keep small problems from becoming

big ones. Nevertheless, ombudsmen should understand that when acting on an informed opinion, they are acting according to a personal standard of “*reasonable cause to believe.*” They should know how this differs from the higher regulatory standards of “*preponderance of the evidence*” or “*clear and convincing evidence*” (in civil matters) needed to sustain charges through administrative due process. “If for nothing else, understanding these rules of evidence will help ombudsmen make better decisions about how, when, and what to refer to other agencies/programs” (Sara Hunt, NLTCOPRC consultant, personal communication, January 7, 2002). Certainly, advanced training (especially for paid staff) should clarify how ombudsmen must themselves have a higher level of evidence to prevail in important matters, or if they expect regulators to back them. More important, ombudsmen must know when to *not* use evidence—when it breaches confidentiality by disclosing the identity of a resident/complainant who has not granted permission to do so. Ombudsmen also need training as to when written permission is needed to disclose a complainant’s name. What form is required, how long is the written request valid? This requirement is largely ignored for expedient’s sake across the country.

Similar gaps appear in problem resolution training. For example, the Alaska Long Term Care Ombudsman Training manual does a great job of explaining how to empower decisionally capable residents through the ombudsman’s supportive involvement as a subordinate ally. However, ombudsmen spend less time empowering residents in some settings than they do acting on their behalf by directly identifying complaints or acting on complaints filed by facility staff, family members, and others.

Training should make it very clear that many problems are solved by merely asking for help; those ombudsmen who don’t nit-pick are less likely to wear out their welcomes. On the other hand, they should understand that *mediation* and *negotiation*, which are liberally discussed as the prime tactics in most LTCOP manuals are, in fact, only 2 of the 5 basic tactics of interpersonal conflict. Those, however, along with *avoidance* and *compromise*, are not always fair, effective or efficient in highly regulated nursing homes, where, *persuasion* (the fifth tactic), often works best. Trainers should present clear situational guidelines as to when these various tactics are effective. There is no one right tactic for all circumstances. Why ignore the *contingent*, or *situational* approach to conflict, which is the hallmark of contemporary problem solving theory and practice? This bears closer scrutiny.

Despite the fact that some enabling statutes specifically stipulate that ombudsmen solve problems through *persuasion* (Oregon law, for example) trainers seem to avoid this term and its equivalent *argumentation*. One ombudsman staff attorney exclaimed “we don’t argue, we advocate.” However, Webster defines *advocate* is one who “pleads a cause,” or “defends and maintains a proposal,” which is the essence of persuasion. The attorney concurred, but claimed that the real problem with the idea of argumentation is semantic. “It sounds bad,” she exclaimed. Perhaps, in a popular sense, it does. But, not to conflictologists. For them, contending is a normal everyday communication technique that should never be nasty; like it or not, effective ombudsmen do it all the time.

In short—a good persuasive argument is often the most efficient and effective tactic in tightly regulated nursing homes. The logic for this is simple. A rule infraction establishes a non-negotiable wrong that the facility must redress. In cases where the facility is resistant, or the resident is in pain, or at risk, and time is of the essence, efficient problem solving demands the persuasive presentation of permissible proof that of an error entailing risk or

harm exists (Nelson, 2000). The ombudsman must calmly, professionally, without anger, or blaming, present, in a polite, empathetic and friendly manner, evidence of an error in order to solicit the correction that is legally obligated (Here, training should emphasize the concept of *style*, a *technique* that makes inherently adversarial argumentation appear discussional, and even friendly).

The goal is not to crush the provider. Active listening is still important as ombudsmen should allow for the discussion of alternate possibilities and must be open to abandoning their positions if their cases prove logically or evidentially insufficient. However, effective advocates will be well versed in their case by (a) knowing how to research applicable rules, (b) stay problem focused (not people focused) and (b) be adept at deflecting erroneous attempts to undermine valid evidence. If the ombudsman follows standards of cultural fairness (no rude interruptions, hostile gestures, smart remarks, anger etc.), and the evidence withstands the opponent's scrutiny and counter-arguments, then the opponent is logically, legally, and morally obliged to solve the problem. How the problem is solved is where the "let's see how we can make this work approach" fits in (Hunt, 2001, p. 16).

Given its semantic difficulties, perhaps ombudsmen are wise to avoid the term *argument*. Nevertheless, they should agree to a more acceptable synonym like *persuasion*, or *advocacy* and develop training for this everyday skill's sub-techniques, stylistic imperatives, and, situational applicability. Mountains of research suggests that *persuasion* can be finely developed through knowledge and skills based training (Deutsch, 1994; Patton, 1995; Nelson, et al., in press) which includes, modeling (role-play, video—some good ones are available through the ombudsman resource center) and intense practice with direct feedback.

Current ombudsman training also risks projecting mediation and negotiation as universally sound tactics, which is not the case. Training should make the limits of these tactics, especially in nursing homes (but less so in assisted living facilities) clear. Ombudsmen should never mediate or negotiate non-negotiables (matters of law or rule). Nor should they bargain away moral principles or the rights of others. Ombudsmen should not enter mediation or negotiation when there is a power imbalance and the ombudsman takes a neutral (mediative) stance (appropriate only in disputes between two residents with mutually stipulated but competing rights). Obviously, urgent situations involving a proven harm, leave little time for open-ended collaborative processes.

Some of the training material designed for ombudsman include whole manuals dedicated to classic mediation (Dize, 2001), with only a brief paragraph about its limitations—but these limitations are, in fact, pervasive—almost invariably the rule and not the exception. Even in assisted living facilities the playing field is not level between the resident and the provider. Hence, classic mediation is often sub-optimal and only occasionally appropriate.

Finally, ombudsmen are sending out mixed messages by calling themselves mediators. At a recent conference of the Gerontological Society of America, a former paid ombudsman coordinator explained that she had been "an ombudsman: an advocate, you know, a mediator." This practice is not uncommon, but it is a bad habit, because, as mentioned before, words have specific meanings. Of course, most ombudsmen who claim to be mediators are not really asserting their neutrality, but they should be careful of the message they are sending out--providers are confused enough. On the other hand, according to

Wood and Karp (1995), some programs are non-partisan, if true, then, they should be careful using the term advocate, which may not fit.

Recommendation 18: *Ombudsmen must develop knowledge and skills-based training processes to develop and hone the advocacy skill of persuasion.*

19. Advocacy Mediation

There is a new form of mediation in the conflict literature from the field of spousal abuse (Forester & Stitzel, 1989): advocacy or activist mediation. In this model, the mediator abandons the principle of neutrality, but otherwise employs the sub-tactics and techniques of mediation. The main difference is that the *advocate-mediator* tries to create a level playing field by making sure both sides get fair (not necessarily equal) time, that the values, needs, and goals of both sides are fully explored, but that provider elites do not abuse their inevitably greater power. The advocate-mediator assures this by constantly channeling information to the less informed side—the resident, and makes sure that the resident has time to deliberate. The activist mediator may also probe and question the provider when necessary. Again, the “advocate mediator” is not neutral, but prefers that the two disputants work out a *modus vivendi* that will keep them working together in the future.

Experience shows that this process works if both sides agree to the rules, and the provider plays fair by not trying to aggressively out-power the underdog. In which case, the advocate-mediator, must become simply, “the advocate.” This model holds great potential for the ombudsman program. If adopted, it should be appropriately labeled to avoid implication with the classic mediation process. Ombudsmen attempting advocacy mediation should fully inform both sides of the rules, including the underlying logic concerning the inherent power imbalance explicit in the provider’s greater system knowledge and control of resources. A well designed pamphlet explaining the process could be given to both sides of a dispute to explain the benefits of the process to all.

Recommendation 19: *LTCOPs should develop detailed protocols for advocacy mediation and promote this as a consciously distinct preference to classic mediation in situations of imbalanced power.*

20. Teaching and Tailoring Tactics to Match Environments

LTCOP trainers tend to ignore the situational applicability conflict tactics that arise in different regulated settings. For example, despite its strengths in nursing homes, *argumentation* is less useful in less regulated settings. In assisted living facilities and board and care homes, for instance, resident empowerment opportunities are more common. Here classic advocacy is tougher because there are fewer opportunities for the advocate to use the law as a leverage to request change (a possible explanation for Estes’ et al’s finding (2001) that ombudsmen feel less effective in community settings than in nursing homes).

In lightly regulated community care settings the time consuming and complex process of problem solving (principled negotiation, classic mediation, and advocacy mediation) move to the forefront of tactics. These collaborative tactics are much more difficult and frustrating because they require the provider’s willingness to work extensively with ombudsmen. Unskilled communicators will be outgunned or ignored in these circumstances. Perhaps this is why some research suggests that ombudsman attrition is

much higher in less regulated community-based facilities (Nelson, Netting, Huber, Borders, & Walter, in progress).

21. Looming Crisis: Training Deficiencies II — Ethics & Values: Autonomy, the Key to Being Resident Centered.

It is now a universal tenet of organizational behavior that “the successful companies of the future, let alone the present, will be based on solid ethical principles. Corporate values will be recognized as the vital lifeblood that pulls people together and keeps them together” (Herman, 1991, p. 59).

Despite increasing challenges from the phenomenological school of psychology, autonomy, remains key to the ombudsman’s “patient’s rights ideology.” One study shows residents’ rights (as expressions of autonomy) are more highly valued by ombudsmen than other nursing home players including grass roots activists, government officials, nursing directors, and nursing home administrators, in that order (Harrington, Woodruff, Mullan, Burger, Carrillo, and Bedney 1996).

However, despite autonomy’s clear legal dominance, as reflected in the centrality of “informed consent” as the chief determinant of legitimate decision making, autonomy often loses to paternalism in day-to-day LTC ethical conflicts (Nelson, 2000). Even so, alternatives to *informed consent* and *autonomy* are increasingly presented as a means to help advocates deal with resident dilemmas (to minimize “poor choices”); Moody’s negotiated consent is the most popular such model—“especially with application to healthcare for elderly” (Smith, 1996, p. 48).

On close inspection, however, these alternatives to informed consent often comprise swirls of layered dialogues between those invested in the resident’s choice and the resident, with the goal of developing admittedly sub-optimal solutions to benefit communal harmony. In this process, everyone with a stake in the outcome (professionals, family members etc.) are allowed to make their points through dialogues with the resident. Of course, if the resident persists in demanding a specific right, then even proponents of negotiated consent agree that the resident’s right must prevail, although this is clearly not the goal (Moody, 1992). In this respect, negotiated consent respects autonomy, but in a “more limited fashion” (Smith, 1996, p. 48)—rather it is “autonomy respecting paternalism” (Smith, 1996, p. 48) manifest in the same old “clash and balance of competing interests” (Smith, 1996, p. 48). Its goal is to promote “shared decision making” (Smith, 1996, p. 50).

Critics see negotiated consent as a form of paternalism: as a thickly veiled means of persuading the resident to meet a portion of everybody’s needs. To be sure, *negotiated consent* offers an appealing, reasonable language that might make the advocate feel good about using a state of the art process that reaches out to all and that is based on the humanitarian instinct to protect. But, in practice, it is a slippery slope that is far too sophisticated for nursing home employees, or ombudsmen to consistently pull off without the risk of trampling on residents rights. And even if they could, what need is there for another complex model that undermines autonomy, as if autonomy were a runaway LTC problem? Against the phenomenologists there is Rogers’ postulation: “The organism has one basic tendency and striving—to actualize maintain, and enhance the experiencing organism....”

“Clinically I find it to be true that though an individual may remain dependent because he has always been so, or may drift into dependence without realizing what he is doing, or may temporarily wish to be dependent because his situation appears desperate. I have yet to find the individual who, when he examined his situation deeply, and feels that he perceives it clearly, deliberately chooses dependence, deliberately chooses to have the integrated direction of himself undertaken by another.” (Rogers cited in Knowles, 1990, pp.42-43)

It is true that the autonomy principle sparks many conflicts by thwarting facility needs and routines. Nevertheless, promoting and defending resident autonomy is the essence of being resident-centered (Hunt & Burger, 1992). Choices made by decisionally capable residents are legally and morally binding, while options that ignore the resident’s informed choice violate the ombudsman’s central duty to optimize resident self rule. Thus, autonomy is the key to effective ombudsman advocacy.

Taking this a bit further, resident centeredness and autonomy are the two related but different concepts that researchers use to define quality of care per se. Resident centeredness refers to “patients’ assessments of their quality of life to indicate the presence of high quality care”(Aller & Coeling, 1995; Gerties, Edgman-Levitan, Daley, & Delbanco, 1993; Lutz & Bowers, 2000, Mattiasson, & Andersson, 1997: Miller, 1997; Pearson et al., 1993,” cited in Bowers, p.539), while autonomy, defined as “active participation” is a second means to assess overall health care quality (Ashwroth, Longemate, & Morrison, 1992; Jirovec & Maxwell, 1993; Kane et al., 1997; Mitchell & Koch, 1997; Wetle, Levkoff, Cwikel, & Rosen, 1988,” cited in Bowers, et al. 2001, p. 539).

Because both issues are central to LTCOP values, they should be among the first subjects addressed in any ombudsman training, for several reasons. First, people volunteer to meet a need, and the discussion of resident-centeredness, and autonomy breaches key needs arising from poor care, dependence, and abject powerlessness. Trainers who realistically underline the severity of these needs, will increase the learner’s motivation to help. This also opens the door to values training, and ultimately, to skills training because the autonomy value *implies a practical precedence protocol for advocacy (PPA) that should be the sole guide to every ombudsman in every conceivable circumstance regarding residents’ rights.*

First, facilitate the patient’s preference in the absence of risk. Treat all resident complaints as potentially legitimate: investigate. Second, when risk is present, the ombudsman must look for signs of decisional capacity and support the patient’s informed choice (accepting the fair influence of family and professionals, but mindful that coercion can have a deceptively benevolent appearance in imbalanced structures). Third, if the resident is decisionally incapable the ombudsman should reconstruct the patient’s voice according to the principles of substituted judgment (determining embedded life behaviors; examining advanced directives, etc.) . . . “and fourth (and only as a last resort), should the ombudsman act on a beneficent, best-interest standard-erring on the side of life, health, comfort, dignity, and safety (adapted from Nelson, 2000, p. 52).

To be sure, following this precedence protocol for advocacy will not solve all ethical dilemmas. There are some real murky, high stake cases out there where more sophisticated processes like negotiated consent may be useful. However, these are far from the norm. Ombudsman records scoured by Kane and Caplan (1990) showed that

most cases handled by ombudsmen are mundane, arising from the routine clash of personal preferences and values with the efficiency demands of the total institution. All of these are easily solved by keeping an eye to the ombudsman's PPA.

At the very least, the PPA will help keep ombudsmen on the right side— resident centered and protected from the very real danger of values-drift, as discussed earlier. Teaching the PPA model also makes theoretical sense in terms of learner readiness. One cannot expect ombudsmen to understand or use advanced ethical problem solving techniques if they are not grounded in the basics. Once the PPA is internalized through much training and practice, it will not be extinguished. Only after the PPA is internalized is the ombudsman ready to deepen his or her understanding of human cognition; or question the real meaning of autonomy for the individual, or learn how to employ a values history as a “jumping off point” for solving murky ethical dilemmas (Gibson, 1992).

Consequently, in the everyday world of LTC, it is best that we have at least one stakeholder group that will err on the side of autonomy, especially when virtually all other groups routinely err on the side of paternalism, and that sole group is the assemblage of ombudsmen.

Recommendation 21 a: *LTCOP's should include education on autonomy and paternalism in all introductory sessions.*

Recommendation 21 b: *LTCOP's Should teach the Precedence Protocol for Advocacy (PPA) as the foundation for all rights-based problem solving.*

22. Term Limits and Facility Rotations

This paper has focused a good deal on core program values and the factors that undermine those values: chiefly, the so-called *capture theory of regulation*. The longer and closer the ombudsman (any ombudsman) works with providers and regulators, the greater the risk that they will develop relationships that will diminish their zeal. Other academic theories (*mobilization*) predict that grass roots organizations will become bureaucratized over time as they gain legitimacy, and as their leaders tire of confrontation, and shift focus from causing change, to protecting turf, increasing power, and surviving. The Organizational Behavior literature predicts that *role immortality* risks dysfunction, including complacency, conflict aversion, and diffused interests (that is, interests beyond those of the client). All this argues for term limits for paid staff, about which I make no firm recommendation. Still, the benefits of protected term limits, independence, vigor, toughness, and fresh perspective demand that this issue be brought into the open and vigorously discussed.

At the local, level, evidence supports rotating ombudsmen facility assignments on a regular basis, perhaps every two years, as is the practice in several states. This is the best guarantee that local ombudsmen won't “go native” —be captured, that is, be co-opted by the facility. Provisions for appeal should be established for areas where alternate placements are not available.

Recommendation 22: *Ombudsmen assigned to specific facilities should be rotated every two years, allowing for appeals in rural areas where no alternate assignment may be available.*

Summary

The ombudsman program performs a vital resident defense and empowerment role; its residents rights orientation and grass roots reliance on volunteers assures it a unique niche among government services. Still, persistent problems of inadequate training and supervision threaten promoting the simultaneous expression of two seemingly incompatible program philosophies operating parallel to each other; one paid, one volunteer, one based on autonomy and patients' rights and the other drifting towards dominant paternalism. The LTCOP must grapple with this possible values dichotomy: to embrace it and make it work as some propose, or to correct it through training. The literature on organizational effectiveness would universally support the latter as the more effective option.

Unfortunately, LTCOP training endeavors, while valiantly trying to cover a broad area of core content, are in some cases practice-deficient. There appear to be some content deficiencies as well. For example, although, partisans by law, most LTCOPs fail to teach persuasion or basic situational conflict resolution. Moreover, the program's apparent over-reliance on classic mediation is inconsistent with program's strategic orientation.

Theories of organizational effectiveness view employee training as continuing beyond the orientation classroom, as an integrated ongoing system's process supported by detailed position descriptions, written policies, regular performance evaluations, intermittent training audits, standardized certification tests and procedures, formal disciplinary and grievance policies as well as other aspects of organizational coordination and communication. It appears that many, perhaps even the majority of LTCOPs are sorely deficient in the various components of this sort of learning infra-structure-largely due to insufficient human and material resources.

Recommendations are presented to move the LTCOP towards the model of a continuously learning organization; one that fully integrates formal and informal learning; and is energized by clear mental models and values that motivate across-staff support for program goals.

Discussion Questions

1. Should there be national LTCOP training standards?
2. What are essential entry-level training topics, and how should they be taught?
3. Should training be centrally controlled, by the state ombudsman?
4. Why do ombudsmen avoid training in persuasive argumentation?
5. Why do most ombudsmen programs focus on mediation training? Is this what they really intend?
6. Should the NLTCOPRC attempt to sponsor a Training Institute?

7. What is more important to motivating good ombudsman behavior: a sense of justice or compassion?
8. What can state and local LTCOPs do to forestall industry attempts to influence ombudsman training
9. Why do ombudsmen rely so heavily on guest educators, and is this really so risky?
- 10.** Why do ombudsmen depend so heavily on lecture: ignorance, or efficiency?

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Appendix VII

Data and Information in Long-Term Care Ombudsman Programs: Challenges, Opportunities

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EXECUTIVE SUMMARY

For many ombudsman programs, data have become a valued tool of the trade. Ombudsmen find them useful not only for reporting to funding agencies but also for informing consumers and other agencies. Data support systemic advocacy, program management, and resource development. However, the age of information has brought with it a cluster of new policy questions and costs.

Data Systems and Data Content

The Administration on Aging (AoA) took a major step in standardizing ombudsman data and in leading states to improve their data collection and management processes when it deployed NORS in 1995. Although AoA has begun improving NORS, refinements are needed. These include more measures of program performance, increased vigilance over data integrity and collection of disaggregated data.

State data management, though expanded and enhanced over the past decade, also need improvement. Many state and regional ombudsmen express dissatisfaction with their software and processes of reporting.

Research and decisions by state and national leaders are needed to assure that programs adequately and accurately paint a picture of the needs of consumers and the performance of the programs. Considerable effort is needed to address issues of the completeness and reliability (consistency) of data.

Use of Data

Policies and practices concerning the utilization of data also require further examination and refinement. Domains for improvement include:

- employment of state-of-the-art practices to evaluate practice and improve performance;
- dissemination of information to consumers; and
- sharing data with other agencies and providers.

Computerization has raised new issues around the practices of maintaining the confidentiality of client records. Security of data and the collection of Social Security numbers require special attention.

Costs of upgrading state data management systems are difficult to estimate. Upgrading may add from \$2.5 to \$5 million to national program costs in the first year and almost a half-million annually thereafter.

SUMMARY OF RECOMMENDATIONS

Administration on Aging (AoA)

It is recommended that AoA:

1. Work with ombudsmen and the Ombudsman Resource Center to assure the ability of NORS to reflect conditions in long-term care facilities, the performance of state programs and the cost-effectiveness of collecting all data elements. Disaggregated data should be preferred over aggregated.
2. Institute measures to improve the integrity of NORS data. Recommended actions include:
 - a. ongoing training in use of the NORS codes to improve consistency of reporting;
 - b. support for state and local programs in similar training; and
 - c. data audits.
3. Develop technical guidance for security of electronic data.
4. Develop a set of data system standards.
5. Award grants to states to purchase necessary hardware and software to meet these standards.
6. Hold the states accountable for use of data systems to meet the various analytic and reporting requirements of the OAA.
7. Provide LTCOPs more timely feedback by publishing NORS data early after they submit it to AoA.

Ombudsmen, with the National Association of State Long Term Care Ombudsman Programs (NASOP), the Ombudsman Resource Center (ORC) and the National Association of State Units on Aging (NASUA)

It is recommended that ombudsmen through their national association, NASOP, with the ORC and NASUA:

8. Develop policies for providing complaint, inquiry and other information to consumers and providers.
9. Continue work on the proposed “Outcome Measures.”
10. Develop or purchase state-of-the-art computer systems and software that assist them in improving services and provide ease of data entry and data analysis.
11. Institute Continuous Quality Improvement to improve the results of their work and its impact on clients.

Department of Health and Human Services (DHHS)

12. It is recommended that DHHS undertake a thorough review of practices and policy regarding release of information that is vital to LTCO advocacy.

DATA AND INFORMATION IN LONG-TERM CARE OMBUDSMAN PROGRAMS: CHALLENGES, OPPORTUNITIES

For many ombudsman programs, data have moved from “necessary evil”—“The Annual Report”—to valued tool of the trade. Statistics, once the province of researchers, now provide support for advocacy positions, bases for priorities, keys to improved processes and rationales for training programs. Further, as the public becomes aware of ombudsman information resources, individuals, advocacy groups, legislators and reporters turn to them for understanding quality of care in the long-term care arena.

Questions accompany the coming of the age of information. Are data being used to their fullest potential? Are the data in the six-year-old National Ombudsman Reporting System (NORS) accurate and reliable? How will ombudsmen respond to the cluster of new policy questions that have ascended for those managing their data with electronic systems? How will programs that do not collect and manage data with computers and those using inadequate, first-generation systems, afford useful systems?

It is the intention of this paper to call attention to the ways ombudsman programs use data, to discuss leading issues and to suggest potential improvements in the management of data and the use of information.

The National Ombudsman Resource Center provided considerable guidance and resources to the author, as did individual state ombudsmen and local ombudsmen. Given the time constraints for developing this paper, no systematic survey was undertaken. Information is largely anecdotal. States and individual ombudsmen are not identified due to the limitations on research and the fact that the paper is not designed as a “best-practice” document.

For brevity, the following abbreviations are used:

- AoA Administration on Aging
- DHHS Department of Health and Human Services
- IOM Institute of Medicine Committee to Evaluate the State Long-Term Care Ombudsman Programs of the Older Americans Act

- LTCO Long-term care ombudsman
- LTCOP Long-term care ombudsman program
- NASUA National Association of State Units on Aging
- ORC National Ombudsman Resource Center
- SLTCO State long term care ombudsman

THE VALUE OF DATA FOR THE OMBUDSMAN PROGRAMS

REPORTING TO FUNDING AGENCIES

The OAA requires State Agencies on Aging to establish “statewide uniform reporting” systems and to submit reports annually to the Assistant Secretary for Aging and other entities. The systems must collect and analyze data. (See Appendix.) Other funding agencies require reports, as do some states.

To facilitate accurate, consistent federal reporting, AoA, in partnership with SLTCOs, created the National Ombudsman Reporting System (NORS). States began reporting on NORS in 1995-96. They must submit their reports on a diskette or by e-mail.

PROGRAM MANAGEMENT

Although accounting to funding sources will continue to be a necessary and important function of LTCO data, LTCOs increasingly use their data for such purposes as planning and quality improvement.

Planning and Decision Making

Many programs consider such factors as numbers of facilities and beds as well as the density of facilities in allocating funds (ORC). They also consider data to target activities. A program may increase LTCO presence in facilities when data show histories of higher than average incidents of problems. A SLTCO said, “One of our interests is tracking complaints by facility ownership. If a corporation is having difficulties, we can move our ombudsman resources to better cover these facilities.”

In a state whose system includes detailed data on the time LTCOs spend on various activities, regional LTCOs consider reports of staff and volunteer time usage and reallocate the number of facilities covered by individual workers to fit their work patterns.

Regional LTCOs in one state submit annual plans. These include detailed goals and objectives that state and regional LTCOs negotiate based on the current year’s data.

Program Evaluation

IOM noted that few scientific program evaluations of LTCO programs have been conducted (IOM, p. 139). Evaluation is thwarted by the lack of clear criteria for evaluation and to the lack of data (IOM, pp. 129-135).

Quality Improvement

Several SLTCOs use data in monitoring regional programs. They provide periodic performance reports to the substate entities or ask them to pull such reports from their systems. Performance data become the focus of quality improvement discussions

between state and regional LTCOs. If case data are available electronically to the state office, monitors within the program study a case without a site visit, reviewing such matters as timeliness and appropriateness of complaint handling. State staff in some states also asks the regional LTCOs to review comparative data from the other regions of the state and discuss variations in performance based on those data.

Training

Observation of recurrent patterns of complaints and questions from the public, shown in analysis of data, assists LTCOs in determining topics for training program and provider staff as well as the general public.

PROVIDING DATA TO SURVEYORS

LTCOs use data systems to retrieve complaint data in the short time they are given to provide such information to licensing and certification surveyors who contact LTCOs at the outset of their reviews of care in nursing facilities.

SUPPORT FOR SYSTEMIC ADVOCACY

The OAA mandates LTCOs to analyze, comment on, recommend changes in and monitor the development and implementation of laws affecting residents. (See Appendix.) Such activities directed at improvement of systems are systemic advocacy.

Solid information is an essential tool in such advocacy. IOM stated as an “essential” practice: “Information from the Office’s work on behalf of residents determines policy decisions about advocacy issues affecting residents and program planning for the office.” It recommended as an “exemplary” practice: “Information from the Office’s work, integrated with comparable data from other sources, determines policy decisions about advocacy issues affecting residents and program planning for the office” (IOM, p. 171)

Ombudsmen use data to identify patterns within states, regions and nursing home corporations. These analyses are used to advocate for changes within a provider corporation and for changes in laws, regulations, provider payment or enforcement. Examples include the use of complaint data to challenge certificate of need decisions (ORC).

An increasing number of states publish complaint data in their annual reports to bring systems issues to the attention of the legislature and the public. Some states also publish survey deficiency information in their reports.

In its efforts to improve the effectiveness of the regulatory process, one state LTCOP employed the data in its annual report. The same program also used data in a successful effort to oppose the purchase of facilities by a provider whose track record, based on complaint and regulatory data, was consistently substandard. Another program noted that “hygiene care” and “staffing” appeared as the first and third most frequent categories of problems. Recognizing that poor hygiene care is usually a result of low staffing and/or poorly trained or inadequately supervised staff, the program pressed for passage of a bill to increase the ratios of nursing assistants and of nurse supervision (Kautz, 1994).

One SLTCO says her program recently became aware of widespread illegal billing of Medicaid recipients in nursing homes. The program added a special code to

its data system and instructed local LTCOs in using the code to track complaints and questions about this practice. The SLTCO now plans to use the information generated by this data gathering in a systemic advocacy effort.

CONSUMER INFORMATION

Ombudsman complaint data

Persons seeking quality long-term care increasingly turn to LTCOs for counsel. In FY 2000, programs reported 244,535 consultations to individuals, an increase of 30% over 1996.

Ombudsmen have responded variously to this public demand. Some provide detailed information, based on their analyses of the most frequently asked questions and complaints. “We have an obligation to help consumers make wise decisions,” said one SLTCO.

Others are reluctant to provide complaint data to consumers. Reasons for not showing complaint summaries include:

- concern that the information is not accurate, up-to-date or consistently reported;
- concern that mitigating circumstances are not explained by mere lists of complaints (see below, “Data explanation.”);
- the danger of breach of confidentiality;
- the fact that facility does not have a right to due process regarding the validation of complaints; and
- time constraints.

Regulatory information

Although LTCOs recognize the value of data from regulatory agencies, they may refrain from distributing them. Instead, they refer consumers to the licensing and certification agency and/or the Medicare web site. One ombudsman explained: “It’s not our data; sharing it is not our responsibility.” Another mentioned that her program does not have the resources to assure that it has up-to-date regulatory reports. Unless low-maintenance, automated, accurate and timely systems provide LTCOs with access to regulatory data, programs are unlikely to provide consumers with such information.

SUPPORT FOR RESOURCE DEVELOPMENT

Programs use performance and needs assessment data to support appeals for state and local funds. One program analyzed its record of resources development and found that, since developing standards and reporting relevant data, it had developed nearly one-half million dollars in new funds. They demonstrated Osborne and Gaebler’s tenet: “If you can demonstrate results, you can win public support” (Osborne and Gaebler, p. 154).

DATA SYSTEMS AND THEIR CONTENT

NATIONAL OMBUDSMAN REPORTING SYSTEM (NORS)

Examinations of LTCO information in 1991 and 1992 showed that the existing data system, using aggregated data and inconsistent data definitions, provided no basis for defining trends in LTC and no opportunity for serious examination or evaluation of LTCOPs (Huber *et al*, 1997).

When AoA implemented NORS in 1995, it took a major step in standardizing LTCOP data and in leading states to improve their data collection and management processes.

IOM considered NORS a “laudable” achievement, but stated that “concerns about the nature and large number of data elements to be collected and mechanisms for ensuring that reliable (reproducible) data would be reported across the states and localities.” It recommended that AoA:

Establish and implement an information system for the ombudsman program that provides an empirical basis for:

- evaluating and improving complaint resolution;
- identifying more precisely the kinds of problems (resolved or not) that affect the lives of residents of nursing and residential care facilities in order to provide a basis for systemic advocacy and change;
- documenting the key efforts made toward systemic advocacy and the results of those efforts; and
- documenting and analyzing the full range of activities of the (LTCO) programs (IOM, pp. 155-156).

IOM also recommended that AoA continue its efforts “to refine, and implement a uniform data collection and reporting systems.” At a minimum, the data system should, in the view of the committee:

- be based on a manageable number of uniform and reliable items—each of which has precisely specified, field-tested definitions;
- be derived from annual statistical reports submitted by long-term care ombudsman offices that provide information in terms of the data items in the previous point;
- include a clear indication of status of complaint resolution from a consumer perspective;
- be used to provide feedback to state and local ombudsman programs;
- be available for public use to foster research and inform decision making;
- incorporate methods and procedures for continuous revision and improvement; and
- be reviewed and updated no less than once every three years (IOM, p. 156).

Many of IOM’s recommendations have been realized. Several may require further attention.

Brevity

IOM suggested that “the burden of reporting” should be “minimized and realistic, given the fact that staff resources are limited and that volunteers are crucial in data collection efforts” (IOM, pp. 157).

States have attempted to minimize the burden of reporting not by eliminating elements from the report (indeed, several have added to the elements), but by developing user-friendly electronic reporting systems. LTCOs, AoA and researchers should periodically review the cost-effectiveness of collecting all data elements.

Evaluation

The addition of outcome measures to NORS might enhance its ability to provide “an empirical basis for evaluating and improving complaint resolution.” However, such expansion may be contrary to IOM’s desire that “burden of reporting” be “minimized.”

Review and revision

AoA has recently reviewed reporting requirements and has proposed changes in definitions and instructions. It is not clear, however, that, after six years of experience, NORS has been subjected to serious analysis to determine the extent to which it meets these recommended criteria.

Design

The greatest limitation of NORS is its design. NORS calls for aggregated data. For purposes of mere accountability, aggregation may suffice. For use in systemic advocacy, however, aggregated data are minimally useful. (See below.)

STATE DATA SYSTEMS

Basic to current state LTCO data systems is the ability to meet NORS reporting requirements. However, a number of states have found it essential and useful to include more data and features than they use to report to AoA. IOM recommended such expansion (IOM, p. 172).

In recent years most programs have developed computerized systems. Forty-three of the 47 states that responded to a survey conducted in April 2001 by ORC said they use computer programs to capture and manage data. They reported using 23 different software programs. Twenty of these were developed in-house by individual states and three are standardized programs – OmTrak, Ombud 2.0/3.0, RASCAL. Twelve were testing or considering using Ombudsmanager. One state has recently replaced its sophisticated twelve-year-old, DOS-based system with a completely new application.

Thirty-five states use relational databases as opposed to “straight aggregated” data (ORC). Relational databases permit more flexibility in entering and retrieving data.

Processes of design

Programs find a “team approach” useful in the early stages of system design. “If a state is choosing to custom design its software it must include local LTCO’s in the process and assess each program’s technology capabilities,” said an LTCO who recently completed a major technical assessment. “We expect residents to be appropriately assessed and have an individualized care plan. Local LTCOs need a tech assessment and individual tech plan to follow.”

At least two programs contracted for computer assessments (“audits”). The contractors analyzed the state’s current data system (which had been developed in-house), web-site needs and issues of communication of data from regional offices to the state offices. They conducted interviews with “stakeholders” (largely state and regional LTCOs) and the states developed plans to upgrade their tracking software and introduce Intranet technology.

Disaggregated data

If LTCOs and researchers expect to develop meaningful information from the data that they collect, they need the detail and flexibility provided by disaggregated data. Disaggregated data contain case and complaint-level details and may include other specifics, such as the name of the facility and complainant and resident demographics. Such systems can report not only how many “inadequate staffing” complaints they received, for example, but the names of facilities where those complaints originated. Using such systems, LTCOs may “drill down” into the data for answers to such questions as “How many verified abuse complaints were resolved?” “What was the number of verified complaints of staffing shortages in Medicaid facilities?” Pursuit of such issues can be the basis of advocacy to prevent the continuation of negative trends and can help LTCOs focus and improve their work.

Recently, researchers using data from six states that have disaggregated, complaint-specific data and demographics were able to make valuable observations about care for minority residents and variations in resolution rates of complaints of ethnic and gender groups (Huber, *et al*, 2001).

Features

What are other features of a useful data system? Conversations with LTCOs and written information suggest that an excellent system:

- is cost-beneficial in the eyes of field LTCOs as well as state office staff (those who enter the data should see the value of the data and know the effort of collecting and entering it was worthwhile);
- is flexible in meeting various reporting requirements and including new items of state interest;
- may be expanded and enhanced;
- has reliable technical support;
- enables regional LTCOs to run reports easily;
- can track individual complaints and complainants;
- enables comparing data from facilities, regions and individual workers;
- enables LTCOs in state and regional offices to research issues by several parameters such as facilities, owners, source of payment, race, sex, ethnicity;
- tracks LTCO performance, such as time to resolve complaints;
- eases data entry; and
- is compatible with data from other states, permitting cross-state research.

AoA would contribute significantly to the standardization and compatibility of LTCO data if it contracted with a proven consultant in systems development and worked in partnership with SLTCOs and other stakeholders to develop a set of system

standards. Such development would be followed by grants to states to purchase necessary hardware and software that meet the standards and to train workers in their use. AoA would hold the states accountable for use of the systems to meet the various analysis and reporting requirements of the OAA.

DATA CONTENT

Data collected and reported by LTCOs must reflect realities that matter. Minimally, they should be useful for systemic advocacy and reveal the program's most significant achievements and the costs of those achievements. They should paint a picture of the quality of residential life and tell the story of the program. According to Osborne and Gaebler in their pivotal book, *Reinventing Government*, "What gets measured, gets done" (Osborne and Gaebler, p. 146).

Despite the abundance of data now being collected, some important measures are missing from NORS. These include extensive performance measurement data, such as information about response and resolution times (Estes, *et al*, p. 6; OIG).

The complaint orientation of NORS has also been questioned. Huber (1994) pointed out the weakness of relying on complaint-specific data only. (IOM, p. 143). Likewise, LTCOs, in an IOM-sponsored workshop, "cautioned about relying too heavily on complaint – specific data to assess effectiveness. They stressed that one of the major effects of their work is to prevent complaints from occurring through education and through attempts to resolve problems before they escalate into formal complaints" (IOM, p. 144).

Nursing facility providers expressed similar concerns, pointing out that "measures of performance and effectiveness that rely on numbers of complaints or percentage of complaints resolved are of questionable validity." They believe that "the ombudsman reporting system creates incentives to show high numbers of complaints" (IOM, p. 145).

The drafting, under the auspices of ORC and NASUA, of outcome measures seeks to remedy some of these deficiencies. A team of LTCOs and others from the aging network created a matrix of measures. Measures of systemic advocacy are particularly inadequate. Many of the items listed as outcomes are actually activities. Further, while the enactment of legislation is an outcome, advocates actually want to know whether the legislation effected improved conditions and quality of life.

In addition, AoA and the Outcomes Work Group should conduct research to test the measures (Estes, *et al*, p. 48) and should consider the following changes, based on the United Way "program logic model" used by the outcomes measures team:

- narrow the number of measures to a few that demonstrate the value of the program and are easily understood by the intended audience;
- identify indicators of the outcomes; and
- identify data sources. Data should be readily obtained, explained and, for any measures to be used for national outcomes, comparable across states.

AoA and LTCOs should probe the goals and objectives of the program to detect the most important areas to be measured. A useful approach may be found in Kaplan and Norton's *The Balanced Scorecard* (1996), a method of strategic planning which uses a selected few measures to aid in setting organizational goals.

DATA COLLECTION IN THE STATE PROGRAMS

For whatever purposes data are used—reporting, counseling consumers or presenting to a legislative committee—data accuracy is vital. An ombudsman who frequently uses data in legislative advocacy says, “I am a stickler for accuracy. I’ve lost track of how many times a legislator has asked me: ‘Are you confident of your data?’”

Completeness

Are all complaints and activities of LTCOs reported? Without audits of data, it is not possible to determine whether they are. However, some observers of NORS data feel that much information goes unreported. They think this is not unusual, given the nature of LTCOP staffing. Workers, pressed for time, probably give higher priority to resolving problems for residents than to data collection and data entry.

Completeness of data depends largely on the motivation of staff and volunteers who collect it and on monitoring cases and data. Many SLTCOs, believing that LTCOs who find data useful for their jobs are more likely to enter data completely, show all staff and volunteers the value of accurate, timely data collection. For example, if LTCOs can track complaints more easily using the data system than by using paper records they will assure the accuracy and completeness of their own data. “The system helps them avoid letting cases fall through the cracks,” says one SLTCO.

When field staff and volunteers become aware of what the data show and see how the data are used in state-level advocacy and resource-development efforts, their interest increases and the accuracy and timeliness of data entry are improved. Manuals in some states show examples of reports that meet the needs of LTCOs. Several state offices also provide feedback from the system through periodic reports to workers. They use the data to discuss performance and plan activities.

One SLTCO mentioned that she uses a “Golden Rule” approach: “If the nursing homes have to follow the practice ‘if you didn’t document it, it didn’t happen,’ then why should not we ombudsmen?”

Simplicity of reporting processes is also necessary, as is monitoring of data. At least one state randomly checks manual case records against data in its system to assure quality of data entry.

Reliability (Internal Consistency)

Are case and activity data coded identically in all states and regions? The Office of Inspector General of the DHHS (OIG) found uncertainty over data rules among the ten SLTCOs it surveyed for its 1999 report. Two said they are “not always sure how to report certain data” (OIG, p. 15). As Huber *et al* noted: “A common reporting system does not necessarily contain comparable data” (Huber, *et al*, 1997, p. 93).

One example from the FY 2000 NORS report may reflect such uncertainty. Two states reported that their LTCOs verified 100% of all their complaints (the national percentage was 74.43%) (NORS). Do LTCOs in the two states interpret reporting rules differently from those in other states? Do their policies lead them to do so? Perhaps they are confused by the NORS instructions: “For all cases *closed*, provide the total number of complaints received.” If, by policy, they close only verified complaints, it follows that they would report only verified complaints. Whatever the explanation, it is not possible to compare without question these states’ records with those of other states.

Inconsistencies often result from decisions that field staff makes in coding. A person assigning a code to a complaint simply may not understand what the forms are asking for. In these instances, written explanations may help. In other cases, variations in coding result from interpretation.

Training may eliminate many of these discrepancies (OIG, p. 17). (See also Huber, *et al*, 2000.) Some state programs provide such training at least annually for leaders of regional programs. They regularly update the glossary of codes and discuss the codes in annual training and periodic site visits. Several SLTCOs said that AoA should provide recurrent training sessions. Such training would adapt methods used by industry and academic researchers and include models that SLTCOs could apply in training regional LTCOs.

Unfortunately, training on consistent use of reports is time consuming and must be conducted repeatedly, given the turnover of staff and volunteers. Few programs find it possible to spend great amounts of time training staff regarding the use of reporting tools.

Policy or philosophy-based differences are more difficult to remedy. Working closely with several states, Huber's team found that abuse complaints appear more frequently in one state than in others because state law and policy differ across state lines (Huber, *et al*, 1997, p. 93). It is necessary to explain such differences wherever the data are reported.

AoA recently took steps to improve consistency by issuing a list of proposed changes to NORS. These amendments, which would reword some complaint categories and provide new definitions, were developed in partnership with a group of state and local LTCOs (AoA, November 8, 2001). If adopted, these changes may improve consistency. They do not, however, provide guidance that addresses the issue cited by OIG (see above). Indeed, with the exception of the instructions that LTCOs should report only "for all cases closed," it is likely that the instructions are as clear as possible on this point. Training may, however, rectify the discrepancies.

In addition to clarification and training, AoA and SLTCOs cannot neglect the need for auditing records for consistency.

Access to Data from Other Agencies

Ombudsmen report difficulty in accessing data from regulatory agencies and CMS. Lack of uniformity appears across the country with regard to obtaining more detail from On-Line Survey, Certification, and Reporting System (OSCAR), the source of comprehensive and uniform data about nursing home resident conditions and deficiencies, and nursing home quality indicators. One SLTCO mentions that LTCOs cannot view facility incident reports in order to analyze them for trends and patterns.

To facilitate the work of LTCOs, DHHS should undertake a thorough review of practices and policy regarding release of information that is vital to LTCO advocacy. Where it finds unessential constraints, DHHS should revise its policies, clarify its procedures and, if necessary, seek amendments to statutes that limit access by LTCOs. Ideally, LTCOs would have seamless, transparent and simple electronic access to such data.

USE OF DATA AND INFORMATION

PROGRAM QUALITY IMPROVEMENT

A General Accounting Office testimony stated that “management approaches that strive to achieve continuous improvement of quality through organizationwide effort based on facts and data, such as TQM, can be a key attribute of high-performing organizations” (Mihm, 1999). (See also, Swiss, 1992).

All workers in a program that seeks to be responsive to its customers know what results their customers demand and measure the degree to which it is achieving those results (i.e., outcome measures). If the program uses Continuous Quality Improvement (CQI), it provides data to all workers that inform them of their record in attaining the desired results. SLTCOs lead these workers to improve their processes in order to achieve improved effects upon the lives of residents. Together, they use outcome, input (e.g., number of staff assigned), output (e.g., number of cases opened) and activities (e.g., time to resolve a case) data to know what policies, priorities, emphases, training and funding work toward achieving desired results.

Quality improvement is, at its best, a continuous process. The adage “If it ain’t broke, don’t fix it” does not apply. A program that strives for excellence improves processes before it discovers them “broke.” Few LTCOPs currently say they employ TQM (CQI)-type methods, however.

DATA DISSEMINATION ISSUES

According to IOM, an exemplary LTCO program “maintains a reputation as one staffed by well-prepared, knowledgeable workers familiar with the latest developments and trends and generously able to help others learn its knowledge and skills” (IOM, p. 164). It “shares information generated from its own resident advocacy services, without violating confidentiality, and shares public information about residents’ concerns with regulatory agencies, resident or family councils, citizen groups, other advocacy agencies, providers, and policymakers” (IOM, p. 172).

While LTCOs have responded positively to these standards, they hold concerns about some aspects of sharing data.

Consumer Guidance

Given the debate amongst LTCOs over means of disseminating information to consumers (see above), state and local LTCOs need carefully considered policies for providing data to consumers. Policies should guide them on:

- explaining the meaning of complaint categories;
- the minimum number of reporting periods that yield statistically-significant data;
- explaining the limitations of complaints as a marker for facility quality; whether to report all complaints or only those that were verified; and
- explaining the timeliness and thoroughness of facilities’ responses to complaints.

If LTCOs do not offer consumers data from regulatory agencies, they should explain to them how to access and interpret the regulatory reports.

How will LTCOPs respond to the demands of citizens for simplification in dealing with public services? State and local social and health services agencies provide “one-

stop shopping” information services. (Customer Service). In this environment, it is unlikely that the public will be pleased with an agency that sends consumers through several doors in their quests for information.

Ombudsmen could become the “one-stop” for information about long-term care. If they did so, the program would gain increased visibility and opportunities for public education. This approach would, however, require LTCOPs to become a channel of information, if not a placement agency, for a wide variety of community-based and institutional services. Considerable restructuring and funding would be necessary. Questions of conflict of interest would, inevitably, arise.

Alternatively, LTCOs could provide complaint information to the “one-stop” agency in their community and to assure that the “one-stop” agency has access to regulatory data. With well-developed electronic data systems, their complaint data, with appropriate explanations, would be available to information and assistance workers who respond to requests to assist consumers in selecting from the various care options. This option would not eliminate LTCO responsibility for accurate data, but it would relieve LTCOs from much of the time-consuming counseling. It has the disadvantages of pushing LTCOs farther from public view and of removing them from control of their data. It would also inhibit LTCOs from establishing important relationships with consumers as they enter the long-term care system.

Dissemination to Other Agencies

Ombudsmen are obligated, under the OAA, to provide their annual reports to the licensing and certification entities in their states. On other occasions, they may refer a case to Medicaid fraud units or regulatory agencies. When they do so, they must follow the same rules of confidentiality as with sharing data with any other entity. (Grant).

Licensing and certification surveyors who contact LTCOs for information during their periodic surveys have narrow time windows. Ideally, the LTCO who is contacted, whether at a regional or state office, will be able to quickly retrieve accurate, timely data in a form that succinctly and accurately informs the surveyor of the problems the program has encountered. Programs that want to use data as part of the information they provide surveyors must have systems that show complaint histories by date and facility.

Consulting with Providers

Ombudsmen express ambivalence concerning the role of furnishing information to providers. Some champion this role, citing the LTCO’s opportunity to prevent poor care as well as to resolve grievances. Consultations to facilities increased 50% between 1996 and 2000; complaints filed by facility administrators and staff declined slightly. However, two states received over 70% of their complaints from facilities (NORS).

Others hold that they do not have time to “become a consultant to providers” and fear LTCOs will divert resources from assisting individual residents. Some LTCOs have apprehension over liability. When consulting with a facility, they seek to draw a line between “telling the facility what to do” and sharing with facility staff findings from their data, experience and long-term care literature.

Ombudsmen must carefully balance their workloads. If the quality of individual complaint resolution services is compromised by the time LTCOs allot to consultation, both the value of LTCO individual advocacy and consultation to facilities are diminished.

Confidentiality

The OAA and many state laws proscribe the circumstances under which LTCOs may disclose a complainant or resident name or other identifying information. Ombudsmen have carefully maintained vigilance over information. However, questions continue to arise, due largely to advances in technology and reporting practices.

System security. For decades, LTCOs have locked their paper files. However, the use of electronic data systems challenges their concern for security of records. Unpublished information from ORC indicates few problems with electronic security, however. Systems in most states remain relatively unsophisticated and most LTCOs store data on their own computers. Transmission of data from regional offices to state offices poses an issue, however. Local programs in some states mail disks to the state office; one transmits through e-mail. These methods are vulnerable to breaches of security. Where programs store data on shared servers, through Intranet systems, firewalls and passwords must limit access to records.

Clearly, as records consume more space in electronic systems and more programs use electronic transmission, programs will require technical and financial support for addressing data security. AoA would contribute to the integrity of the LTCOPs by developing technical guidance for electronic security.

Social Security Numbers. Recently, LTCOs have discussed whether to collect Social Security numbers of residents or other complainants. The two states that collect Social Security numbers maintain that having the number helps them avoid tracking the wrong case in the event that two people with the same name reside in the same nursing home (ORC). On the other hand, at least one SLTCO believes that collection of Social Security numbers would, in fact, inhibit consumers from utilizing LTCO services.

AoA requires a discrete identifier for clients of other individual services but says that the practice of maintaining an “unduplicated client count” does not apply to LTCO program data. If an LTCO has access to a Social Security number, disclosing it falls within the disclosure and consent provisions in the Act. The OAA “prohibit(s) the disclosure of the identity of any complainant or resident with respect to whom the Office of the Ombudsman maintains such files or records unless the resident or complainant, or their legal representative, consents to disclosure” (AoA, 2001).

These provisions do not prevent LTCOs from assigning a discrete number to each complainant and complaint, however. Such complainant numbers, which are useful in tracking the numbers and types of complaints proffered by individuals over the course of time, are safeguarded for purposes of confidentiality.

Advocacy. Although numeric and qualitative data that demonstrate conditions of residents and long term care facilities support education and advocacy efforts, LTCOs may be reluctant to use them due to concerns over confidentiality, as a legislative committee may request data to substantiate claims made in testimony. Grant outlines conditions under which LTCOs disclose information and safeguards they take to protect privacy. (Grant). Generally, LTCOs remove names and other personal identifiers when relating incidents. Aggregated data conceal identities. LTCOs should consult legal counsel to develop policies and procedures to guard against disclosure of files in this eventuality.

Legal actions. LTCOs may face exposure of their sources and of complainant identities if their data are challenged in or requested by a court of law.

In Pennsylvania, a plaintiff requested by subpoena that a program provide “all ombudsman files pertaining in any way to eight facilities.” The court quashed the subpoena. “It found that federal and state legislative intent is to ‘permit disclosure where necessary only to promote, safeguard or manage resident care. The public policy of honoring the confidentiality of these records/information far outweighs the need of a private litigant to discover them in connection with its civil suit for breach of contract” (Grant, pp. 13-16).

While this case does not deal with a request for LTCO files related to a case in which the ombudsman was a party, it demonstrates the logic that a court may use to deny access to LTCO records. LTCOs will continue to exercise caution and rely on sound legal advice in weighing the costs and benefits of using data to bring about systemic change.

Data explanation

In the complex LTCO environment, data without explanation may mislead. As Huber, *et al* said, “it is important for the persons who interpret (LTCO) data to have close linkages with state and local LTCOs. Interpreters must link qualitative data (policies, philosophies, and observations) with quantitative data” (Huber *et al*, 2000, p. 22).

Although Huber was discussing the linkage between LTCOs and researchers, the principle also applies when LTCOs consider disseminating data to the public. Primary among LTCO concerns over reporting numbers of complaints by facility are:

- Reporting numbers of complaints without explaining how readily the facilities resolved the complaints is not fair to responsive facilities.
- Reporting complaints without noting how frequently LTCOs are available to residents may skew data. Complaint frequencies may vary not on the basis of quality of care but on the grounds of ombudsman presence.
- In some facilities residents feel freer to express themselves while in others (whose complaint rate may be lower) residents are reluctant to share concerns with an ombudsman. Reports that do not explain the difference would be misleading and favor more repressive facilities.
- Unexplained data may not account for recent events such as the impact of changes in ownership, management, enforcement actions, or financial difficulties.

Some LTCOs choose not to publish complaint information by facility. They prefer that consumers have a discussion with an LTCO or log onto a program web site that provides more complete guidance regarding factors to consider in selection of a facility. Some feel that information about specific facilities obtained from the local LTCO is more reliable, up-to-date, and thorough information than can be offered from a state office (ORC).

DATA NOT IN COMPUTERS

Although the preponderance of recent concern has been with numeric data entered in and managed by computers, other, “qualitative,” data continue to serve important purposes. When combined with quantitative data, findings from interviews and focus groups, for example, are used for advocacy and program quality improvement and may be used for needs assessments.

One state conducted focus groups and found that most of the residents did not know who the LTCOs were or how to reach them. Performance data showed that

LTCOs visited the facilities weekly. The program is considering whether weekly visits are as cost-effective as other methods for enhancing resident access to LTCOs.

RESOURCE NEEDS

SYSTEM DEVELOPMENT

Costs of designing and installing data systems for LTCOPs are not well documented, making estimates for costs of expansion and improvement difficult. The following broad estimates are provided for purposes of discussion.

With the exception of those states whose systems are relatively new and responsive to their needs, most states would need \$50,000 to \$60,000 to bring their systems up to standards. If all states upgraded using a system that provided on-line, Intranet function, cost nationally would be between \$4 to \$5 million.

These estimates are based on the following factors:

- The median state office has one state office plus nine regional offices. (The average program has 11 regional offices.) (NORS)
- The cost of reporting software for the first year for each of the “median” states would be \$16,000. For an average size program, the cost would be \$19,785. Total first year costs, nationally, would be \$1,028,800.¹
- The costs of purchasing computers, servers, secure, fast-access telephone lines and communications software may be \$40,000 to \$50,000 for average states (\$2,000,000 to \$3,000,000 nationwide).

Ongoing support costs would be \$7,500 for the median state, \$9,274 for the average state, \$482,250 nationally.

Not all states would require purchases of hardware and software, however. Total costs might be as low as \$2.5 million in the first year. However, eleven state LTCOPs operate on budgets of under \$300,000. The cost of purchasing a system would add about 5% to one of these low budget states with no substate entities, more to those such as Nebraska, North Dakota and South Dakota, which have low budgets and regional programs.

OPERATING COSTS

Time costs must also be considered. SLTCOs experienced in vigorous use of data admit to spending considerable time in the pursuit. “The program and the home agency must make it a priority,” said one LTCO. “In a extensive program such as ours, we could not do what we do without one person’s time being committed largely to data.” For states with few staff in the state office, data management can be daunting. Some programs solve this by dividing the time of a data expert with other programs.

CONCLUSION

¹ Based on the Winter 2001 price list for Synergy’s “Ombudsmanager.” This software appears to meet most, if not all, of the criteria listed above for an ombudsman system.

The Administration on Aging and the LTCOPs have taken remarkable strides to improve the quality of their data and access to their information through NORS and state data systems. Efforts to enhance LTCO information should focus on the integrity and security of data and on standards for electronic systems.

Public demand for access to reliable information on the quality of long-term care underscores the importance for LTCOs to continue their dialog and develop clear national and state policies on issues related to data sharing.

SUMMARY OF RECOMMENDATIONS

Administration on Aging (AoA)

It is recommended that AoA:

1. Work with ombudsmen and the Ombudsman Resource Center to assure the ability of NORS to reflect conditions in long-term care facilities, the performance of state programs and the cost-effectiveness of collecting all data elements. Disaggregated data should be preferred over aggregated.
2. Institute measures to improve the integrity of NORS data. Recommended actions include:
 - a. ongoing training in use of the NORS codes to improve consistency of reporting;
 - b. support for state and local programs in similar training; and
 - c. data audits.
3. Develop technical guidance for security of electronic data.
4. Develop a set of data system standards.
5. Award grants to states to purchase necessary hardware and software to meet these standards.
6. Hold the states accountable for use of data systems to meet the various analytic and reporting requirements of the OAA.
7. Provide LTCOs more timely feedback by publishing NORS data early after they submit it to AoA.

Ombudsmen, with the National Association of State Long Term Care Ombudsman Programs (NASOP), the Ombudsman Resource Center (ORC) and the National Association of State Units on Aging (NASUA)

It is recommended that ombudsmen through their national association, NASOP, with the ORC and NASUA:

8. Develop policies for providing complaint, inquiry and other information to consumers and providers.
9. Continue work on the proposed “Outcome Measures.”
10. Develop or purchase state-of-the-art computer systems and software that assist them in improving services and provide ease of data entry and data analysis.

11. Institute Continuous Quality Improvement to improve the results of their work and its impact on clients.

Department of Health and Human Services (DHHS)

13. It is recommended that DHHS undertake a thorough review of practices and policy regarding release of information that is vital to LTCO advocacy.

QUESTIONS FOR DISCUSSION

1. Is NORS too extensive in what it requires states to report? If NORS were abbreviated, what should be removed?
2. Does NORS show adequately what the LTCOPs are doing? What they are achieving? What problems they encounter with facilities? What issues they encounter when dealing with regulation and enforcement?
3. Are you confident in the quality and integrity of the data shown in NORS? In your state's reports? Are data entered completely and consistently across programs? What should states do to improve data integrity? What should AoA do?
4. How can data systems improve the usefulness of data, while minimizing the burden of reporting?
5. What sort of data system would work best to achieve all that the OAA requires of ombudsman data analysis and that you would like to do in your job?
6. How satisfactory are the proposed "Outcome Measures"? What would you do to improve them?
7. What are your concerns regarding the confidentiality of data? In your computer? In intra-state transmission of data? When you provide non-ombudsman technical support staffs access to data? When you use it for systemic advocacy? When you provide information to licensing or certification agencies? Is there a need for general reconsideration of what must be considered "confidential" information?
8. How can ombudsmen satisfy the public demand for ease of obtaining information about long-term care? Would you make available your complaint analyses to a "one-stop" information and assistance agency for distribution to consumers? Why or why not?

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APPENDIX
Older Americans Act
Sections Concerning Data

Title VII, Chapter 2, Section 712
2000 Amendments to the Older Americans Act

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

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

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

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

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

(C) the Assistant Secretary; and

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

(h) Administration. --The State agency shall require the Office (of the State Long Term Care Ombudsman) to

(1) prepare an annual report—

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

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

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

(D) containing recommendations for—

(i) improving quality of the care and life of the residents; and

(ii) protecting the health, safety, welfare, and rights of the residents

(E) analyzing the success of the program including success in providing services to residents of board and care facilities and other similar adult care facilities; and identifying barriers that prevent the optimal operation of the program; and

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

- (3) (A) provide such information as the Office determines to be necessary to public and private agencies, legislators, and other persons, regarding—
- (i) the problems and concerns of older individuals residing in long-term care facilities; and
 - (ii) recommendations related to the problems and concerns; and
- (B) make available to the public, and submit to the Assistant Secretary, the chief executive officer of the State, the State legislature, the State agency responsible for licensing or certifying long-term care facilities, and other appropriate governmental entities, each report prepared under paragraph (1).



Appendix VIII

LONG TERM CARE OMBUDSMAN PROGRAM EFFECTIVENESS: BUILDING STRONG ADVOCACY

By Robyn Grant

EXECUTIVE SUMMARY

Over the years a number of studies have analyzed the effectiveness of the ombudsman program from a variety of perspectives. This paper defines an effective ombudsman program as one that vigorously pursues individual advocacy (addressing individual resident issues) and systems advocacy (representing the interests of residents in general) based on the requirements of the Older Americans Act (OAA). It identifies the elements of such a program, recommends what would be needed to achieve this optimal level of ombudsman program effectiveness nationwide and discusses the fiscal resources that would be required.

KEY ELEMENTS OF OMBUDSMAN PROGRAM EFFECTIVENESS AND RECOMMENDATIONS

◆ ACCOUNTABILITY

The ombudsman program is accountable to the Administration on Aging, the State Unit on Aging, the state legislature, residents and the general public.

Recommendations:

- The Administration on Aging should:
 - Promulgate rules for Title VII of the Older Americans Act.
 - Develop and enforce national standards for program performance.
 - Develop, implement and enforce sanctions for not complying with OAA requirements.
- Ombudsman programs should establish an advisory board made up of a majority of consumers.

◆INFRASTRUCTURE

Program placement: The long term care ombudsman program must be housed in a location that allows it to independently advocate for residents and be free of conflict of interests.

Recommendations:

- The OAA should be amended to require that the long term care ombudsman program be placed in an independent, freestanding, non-profit agency outside of state government. Neither this agency, the Office of the State Ombudsman, nor ombudsman program representatives should be involved in any activity that potentially conflicts with the ombudsman role.
- In the interim, or should such an amendment not occur, federal rules or national standards should require that:
 - The State Ombudsman be independent in all actions, and that the State Ombudsman and program representatives (at the direction of the State Ombudsman) are able to represent residents through direct communication with directors of government agencies, legislators, policymakers and the media.
 - The Office of the State Ombudsman and ombudsman program representatives are prohibited from participating in activities which potentially conflict with their role.

Program Organization: An effective ombudsman program is characterized by clear lines of authority and accountability. The State Ombudsman is the undisputed head of the program and directs all aspects of program operation.

Recommendations:

- The Older Americans Act should be amended to centralize the ombudsman program under the direction of the State Ombudsman.
- In the interim, or should such an amendment not occur, federal regulations or standards should require that the State Ombudsman:
 - have final decision making authority in all aspects of designation of local ombudsman entities and ombudsman representatives (including revocation of designation);
 - be permitted to participate in the hiring of representatives; and
 - supervise and direct the program related activities of the local ombudsmen.

Fiscal management: The state ombudsman must manage the program budget.

Recommendations:

- The Older Americans Act should be amended to require that the State Ombudsman manage all fiscal resources related to the program.

- In the interim, or should such an amendment not occur, federal regulations and standards should require that the State Ombudsman have responsibility for making decisions about the use of the fiscal resources of the Office of the State Long Term Care Ombudsman.

Legal resources: The State Ombudsman and program representatives have ready access to an attorney who has relevant experience and expertise and who is not involved in any of the activities noted under “program placement.”

Recommendation:

- The Office of the State Ombudsman should directly employ, contract, or otherwise have a formal agreement with an attorney who has relevant experience and expertise and who is free of the conflicts of interests defined under “program placement.”

Staffing: The ombudsman program has sufficient numbers of well-trained and well-supervised volunteers and paid staff to fulfill all the mandates of the OAA. All program personnel, including the State Ombudsman, have the expertise, skills and depth of knowledge to perform well in their assigned tasks.

Recommendations:

- The IOM minimum ratio of 1 FTE : 2000 beds must be implemented in every state. However, the State Ombudsman and state ombudsman office staff should not be included in calculating this ratio (unless they personally investigate complaints in facilities).
- Each local program should have at least one full time paid ombudsman (not 1 FTE). Additional paid ombudsman program staff may be part-time, but must be devoted solely to ombudsman work and have *no* other duties.
- The concept of “front line ombudsman” should be adopted. Front line ombudsmen are those individuals who work directly with residents in facilities in addressing resident concerns. The core duties of this ombudsman are complaint investigation/resolution and resident visitation. Other tasks may be assigned depending on the ombudsman’s skills and interests.
- There must be sufficient numbers of other program paid staff to fulfill all the other duties required of the Office.
- The Older Americans Act should be amended to require that an ombudsman program staffing study be conducted to evaluate and recommend the staffing necessary to fully comply with the OAA requirements.
- Regulations under Title VII of the OAA should be promulgated to require the staffing standards recommended by such a study.
- At a minimum, the state ombudsman and any ombudsman program representative must complete a standardized initial training program and meet continuing education requirements based on the duties they are assigned to perform. State Ombudsman training must include leadership and management skill development.
- Minimum qualifications, including necessary skill sets, should be established for the State Ombudsman.

- Regulations must be promulgated under Title VII of the OAA to establish minimum hours of training and training content.

Volunteer program: An ombudsman program must have an active volunteer program.

Recommendation:

- Regulations under Title VII of the OAA should require that each state ombudsman program have a volunteer program in place or provide documentation explaining why the development of a volunteer program is not possible.

◆PROGRAM GOALS AND PRIORITIES

An ombudsman program must base its goals and priorities on the program's status in complying with the mandates of the OAA.

Recommendation:

- Each state ombudsman program and each local program should develop a bi-annual action plan that includes specific measurable and scheduled objectives for each area of ombudsman program function required by the OAA. This plan should be revisited and revised annually.

◆PROGRAM OPERATION

Visits: Visits are essential to providing residents with access to ombudsman program services and gaining sufficient resident trust and confidence to permit residents to voice their concerns.

Recommendations:

- Ombudsmen should visit nursing homes at least once a week. Visits to board and care facilities should occur at least monthly, with more frequent visits dependent upon the characteristics and needs of the resident population.
- The minimum length of a visit should be dependent upon facility size and the characteristics and needs of the resident population.
- These frequency rates should be adopted as a national ombudsman program standard.

Prioritizing complaints/response times: An ombudsman program must develop and uniformly implement a system for prioritizing its complaints and responding to complaints according to their urgency and potential harm to residents.

Recommendation:

- Priority levels and response times should be defined and adopted as a national ombudsman program standard.

Case work: Good casework is crucial to resolving individual resident problems and determining the underlying systems issues.

Recommendation:

- The primary components of good case work should be further discussed and then adopted as a national ombudsman program standard.

Policies and procedures: An ombudsman program must have standards and policies and procedures governing program operation in order to ensure consistency, uniformity and quality statewide.

Recommendation:

- Each ombudsman program should be required to develop, implement and enforce statewide policies for program operation.

◆ **RELATIONSHIPS WITH OTHER AGENCIES/PROGRAMS/GROUPS**

Effective ombudsman programs have strong working relationships with other agencies, such as the regulatory agency, and join with citizen groups in systems advocacy efforts.

Recommendations:

- Ombudsmen should clearly articulate their role, and its limitations, to other agencies and citizen groups and regularly communicate and share information with them.
- The ombudsman program should become more actively involved in forming and strengthening resident and family councils.

FISCAL RESOURCES

More data are needed in order to accurately determine the exact amount of funding needed to fully implement the mandates of the OAA and the recommendations proposed in this paper. At the very minimum, very rough and unsophisticated calculations indicate that at least \$69 million dollars would be required.

LONG TERM CARE OMBUDSMAN PROGRAM EFFECTIVENESS: BUILDING STRONG ADVOCACY

BACKGROUND

Since the inception of the long term care ombudsman program (LTCOP) a number of studies have examined its effectiveness. Monk and Kaye conducted a survey to assess perceived effectiveness by looking at reports of satisfaction with resolving complaints from the perspectives of nursing home residents, staff, and the ombudsman¹, while Dr. Ralph Cherry looked at the relationship between the ombudsman program and quality of care in nursing homes.² The Office of Inspector General, Department of Health and Human Services, has issued several reports that discuss the program. The first report, published in 1990, identified characteristics of the most successful LTCOPs,³ while a study released in 1999 pointed out ways in which the effectiveness of the program was limited by various factors, including insufficient staffing.⁴ By far the most comprehensive evaluation of the program was the Institute of Medicine report of 1995.⁵ Most recently, the report entitled, “Effectiveness of the State Long Term Care Ombudsman Programs,”⁶ followed up on many of the issues raised in the IOM report and looked at how state ombudsmen view the effectiveness of their programs.

State long term care ombudsmen have welcomed and valued these studies which provide them with information and data to use in advocating for improvements in their programs.

I. DEFINITION OF EFFECTIVENESS

Reports on the ombudsman program have analyzed program effectiveness using a variety of approaches. This is due in part to the numerous ways in which “effectiveness” can be defined and to conflicting perspectives of diverse constituencies.⁷ Nursing home residents, nursing home administrators, regulators, and citizens’ advocacy groups, for instance, are likely to have dissimilar views of what effectiveness means.

In general, a program of any nature in our society is evaluated by whether it attains its stated goals. Any discussion of ombudsman program effectiveness must therefore begin by clearly establishing what it is that the ombudsman program should be effective at accomplishing. The mission of the ombudsman program is often described by ombudsmen and others as being to “improve the quality of care and quality of life of residents of long term care facilities.” According to this definition, ombudsman program effectiveness would be determined by the program’s ability to achieve this goal.

While improving the quality of life and quality of care of residents is extremely important, this paper will not define ombudsman program effectiveness by its ability to reach those goals. There are several reasons for not discussing effectiveness in this manner. First, although the program certainly hopes to positively impact resident well-being, it is virtually impossible to measure the achievement of such a goal. Second, no one program can be expected to achieve such a goal singlehandedly. The long term care system is extremely complicated and involves a myriad of players and complex political

forces. Moreover, the ombudsman program advocates for improved services delivered by third parties (e.g., facilities, government agencies), but it does not directly provide, or control the provision of, these services. As a result, to look to the ombudsman program by itself to improve quality of care and quality of life is unrealistic and automatically sets up the program for failure.

Finally, an analysis of the Older Americans Act (OAA) language supports a more focused definition of the ombudsman program's purpose. A careful reading of the federal legislation shows that the OAA requires the program to **advocate** for residents' interests on both an individual and systems level, but it does not mandate that the program achieve resident quality of care and life.

Consequently, this paper will define an effective ombudsman program as one that vigorously pursues individual advocacy (addressing individual resident issues) and systems advocacy (representing the interests of residents in general) as required by the Older Americans Act in Section 712 (a)(3). The paper will present the elements of an effective program and outline recommendations for achieving this optimal level of ombudsman program effectiveness nationwide. Discussion will be based on the program's current mandates under the Older Americans Act and an assumption that all the necessary funding is available. However, since fiscal resources are critical to program effectiveness, the paper will also address the question of funding.

II. KEY ELEMENTS OF OMBUDSMAN PROGRAM EFFECTIVENESS AND RECOMMENDATIONS

A. CLARITY OF ROLE

The effective performance of any task depends upon a clear understanding of role expectations. One study suggests that substantial differences in the definition of the appropriate role for volunteer advocates can be fertile ground for conflict and misunderstanding between volunteers and administrators of long term care facilities.⁸ Obviously, lack of clarity about the ombudsman role can create problems for paid staff as well as volunteers. In an effective ombudsman program, all program representatives - both paid and volunteer - thoroughly understand the ombudsman's role and functions to carry out that role. They are able to clearly articulate this role, and its limitations, to residents, families, providers, regulators, the public and all those with whom the program comes into contact.

As noted in the previous section, defining the ombudsman role as improving resident quality of life and quality of care is problematic because it sets up unobtainable expectations of the program. For instance, the ombudsman may be expected to "make" a facility comply with regulations that would result in better care, even though the ombudsman does not have the authority to enforce regulations.

This very broad description of ombudsman work can also obscure the specific functions of the program and lead to "mission creep" – the belief that anything pertaining to long

term care is the responsibility of the ombudsman program. When programs are not clear about their obligations and responsibilities, they become everything to everyone and in essence are the “dumping ground” for what others can’t or won’t do. As a result, programs are pulled in too many different directions and have no time or resources left to do what they alone are mandated to do.

Effective programs define their role in a concrete, well-focused way.

B. ACCOUNTABILITY

The ombudsman program is accountable to several entities and constituencies, including the Administration on Aging (AoA), the State Unit on Aging (SUA), the state legislature, residents of long term care facilities and the general public. At a minimum, the reporting of ombudsman program activities and use of funding is one way in which these entities and constituencies can hold the program accountable.

A more detailed look at ombudsman program accountability and the AoA, the SUA and residents follows.

Administration on Aging: The ombudsman program is responsible for complying with the requirements of the Older Americans Act. The role of AoA is to oversee the ombudsman program and determine program compliance with the OAA and AoA regulations and guidance.

Three factors are necessary for an ombudsman program to be effective: 1) the program must understand what exactly is expected of it by AoA; 2) it must receive the training, guidance and technical assistance necessary to achieve full compliance; and 3) sanctions for failure to comply must be clear and enforced.

State Units on Aging: Ombudsman programs in independent agencies and local ombudsman entities that receive funds from the State Unit on Aging are accountable for meeting the provisions of the contract established between them and the state. The terms of the contract must be explicit, monitored and enforced.

Residents of long term care facilities: The ombudsman program is accountable to the residents it serves and must be resident-driven and resident-centered. An effective program is accessible to residents (as indicated in part by the program’s percentage of resident complainants), responds in a timely manner to their concerns, and resolves resident complaints to the satisfaction of residents (again, as indicated by program data). Furthermore, the program’s systems advocacy efforts correspond to residents’ needs and concerns as determined by a) analyzing ombudsman program complaint data; and b) directly soliciting and considering resident input and recommendations.

Recommendations:

◆ The Administration on Aging should:

- Promulgate rules for Title VII of the Older Americans Act.
- Develop and enforce national standards for program performance. Such standards should clearly articulate AoA's expectations of the program and establish concrete measures for evaluating whether those expectations are met.
- Develop, implement and enforce sanctions for not complying with OAA requirements.

Clear guidance and strong monitoring by AoA has been lacking to-date as indicated both in the IOM report and Dr. Estes' study on effectiveness. Despite many state ombudsmen's best efforts to comply with the OAA, many will never be able to fulfill the statutory requirements without external pressure and action by AoA.

◆ Ombudsman programs should establish an advisory board whose role is to advise and consult with the State Ombudsman regarding the planning and implementing of the program's advocacy agenda and its future service delivery components.⁹ To guarantee that the voices of residents and citizens are heard by the ombudsman program, the board should be made up of a majority of consumers (individual residents of long term care facilities, resident council representatives, individual family members, family council representatives, individual citizens over 65 years of age, individual citizens with disabilities, and representatives from consumer advocacy groups representing older adults and persons with disabilities).

C. INFRASTRUCTURE

Effective advocacy in the ombudsman program is built upon structures that facilitate and support the ombudsman's work on behalf of residents. Such structures include:

1. Program placement
2. Program organization
3. Fiscal management
4. Legal resources
5. Program staffing
6. Volunteer program

1. Program Placement

To effectively represent residents, the long term care ombudsman program must be able to independently advocate for residents and be free of conflict of interests. To this end, the program must be unencumbered in its:

- response to complaints made by or on behalf of individual residents. This includes working within facilities to resolve problems, representing residents in administrative

hearings and public hearings, and seeking appropriate intervention from other agencies or organizations.

- ability to represent the concerns and interests of long term care consumers through ombudsman program public reports, forums, printed information, and media contacts.
- ability to make public recommendations and communicate directly with legislators, policy makers, and the media.

The location of the program impacts its capacity to carry out the functions described above. In the 2001 report entitled, “Effectiveness of the State Long Term Care Ombudsman Programs,” more than one half of state ombudsman programs reported that their organizational placement creates difficulties for service provision, with conflict of interest and lack of program autonomy identified most frequently as concerns. The study also found that there is a significant association between program autonomy and effective legislative and administrative policy advocacy.¹⁰

Since systems advocacy is most directly affected by program placement, the ombudsman program must be housed within an organizational structure which ensures the program’s independence and avoids actual or perceived conflicts of interest.

Recommendations:

◆ The long term care ombudsman program must be placed in an independent, freestanding, non-profit agency outside of state government. Neither this agency, the Office of the State Ombudsman, nor ombudsman program representatives should be involved in any activity which potentially conflicts with the ombudsman role. This includes, but is not limited to the following activities:

- **Licensure, certification, registration, or accreditation of long term care residential facilities;**
- **Provision of long term care services, including Medicaid waiver programs;**
- **Long term care case management;**
- **Adult protective services or program units which develop and carry out care plans for, provide involuntary services to, are authorized to take temporary custody of, or serve as guardians, conservators or legal representatives for any clients (except to serve in such capacity for a family member or another with whom the ombudsman has a close personal relationship originating outside of the role as ombudsman);**
- **Reimbursement rate setting for long term care services;**
- **Eligibility determination for Medicaid or other public benefits;**
- **Preadmission screening for long term care services or residential placements;**
or
- **Decisions regarding admission of elderly individuals to long term care services or residential facilities.**¹¹

Research and data support program placement outside of state government. The 1995 IOM report noted the prevalence of conflicts of interest, both real and perceived, that arise from the structural location of many of the Offices of the State Long Term Care Ombudsman Programs. It stressed that “all conflicts of interest work to the disadvantage of the vulnerable client.”¹² While the committee did not make a formal recommendation, its review and discussion of state-specific information on effectiveness, conflicts of interest, and organizational location led it to conclude that “states can comply fully with the OAA goal of avoiding conflict of interest only if the ombudsman program is located outside state government in a free standing organization that has a commitment to an advocacy mission.”¹³

Six years later, Dr. Estes’ study found that ombudsman programs housed in an independent agency outside of state government report a greater degree of program autonomy. This is in striking contrast to her data indicating that 71% of LTCOPs are part of the State Unit on Aging, with, as noted above, more than one half of state LTCOPs reporting difficulties with conflict of interest and program autonomy as a result of organizational placement.

Clearly the recommendation for program placement outside of state government requires that the OAA be amended. Recognizing that such an endeavor takes time and in fact might not occur, the following recommendations should be implemented immediately through federal rule promulgation and/or national standards:

- ◆ **The State Ombudsman shall be independent in all actions, but shall consult with the director of the State Unit on Aging or his or her designee to keep the director apprised of ombudsman program positions and actions and to coordinate any possible efforts.**

- ◆ **The State Ombudsman and ombudsman program representatives, at the direction of the State Ombudsman, shall advocate on behalf of residents in the following nonexclusive ways:**
 - **Represent the interests of residents before governmental agencies, legislative committees, individual legislators and other individuals, groups or entities where issues that affect residents are addressed.**
 - **Communicate directly with directors of government entities, legislators, policy makers and the media about issues affecting residents.**
 - **Provide uncensored public testimony.**

- ◆ **The Office of the State Ombudsman and ombudsman program representatives are prohibited from participating in the activities identified earlier.**

2. Program organization

An effective ombudsman program is characterized by clear lines of authority and accountability. The State Ombudsman is the undisputed head of the program and directs all aspects of program operation. The State Ombudsman has final authority in

determining who serves as a program representative and what local entities house the program. Local ombudsmen take their direction and guidance from the State Ombudsman.

In addition, the program is unified, cohesive, and integrated.¹⁴ All program staff and ombudsman representatives view themselves as part of a statewide program which functions as a team with everyone pulling in the same direction.

Recommendations:

◆ The ombudsman program must be centralized as a statewide program with both the state office and all program staff located outside of state government. The program shall be under the direction of the State Ombudsman who is responsible for hiring and firing employees, certifying and training ombudsman representatives, designating any local programs, supervising the work of program representatives and guiding day to day program operations. (Note: the State Ombudsman can choose to delegate these tasks to other program staff.)

The current system in which the local program may be contracted out and in which local ombudsmen are employees of the contracted agency leads to fragmentation and confusion. Local ombudsmen often feel they have “two bosses” (or even more!) and are frequently pulled in opposite directions by the directives of the State Ombudsman, their agency supervisor and the Area Agency on Aging director. Furthermore, the interests of the local agency rather than the ombudsman program may determine priorities for the local ombudsman program. Local ombudsmen, for instance, may be told not to pursue an individual advocacy case or a systems advocacy issue that might negatively affect the relationship between a long term care provider and the agency housing the local ombudsman program.

Centralization eliminates these multiple, sometimes conflicting, layers of accountability and establishes a direct line of authority between the local ombudsmen and the State Ombudsman.

This allows a program to respond to problems in a more prompt and consistent way because the State Ombudsman does not have to coordinate efforts among numerous local entities. Centralization also deepens the sense of ombudsman values and mission felt by the local ombudsmen since they are not torn between the values of their employing agency and the ombudsman program. This increased sense of “ombudsman culture” enhances dedication and commitment to helping residents. Finally, centralization promotes united action that is essential for effective systems advocacy, particularly given the considerable power of the long term care provider industry.

The above recommendation will require a statutory change in the OAA. Until such time as this change occurs or in the event that it does not happen, the following recommendations should be implemented without further delay through federal regulations and/or national standards:

◆ **The State Ombudsman shall have the authority to designate local ombudsman entities and ombudsman representatives, participate in the hiring of representatives, and revoke designation if necessary. All final decisions relating to designation are to be made by the State Ombudsman.**

◆ **The State Ombudsman shall supervise and direct the program related activities of the local ombudsmen.**

◆ **The State Ombudsman shall control the administrative, advocacy, budget and program decisions of the Office.**

3. Fiscal management

To oversee an effective program, the state ombudsman must manage the program budget. Decisions about the use of fiscal resources of the Office of the State Long Term Care Ombudsman must be made by the State Ombudsman, based on the goals and priorities established by the program and program needs. The program should have the latitude to use its money as it sees fit – with the accompanying obligation of remaining within the budget that has been awarded to the program. This approach to fiscal management is supported by the 1995 IOM report which recommends that “the Office of the State Long-Term Care Ombudsman be delegated responsibility for managing all the... fiscal resources earmarked for the state ombudsman program.”¹⁵

When the Office is not in charge of how money is spent, precious time and energy are expended justifying how ombudsman money is to be used - time and energy that could be better used in other efforts. Moreover, ombudsman program efforts to justify expenditures are often in vain, since budget decisions are made by individuals who are not familiar with the program and its needs and who are under political or other constraints. Consequently, the money may be used for projects that do not correspond to the program’s greatest needs or, in some cases, not spent at all in order to meet political pressures to be fiscally conservative.

Recommendation:

◆ **The Older Americans Act should be amended to require that the State Ombudsman manage all fiscal resources related to the program.**

Once again noting that this statutory change requires time and may not occur, the following recommendation should be implemented without further delay through federal regulations and/or national standards:

◆ **The State Ombudsman shall have responsibility for making decisions about the use of the fiscal resources of the Office of State Long Term Care Ombudsman.**

4. Legal resources

An ombudsman program that conducts effective advocacy has ready access to an attorney who has relevant experience and expertise and who is not involved in any of the activities noted under “program placement.”

Such counsel advises ombudsmen related to complaint processing for individual residents, addresses policy and systems advocacy issues and represents ombudsmen against whom legal action may be taken or threatened. Specifically, ombudsman program legal counsel clarifies laws and regulations for ombudsmen and assists ombudsmen in developing arguments and strategies that benefit residents. In the event that a provider turns to its legal counsel to counter the arguments made by the ombudsman, the additional weight and support provided by ombudsman legal counsel can sometimes make the difference between success and failure. On a systems level, legal counsel assists in analyzing existing and proposed laws, regulations and policies from the resident perspective and helps in ombudsman program efforts to pass or defeat such laws, regulations or policies. Finally, legal counsel is also essential in challenging interpretations by providers and state agencies that are detrimental to resident well-being.

The importance of legal assistance is underscored in the recent study, “Effectiveness of the State Long Term Care Ombudsman Programs,” which found that the effectiveness of legal counsel is significantly associated with effectiveness of work with nursing facilities and overall effectiveness of the program at the state level.¹⁶

Recommendation:

◆ The Office of the State Ombudsman should directly employ, contract, or otherwise have a formal agreement with an attorney who has relevant experience and expertise and who is free of the conflicts of interests defined under “program placement.”

5. Program Staffing

Staffing remains one of the most essential elements of an effective ombudsman program. An effective program has sufficient numbers of well-trained and well-supervised volunteers and paid staff to fulfill all the mandates of the OAA. All program personnel have the expertise, skills and depth of knowledge to perform well in their assigned tasks.

Recommendations:

◆ The IOM minimum ratio of 1 FTE : 2000 beds must be implemented in every state. State ombudsman and state ombudsman office staff should not be included in calculating this ratio (unless they personally investigate complaints in facilities).

The nature of ombudsman complaint work has become steadily more complex over the years, and problems take far more time to address. The days of addressing cold coffee have been replaced with cases involving complicated issues such as challenging behavioral symptoms or difficult and time-consuming transfer/discharge cases. This requires more “front line” ombudsman time.

◆ Each local program should have at least one full time paid ombudsman (not 1 FTE). Additional paid ombudsman program staff may be part-time, but must be devoted solely to ombudsman work and have *no* other duties.

The following points outline the basis for this recommendation:

- A “critical mass” is needed to be most efficient. When individuals only have a few “ombudsman hours” a week, their ability to be productive and to follow through can be seriously compromised. This can affect complaint resolution, particularly given the complex nature of today’s complaints.
- Focusing solely on ombudsman work: 1) permits the ombudsman to develop and maintain a higher level of competency and expertise. A person’s level of expertise can suffer when he or she is spread too thin among too many different programs and roles; 2) avoids the conflict of interest that can arise when the ombudsman is assigned duties that fundamentally conflict with the ombudsman role; and 3) increases the ability to respond in a prompt manner to individual complaints as well as systems issues. Situations frequently arise in ombudsman work that require immediate attention. Effectiveness is negatively impacted if the ombudsman cannot respond as necessary because he or she is involved with the “other” part of his/her job at the time.
- Having at least one full time paid ombudsman more effectively uses ombudsman program funds and human resources by reducing time and money needed for training, management and supervision.

◆ The concept of “front line ombudsman” should be adopted. Front line ombudsmen are those individuals who work directly with residents in facilities in addressing resident concerns. The core duties of this ombudsman are complaint investigation/resolution and resident visitation. His or her tasks may include other program activities (for example staff inservice training or resident/family council development), depending on the skills and interests of the ombudsman and as deemed appropriate through a screening process.

This approach allows paid ombudsmen to specialize and develop a level of knowledge and expertise. The skill sets required for a good investigator/problem solver are completely different from those needed to organize family councils or conduct a facility inservice. Yet local ombudsmen are currently expected to carry out all these tasks and more. It is unrealistic to demand that one individual be capable of doing everything.

◆ There must be sufficient numbers of other paid program staff to fulfill all the duties required of the Office, including but not limited to the following functions:

- Assistance to the State Ombudsman
- Supervision of the work of the front line ombudsmen
- Volunteer coordination
- Training of the front line ombudsmen
- Oversight of the certification process
- Education of facility staff, residents, families and the general public
- Resident/family council development
- Program outreach to the general public (e.g., informational publications, letters to the editor, responses to inquiries, press releases)
- Systems advocacy and policy analysis
- Legal counsel
- Human resources/payroll management
- Information management (e.g., software support, report development)
- Data analysis (e.g., analyzing, reporting program data)
- Clerical support

Consideration should be given to contracting outside of the program for some of these services.

◆ The Older Americans Act should be amended to require that an ombudsman program staffing study be conducted to evaluate and recommend the staffing necessary to fully comply with the OAA requirements. Such a study should:

- Conduct some type of “time motion” study of the ombudsman program to determine the amount of time needed to complete ombudsman program activities.
- Revisit and revise, if appropriate, the IOM recommended standard of 1 FTE: 2000 beds to take into consideration geographical distances that ombudsmen must sometimes travel, facility size, and the points raised in this section of the paper about efficiency, expertise, etc.
- Determine whether minimum ratios of: a) ombudsman program supervisors to front line ombudsmen, and b) volunteers to beds are needed, and if so, what those ratios should be.
- Reassess the IOM recommended ratio of 1 full time volunteer coordinator to 40 volunteers.
- Determine whether minimum standards to carry out activities such as policy analysis, training, resident council development, etc. should be established.

◆ Regulations under Title VII of the OAA should be promulgated to require the staffing standards recommended by such a study.

◆ At a minimum, the State Ombudsman and any ombudsman program representative must complete a standardized initial training program and meet continuing education requirements based on the duties they are assigned to

perform. State Ombudsman training must include leadership and management skill development.

- **Regulations must be promulgated under Title VII of the OAA to establish minimum hours of training and training content.**
- **Minimum qualifications, including necessary skill sets, should be established for the State Ombudsman.**

Strong State Ombudsman leadership is essential to an effective ombudsman program. The State Ombudsman must have the expertise and experience necessary to inspire local ombudsmen, as well as gain their respect and confidence. In addition, the State Ombudsman must have the skills to vigorously speak out on behalf of residents, while earning the respect of providers, regulators and others with whom he or she must interact.

6. Volunteer program

Ombudsman programs must have an active volunteer program to be effective. Most state ombudsmen (91.5%) report that the number of volunteers contributes to the effectiveness of their local programs.¹⁷

A program cannot consider itself effective in advocacy if residents themselves don't have the ability to file complaints. Research shows that more than 50% of nursing home residents may have difficulty advocating for themselves because of frailty, sickness, mental retardation, dementia or other psychiatric diagnoses.¹⁸ These physical and/or cognitive impairments make it difficult, if not impossible, for many residents to call or write the ombudsman program for assistance. The inability of these residents to request help from the ombudsman program is further compounded by the fact that many of them do not have family members who can contact the program on their behalf (the figure most commonly cited is that approximately 50% of residents have no family involvement). Consequently, the only way for these residents to access ombudsman services is through a face-to-face visit by an ombudsman.

A very rough analysis of 2000 National Ombudsman Reporting System (NORS) information for nursing homes and board and care facilities seems to support the significance of volunteers in providing residents access to individual advocacy services. In general, in states where the ratio of facilities to volunteers is higher than the national average, the percentage of resident complainants is lower than the national average (the national average of facilities to volunteers is 5.88:1 for nursing homes and 15.3:1 for board and care facilities; the national average for the percentage of resident complainants is 21.38% for nursing homes and 25.82% for board and care facilities).

In addition, if one measure of effective individual advocacy is considered to be the ability of the program to resolve complaints to the satisfaction of the resident or complainant, data also support the importance of a volunteer program. The IOM report cites an OIG study in 1991 which found patterns of program activity suggesting that volunteers are a contributing factor to high complaint resolution rates.¹⁹ This is further confirmed by 2000 NORS data for nursing homes which indicate that of the 42 states reporting fewer facilities per volunteer than the national average, (5.88 facilities: 1

volunteer), 25 of those states had a complaint resolution rate higher than the national average (56%).

Recommendation:

◆ Regulations under Title VII of the OAA should require that each state ombudsman program have a volunteer program in place or provide documentation explaining why the development of a volunteer program is not possible.

D. PROGRAM GOALS AND PRIORITIES

Since the work of the ombudsman program flows from the mandates of the OAA, an effective ombudsman program bases its goals and priorities on the program's status in complying with those mandates. This process begins with an assessment of how the statewide program is carrying out its duties. There are several components to this process. First, the program must assess how it is doing in carrying out its duties. Such an assessment must include analysis of program data, including, but not limited to determining what the data show in terms of how frequently facilities are visited routinely, how many complaints come from residents, types of complaints, and complaint resolution. Next, problem areas/gaps in service need to be identified. Finally, the top areas for improvement should be selected and then specific goals, objectives and action steps developed for those areas. All goals must be concrete and measurable so that everyone knows when they have been reached.

Part of the goal setting process must involve forming a systems advocacy agenda. Again, ombudsmen need to carefully review their program data when establishing this agenda because the data should drive the goals and actions steps. For instance, the exact nature of the problem, where it occurs and how widespread it is will shape the approach used to address the problem.

The goals and priorities become incorporated into the program's action plan for a designated period of time. The development of this action plan must be a *team* effort which includes all program staff and members of any advisory board connected to the program. This is essential to ensure that the plan reflects everyone's best thinking and perspective, including the ideas of residents and citizens.

In states where there are local programs, State Ombudsmen should assist local programs in conducting the same process for setting goals/priorities for their own programs. To be effective, these local program goals and priorities *must* stem from state goals/priorities so that the entire program is moving forward in a unified, integrated manner.

Ombudsman work is often overwhelming, and the program is constantly bombarded with new issues and problems. To stay on track requires planning and conscious, collective and well thought out decision making about program efforts.

Recommendation:

◆ Each state ombudsman program should develop a bi-annual action plan that includes specific measurable and scheduled objectives for each area of ombudsman program function required by the OAA. This plan should be revisited and revised annually. Local programs should also develop such a plan.

E. PROGRAM OPERATION

1. Visits

The importance of ombudsman visits to nursing homes and board and care facilities cannot be overemphasized. Visits serve many purposes:

Routine visits:

- Allow the ombudsman to provide residents with information about the ombudsman program.
- Give residents the opportunity to speak directly to the ombudsman, thereby providing them with access to the program. A very rough analysis of 2000 NORS data appears to suggest that there is a correlation between visits and complaints from residents. States that have a percentage of visitation to nursing homes that is above the national average (76%), have a percentage of complaints from residents that is higher than the national average (21.38%).
- Permit the ombudsman to monitor the condition of residents and the conditions in the home.
- May improve care.²⁰ (Research conducted by Dr. Ralph Cherry found that quality of care was generally better in Missouri nursing homes with active ombudsman programs.)
- Connect residents to the outside world.
- Provide company, stimulation to residents.

Visits as part of complaint work:

Many of the benefits realized through routine visits also apply to visits made in response to complaints.

Finally, visits of any type are critical for effective systems advocacy. To bring about legislative, regulatory or administrative change, ombudsmen must make a compelling case for such a change. To do so, the ombudsman must know what he/she is talking about and be able to tell the story and paint the picture of conditions that must be improved. Ombudsmen can do this best when they have been in the facilities themselves and have seen first hand the problems experienced by residents.

Frequency

In an effective program, ombudsmen conduct routine visits to residents in each nursing home and board and care facility on a regular basis. Visits must be frequent enough to allow residents to get to know the ombudsman, trust him or her and to establish rapport. Only then will residents feel comfortable enough to open up and confide any concerns they might have with the ombudsman. Similarly, the frequency of these visits must be such that the ombudsman can develop sufficient knowledge of individual residents to know when “something is not right with Mrs. Roberts.”

Recommendations:

◆ **Ombudsmen should visit nursing homes at least once a week.**

◆ **Ombudsmen should visit board and care facilities at least once every month. (Note: the OAA mandates coverage of nursing homes, board and care facilities and other similar facilities, which includes assisted living facilities.) Frequency of visits in board and care facilities depends on the residents. In cases where residents are relatively independent, an adequate rate of visitation is *monthly*. However, recent information has shown that assisted living facilities are increasingly retaining more impaired residents – residents who are at times just as incapacitated as nursing home residents.²¹ When this is the case, visits need to be conducted at the same frequency level as visits to nursing homes.**

◆ **The minimum length of visits in nursing homes and board and care facilities should depend on the size of the facility and the needs and characteristics of the resident population.**

◆ **These frequency rates should be adopted as a national ombudsman program standard.**

2. Prioritizing complaints/response time

An ombudsman program must develop and uniformly implement a system for prioritizing and responding to complaints.

In determining complaint priorities, a program should first consider the seriousness and immediacy of harm to residents. For complaints of similar seriousness/immediacy, priority should be determined by whether residents have any other advocate (such as family) available to assist them, with residents with no advocates receiving top priority.²²

Recommendations:

◆ **Ombudsmen should prioritize and respond to complaints in the following manner:**

COMPLAINT PRIORITIZATION AND RESPONSE TIME

PRIORITY LEVEL (From most urgent to least urgent)	TYPE OF COMPLAINT	RESPONSE TIME
Priority 1	Abuse or gross neglect and the ombudsman has reason to believe that a resident may be at risk	Within the next working day
Priority 1	Actual or threatened transfer or discharge from a facility and the ombudsman has reason to believe the transfer or discharge will occur immediately	Within the next working day
Priority 2	Abuse or gross neglect and the ombudsman has no reason to believe that a resident is at risk	Within 3 working days
Priority 2	Actual or threatened transfer or discharge from a facility, and the ombudsman has no reason to believe that the transfer/discharge will occur immediately	Whichever occurs first: <ul style="list-style-type: none">• 5 working days• last day of bed hold period if resident is hospitalized• last day for filing a transfer/discharge appeal
Priority 3	Other types of complaints	Within 7 working days

Note: These complaint prioritization and response time standards have been drawn, with some modification, from the policies in Georgia and Alaska.

◆ **These priority levels and response times should be adopted as a national ombudsman program standard.**

3. Casework

Good casework is crucial to resolving individual resident problems and determining the underlying systems issues.

The components of strong casework include:

- Timely response (see previous section).
- Being resident focused, resident centered and resident directed. This means: starting by talking with the resident and obtaining resident permission to proceed, forming a plan with the resident (not for the resident), determining with the resident what the “bottom line” will be in any negotiations with the facility (what is/is not acceptable), working for the result the resident wants, checking in with the resident at various stages of the complaint investigation and resolution process.
- Explaining to the resident/complainant the parameters of confidentiality of the information they provide to the ombudsman, maintaining those parameters appropriately.
- Effective communication skills: listening to what people are (and aren’t) saying, ensuring that everyone is hearing and understanding the same thing.
- Good knowledge and understanding of laws, regulations, and standards.
- Obtaining and documenting appropriate consent before reviewing resident files.
- Thorough investigation, gathering all the facts first, interviewing without preconceived notions, not jumping to conclusions, being purposeful in interviews, observations and documents consulted.
- Empowerment: working to help the resident be his/her own advocate (or the family member, council, etc.) rather than doing everything for the resident.
- Professional relationships with staff /administrator.
- Using a “let’s see how we can make this work” approach instead of a regulatory approach.²³
- Referring appropriately: knowing when to refer, obtaining resident permission to refer; putting together as complete and detailed a case as possible for the referral agency (including any photos that the resident or family may have taken).
- Follow-up to determine whether commitments to change have been implemented.
- Persistence until the problem has been resolved as best it can be.
- Accurate, complete documentation.

Recommendation:

◆ The primary components of good case work should be further discussed and then adopted as a national ombudsman program standard.

4. Policies and Procedures

A state ombudsman program must have standards and policies and procedures that govern program operation. These standards and policies should include the consequences for failing to meet them. Standards and policies should be developed, and when necessary revised, with input from all program representatives. Program standards and policies are essential for program consistency, uniformity and quality

Recommendations:

- ◆ **Each ombudsman program should be required to develop, implement and enforce statewide policies for program operation.**
- ◆ **Training on the content as well as how to implement policies and meet the standards must be provided to all ombudsman program representatives and anyone connected to the program through a contractual relationship or involved in the monitoring or oversight of the program.**
- ◆ **The State Ombudsman office staff must provide guidance, assistance and regular feedback to ombudsman program representatives regarding the implementation of program standards and policies/procedures.**
- ◆ **The work of front line ombudsmen, as well as other ombudsman program staff, including the State Ombudsman, needs to be periodically evaluated. Performance reviews should be conducted on an annual basis.**

F. RELATIONSHIPS WITH OTHER AGENCIES/PROGRAMS/GROUPS

Ombudsman advocacy efforts are significantly influenced by the program's relationships with other entities.

1. Agencies/programs

The report "Effectiveness of the State Long Term Care Ombudsman Programs" shows that ombudsman political advocacy efforts are impacted by difficulties with regulatory agencies and by the relationship between long term care ombudsmen and representatives of the state unit on aging and area agency.²⁴ A good working relationship between the ombudsman program and other organizations is therefore vital to effective advocacy.

Recommendations:

- ◆ **The ombudsman program must ensure that all parties clearly understand the roles, responsibilities, capabilities and limitations of the ombudsman.²⁵ Ombudsmen must clearly articulate that their role is to: a) push agencies/players in long term care service delivery, regulatory, and financing systems to fulfill their responsibilities to residents; b) monitor to see that residents' needs are being met and their preferences and rights are being honored; and c) point out when they are not.**
- ◆ **Ombudsmen must be respectful, yet direct, open, straightforward and honest in their interactions with others. Regular communications must be held between the ombudsman program and other agencies at the national, state and local levels.**

2. Residents, families and citizen groups

Individual residents and family members

2000 NORS data suggest that residents and families generally view the program as being helpful (almost 77 % of residents or other complainants indicated to the ombudsman that complaints handled by the ombudsman were resolved or partially resolved to their satisfaction). However, effective programs gather more direct input about the quality of their services from residents or their families by conducting client satisfaction studies.

Resident and family groups

The Older Americans Act mandates that ombudsmen “provide technical support for the development of resident and family councils.” Unfortunately, many ombudsman programs struggle to fulfill this responsibility when faced by the overwhelming nature of complaint work. In fact, only 17% of state ombudsmen report that they are “very effective” in resident and family education.²⁶

The actual ability of resident and family groups to improve conditions for residents is largely unknown and needs to be formally evaluated. However, numerous family council successes have been documented in the National Citizens’ Coalition for Nursing Home Reform Maryland Family Council Project.²⁷ Other beneficial outcomes are also associated with councils. Resident and family groups promote empowerment, a principle that is at the heart of ombudsman work. Councils that advocate on their own behalf and address problems themselves can maximize the ombudsman’s time and resources by freeing up the ombudsman to focus on other program responsibilities. Finally, councils can join forces with ombudsmen in their efforts for systems advocacy, thereby adding strength and numbers that can make a difference in the political arena.

The benefits and possibility for positive change that can come from council formation suggest that resident and family group work must be placed higher on the list of ombudsman program priorities.

Recommendation:

◆ The ombudsman program should become more actively involved in forming and strengthening councils. To accomplish this, consideration should be given to identifying a program staff member who specializes in and focuses on council work or subcontracting council work to an outside agency as is done in Minnesota.²⁸

Citizen groups

Effective relationships with citizen advocacy groups are significantly associated with effective ombudsman program legislative and administrative policy advocacy.²⁹ This is not surprising given the enormous power of the provider industry. Since resident

interests are best served when citizen advocacy groups and ombudsmen work together in joint efforts to bring about change, effective ombudsman programs make supporting citizen groups an important priority.

In some areas of the country conflict and tension have arisen between citizen advocacy groups and ombudsman programs. A number of citizen advocacy groups have expressed their belief that the ombudsman program is ineffective, based in part on their perceptions that the ombudsman is unable to change provider behavior. Frustration has stemmed in many instances from a fundamental misunderstanding about each other's roles. While sharing a common goal, there are numerous distinctions between the two, such as scope of activities and approaches to change.

Recommendation:

◆ Ombudsmen should build bridges and alliances with citizen groups in the following ways:

- **Work to clarify the ombudsman role**
- **Explore how to maximize each other's strengths**
- **Communicate on a regular basis**
- **Share information. Ombudsmen receive and are familiar with information that citizen advocacy groups can use, but may not have access or knowledge of.**
- **Provide knowledge and expertise**
- **Assist in analyzing policy issues**
- **Disseminate information about citizen advocacy groups to residents, families and the public**
- **Provide specific case examples to support the need for legislation spearheaded by citizen groups**

III. FISCAL RESOURCES NEEDED FOR OMBUDSMAN PROGRAM EFFECTIVENESS

Both the IOM report and the 2001 study of the program by Dr. Estes support the need to increase funding of the ombudsman program in order to fulfill the OAA requirements. However, determining the exact amount of fiscal resources necessary to achieve this goal is extremely difficult since critical data are not available. For instance, there is no accurate information about how much staff would be required to meet the visitation standard described in this paper, or how many more staff would be necessary to meet the 1 FTE: 2000 bed ratio if the State Ombudsman and state office staff were not included in the calculation. Consequently, it is only possible to provide a very rough "ballpark" estimate.

There are two ways to arrive at this approximate amount. The first way is to use 2000 NORS data and the IOM recommended standard of 1 FTE: 2000 beds. This approach indicates the need for a total of 81.3 million dollars. The second method is to draw from Dr. Estes' research in which each State Ombudsman estimated the amount of

additional funding their state program would need to carry out currently neglected program requirements.³⁰ In this case, a total of 69 – 73 million dollars is necessary.

Without knowing the true staffing needs of the ombudsman program, determining the fiscal resources needed will continue to be problematic. The staffing study discussed earlier in this paper must be conducted before the full cost of operationalizing the practices outlined in this paper can be truly determined.

SUMMARY

Over the years a number of studies have analyzed the effectiveness of the ombudsman program from a variety of perspectives. This paper defines an effective ombudsman program as one that vigorously pursues individual and systems advocacy on behalf of residents of long term care facilities based on the requirements of the Older Americans Act. In order for ombudsman programs nationwide to fully comply with the OAA mandates, key recommendations include but are not limited to: locating the program outside of state government, a centralized structure, at least one full time paid ombudsman in every local program, requiring part time staff to have no duties outside the ombudsman program, State Ombudsman control of the program's budget, and a required resident visitation rate of at least weekly for nursing homes and monthly for board and care homes. Since many of these recommendations require statutory changes, the paper outlines other recommendations that can be implemented through regulation or standards. Fiscal resources of at least \$69 million are necessary if all long term care ombudsman programs are to reach the level of effectiveness described in this paper.

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Appendix IX

THE CHANGING LONG-TERM CARE RESIDENT POPULATION AND ITS NEEDS

by Elma L. Holder, M.S.P.H.

EXECUTIVE SUMMARY

The Long-Term Care Ombudsman Program was formed in 1971 after several years of intense exposure of problems in America's nursing homes and board and care facilities. Like other social programs that are necessary to serve and protect vulnerable people, the ombudsman program has never been adequately funded to deliver its mandated services. At the same time, the demands on the program are growing steadily. The elderly population, particularly the oldest-old is increasing and will multiply significantly as the Baby Boom population ages. Long-term care residents continue to be the victims of poor care, neglect and abuse – a problem exacerbated by a dwindling work force available to work in long-term care institutions. More and more elders suffer from Alzheimer's diseases and related dementias, as well as depression, confusion and other mental health disorders. Veterans receiving long-term care services and various ethnic and cultural groups are often underserved and need special assistance. New-fashioned health care programs such as managed care present new complexities and problems for consumers. Victories for consumers, such as the *Olmstead decision*, will enable many people with disabilities to live in the community instead of an institution, but they need specialized advocates to assist them in this quest. Many health care services to people in their homes are organized and driven by corporate interests rather than by the needs of clients, making it necessary to expand advocacy services to home and community-based care. All of these factors have a tremendous impact on the ombudsman program. Training programs must address new, complex topics. Ombudsmen are continually challenged to make decisions about priorities in service and to meet existing obligations while advocating for ombudsman services for all. This paper provides a brief overview of the changing population, new challenging groups to be served and current funding for the

program. It closes with a presentation of serious considerations to take into account when decisions about program expansion are made, and with the following recommendations for discussion, modification and potential adoption:

1. Any expansion of the program into new arenas will not be undertaken unless the program is adequately funded to meet its current obligations and to fulfill new responsibilities.
2. The National Association of State Long-Term Care Ombudsman Programs (NASOP) will join with National Association of Local Long Term Care Ombudsmen and other allies to produce timely, accurate information about what the actual costs of the program would be if all nursing homes and related facilities were adequately served.
3. Ombudsmen and NASOP will join other organizations in continuing to advocate for well-funded ombudsman-type services for various populations groups, such as people with Alzheimer's disease, people enrolled in managed care, veterans, differing ethnic and cultural groups, young people with disabilities.
4. State ombudsman programs will provide leadership and work in close coordination with other ombudsman-type programs developing in their state to assure that all people needing advocacy assistance are served and to prevent duplication of services.
5. Where programs do expand, with needed financial support and independence, training programs will focus on developing specialized ombudsmen to make sure that differing population groups are well-served.

THE CHANGING LONG-TERM CARE RESIDENT POPULATION AND ITS NEEDS

**A Background Paper by Elma L. Holder, M.S.P.H.
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The Long-Term Care Ombudsman Program was the inspiration of the renowned national leader, Dr. Arthur A. Flemming, who recognized and understood an increasing public concern for the plight of older people living in American nursing homes. The late Dr. Flemming, when Advisor on Aging to President Richard Nixon in 1971, concluded that each person in a long-term institutional setting would benefit from having an advocate to assist him or her when at risk with care, service or benefit problems. At the same time, he determined that advocates—from outside the nursing home (and board and care) setting—were necessary to monitor the overall care being provided and to activate systemic changes that would benefit all residents.

Like other social programs that are necessary to serve and protect vulnerable people, the ombudsman program has always been under-funded to deliver the services it is mandated to provide and to meet ever constant and mounting consumer needs and expectations.¹ Yet, there is no doubt that the ombudsman program has made a major difference in national on-going efforts to protect residents and assist their families, even though serious, well-documented problems continue to exist in institutional facilities. Moreover, Americans are witnessing an escalating growth in the older population and the unbalanced growth of aging services struggling to meet long-term care needs. Such services are often formed and driven by private investor interests, rather than the actual needs of the community. For these reasons (almost since the programs' inception) ombudsmen have been repeatedly challenged to consider the needs of older people in various care settings beyond the traditional nursing home, as well as the diverse needs of distinct categories of people such as those with Alzheimer's disease and related dementias and people of differing ethnic and cultural backgrounds.

Even though consumer needs and problems have increased, ombudsmen have always been constrained in any aspiration or plan to serve differing consumer populations - not only because of limited resources - but also because of statutory and organizational boundaries, a shortage of fully trained staff and volunteers, and, at times, resistance from various stakeholders in the long-term care system.

Regardless of the escalating need for ombudsman services, any thorough review of the ombudsman program will reveal that there are still gaps in monitoring and advocacy services for all nursing and board and care facilities. Noting that ombudsmen "play an important role in assuring quality care in nursing homes", a 1999 Office of Inspector General (OIG) study of ombudsman services in nursing homes determined that the program is limited by staffing constraints.²

These findings held true in the most recent national review of the ombudsman program conducted by the Institute for Health and Aging of the University of California.

According to its review of nationwide ombudsman statistics (NORS data for FY 1999) ombudsmen visit 83 percent of nursing facilities but only 47.4 percent of board and care facilities. All state ombudsmen report that nursing facility residents are one of the primary target populations for their services. Other targeted populations include board and care residents (75 percent), assisted living (69 percent), home care beneficiaries (twenty-one percent) and managed care clients (12 percent).³

Despite these drawbacks, this commendable program—rich in information, experience and skills—is often promoted as a potential home for new ventures to protect differing population groups often outside institutional-based long-term care. A brief overview of America’s aging population provides the reason why the ombudsman program is so important and why expansion of its services is an issue.

Ageing Persons – Present and Future

America today is in the midst of a demographic revolution, one that will transform the country into a much older nation... There are now five times as many older adults as there were when Social Security was introduced in the mid-1930's, and ten times as many Americans over 65 as there were in 1900. The proportion of individuals in later life has tripled, overall, since 1900, to produce an end result that is truly staggering. Half of all the people who have ever lived to age 65 are currently alive... The addition of three decades to the average life span in less than a hundred years—an increase in longevity greater than the total change over the previous 5,000 years—is surely one of the great wonders of the twentieth century... In short, we've added a new stage to life, one as long in duration as childhood or the middle years (Marc Freedman, 1999).⁴

An elderly population explosion between 2010 and 2030 is projected to be inevitable as the Baby Boom generation reaches age 65. About one in five U.S. citizens will be elderly by 2030. The elderly population numbered 30 million in 1988, will not reach 40 million until 2011, then will reach 50 million in only eight years (2019.) In the 1990's, Baby Boomers are in their economically productive years and represent nearly one-third of the U.S. population. When this generation begins turning age 65 in 2011, there will be a rapid growth in the number of persons 65 and over. This large cohort will strain services and programs required by an elderly population.

By 2020, the Baby Boomers will be pre- and early-retirement ages (55 to 64 years) and the young old ages (65 to 74 years). Between 1990 and 2020, the population age 65 to 74 would grow 74 percent under middle series projections, while the population under age 65 would increase only 24 percent. Not surprisingly, according to testimony at a recent congressional hearing, “Few Baby Boomers are planning to use institutional care when they reach their later years, although the federal government continues to spend more than half of its Medicaid funding on institutions such as nursing homes while nursing home residents represent only 25 percent of the Medicaid population.”⁵

During the period 1990-2010, the elderly growth rate will be lower than during any 20-year period since 1910, a result of the low fertility of the 1930's. By 2020, the size of the population age 85 and over is projected to double to 7 million. The oldest old will again double to 14 million by 2040 as the survivors of the Baby Boom cohort reach the oldest ages. Under the "highest" projection series, the oldest old could number as many as 31 million in 2050. Since the oldest old often have severe chronic health problems that demand special attention, the rapid growth of this population group has many implications for individuals, families, governments, and certainly the ombudsman program.

Aging people often need close attention and support in their living environments. Among non-institutionalized persons age 65 to 74 in 1995, 64 percent were married and living with their spouse, and 24 percent were living alone. As age increases, so does the proportion living alone. Among those persons age 85 and over, only 21 percent lived with their spouse, and 54 percent lived alone.

In 1990, five percent of all elderly (nearly 1.6 million persons) lived in nursing homes. While most elderly live in individual homes, the proportion of elderly living in nursing homes increases with age. The elderly nursing home population increased by 55 percent from 1970 to 1980 and by 29 percent from 1980 to 1990. Most people in nursing homes in 1990 were elderly (90 percent) and most commonly, oldest old women (34 percent of nursing home residents were women age 85 and over). Four out of five residents of nursing homes were age 75 or older, and 7 out of 10 were women. Nearly one in four older persons over age 85 (24.5 percent) lived in a nursing home in 1999.

Percentage increases in the U.S. nursing home population in the 1970s and 1980s were less than percentage increases in the oldest old population. However, accelerated growth of the 85-and-over population, combined with increasing labor force participation of women (often the primary caretakers of elderly individuals), suggests that the number and proportion of elderly living in institutions may rise. Whether the frail elderly receive care in nursing homes, from families, or from paid help in their own home, more people will experience the economic, emotional, and physical stresses of long-term care for frail elderly persons.⁶

People in the aging network, including ombudsmen, are concerned to make sure that services will develop to appropriately and fully meet the needs of people of differing ethnic and culture groups. In 2000, 16.4 percent of persons 65+ were minorities—8.0 percent were African-Americans; 2.4 percent were Asian or Pacific Islander, and less than 1 percent were American Indian or Native Alaskan. Persons of Hispanic origin (who may be of any race) represented 5.6 percent of the older population. 8.9 percent elderly Whites was poor in 2000, compared to 22.3 percent of elderly African-Americans and 18.8 percent of elderly Hispanics.⁷

In a comprehensive review of future needs for the elderly with disabilities, one prominent researcher projected:

In the future, a number of factors will converge to share the magnitude, scope,

and nature of the demand for long-term care: changing demographics and the health and functional status of the population; the availability of family members and other unpaid, “informal” caregivers; the financial status of various generations and the degree to which they plan in advance for long-term care; and the availability and cost of institutional care and community-based alternatives. A crystal ball is invariably inaccurate. Projections must therefore be examined cautiously. Major progress in the treatment of Alzheimer’s disease, for example, or a pandemic that wipes out a large subpopulation could significantly influence the size and character of the long-term care population (Stone, 2000).⁸

Our country is greatly challenged to provide advocacy services to meet the needs of all citizens in the healthcare system, especially in long-term care. Serious questions remain about what role the ombudsman program, with its special features and responsibilities, will play in this unsettling *real people, real problems* drama.

Past and Future Expansion of the Program

The federally mandated ombudsman program emerged because of the continuous public exposure of serious problems encountered by old, ill, frail and vulnerable people living primarily in nursing homes and, secondarily in board and care homes. However, in the early 1970's long-term care facilities—similar to today’s assisted living facilities—had begun to appear.

The federal law specifies and defines what long-term care facilities ombudsmen are obligated to cover.⁹ Soon after the program formed, ombudsmen began to detect that within (and without) nursing and boarding care homes there are various categories of older people who have similar, but also differing, needs for attention and protection.

The National Association of State Long Term Care Ombudsman Programs (NASOP) has recognized that the frail elderly have a great need for advocacy services and quality assurance, regardless of where they are living. In a position paper adopted in 2000, NASOP noted, “Individuals living in the community move from one setting to another: apartment, assisted living, hospital, nursing home. Following a stay in a nursing home, they may return to their home or to an assisted living facility. Advocacy during these transitions is especially critical to support elders’ rights to self-determination and maintain continuity of care.”¹⁰

Historically, state and local ombudsman programs have been called on to assist people of varying ages in a variety of long-term care settings and service delivery systems. An overview of selected categories follow:

Residents in Nursing Facilities: Nursing homes represent the primary facilities covered by all ombudsman programs in the aging network. Still, the states differ in the amount of coverage they provide.

In an ideal world, each nursing facility owner and management staff would meet the facility's contractual obligation to achieve and maintain, at least, the minimum standards set forth in *Title C, Nursing Home Reform, of the Social Security Act*. Likewise, each state licensure, survey and enforcement agency would meet its oversight and protection responsibilities to ensure that such standards are met. If this scenario were the case, the work of the ombudsman program would be less burdensome. Of course, the program would still be needed; individual problems and complaints are a natural occurrence in any living environment, good or bad. Also, residents seek assistance with problems that are not directly connected to the care and services of the facility, such as assistance with issues relating to Medicare, Medicaid or other insurance benefits. The harsh reality is that increasing evidence documents that America's nursing home residents are either suffering from harm or at great risk.

The most pervasive problem fueling the potential for poor care, neglect and abuse is the well-documented staff shortages in nursing homes and other long-term care facilities. One notable government study found that nursing facilities are understaffed to the point that residents in nursing homes may be endangered (Health Care Financing Administration, 2000). 31 percent of facilities were found to fall below minimal levels needed for professional nurses and 54 percent could not meet the nursing assistant recommendation. The study also concluded that residents should be receiving an average of almost three hours of care a day from nursing assistants and that as many as 93 percent of nursing facilities do not meet that standard for some or all of their residents.¹¹

According to the findings of the 1999 OIG study of the ombudsman program, "The type and extent of survey deficiencies and ombudsman program complaints...suggest that nursing home staffing levels are inadequate." In 2001, the American Health Care Association (AHCA) released the preliminary results of its 2001 nursing position vacancy and turnover survey, reporting some 100,000 nurse and nursing assistant vacancies in the nation's nursing homes. Annual turnover rates were nursing assistants 76.1 percent; RNs 55.5 percent; and LPNs/LVNs 51.5 percent.¹²

A congressional report released in July 2001 found that 5,283 nursing homes – almost one out of every three – were cited for an abuse violation in a two-year period from January 1999 through January 2001. All of these violations had at least the potential to harm nursing home residents. In over 1,600 of these nursing homes, the abuse violations were serious enough to cause actual harm to residents or to place the residents in immediate jeopardy of death or serious injury.¹³ Other recent studies noting the severity of problems have found linkages to staffing (Eaton, Harvard, 2000),¹⁴ (Kaiser Family Foundation, Harvard, 2001),¹⁵ (Harrington *et al.*, 2000).¹⁶

Thousands of residents of nursing homes are at peril. During this accelerating crisis in staffing, the need for increased monitoring by ombudsman programs and survey agencies is vital. While a relatively small number (1.56 million) and percentage (4.5 percent) of the 65+ population lived in nursing homes in 2000, the percentage increases dramatically with age, ranging from 1.1 percent for persons 65-74 years to 4.7 percent for

persons 75-85 years and 18.2 percent for persons 85+.¹⁷ As measured by the National Center for Health Statistics in their 1997 National Nursing Home Survey, the average length-of-stay (admission to interview) for nursing facility patients is 2.38 years. Persons over the age of 85 have been in the facility an average of 2.55 years. Single persons are likely to spend significantly more days in a nursing facility than their married counterparts.¹⁸

The 1999 National Nursing Home Survey found that nursing homes increasingly focus on patients with severe disabilities and “on a group of patients barely in evidence in 1985: people receiving temporary, Medicare-covered care following surgery or illness.” It also revealed that the proportion of elderly Americans living in nursing home has declined over the past decade, attributing the change to a shift in home-delivered care and assisted living.¹⁹

Residents in Board and Care and Assisted Living Facilities: The care and service needs of residents in board and care facilities is less clear. This is largely because there is no national protective program similar to that of nursing facilities. Statistics are illusive; state regulations, definitions, and oversight vary greatly from state to state.

In 1996, only 17 percent of closed ombudsman complaints were from board and care and “similar adult care” facilities. Though the number of board and care and assisted living facilities increased 18 percent between 1996 and 1998, ombudsmen are still visiting these facilities less regularly than nursing homes. In 1999 ombudsman staff and volunteers made “friendly visits” (not in response to a complaint) in 83.1 percent of nursing homes but only 47.4 percent of board and care homes (Kaiser, Estes *et al.*, 2001; NASUA, 1999; AoA, 2001).

When analyzing the effect of regulation on the quality of care in board and care facilities, Hawes found that in states with extensive regulation of board and care, facility staff are much more likely to know the name and phone number of the ombudsman. The facility staff in states with high regulation are also more likely to call an ombudsman and more likely to refer families or residents to an ombudsman in the event of a problem (Kaiser, Estes *et al.*, 2001; Hawes *et al.*, 1995).

One in-depth look at long-term care for the elderly with disabilities concluded that “over the past three decades, sporadic attention has focused on scandalous mistreatment of residents in board and care homes, a version of homes for the aged that also became a refuge for the people with chronic mental illness in response to the deinstitutionalization frenzy of the 1960’s (Stone, Milbank 2000).²⁰

Estimates of the number of assisted living facilities (ALFs) and persons living there can vary greatly; often depending on what definition is used. According to one author, “With the increase in prosperous seniors during the past 10 years, assisted living has become a popular, though costly, alternative to living alone or to nursing homes for those who can no longer manage a household. Without federal regulations or uniform

definitions, numbers are imprecise, though the funding sources are not: it's every senior for him-or herself, with almost no help from Medicaid. *Consumer Reports* claims that 500,000 Americans live in places loosely called assisted-living facilities; the Assisted Living Federation of America believes that a million people dwell in some 30,000 facilities.²¹ Another national survey at the beginning of 1998 estimated there were 11,500 assisted living facilities nationwide with more than 611,000 beds (Hawes, Rose & Phillips in 1999).

Although the growth of assisted living is slowing in many areas already saturated with ALFs, there is a clear desire by consumers and some states to develop affordable assisted living to provide an attractive alternative to nursing homes.²² Today, the assisted living market is primarily composed of the well-off elderly, with little available to moderate- or low-income consumers. This gap is due, in part, to the limited sources and inadequate amounts of public financing (primarily SSI and SSP), which could help subsidize room, board, and care for financially strapped individuals and their families (Stone, Milbank, 2000).

The streamlining of the Medicaid waiver approval process in recent federal legislation should increase the number of Medicaid beneficiaries in assisted living. At least ten states have now instituted a Medicaid waiver for assisted living with more sure to follow.²³ While the majority of assisted living providers are not involved in the Medicare or Medicaid programs, many of their residents may receive Medicare or Medicaid services.²⁴

Ombudsmen often see residents in nursing facilities that could be living in a less restrictive, yet protective environment, such as an assisted living facility. They also see residents living in assisted living facilities that are in need of greater protection and health care services than a given assisted living facility can or will actually provide. Most importantly, there is increasing evidence—based on congressional hearings, commissioned reports, and media coverage—that persons living in assisted living often face serious problems, similar to those faced by residents in nursing homes. Frequently identified problems include inadequate or insufficient care to residents; insufficient, unqualified, and untrained staff; and provision of inappropriate medications or improper storage of medications.

One federal government funded study found that staff in assisted living “was almost completely unaware of what constituted normal aging and what signs and symptoms warranted referral for evaluation and treatment.” Another increasing problem is that rather than “aging in place” as residents expect, they can be readily discharged if their need for services take a downward spiral, or if a resident develops troublesome behavioral symptoms or they run out of private funds to pay for the care. Equally troubling is when assisted living facilities house residents who need greater services than the facility provides (Hawes, *et. al.*, 1995).²⁵

Although issues and problems in assisted living are similar to those in nursing homes, there are some notable differences that require specialized training techniques for

ombudsmen. Easy and full access to individuals in their apartments can be difficult and can present obstacles related to confidentiality requirements. A key challenge is learning about and monitoring “negotiated risk contracts.” Essentially, the facility negotiates an agreement with the resident as to which services the resident requires, and the risks that the resident is willing to take. It is clear that many clients and their families need assistance in such negotiation, requiring the assistance of a skilled advocate.²⁶ The problems are magnified when the resident has been left out of the negotiation process and/or the resident has Alzheimer’s disease or related dementia. Furthermore, when there are few ALF quality standards and a lack of regulatory oversight, ombudsmen must use their power of persuasion to convince providers to “do the right thing” based on principles of fairness, consumer satisfaction, and best practices.

Although there is increasing regulation of ALFs, states continue to vary greatly in the extent of their regulatory and enforcement activities. Consumers of assisted living, including residents and their families, are increasingly vocal about the problems they encounter, often approaching ombudsman programs and consumer groups for assistance. One industry historian points out that “Assisted living shares with nursing homes the problematic reliance on a labor force which is scarce, under-trained, and volatile.”²⁷

While the public’s interest in federal regulations grows, in an effort to ward off national regulations for assisted living, long-term care provider associations (American Health Care Association, American Association of Homes and Services for the Aging, and the Assisted Living Federation of America) joined with the two major consumer groups representing older persons (AARP and the Alzheimer’s Association) to develop voluntary guidelines for quality rather than regulations.²⁸ Standards are now being applied to facilities voluntarily accredited by the Joint Commission on Accreditation of Healthcare Organizations.

Currently, ombudsman representatives are involved in a national broad-based Assisted Living Work Group that will attempt to reach consensus on a host of important issues including residents’ rights. The group’s work was stimulated by the Senate Special Committee on Aging after public hearings that aired consumer issues including the need for national regulations to protect ALF residents.²⁹ Most likely, ombudsman services to residents of assisted living will be discussed in these work group sessions, scheduled to be completed in 2002.

The residents in ALFs with high levels of privacy or service are reported to be largely white, widowed females, who are quite elderly. In a recent report, the average resident was 84.5 years old. Residents are both relatively well educated and relatively affluent. Most of them moved into assisted living from their own home or apartment, often making the decision in concert with their families. However, almost one-quarter of residents indicated that they had little or no control over the decision to enter a facility (Hawes, *et al.*, 2000); so, it is likely they did not participate in negotiating their contract.

Over one-quarter of the residents suffered from moderate to severe cognitive impairment, and roughly one-fifth of the residents received assistance in some activity of

daily living (ADL). The overwhelming majority received help with their medications, and many used assistive devices, especially to aide with locomotion. Roughly two-fifths of residents considered themselves in only fair or poor health. The greatest points of concern were about the adequacy of staffing levels and staff retention by the facility, with fewer than half the residents reporting that the ALF in which they lived always had sufficient staff and were able to retain staff. Similarly, residents were not overwhelmingly positive about activities in ALFs. One of the more unexpected findings was that almost three-fifths of residents indicated that staff never or only sometimes asked them about their activity preferences (Hawes, *et al.*, 2000).

The Administration on Aging (AoA) has defined assisted living facilities to be “a related facility.”³⁰ In a 1999 Ombudsman Resource Center survey, thirty-six of the reporting states indicated that they were *required* to handle complaints that occur in assisted living. One thing is clear, problems for older consumers in assisted living are now regularly exposed. Since the same situation led to the formation of the ombudsman program, the end result will most likely be a stronger public demand for enhanced ombudsman services for ALF residents. Elevated resources will certainly be necessary to expand ombudsman services to this more independent, but still vulnerable, growing population of elders.

Persons with Physical Disabilities (Older and Younger) in Long-Term Care Settings: With Implications from the Olmstead Decision. Although the OAA specifies that *older individual* means a person who is 60 years of age or older, ombudsmen often encounter younger citizens of all ages living in long-term care settings who need advocacy assistance. One of the agency’s long-standing positions is that “the program may serve disabled individuals under the age of 60 who are living in long-term care facilities serving primarily older people, *if* such service does not weaken or decrease service to older individuals covered under the Act.” One AoA document states, “It is very likely that resolving a question or complaint that comes from a younger resident will affect the overall operation of the home and therefore will positively affect the older residents of the facility.”³¹

There are various service and protective programs designed to help children and other adults under age 60, however, services are sometimes limited, especially in long term care institutions. Lines of authority and communication can be easily blurred, creating some gaps in service and protection for the younger person. Furthermore, with a few state exceptions, there is nothing like the ombudsman program designated to offer on-going specialized advocacy assistance to other age groups.

In a survey conducted by the National Long Term Care Ombudsman Resource Center (ORC) in 2001, ombudsmen programs were asked about the ages of persons they serve. Of the 29 states responding, 22 states indicated that they provide services to all residents in long-term care. Some state laws specify that the program is to serve all residents and persons, especially in various facilities providing long-term care.³² The actual extent of such services is unknown.

At minimum, when an ombudsman encounters a younger person in long-term care needing help, he/she needs to have sufficient knowledge to provide a timely and appropriate referral service. This situation has implications for ombudsman training resources.

The Olmstead Decision. In 1995 two young developmentally disabled women sued the state of Georgia for violating the Americans with Disabilities Act (ADA) by keeping them in a state psychiatric hospital after their attending physician determined that living in the community would be better for them. By June 1999, the United States Supreme Court made a momentous decision that the ADA grants consumers new rights to live in a place other than an institution when health or supportive services are needed. As a result of *Olmstead vs. L.C. and E.W.*, ombudsman programs now have new tools to respond to frequent pleas from residents who want to leave a facility and live in the community.³³

By 2000, the U.S. Department of Health and Human Services (DHHS) had turned the *Olmstead* decision into a major policy initiative. Every Governor and Medicaid Director were notified that a state could meet its obligation under ADA by having a comprehensive, effectively working plan to ensure that individuals with disabilities receive services in the most integrated setting appropriate to their needs. Several state ombudsmen have become actively involved in their state's planning process. Now, numerous ombudsman and advocacy groups report that people are being taken out of nursing homes and placed in the community with needed services. No doubt, this new opportunity to provide assistance requires substantial advocacy time; however, ombudsmen are beginning to work with other agencies, such as Protection and Advocacy Systems and mental health programs to advocate for individual consumers. Additionally, most ombudsman programs are now incorporating issue and skills training on *Olmstead* in their regular training programs (Turnham, ORC, 2001).

The Centers for Medicare & Medicaid Services (CMS) has announced that it will award \$464 million in new grants to 37 states and one U.S. territory to develop programs for people with disabilities. The grants include \$40.8 million to help states improve community-based long-term care programs; \$7.6 million to boost state personal assistance services; \$11.1 million to help states shift individuals from nursing facilities to the community; and \$4.9 million to provide technical assistance, training and information to states, residents and organizations (DHHS-CMS press release, September 28, 2001.)

Of significance to older persons and their advocates, the Senate Special Committee on Aging held a hearing in September 2001 examining the need for reform of our country's long-term care system in light of the *Olmstead* decision. According to Chairman John Breau, "Older Americans in every part of our country want to prolong their independence and freedom...And, we need to remember that the functional limitations associated with aging are a form of disability and that we can draw upon the independent living skills learned by individuals who have developmental disabilities or disabilities caused by chronic or catastrophic illness or mental illness."³⁴

According to a 2001 General Accounting Office (GAO) study, it is uncertain what the *Olmstead* decision will dictate in major shifts in long-term care services from institutional to home and community-based settings. “What is more certain, however, is that responses to the decision will take place in the larger context of preparing for the tidal wave of aging Baby Boomers who will increasingly tax the current capacity of public and private resources. This aging generation, with the associated expected increase in the numbers of people with disabilities, could increase the number of disabled elderly people who will need care to between 2 and 4 times the current number.”³⁵

Although most states are still in the planning stages, a profusion of individual and class action lawsuits (some representing residents living in nursing facilities) are already utilizing the *Olmstead* decision to benefit people with disabilities. The decision and subsequent state plans and activities offer sound reasons to project an increasing interest in the expansion of ombudsman/advocacy services to people who desire to live in the community.

Persons Living in Home and Community Based Care: Older, vulnerable people in the community are regularly brought to the attention of the ombudsman program. As people in their homes grow older and frailer, they often need assistance with problems and complaints about their care and services.

For the most part, older persons living in the community enjoy a higher level of functioning than those in institutional settings, however, many have equivalent limitations in their ability to perform basic ADLs. Over 4.5 million (14.2 percent) had difficulty in carrying out ADLs. They are often in need of assistance from family and friends because of their vulnerability. Disability takes a heavy toll on the very old. Almost three fourths (73.6 percent) of those aged 80+ report at least one disability. Over half (57.6 percent) of those aged 80+ had one or more severe disabilities and 34.9 percent of the 80+ population reported needing assistance as a result of disability.³⁶ What's more, according to the U.S. Senate Special Committee on Aging, more than 820,000 older and developmentally disabled individuals cared for by family members or other community-based caregivers are subject to abuse, neglect and exploitation. The adult abuse protection program is designed to assist older persons who are victims of abuse and neglect; however, given long-term care needs are often involved, ombudsmen programs are periodically involved in assisting with these special cases.³⁷

By 1999 ten states were mandated by state law to extend their services to persons who receive home and community based care. (Alaska, Idaho, Maine, Minnesota, Ohio, Pennsylvania, Rhode Island, Virginia, Wisconsin, and Wyoming). Two state programs (Oklahoma and Nevada) may investigate concerns about home care services that are provided to residents of assisted living facilities; and, two other states (Nevada and Vermont) have created independent ombudsman programs with responsibilities that include home care advocacy. Several of the states have been mandated to provide home care service since the mid-1980s; however, most of the states report limited activity. Currently, Maine, Minnesota and Ohio exhibit the most extensive programs.

The degree to which the states handle home care related complaints appears to be based upon the funding for that service and/or the public's knowledge about the program. A few of the states that have expanded the state legislative mandate have not provided additional funding for the service and some states do not fully publicize the program. Another problem is that the home care setting does not permit easy access for ombudsmen, especially for volunteers. Only two states (Maine and Minnesota) require home care providers to inform their clients about ombudsman services. Funding for such services are typically drawn from state general revenue funds. Monies also come from long-term care bed fees, and, potentially, Medicaid waiver funds. According to the latest Ombudsman Resource Center survey, most ombudsman programs with home care responsibility have not been able to expand their advocacy activities in this area since they responded to a previous survey in 1994.³⁸

Persons with Mental Health Conditions, Including Dementia and Alzheimer's Disease: Most ombudsmen and their volunteers encounter people with Alzheimer's disease and related dementias on a regular basis in their facility visits. Many of the issues, complaints and problems they handle are associated with people with various levels of dementia who are often victims of poor care, neglect or direct abuse. Just as problematic is that facility workers, often poorly trained and understaffed, reach out for ombudsman assistance when residents become seriously agitated and difficult to handle. The resources needed, especially for continuing state-of-the-art training, are paramount for every ombudsman program.

About 4 million Americans—90 percent of whom are age 65 and older—have Alzheimer's disease. The prevalence of the disease doubles every five years beyond age 65. Unless prevention or a cure is found, the number of Americans with Alzheimer's disease could reach 14.3 million 50 years from now. The majority of the elderly population with Alzheimer's and related dementia are in fair to poor physical health, and experience limitations in their daily activities. The majority receive care at home from family and friends. Although many aspects of care giving can be rewarding, providing such care is particularly demanding. It is common for this population to have coexisting conditions, both acute and chronic. Difficulties in care giving often result in institutional placement.³⁹

Slightly over half—51 percent—of elderly nursing home residents suffer from dementia which is most common among residents age 85 and older. Some 54 percent of residents age 85 and older have dementia, compared to 39 percent of residents age 65 to 74. Up to one-third of nursing home residents may have Alzheimer's disease. As the U.S. population ages, the number of people with the disease is expected to rise substantially (National Academy on an Aging Society, 2000, Number 11).

According to one research team's survey, several recent studies suggest that persons with dementia are at increased risk of elder abuse. Also, studies on self-neglect show its association with dementia.⁴⁰ Family members, so often frustrated and unenlightened about the condition of people with Alzheimer's disease, find it difficult to sort out what is actually happening with the care of their loved ones. They need

knowledgeable advocates to help provide them education and support, especially when they suspect problems in the care received.

People with mental health problems in nursing homes require specialized services that can mostly be found in institutions established specifically for their care – mental health/mental retardation (MH/MR) facilities. The 1987 Nursing Home Reform Act, directed states to set up a screening process, Preadmission Screening and Resident Review (PASRR) is intended to ensure that only individuals with serious mental illness who are in need of nursing facility care be admitted and continue to reside in nursing facilities, and to determine whether persons with serious mental illness need specialized mental health services. Changes in national law in 1990 made it mandatory for nursing facilities to provide all needed mental health and mental retardation services that are not specialized services. (PASRR screens for persons with schizophrenia, mood disorders, paranoia, severe panic or other anxiety, and psychotic disorders – essentially any mental disorders that would lead to chronic disability except Alzheimer’s disease which was excluded from the statute because of strong advocacy from the Alzheimer’s Association.) Government review of this system has found that people with mental disabilities do end up in nursing facilities that are often unable to meet their needs.^{40a 40b} Ombudsmen are often called on for assistance with such cases.

Depression is a common condition experienced by older residents in long-term care. This can result from the serious losses they encounter and, when in institutions, the radical changes in their day-to-day living environment. For an elderly person with a chronic health condition, the depression, coupled with immobility, can lead to a downward spiral in physical and mental health.

Ombudsmen are faced with appreciable challenges in handling complaints related to the care of persons with mental health conditions, Alzheimer’s disease and related dementias. Mental health issues are essential topics in local, state and national training programs, with ombudsmen continually aware of the need for more and more sophisticated training as new and varied approaches to communication and care giving are identified.⁴¹

Patients with Long-Term Care Needs in Managed Care: The managed care system can be very complicated and too difficult for many consumers to navigate. Most consumers do not understand the options they have or know the questions to ask.⁴² The need for ombudsman-type services for people enrolled in managed care is widely recognized. In a 1999 ombudsman survey, three states (ID, PA, and WI) indicated that they are required to handle complaints regarding managed care. The Kaiser study reported that only eight states advocate in the arena of managed care while 14 (28 percent) indicated that reports of complaints regarding managed care are coming to the attention of the state programs. Still, another 31 or approximately 70 percent anticipated that managed care would affect their program in the future (Kaiser, Estes, *et al.*, 2001).

Minimally, an independent advocacy program for managed care needs to a) monitor continuing access to care by enrollees; b) monitor the quality of care; c) assure

that any consumer grievance and fair hearings/appeals system is fair and working on behalf of the consumer; d) hold plans accountable for systemic improvements; e) provide consumer information with which to select a plan, and f) help find resolution for individual consumer complaints.^{43 44} These functions are well known to the ombudsman program network. Many programs take on the important task of representing residents in hearings, often related to transfer and discharge. The Consumer Coalition for Quality Health Care, advocating for consumer interests at the national level, has involved key state ombudsmen in its efforts to bring consumer focus to managed care. Models of monitoring, complaint resolution and other advocacy models have been developed in California by the Center for Health Care Rights.

Additionally, the Local Health Plans of California (LHPC), a statewide association of eight publicly owned not-for-profit health plans, developed “Guidelines for Ombudsperson Programs.” Recognizing in 1998 that “trust in HMOs is at an all time low,” LHPC contended that “providing access to an external and independent ombudsperson is a critical step toward restoring trust with health care consumers and the public in general.”⁴⁵ In 1999, the Wisconsin state legislature authorized expansion of the program, with funding, to provide contract services to the state’s managed long-term care pilot program. With numerous pitfalls and shortcomings, managed care is still on a rocky road in development, though it continues to surface as an issue of concern in the ombudsman world.^{46 47}

Without question, there are complicated issues in managed care that require sophisticated knowledge and advocacy skills. Although some ombudsman programs are now involved in state planning and development activities and planning for consumer protection, only a handful have been major players. Still, the historical experiences of the ombudsman program assisting vulnerable elders, dealing with long-term care providers, and negotiating consumer complaints should be extremely valuable in designing and providing consumer protection in managed care. According to one national expert, “The need for an informed, sophisticated consumer advocacy network has never been greater.” Furthermore, any “promise of a new, more efficient, accountable and valuable healthcare system...may never be realized...without strong and informed consumer advocacy.” Moreover, “Medicaid managed care brings its own separate and urgent consumer protection issues. Separate because enrollment is not usually voluntary, and urgent because of the vulnerable nature of the Medicaid population, who have little financial or political clout to protect themselves.” (Rother, 1996)⁴⁸

Meanwhile, Families USA, a national advocacy organization, has received a substantial, three-year grant from the Robert Wood Johnson foundation to establish a Consumer Health Assistance Partnership (CHAP) program. The center will provide training, technical assistance, and educational guidance to over 2000 “ombudsman” offices around the country that help Medicare, Medicaid, and private-sector health care consumers understand and secure their health care rights. The Ombudsman Resource Center has initiated a dialogue with CHAP to help assure cooperative, non-duplicative efforts.

Proposed federal legislation—the *Patients Bill of Rights (S. 1052)*—would establish grant programs to provide funds for states to establish consumer assistance offices. The latest proposed language changed an earlier version specifying that the new offices were to be distinguished from other programs, such as the State Long Term Care Ombudsman Program.⁴⁹ If legislation is enacted, it is conceivable that, in some states, the ombudsman program will be considered the place to establish the service.

One of the Kaiser study recommendations is that research should be conducted on the implications of managed care. This should include monitoring the effects of managed care on long term care services and increasing advocacy with a focus initially on concerns identified by ombudsmen, such as denial or reduction of services, premature discharges, and claim and payment denials. Clearly, many ombudsmen across the country will be called upon increasingly to share their expertise in complaint processing and systemic advocacy.

Patients with Long-Term Care Needs in State or Federal Facilities, such as Veterans Administration Facilities and Private Pay Only Facilities: Although the Department of Veterans Affairs (VA) directs that the services and quality of care of all veterans living in its own long-term care facilities, state-owned veterans' facilities, and community nursing homes are to be monitored by agency personnel, there are lapses in this surveillance. Nationally, the VA contracts with approximately 3,400 community nursing homes to care for veterans. Although most of these facilities are monitored by an ombudsman program, the ombudsman role is often uncertain. Periodically, veterans or their families seek ombudsman assistance. Minimally, ombudsmen provide referral services.

In 2001, a GAO report found that fewer than half of the ten VA medical centers visited by investigators followed VA's community nursing homes oversight policies (monthly visits) and annual inspections of VA facilities were off schedule. The report concluded, "This lack of oversight may have serious implications because, according to our analysis of HCFA [Health Care Financing Administration, now CMS] data from calendar years 1999 and 2000, about 30 percent of homes in the VA community nursing home initiative were cited in their most recent state inspections for deficiencies serious enough to cause harm to residents." The GAO also recommended that the VA drop its plans to switch to CMS-sponsored surveys because of the inconsistency in quality of the national survey and enforcement system. Subsequently, a U.S. Senate Resolution was introduced which calls upon VA and HHS Centers of Medicare and Medicaid Services to improve nursing home care for veterans.⁵⁰

Fifteen of the states responding to one ombudsman program survey noted that they are required to handle complaints in VA facilities. In one 2001 example of ombudsman advocacy for the rights of veterans, the New York State Ombudsman Association publicly called upon state officials to take action to assure that eligible veterans receive the \$90 a month Federal VA pension to which they are entitled.

Private-Pay Residents. AoA has interpreted the OAA to mean that the ombudsman program is to cover facilities where all residents pay privately. The OAA is for all older people in the U.S. age 60 and above, and the definition of “resident” is “an older individual who resides in a long-term care facility.”⁵¹

Citizen Organizations, Resident and Family Councils: Nationally, there are about sixty active citizen organizations that focus on providing institutional reforms. Like ombudsman programs, they vary in strength and resources; however, there is no question that they can provide valuable advocacy for elders. Citizen advocacy can supplement or bolster the work of ombudsman programs, especially when understandings and partnerships are developed. Other types of community and state groups, such as AARP, can also be of valuable assistance in calling for quality care and reforms in the regulatory systems when needed.

In addition to the individuals residing in specific facilities covered by the program, the OAA stipulates that ombudsmen will promote the development of citizen organizations - to participate in the program; and will provide technical support for the development of resident and family councils - to protect the well-being and rights of residents. Given the problems faced by so many people in long-term care, this mandated activity makes good sense. In one training session conducted by the National Citizens' Coalition for Nursing Home Reform (NCCNHR), a workshop was devoted to enhancing relationships between citizen organizations and ombudsman programs. Several common themes emerged: the groups are successful a) when a focus on benefiting residents is maintained, b) respect for each other's role is practiced, c) the strengths of each group/program are maximized, d) the view is sustained that more than one consumer voice is essential, and d) direct communication with each other is maintained. Still, achieving this goal is far from simple and also requires sufficient funding for support and training staff in a program already stretched to its limits.⁵²

Although the majority of long-term care facilities usually claim that they have functional resident and family councils, a closer look reveals that they are facility-controlled and often ineffective at resolving individual and systemic problems in the facility. Providing even limited assistance to the leaders of voluntary groups requires more than time. It requires ombudsmen with the right disposition, patience and determination, plus training in organizing skills. Most all ombudsman programs understand the value of training and empowering other advocates. However, most programs that engage regularly in nourishing the advocacy of others expend already strained resources and do so at the peril of limiting other mandated services, unless they are fortunate to obtain special funds for that purpose.

Still, well-motivated, organized, judicious family and resident councils, when given needed back-up support, can be valuable resources in helping to resolve routine facility problems. A growing number of local ombudsman programs are gaining expertise in working with facility councils. In the state of Maryland, NCCNHR has been granted state civil monetary penalty funds to work with ombudsman programs, facilities and private citizens to build and strengthen family councils.

Patients with Long-Term Care Needs in Acute Care Hospitals: Patients in hospitals need information about long-term care services and facilities and often need skilled help related to admission and discharges. Although discharge planners are often social workers who strive to help secure appropriate placements, they are frequently pressured to get a person out of the hospital as quickly as possible. The result is that people often have no choice but must take whatever bed is available, even if it is in a substandard facility. Problems also occur when patients are transferred from a mental hospital to a hospital psychiatric ward and refused readmittance to the hospital or transferred from the nursing facility to a hospital and then refused readmittance to the facility. It is frequently necessary for ombudsmen to carefully monitor what happens to the resident and to intervene as needed. The ombudsman must work closely with hospital discharge planners, requiring extra time and resources.

Other Groups Identified with Special Needs

People approaching the end of life need specialized care and attention. In recent years, researchers and medical specialists have begun to look carefully at the care of the dying in medical care and long-term care institutions.^{53 54}

The literature is reporting serious flaws in the care system and more attention and oversight is in demand. “Indeed,” contends one expert, “no one can *count* on good care” (Lynne, 2001). One study found that fully 26% of patients in nursing homes with daily pain received no pain medication at all and nearly half had orders for medications that could not be expected to keep them comfortable (Bernbai et al. 1998).⁵⁵ “Advocacy groups that represent the issues most important to individuals at the end of life must take the lead in educating policymakers about the needs of patients and the type of care to which they are entitled, the need for a better understanding of the epidemiology of dying, and urging funding of studies that will further illuminate the experiences of patients near the end of life. The poor and disenfranchised are not politically powerful, and this is the situation in which many of the chronically ill find themselves. Advocacy groups will need to fill this vacuum, while ensuring that they solicit the input of those whose interests they represent. Several different types of advocacy organizations have a role to play, as each has a unique focus and unique perspective to bring to bear.” There is a new growth of research articles calling attention to the needs of people who are approaching death.^{56 57}

Hospice contracts with long term care facilities have recently come under scrutiny. The OIG has issued two reports on abuses associated with providing hospice care to long-term care residents.⁵⁸ Persons receiving hospice can clearly benefit from the increased services of ombudsmen, especially when hospice care is provided in the nursing home. Hospice services, increasingly run by large corporations, vary in quality and quantity. Additionally, it is not uncommon for nursing homes to pull back on their routine services for a resident when the person is receiving hospice care, no matter how minimal.

Older Americans Act Priorities: Beyond all the people covered by Title III to be served, the reauthorization of the OAA in 2000 specifies that the State agency plan must give preference to certain populations. These include people in rural areas, those in greatest economic need, with particular emphasis on low-income minority individuals, older persons with limited English-speaking ability, and those with Alzheimer’s disease and related disorders, as well as Native Americans. These priorities may require additional consideration for ombudsmen in some state agencies. (See Appendix 2.)

Statutory Changes Required for Program Expansion

Because the OAA limits the ombudsman to providing services to “older individuals who are residents of long-term care facilities,” any nationwide expansion of services to select populations (i.e. older persons enrolled in managed care programs), will require statutory amendments if OAA funds are to be utilized. Exceptions are where state legislative language has expanded the program by statute. Because public officials often look favorably on the ombudsman program and expect it to provide more services, expansion of the program is increasingly built into proposed legislation.

Funding Needed Services and Expansion

This paper documents that the need for ombudsman monitoring and advocacy services is increasing in every segment of long-term care. More ombudsmen are required but, realistically, they cannot be recruited, trained, and sustained without adequate funding. Insufficient funding and inadequate levels of staff and volunteers are the greatest barriers to the overall effectiveness of the program.

A pivotal evaluation of the program by an IoM Committee in 1995 concluded that, “the present level of support for the ombudsman program is completely insufficient to enable it to expand to satisfy *unmet needs* in all of long-term care.” Furthermore, the Committee asserted unequivocally that the first priority is that the program be provided with resources commensurate with meeting all current mandates, “including those that have existed, but have been neglected, since 1981.” The Committee adopted a specific recommendation that, *if Congress mandates additional responsibilities for the ombudsman programs, then Congress should also provide adequate additional appropriations to it.*⁵⁹

The bulk of money to support ombudsman services still flows from federal OAA funds, with some states supported by Medicaid dollars. Other sources of funds come from state general revenues and local governments with minor, occasional contributions from foundations, and at the local level, United Way. Although there have been periodic increases in the national program funding over the years, and some states have succeeded in achieving increases in state-level funding, the increases have not been sufficient to assure that the program meets its current obligations or expands its services. The exception is that on occasion, a program - usually local – will receive a grant or one-time source of funding that allows expansion during a specified, limited time period. Another boost in funding for several state and local ombudsman programs has come from federal funds from Operation Restore Trust. However, this funding is almost exclusively

used for *extra* advocacy training and services to detect and report fraud in the provision of Medicare services in nursing facilities, hospice and home health settings.⁶⁰

In 1999, long-term care ombudsman programs nationally received \$51.3 million in funding, an increase of almost \$4 million from the previous year. Paid program staff consisted of 974 full-time equivalents (FTEs) in 587 local programs. In addition, the programs used 8,451 certified volunteers. (Kaiser, Estes *et al*, 2001)

OIG reported that staffing levels among the ten states studied varied—ranging from a ratio of 5,003 beds per paid staff person in Florida, to 1,115 beds per paid staff in California. Also, most of the state and local ombudsmen identified insufficient staffing as an obstacle affecting their effectiveness. Ombudsmen reported that most nursing homes did not have regular volunteers assigned to them, with many homes visited just once or twice a year for no longer than one to three hours. In four states there were nursing homes that never have regular visits by volunteers or by paid staff (OIG, 1999; OEI-02-98-00351, Executive Summary).

Among the programs surveyed by Families USA in 2001, state budgets in 2000 ranged from \$99,400 to \$3.95 million, with an average staffing of 5.1 FTEs. Two-fifths of the programs had at least one attorney on staff, and one-seventh had at least one registered nurse on staff. At the local level, program budgets ranged from \$4,000 to \$425,000, with a median budget of \$57,000 (which funded services to more than 100 consumers.) In comparison, budgets of state-level Protection and Advocacy programs (P&A) responding to the Families USA survey, ranged from \$275,000 to \$3.9 million. The median budget of \$1,083,000 enabled programs to serve 581 consumers. On average, P&A respondents in 2000 had 18 FTEs, and virtually all programs had at least one attorney on staff.

Not surprisingly, 66.7 percent of state ombudsmen responding to the Kaiser survey noted that their budget in the last three years was inadequate to meet federal requirements, and 73.5 percent reported that their budget was inadequate to meet their state requirements. According to the study, because of inadequate funding, ombudsman programs are forced to neglect routine visits to facilities; community outreach and education; complaint investigation and resolution; timely response to complaints; development of resident and family councils; systemic advocacy; volunteer recruitment and supervision; and expansion (even into board and care and assisted living). (Kaiser, Estes, *et al*, 2001)

Respondents to a Families USA survey related that inadequate funding and a shortage of volunteers are obstacles to the program's success. Funding is a particular problem for rural programs, where staff (and volunteers) have to travel long distances to visit facilities.⁶¹

In the 1995 IoM study, the Committee recommended that there be at least one ombudsman per 2000 nursing facility beds. In the 2001 Kaiser study, only 21 states (40.4 percent) stated that their programs met the 1995 recommendation.

The Kaiser study explored the ombudsmen's opinion about the amount of additional funding needed to carry out the mandate of the program. 61.3 percent indicated that they would need an increased funding of over \$200,000; 38.7 percent indicated they would need less than \$200,000. 32.3 percent projected that they would need an increase anywhere from \$200,001 to \$700,000; with 29 percent projecting a need for \$700,001 to over \$1,000,000. These projections do not account for the current volume of services handled by any given program or the desires of plans for expansion into new service areas; however, they do give good indications of the shortages of funds available for meeting the current program mandate.

To place ombudsman program funding levels into some understandable context, in 1998 total nursing facility expenditures were \$87.8 billion dollars, with nearly half of that amount - \$40.6 billion – attributable to Medicaid spending, 11.9 percent Medicare; and, 32.5 percent out-of-pocket expenses. The remaining 9.3 percent came from private health insurance, veterans administration, general assistance, or private philanthropy.⁶² In 1997, Medicaid spent \$13.6 billion on home and community-based care.⁶³ In 1995, approximately \$106.5 billion was spent on long-term care. Public resources accounted for 57.4 percent of it (Stone, Milbank, 2000).

Ombudsmen have reported several realistic obstacles to obtaining needed funding: lack of program visibility; level of priority within a state agency; nursing home industry lobby opposition; the legislative process; the state fiscal situation; the federal budget process; and, the political climate - with competition for funding of any program (Kaiser, Estes, *et al.*, 2001). The 1995 IOM study, as well as Kaiser, recommend enhanced funding to allow LTCOPs to meet federal and state requirements, and to support the standard of 1 full time equivalent (FTE) staff ombudsman for 2000 LTC beds. In 2001 Kaiser recommends that this ratio should be reevaluated, "given the extent of policy change, the increase of ombudsman responsibilities, the growth of alternative LTC settings, and the increasing elderly population."

In fiscal year 1999 there were only 974 FTE and 8,451 certified volunteer ombudsmen in the program. Only 22 percent of state ombudsmen reported that they believe they have a sufficient number of volunteers in their program. The Kaiser study questions the use of FTE staff in any proposed ratio, given that one full-time equivalent staff may be composed of multiple part-time staff, each of whom require training, supervision, resources, and program coordination (and therefore result in increased time and cost).

Persistent advocacy from ombudsmen and their constituents in 2001 led to increases in the ombudsman program budget over the \$1 million in increase in funding for year 2000. The final appropriations bill brought the total 2002 OAA funding for ombudsman-elder abuse programs to \$17,681,000. This was a \$3.5 million increase for both programs, with \$3 million of the increase going to the ombudsman program. The Senate called for "continued and increased" funding of the federal support center for ombudsmen, the Ombudsman Resource Center housed at NCCNHR. In 2001 the level of

funding for the ORC was \$550,000, 2002 is projected to be the same. In advocating for the increases in the program budget, the Senate Special Committee on Aging stated its awareness of the IoM recommendation for increasing the ratio of ombudsmen to nursing home beds, claiming that its projected increase “will allow the program to hire additional ombudsman staff, expand public information and education campaigns, and upgrade technology.” Regardless of congressional support for the program, these financial gains pale in the face of the tremendous needs of service and advocacy needed by older persons receiving institutional long-term care.⁶⁴

Selected Potential Approaches to Funding: In 2001, researchers at the University of California undertook a study of the performance of state survey agencies in relation to their funding resources. Upon finding that agencies with sufficient resources are better able to identify quality problems and are more willing to take actions against such facilities, the researchers suggested that one of the future approaches for funding would be for Congress to establish the amount of funds for regulation of nursing facilities as a fixed percentage of the estimated federal trust funds spent on nursing facilities each year. Their report indicated, “This would remove the political considerations around federal funding and build in greater stability in regulatory funding.”⁶⁵ A similar approach would be relevant for funding of ombudsman programs.

Several local ombudsman programs, especially those established through an independent community organization, have been successful over the years in building their budgets through a variety of sources such as private foundations, private donations, and United Way. One outstanding example is the Nursing Home Ombudsman Agency of the Bluegrass – a local Kentucky program largely successful because of its volunteer board of directors made up of a host of committed and influential community leaders.⁶⁶ Of course, it is common knowledge that fundraising activities are extremely time consuming, requiring special skills and fortitude, and that the competition for funds is becoming increasingly fierce. It should be seriously questioned whether ombudsmen, designated to provide critically mandated services for vulnerable elderly, should be heavily involved in time-consuming fundraising tasks. Even so, the National Association of State Long-Term Care Ombudsman Programs and its allies need to continue to join forces to identify potential supplemental funding support from the private sector. Some large foundations, such as the Robert Wood Johnson Foundation (RWJ), have a history of providing lengthy, generous support for important programs. Through the years RWJ has shown an interest in the program by funding research about its work (Feder, *et al.*).

One recent ORC report explored the availability of Medicaid support for state ombudsman programs. A handful of states (DE, ME, NJ, OR, WA, SC, NH and WI and formerly GA) have been successful. According to the report, in 2001 the Oklahoma Ombudsman Program was to receive funds under a newly enacted “Quality Assurance Fee” to be collected from nursing homes based on 4% of their gross receipts. The funds collected by the state are used as match for drawing down additional Medicaid funds. In Oklahoma this special funding enabled the program to hire ten additional ombudsmen. It is important to note that this boom in funding stemmed from the revelation of serious nationally publicized problems in the state’s nursing home system. It is not uncommon for

state legislators to become more supportive of the ombudsman program when publicity exposes neglect and abuse of the elderly and/or serious flaws in the state's enforcement program. Another significant fact is that overall budgetary constraints are forcing the Oklahoma state legislature to consider a proposal to cut back on its special Medicaid funded initiatives.

In Minnesota a \$5.00 per bed surcharge is dedicated to resident and family education. The funds have been declining in recent years as the number of nursing home beds goes down. Reportedly, there is no legislative interest in increasing the surcharge or adding it to newly developed services like assisted living (Zoesch, 2002).

Without doubt, achieving support from Medicaid dollars is a great challenge, although it is a legitimate exploration for support, given the billions of Medicaid dollars spent on long-term care services. State ombudsmen and other advocates must continually lobby for retention of any expanded resources, especially from Medicaid dollars.

Considerations for Decisions about Program Expansion: There can be no question that well-trained, qualified ombudsmen can provide valuable advocacy services to people and population groups reviewed in this paper - all who face obstacles to receiving consistent high quality long-term care. The ombudsman's ability to do so depends greatly on how well their state and local programs are funded and numbers of staff. Yet, it also depends on personal commitments, high-quality issue and skills training, and quality administration. Personal guidance, emotional and support for staff and volunteers are also necessary because although this important work is rewarding, it has proven to be complex, difficult and emotionally draining. The history of the program, as reviewed by many experts, provides evidence that the ombudsman program requires and merits greater financial support in order to meet its responsibilities and obligations to people needing long-term care and services.

Decisions about future expansion of services are challenging and require serious consideration. Some of the factors to be considered follow. Realistically, all of them require decisions relating to staff time and budget.

- Program budgets will, no doubt, always be under funded to meet the needs of all long-term care residents. High value can be placed on a priority to provide the highest quality performance for those who *can* be served, rather than stretching the program's services so thin that they fail to achieve the goals of the program.
- Residents in all the long-term care facilities historically mandated to be served, are not now being fully assisted and protected by the program.
- Ongoing training is always needed because of staff and volunteer turnover, changing needs of people served by the program, new research and information about physical and mental health care needs and services. When expansion into new services occurs, the costs of high-quality training must be considered.

- There is great value in ombudsman advocacy work to motivate and help assure that other programs in the aging, healthcare, and regulatory network are fulfilling their responsibilities to people receiving long-term care.

- The ombudsman program has grown immensely. Though it is still under development and underdeveloped in some areas, many of its participants can be essential teachers for new staff in other advocacy programs that may desire, or be enlisted to provide ombudsman/advocacy services to new or expanded population groups.

- Ombudsmen can provide effective advocacy by participating in the plans for any new consumer assistance programs to help assure that fundamental principles like confidentiality and independence are followed and to assure that the work of the ombudsman program will not be jeopardized by any new programs.

- Research is needed to determine the realistic cost of providing regular, timely, high-quality ombudsman services to individuals in need.

- In each program, local and state, there is merit in on-going self-evaluation to methodically review and accurately report the coverage that is actually provided to residents in existing mandated facilities. With this information, the public, elected and government officials can understand why the gaps in advocacy services must be closed and what it will cost to assure that long-term care residents receive assistance when needed.

Recommendations

1. Any expansion of the program into new arenas will not be undertaken unless the program is adequately funded to meet its current obligations and to fulfill new responsibilities.
2. The National Association of State Ombudsman Programs will join with National Association of Local Ombudsman Programs and other allies to produce timely, accurate information about what the actual costs of the program would be if all nursing homes and related facilities were adequately served.
3. Ombudsmen and NASOP will join other organizations in continuing to advocate for well-funded ombudsman-type services for various populations groups, such as people with Alzheimer's disease, people enrolled in managed care, veterans, differing ethnic and cultural groups, young people with disabilities, and others.
4. State ombudsman programs will provide leadership and work in close coordination with other ombudsman-type programs developing in their state to assure that all people needing advocacy assistance are served and to prevent duplication of services.
5. Where programs do expand, with needed financial support and independence, training programs will focus on developing specialized ombudsmen to make sure that differing population groups are well-served.

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APPENDIX I

ASSISTED LIVING: CHARACTERISTICS OF RESIDENTS

From: "High Service or High Privacy Assisted Living Facilities, Their Residents and Staff: Results from a National Survey," conducted by Catherine Hawes, Ph.D. and Charles Phillips, Ph.D., Texas A&M University System Health Science Center, and Miriam Rose, Ph.D., Myers Research Institute, under contract with the U.S. Department of Health and Human Services. November 2000.

Individuals residing in ALFs were overwhelmingly white, widowed females, also quite elderly. The average resident was 84.5 years old. More than 96 percent were over 65 years of age, and 54 percent were aged 85 or older. By comparison, 49 percent of U.S. nursing home residents, in 1998, were 85 and over." One notable difference was that about three-quarters (76 percent) of ALF residents had one or more living children, and most (86 percent) had a relative within a one-hour drive of the facility. Also, the vast majority (91 percent) reported being visited by friends or relatives within the last month, and more than one-third (36 percent) reported receiving visitors either daily or more than once a week. They were, on the whole, a relatively well-educated and affluent group. Almost three-quarters (73 percent) of the residents were cognitively intact or had only mild symptoms of cognitive impairment, while 14 percent had severe cognitive impairment. Thus, more than one-quarter of assisted living residents (27 percent) exhibited symptoms of moderate to severe cognitive impairment. While residents in assisted living make relatively light use of staff assistance, they made considerable use of assistive devices to compensate for functional limitations: In the week prior to the interview, at least one-fifth of the residents used a cane or wheelchair to assist them with locomotion, while slightly more than two-fifths (44 percent) used a walker. One-third (32 percent) had some urinary incontinence during that same seven-day period. About three-quarters (77 percent) of residents received assistance in managing medications.

These levels of impairment in physical functioning are much lower than those found among nursing home residents, where nearly three-quarters of the residents received help with three or more ADLs (Krauss and Altman, 1998). They were roughly similar to the levels observed in board and care homes, where about 12 percent of the residents received "hands-on" assistance with three or more ADLs (Hawes et al., 1995b and 1995c). Most residents (60 percent) reported having good to excellent health; however slightly less than two-fifths of residents reported their health as only fair (29 percent) or poor (10 percent). These self-reported health rates were relatively similar to those of residents in board and care homes (Hawes et al., 1995c). Residents also reported health conditions with the potential to limit physical functioning. For example, more than one-third of the residents (37 percent) also reported a fall in the last year, and one quarter (25 percent) reported that pain interfered with their normal activities some or all of the time during the preceding month.

Hospitalization was also relatively common. Residents reported a relatively high rate of use of hospital care. One-quarter (24 percent) indicated that they had visited an emergency room in the 12 months prior to the interview, and almost one-third (32 percent) had an overnight stay in a hospital distinct from any emergency room visit. Again, these results are similar to the utilization rates observed among board and care home residents (Hawes et al., 1995b and 1995c).

APPENDIX II

OLDER AMERICANS' ACT PRIORITY SERVICE AREAS

According to Year 2000 reauthorization of the Older Americans Act, (P.L. 89-73 through 106-501) Title III - Section 307, (a) (16) the State Agency on Aging is to develop a plan that will require outreach efforts that will (A) identify individuals eligible for assistance under this Act, with special emphasis on (i) older individuals residing in rural areas; (ii) older individuals with greatest economic need (with particular attention to low-income minority individuals and older individuals residing in rural areas); (iv) older individuals with severe disabilities; (v) older individuals with limited English-speaking ability; and (vi) older individuals with Alzheimer's disease or related disorders with neurological and organic brain dysfunction (and the caretakers of such individuals). (21) the plan shall— (also) (B) provide an assurance that the State agency will pursue activities to increase access by older individuals who are Native Americans to all aging programs and benefits provided by the agency.

ENDNOTES

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⁵ "Long Term Care: Who Will Care for the Aging Boomer?" U.S. Senate Special Committee on Aging, June 28, 2001.

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¹⁹ National Center for Health Statistics. National Nursing Home Survey. 1995 data. Reported 1999.

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- ⁶³ "New Directions for State Long-Term Care Systems: Second Edition, by Barbara Coleman, AARP Public Policy Institute, # 9809, October, 1998, pg. iii.
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APPENDIX X

List of Resources Provided to Participants

- Older Americans Act – Public Law 106-510
- *Reauthorization of the Older Americans Act and Older Americans Act Amendments of 2000 - A Discussion of Major Provisions Pertinent to the Long-Term Care Ombudsman Program.* Turnham, Hollis. NASOP, 2000.
- *Proposed Regulations for the Long-Term Care Ombudsman Program.* NASOP, 2002.
- *The Long-Term Care Ombudsman Program Unique Characteristics.* Hunt, Sara S. NASOP, 2000.
- State Annual Ombudsman Report to the Administration on Aging, OMB # 0985-0005.
- Older Americans Act Fiscal Year 2002 Appropriations. *AoA News*, U. S. Administration on Aging, Washington, DC. January 11, 2002.

Additional Resources of Interest

- *Real People, Real Problems: An Evaluation of the Long-Term Care Ombudsman Programs of the Older Americans Act.* Edited by: Harris-Wehling, J., Feasley, J., & Estes, C. Institute of Medicine. Washington, DC. 1995.
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- Office of Inspector General. *Ombudsman Output Measures: Management Advisory Report*. Washington, DC.: Department of Health and Human Services, 1991. OEI-02-90-02121.
- U. S. General Accounting Office. *The Older Americans Act: Access to and Utilization of the Ombudsman Program*. Report to the Chairman, Subcommittee on Aging, Committee on Labor and Human Resources, U.S Senate. Washington, D.C. May 1992. GAO/PEMD-92-21.



Appendix XI

RETREAT EVALUATION RESULTS

To help us ensure that our retreat met your needs, please take a few minutes to answer the following questions. (Key for question 1.-2...: 1 = poor; 2 = fair; 3 = good; 4 = excellent)

1. Please rate this retreat as to:	Poor	Fair	Good	Excellent	NA
Overall Quality.....	1	2	3 (2)	4 (31)	(1)
Useful/Relevant.....	1	2	3 (3)	4 (30)	(1)
Interesting.....	1	2	3 (3)	4 (30)	(1)
Quantity of Information.....	1	2	3 (2)	4 (31)	(1)
Quality of Information.....	1	2 (1)	3 (1)	4 (30)	(2)
Retreat Format.....	1	2 (1)	3 (5)	4 (28)	
Conference Facilities.....	1	2	3 (3)	4 (31)	
NASOP Staff Response.....	1	2	3 (2)	4 (30)	(2)
Quality of the Papers:					
<i>Independence: The LTC Ombudsman Program's Ability to Fully Represent Residents</i>	1	2 (2)	3 (5)	4 (21)	(6)
<i>Systems Advocacy in the Long-Term Care Ombudsman Program</i>	1	2 (1)	3 (7)	4 (17)	(9)
<i>Training and Qualifications for the Long-Term Care Ombudsman Program</i>	1	2	3 (11)	4 (14)	(8)
<i>Long-Term Care Ombudsman Program Data and Information</i>	1	2	3 (10)	4 (14)	(10)

Retreat Evaluation

<i>LTC Ombudsman Program Effectiveness</i>	1	2 (3)	3 (9)	4 (14) (8)
<i>The Changing Long-Term Care Resident Population and Its Needs</i>	1	2 (2)	3 (5)	4 (21) (6)

2. **Did this retreat meet your expectations?** 1 2 (1) 3 (4) 4 (28)(1)

3. **Are there any issues relative to this retreat topic that you would have added to the agenda?**

- Yes, the role of meaningful legal services as part of systems advocacy and how to promote culture change in LTC facilities.
- Culture change/pioneer movement.
- There will always be more issues than can be addressed in the time allotted, but these issues certainly are very relevant at this time.
- A paper on the “Culture Change” paradigm and more discussion on workforce issues.
- No.
- No. Issues that were imbedded in the chosen topics emerged in the discussions and debates. The fact that various task groups, etc. will be formed will address those that weren’t worked to death.
- Discussion of the federal mandated role of ombudsman—new revision and changes and their impact.
- The subjects were very comprehensive.
- Goals and objectives of the LTCOP.
- No, the topics were excellent!
- No, you all did a fabulous job. Excellent retreat. Excellent papers – full incorporation of papers was very helpful.
- Whether OAA should be amended upon re-authorization to expand ombudsman services to long-term care beneficiaries being served in the community (and their homes). I have grave concerns that as these seniors receiving long-term care services will have adequate safeguards and advocacy for quality care.
- The papers, discussion and process were well thought out and useful.
- The passing of the Older Americans Act, which will lead to be understood. Implementation of the LTCOP Program.
- More detailed discussions of how adequate resources affects implementation of all recommendations, to include discussion of funding formula and minimum allotment states. Formula and funding don’t take into account such things as geography or the fact that state ombudsman and their programs are still mandated to complete and comply with all the same requirements, regardless of what their federal allocation of resources is. Also, program effectiveness needs to include budget management and access to independent legal counsel.
- No.
- No time.
- No.

Retreat Evaluation

4. If you had planned this retreat, what would you have changed?

- This was a good process, no change.
- More time.
- Nothing.
- Orientation and more direction for facilitators – the work of the committees was very difficult to do in a short time and guidance on process would have resulted in better use of committee time.
- Not a thing! Very well planned. Process for consensus worked well. Authors developed very thorough quality papers. Group was a good representation. Work accomplished. Facility very nice. Food – WOW!!
- Combine papers/topics to consider four or expand time to a full day on Saturday followed by a Sunday morning NASOP breakout.
- Add state to name tags for easy identification. Add a little more structure to issue groups, as a way to get discussion moving and sway from recommendations in paper, i.e., 15 minutes brain storming, then move forward. Conference committee sessions were an interesting approach.
- Nothing.
- One more day.
- Wonderful organization.
- Make it just a little longer- until Sunday a.m.
- Nothing.
- Nothing. This has been the most productive, constructive, amicable working meeting/retreat I have ever attended. I wish we could duplicate this process more often on the hill!!
- I would have included an additional half day for more discussions in groups.
- Throughout the retreat, I was struck by the number of individual participants who approached and reacted to the recommendation process from a very personal “what is best for me/my program” viewpoint instead of from a “how can we improve the LTCOP for the future” more global perspective. My understanding, coming into the retreat, was that we were supposed to be thinking in a larger frame of mind. Perhaps that instruction should have been emphasized at the beginning of the retreat. I am very comfortable with the work we did here and believe that we developed solid recommendations, but I think the process would have been smoother had the expectation instruction been emphasized from the beginning.
- Nothing. The best facility I’ve attended.
- Process of reaching consensus. This process promoted “speeches” by the most verbal participants, left many comments unstated. Also, it brought out equally minor issues along with major ones. Other techniques are available that promote faster, more accurate prioritizing of issues and decisions on pivotal issues. This is not to say that Bill Benson’s handling of wrap-up was not skillful. Just that it was not the optimal process.
- Longer sessions for the breakout groups and additional attendance of AAA directors.
- More focus and guidance to the group facilitators. They really didn’t seem to have a handle on what was the expected outcome. It would have helped pace the sessions better.
- The conference was excellent!

Retreat Evaluation

- Another half day would be helpful.
- More time for discussions – one more day would have been good for more clarification and then to work on implementation. Design of the conference was great!
- Absolutely nothing. Thank you so much for all the thought and planning that went into it.
- Maybe add another half day to allow for a little more discussion in the full group.
- Better balance between culture change, enforcement paradigms. Better computer/printer access in conference rooms. I would have made Elma Holder's paper on Changing Population "required" as a stand-alone paper to give an overview of the future before launching the separate workshops.

(Meaning: The instructions pre-conference might have been, at a minimum, read Elma Holder's paper and the paper for your given workshop). More time for exercise and clearer information up front about importance of bringing sneakers.

- Nothing, it was very worthwhile with excellent work being accomplished. Thanks for a great retreat!
- Nothing.
- We needed more time to discuss the issues. Also, we needed some "down time" to take advantage of this lovely facility.

5. What was the single most important thing you got out of the retreat?

- I'm not sure. I think some good efforts were made, but I don't think it was as visionary as I hoped. Too many people were thinking inside the box.
- Thoughtful, compassionate dialogue providing insights from different perspectives.
- To bring together such a diverse group to discuss issues of importance to strengthen the ombudsman program.
- Renewed energy for systems advocacy. Thanks for a job well done.
- A renewed commitment to the ideals and values that drive the program on a national advocacy effort.
- Thank you for inviting me. I enjoyed the vigorous debate. I gained insight and was able to re-evaluate my own practices as well as gaze into the future with hope.
- Re-energizing – thank you for including me!
- The consensus format was very useful in encouraging in-depth discussions of difficult issues.
- Ideas to get NALLTCO more involved in issues being heard and decision making on critical national issues.
- Networking. Re-focusing on the core mandate for LTCOP
- The complexity of difficulties associated with LTCOs ability to meet the OAA mandate and go beyond the need for greater communication at the federal, state, local level between S and L LTCOs and the entities to whom they are accountable.
- Understanding of issues. Meeting some great advocates.
- The conference facilities were great!
- The knowledge I gained about the complexity of the LTCOP – very, very helpful and relevant to my work. An excellent learning experience.
- We need more independent study and action to become a stronger nationwide advocacy system.

Retreat Evaluation

- Insight into the future of the long-term care ombudsman, renewed passion and energy for ensuring quality of care for seniors and increased respect for the advocates who serve them.
- A renewed sense of commitment to the ombudsman program and pushing to make it work the way it should.
- A better focus for performing my duties on a local level. Great experience!
- The “give and take” in all sessions.
- Opportunity to have in-depth discussions on a number of extremely relevant issues with representatives from a variety of perspectives.
- Increased knowledge of issues important to ombudsman programs.
- Better understanding of the need for independence of the program at all three levels and its impact on effectiveness. Thanks for a great conference. My conviction and enthusiasm juices are flowing again!
- Reinforcement of efforts undertaking to address issues and LTCOP. Recognition of issues by national entities and possibilities of strategies to address these issues.
- Lots of great ideas.
- Information and a chance to participate in developing the future of the ombudsman program.
- The evaluation building. By having so many other agencies available to hear everything said!
- That we, state ombudsmen and local ombudsmen, can work together to help long-term residents have a better quality of life.