

**TRANSLATING
NURSING HOME OMBUDSMAN SKILLS
TO ASSISTED LIVING:
SOMETHING OLD, SOMETHING NEW**

Robyn Grant, Consultant

March 2003

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**National Long-Term Care Ombudsman Resource Center
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Translating Nursing Home Ombudsman Skills To Assisted Living: Something Old, Something New

I. INTRODUCTION

The Older Americans Act (OAA) has mandated that the Long-Term Care Ombudsman Program advocate for residents in assisted living facilities since it was amended in 1981. Ombudsmen are required to cover residents of long-term care facilities, which the Act defines as:

(A) any skilled nursing facility, as defined in section 1819(a) of the Social Security Act (42 U.S.C. 1395i-3[a]); (B) any nursing facility as defined in section 1919(a) of the Social Security Act (42 U.S.C. 1396r[a]); (C) for purposes of sections 307(a)(9) and 712, a board and care facility; and (D) any other adult care home similar to a facility or institution described in subparagraphs (A) through (C).¹

The Act then defines a “board and care facility” as “an institution regulated by a State pursuant to section 1616(e) of the Social Security Act (42 U.S.C. 1382e[e]).”² The Administration on Aging (AoA) interprets this definition to mean that the Long-Term Care Ombudsman Program is both authorized and required under federal law to respond to complaints made by or on behalf of residents of nursing homes, board and care homes, adult residential care facilities, assisted living facilities and any other type of congregate adult care home, the majority of whose residents are age 60 and above.³

Ombudsman work in assisted living varies greatly by state. In many programs, long-term care ombudsmen are generalists: they assist residents in both nursing homes and assisted living facilities. However, different models exist. Sometimes local programs within a state assign one or more ombudsmen just to cover assisted living. In other instances, such as in Montgomery County, Maryland, the local program is comprised of two separate entities – the nursing home ombudsman program and the assisted living ombudsman program. Massachusetts has taken yet another approach by establishing an assisted living ombudsman program that is outside of and completely unconnected to the long-term care ombudsman program. A further difference

¹ Older Americans Act, Section 102(32).

² Older Americans Act, Section 102(18).

³ Email communication from Sue Wheaton, Ombudsman Program Specialist, Administration on Aging, November 25, 2002.

between states is the number of years the program has spent on assisted living work. While many state ombudsman programs have been actively addressing assisted living issues from the very beginning of their programs, others are just now venturing into this arena.

Regardless of a program's experience with assisted living, ombudsmen will find that the skills and knowledge they have gained in the nursing home arena can be applied to successful individual and systemic advocacy in assisted living. Assisted living advocacy is not a "whole new ball game;" there is much that can be transferred from ombudsman nursing home experience. On the other hand, there are also features of assisted living that pose special challenges for ombudsman advocacy and that call for ombudsmen to approach their work in a different way.

The purpose of this paper is to strengthen ombudsman assisted living advocacy by drawing upon the effective strategies already employed by ombudsmen in the nursing home arena. The paper will look at the commonalities and differences between ombudsman practice in assisted living and nursing homes and will present a range of ombudsman strategies for assisted living work. Seven important issues will be examined: care or service planning, promoting residents' rights, resident autonomy/choice, transfer/discharge, staffing, resident agreements/contracts, and disclosure. The paper will also discuss the type of ethical issues that arise in assisted living and how ombudsman programs can develop internal program guidance for addressing them. Specific examples from various states are used throughout the paper to illustrate the type of ombudsman advocacy that is happening around the country. However, it should be noted that good practice and case work are most definitely not limited to the states referenced in this paper!

II. DEFINITION OF ASSISTED LIVING

When the ombudsman program requirements were expanded to cover adult care homes, the term "assisted living" did not exist. Today, however, it is a broad term that applies to a wide range of housing and care options. In her paper entitled "Consumer Issues in Assisted Living," Stephanie Edelstein of the American Bar Association writes:

Facilities labeled as assisted living may range in size from mom and pop homes for fewer than five residents to apartment-style complexes housing several hundred persons....They may be freestanding, or part of a continuing care retirement community or nursing home.... Providers may be individuals caring for others in their homes, private for-profit or not-for-profit organizations, public entities, or large hotel chains....⁴

⁴ Edelstein, S. *Consumer Issues in Assisted Living*. Unpublished. p. 1.

Definitions of assisted living vary greatly from state to state, and there is no federal definition of this term. Indeed, the current reality of assisted living in the United States is an immense lack of clarity around what we think assisted living is or should be.

In 2001, a national “Assisted Living Workgroup” (ALW) was convened by the U. S. Senate Special Committee on Aging to develop both a definition and recommendations for assisted living. The workgroup, composed of numerous stakeholders, struggled to find a definition that aptly describes this type of care and that could be agreed upon by the many group members. One of the difficulties the group faced was defining the aspirations of assisted living, such as independence, choice and dignity, in a way that would be concrete and measurable from a regulatory perspective. At the time of the writing of this paper (March 15, 2003), the ALW had not been able to reach a consensus definition.

In the meantime, “assisted living” continues to have different meanings across the country. To reflect the diversity that exists nationwide and because a uniform definition of assisted living does not appear imminent, this paper will define assisted living very broadly and simply. The term will refer to long-term care facilities that are not licensed as nursing homes. It will include residential care facilities and “housing with services establishments” that are often larger and sometimes corporately owned, as well as adult foster care, adult foster homes, personal care homes, board and care homes and adult care homes that are frequently quite small and may be owned and run by one caregiver. However, to acknowledge that significant distinctions exist within the broad range of this definition, some sections of the paper will refer to “small” homes or facilities. This expression will denote a setting in which the operator/provider cares for individuals in her⁵ own home and the environment and interaction are more like that of a family (for instance, residents, provider, and staff live on the premises and share meals together). The definition will exclude services such as homeless shelters or shelters for victims of domestic violence.

III. COMMONALTIES BETWEEN OMBUDSMAN WORK IN NURSING HOMES AND IN THE ASSISTED LIVING ARENA

When long-term care ombudsmen advocate in assisted living, they find much that is familiar to them from their nursing home experience. This is primarily because there are many similarities between nursing homes, assisted living facilities and their residents.

To begin with, a number of the same services are provided in both settings. Specifically, nursing homes, as well as a number of assisted living facilities, administer medications and provide assistance with activities of daily living.

⁵ Throughout the paper, the female pronoun will be used when referring in the singular to a resident or a small assisted living facility operator. Not only does this avoid the awkward use of “he or she,” but it also reflects the fact that most residents and small assisted living providers are women.

Even more striking are the ways in which the characteristics of assisted living residents are becoming increasingly similar to those of nursing home residents. Notably:

- The majority of residents in both environments are elderly.
- The acuity level of some assisted living residents is close, if not identical, to that of many nursing home residents. In fact, states with Medicaid Waiver funded assisted living **require** residents to have nursing home level of care in order to qualify for such assistance.
- As in nursing homes, a significant number of residents have dementia. In a statewide probability sample of North Carolina residents in 1995,⁶ 65% were found to have moderate to severe cognitive impairment, while 40% of residents had moderate to severe impairments in a 10-state sample of licensed and unlicensed board and care homes.⁷

Residents in assisted living must also deal with the same sense of loss and grief as nursing home residents. Regardless of the type of facility, the emotions accompanying a move from one's own home into an institutional setting and the feelings about loss of independence, health, and control are comparable.

These psychosocial needs and the physical and cognitive impairments that assisted living residents have upon admission, and that increase over time, lead to many of the same problems and issues experienced by nursing home residents. These include involuntary transfers and discharges; abuse, gross neglect and exploitation; insufficient numbers of adequately trained staff; substandard care; and lack of respect, dignity and choice. Assisted living residents, like residents in nursing homes, are even facing facility bankruptcy and closure as assisted living facilities struggle to fill their beds in light of overbuilding within the industry.

The vulnerability of these residents, combined with the problems they encounter, make their need for ombudsman services no less compelling than it is for nursing home residents.

Principles that translate to assisted living

Ombudsman advocacy in assisted living is guided by exactly the same philosophy as it is in the nursing home setting. It is resident-centered, and actions begin and end with the resident. The ombudsman must be directed at all times by what the resident wants and always seeks to empower the resident.

⁶ Hawes, C., Lux, L., Wildfire, J., Green, R., Packer, L.; Iannacchione, V., and Phillips, C. *Study of North Carolina Domiciliary Care Home Residents*. Research Triangle Institute, Research Triangle Park, NC. 1995.

⁷ Hawes, C., Wildfire, J., Mor, V., Wilcox, V., Spore, D., Iannacchione, V., Lux, L., Green, R., Greene, A., and Phillips, C. *A Description of Board and Care Facilities, Operators and Residents: Analysis of the Effect of Regulation on the Quality of Care in Board and Care*. Research Triangle Institute, Research Triangle Park, NC. 1995.

The same fundamental ombudsman principles for individual advocacy apply in both settings. These are:

- Establishing the outcome the resident is seeking;
- Getting resident consent before proceeding and moving forward only with resident permission;
- Encouraging and, if necessary, assisting the resident in self-advocacy;
- Obtaining resident permission to reveal identity and talk to others about the problem;
- Checking back with the resident at different stages of the complaint investigation/resolution;
- Reporting investigation results back to the resident and determining whether she wants to continue;
- Discussing possible solutions with the resident and developing a resolution strategy that the resident wants; and
- Involving the resident to the greatest extent possible in the resolution process, if the resident is uncomfortable with self-advocacy.⁸

Strategies that translate to assisted living

Ombudsmen use the same general methods and techniques to solve complaints on behalf of individual residents in assisted living as they do in their nursing home work. A discussion of a number of these strategies follows.

- **Self-advocacy:** This approach involves empowering residents and families to take action themselves. It can mean encouraging the resident and/or a family member to try to solve the problem on her own or to directly participate in the resolution process if the ombudsman takes the lead or at least provides support. It also includes helping a resident or family member take a concern to a resident or family council.
- **Negotiation:** Negotiating is a method whereby the ombudsman bargains with another party, usually the administrator and/or department head, to arrive at a binding agreement.

⁸ Hunt, S. *Beyond the Basics: Resolution Module*. Illinois State Long-Term Care Ombudsman Program. 2001. pp. 9, 15, www.ltombudsman.org/ombpublic/49_506_3138.CFM.

- **Mediation:** This technique is a process in which the ombudsman tries to get the resident and/or complainant and another individual or individuals to develop a mutually agreeable solution. Mediation in ombudsman work in both assisted living and nursing homes is used in situations where the parties are equal in power, such as in a case involving two residents.
- **Education and promoting best practices:** This strategy entails sharing information and knowledge that can assist in solving a problem. It includes informing providers about approaches to an issue or best practices that have been successfully used in similar situations.
- **Referral to another agency/entity:** Referring the complaint involves obtaining resident and/or complainant consent to send all the information relating to the case to an appropriate agency for investigation (frequently the state regulatory agency).
- **Community action:** In this approach, ombudsmen work with citizens in a community, such as representatives from social services agencies, hospitals, religious groups and advocacy groups, to bring pressure to bear on the facility to correct problems.
- **Legal action:** While some ombudsman programs are able to pursue legal remedies themselves, this strategy generally involves connecting the resident to a private attorney or a legal assistance organization.
- **Media:** This approach consists of informing local newspapers, radio and/or television stations about the problem in the facility and the facility's unresponsiveness. The idea is to generate attention to create an incentive for the home to fix the problem.

Systems advocacy

Many of the same strategies that ombudsmen employ when they represent residents' interests in nursing home advocacy apply to licensed assisted living facilities as well.

- **Empowerment of residents and families:** This strategy involves informing and educating residents and families about an issue and teaching them how to speak out in an effective way (ex. contacting their legislators).
- **Public education:** This approach is similar to the above strategy except that ombudsmen work with the general public.
- **Promoting "best practices" and facility education:** In this method, ombudsmen disseminate information about successful practices and promote "culture change" to improve the care and quality of life of residents. This approach also includes conducting inservice trainings, holding conferences and roundtables, and distributing written information.

- **Representing residents:** This approach involves participation in long-term care committees, task forces, governmental workgroups, etc. to bring about improvements in the long-term care system.
- **Coalition building:** This strategy entails organizing individuals and groups into a unified coalition to build support and push for a particular issue. It is one of the most important systems advocacy strategies that ombudsmen can employ.
- **Media attention:** Getting attention focused on a particular issue consists of informing and educating the media about a problem or need faced by residents and providing specific examples demonstrating how that problem affects nursing home residents.

In both the assisted living and nursing home arenas, systemic advocacy is based upon and flows from the individual advocacy work of long-term care ombudsmen. Changes that result from this systems work then provide ombudsmen with improved or new tools to use in helping individual residents. In this “advocacy cycle,” individual and systems advocacy feed into and lead back to each other.

However, to conduct any type of advocacy, the ombudsman program must establish itself as **credible**. Credibility means that ombudsmen are consistently resident-directed, fair, respectful, knowledgeable about laws and regulations, in command of the facts, and clear about how their role differs from that of a regulator.

IV. DIFFERENCES BETWEEN OMBUDSMAN WORK IN NURSING HOMES AND IN THE ASSISTED LIVING ARENA

While ombudsman work in nursing homes and assisted living facilities clearly have much in common, there are also significant distinctions that stem from the nature of assisted living at this time in the United States. Several unique aspects of assisted living are described below.⁹

- The term “assisted living” means something different in every state.
- The size of the facility and the services provided may vary greatly both within and between states.
- Assisted living facilities are far less regulated than nursing homes.

⁹ Many of the points in this section are taken from Chapter 7, pp. 37-38 of the *Alaska Long Term Care Ombudsman Program Manual* by Sara Hunt. The manual can be accessed at www.ltombudsman.org/ombpublic/49_506_1787.CFM

⇒ There is no federal set of regulations that applies nationally; regulations differ from state to state and are generally not as comprehensive as nursing home regulations. Some states have no or extremely minimal regulations.

⇒ Oversight mechanisms are less stringent. While Medicaid and Medicare certified nursing homes are inspected every 9-15 months, assisted living facilities in some states may only be surveyed every 2-3 years or only when there is a problem. Moreover, in some parts of the country, the oversight agency takes a “collaborative” approach to its duties. For instance, until very recently, assisted living investigations in Iowa were conducted in an informal manner, with inspections announced before they happened and some findings communicated orally without being documented.¹⁰

- Consumer understanding and expectations of assisted living vary enormously. Consumer understanding is further complicated by the fact that assisted living facilities and nursing homes are frequently co-located. As a result, residents and their families may not know that there is a different set of rights and responsibilities in each setting or may not anticipate that a transfer from the assisted living section of a facility to its health care center can be just as traumatic as moving to a freestanding nursing home.
- There may be far fewer residents in an assisted living facility than in a nursing home. Some small assisted living homes may only house 2-3 residents.
- Assisted living operators and staff frequently have less training than nursing facility administrators and staff. In addition, training is not standardized as is the case with nursing assistant training in nursing homes around the country.
- Assisted living facilities may be operated by only one caregiver who may or may not employ staff. As a result, there are fewer professional staff - if any - on hand or available to advise the operator. This means that the caregiver running the home may have to serve as administrator, nursing staff, dietary manager, housekeeper and bookkeeper all in one. Assuming so many different roles requires an enormous amount of time, energy, and knowledge.
- Operators in some assisted living facilities are providing care in their own personal home. This is often the case in very small homes.
- In small assisted living homes where the operator is the only caregiver and is caring for residents in her own home, the ego of the operator may be much more involved than it is in nursing homes. In these circumstances, the caregiver’s involvement with the resident and the home is extremely personal. How the operator cares for residents and runs her home stems from who she is as a person. Her care is directly tied to how she was raised, how she raised her children, her history, her ethnicity, her culture, and her religion.¹¹

¹⁰ Iowa *Des Moines Register*, 4/14/02, 4/17/02.

¹¹ Phone conference call with Sally Reisacher Petro, publisher of *Board and Care Quality Forum*. 5/1/02.

- States may or may not have a “Bill of Rights” for assisted living residents.
- In many states, there is no standard set of services that an assisted living facility must provide. This contrasts sharply with nursing homes where certain services must be furnished under federal law and regulation.
- Resident level of care varies greatly in assisted living. Some facilities serve residents who are very independent and need only occasional assistance with activities of daily living, while other facilities care for residents who have significant physical and/or cognitive impairments and who may have nursing home level of care. This complicates systems advocacy, since it can be very difficult to cast a wide enough “net” to cover the range of resident needs.
- The majority of assisted living facilities that offer private occupancy units are private pay and not Medicaid-certified.
- There is generally a larger percentage of younger residents in small assisted living facilities than in nursing homes. Many of these individuals have a primary diagnosis of mental illness and/or mental retardation.
- A large number of residents in small assisted living homes are involved in community-based services, such as senior centers, adult day centers or day treatment centers.
- Admission/discharge criteria vary from state to state and sometimes within a state.
- Due to the very small size of some homes, residents may have a greater fear of retaliation since it is harder for them to remain anonymous if they speak up about a complaint. It is likewise harder in these small homes to find space for a private meeting between the ombudsman and the resident.

A chart in Appendix 1 provides a helpful comparison between complaint work in nursing homes and assisted living homes.¹²

Strategies to address the uniqueness of assisted living

The unique features of assisted living facilities, such as the less regulated environment and small size of some homes, require that some ombudsman strategies be adapted or that new ones be developed. Ombudsmen have to utilize approaches that are based more on resident agreement or contract provisions, their ability to develop a connection with the provider, and their skills in convincing the provider to take certain actions. These strategies are

¹² Hunt, S. Alaska Long Term Care Ombudsman Program Manual. Chapter 7. pp. 39-43.

also used in nursing home work, but become much more important in assisted living because of weaker regulatory/enforcement mechanisms.

A number of effective approaches used by ombudsmen in their assisted living advocacy are outlined in this section.

- **Using “advocacy by analogy.”** This generally involves finding a similar situation in another setting and then applying it to the assisted living arena. For instance, the State Ombudsman in Oregon argued that regulations prohibiting nursing home duration of stay contracts (contracts requiring residents to pay privately for a specified period of time) should be extended to assisted living facilities since assisted living in their state was Medicaid-based. After obtaining a legal opinion from the Oregon Department of Justice stating that duration of stay provisions violated the intent and purpose of Medicaid law, the State Ombudsman asked the regulatory agency to change state policy allowing such contracts. The regulatory agency responded by deciding to no longer support these contracts. The agency then issued a letter to all assisted living providers stating its position and requesting that facilities no longer require prospective residents to agree in writing to a period of private pay status as a condition of admission.

“Advocacy by analogy” can also mean helping providers to think through how they would feel in an analogous situation to try to better understand and accommodate a resident’s preference or choice.

- **Applying the “community standard.”** This approach consists of convincing an operator to take a particular action because it’s the “right thing to do” within the context of the community the operator lives and works in. One North Carolina regional ombudsman points out to providers that if they don’t provide good services, everyone will know about it because in their community, “everyone lives, works and worships together.” She emphasizes to the provider what a “reasonable person” in the community would think about the provider’s action. She then stresses that if the operator wants to continue doing business in the community, the operator needs everyone on her side and cannot afford to have people think that the home isn’t doing a good job. This method is particularly effective for volunteer ombudsmen who actually live in the provider’s community. (Caveat: Before using this strategy, ombudsmen should make sure that the “standard” for the community promotes quality care and treatment of residents!)

- **Providing education/technical assistance and promoting best practices.** This may be the most important strategy that ombudsmen can use in assisted living, particularly in small assisted living homes where operators often have far less access to training and resources than in larger facilities. In this method, ombudsmen help operators to identify potential solutions to a problem and either connect them to or provide them with the resources, information and training to implement those solutions. One way to do this is by sharing “best practices” so providers can learn how their peers were able to successfully address the same issue. The ombudsman almost becomes a “coach” - teaching,

encouraging, praising, and motivating the provider. A critical component of this approach is building understanding with the provider and developing a relationship of mutual trust and respect. Without this trust, operators are unlikely to be open or responsive to ombudsman suggestions or information.

However, at the same time, ombudsmen must avoid turning into “unpaid consultants” to the provider. Ombudsmen need to be careful that they do not become too aligned with and sympathetic to the provider’s perspective, hardships and concerns. Equally important, ombudsmen must conduct themselves in such a way that they themselves are not seen as being “on the provider’s side” or serving the provider’s interests. While education and technical assistance are helpful and valid, ombudsmen must be thoughtful in determining how and when to use this strategy.

- **Connecting within the community.**

- ▷ **Networking/building relationships with community resources/service providers.**

- In this approach, the ombudsman connects with other professionals, such as case managers, home health staff, hospital workers and health department personnel who go into an assisted living facility or come into contact with the residents of a facility. Residents in small assisted living homes are frequently more isolated than nursing home residents, and there are usually far fewer people coming in and out of the facility. Consequently, regular communication with other service providers can help the ombudsman monitor residents’ well-being, determine if a provider has addressed a problem, and identify new problems. For instance, after having established a relationship with a local day care center, the assisted living ombudsman in Maryland received a call from a center worker about a concern. The employee reported that a resident was coming to the center every day in the summer with winter clothes that were far too warm. Alerted to the problem, the ombudsman was able to resolve it. The Maryland assisted living ombudsman seeks to develop and maintain professional relationships by attending a monthly meeting of community social service providers.

- ▷ **Visiting with residents outside of the assisted living facility.** This method, in which the ombudsman connects with residents when they are in community settings (ex. a senior center, sheltered workshop, or day treatment facility), gives residents the opportunity to talk freely with the ombudsman about conditions and any problems they might be experiencing in the assisted living facility. Such conversation is essential because of the difficulty in protecting the identity of the residents and assuring confidentiality in very small assisted living homes. These visits improve the ombudsman’s ability to identify and investigate a complaint and to conduct complaint follow-up. The Georgia Ombudsman Program utilizes this approach frequently in its assisted living work, often visiting with residents at senior centers or mental health centers.

- **Applying contract provisions.** Since assisted living facilities are generally less regulated than nursing homes, the resident contract or agreement takes on critical

importance. In this approach, ombudsmen review the contract to determine if the problem stems from a failure of the facility to live up to the contract provisions and advocates for the provider to meet its obligations. This strategy is discussed in more detail in Section V of this paper.

- **Ensuring regular ombudsman presence.** This strategy involves constant, consistent ombudsman visits to residents in the facility, using volunteers from the community, if at all possible. Regular visitation is very important in assisted living facilities for several reasons. First, as discussed earlier, the small size of some homes tends to make residents even more fearful of retaliation than in nursing homes. Frequent ombudsman visits can reduce this fear and provide better resident protection. Residents are far more likely to speak out about a problem if they can count on the fact that the ombudsman will be back in the home the next week. Moreover, since assisted living homes may not be inspected nearly as often as nursing homes, regular visits provide some oversight of the home and remind providers to comply with regulations. This may be even more likely to happen when the ombudsmen are volunteers who have strong ties to the community and perhaps even some local political connections. Regular visitation is an important preventative approach.

V. TRANSLATING NURSING HOME STRATEGIES TO ASSISTED LIVING: A CLOSER LOOK

To gain a more in-depth understanding of assisted living advocacy, it is helpful to look at specific issues and how ombudsmen can address them in their work. This section will examine seven areas:

- care or service planning
- promoting residents' rights
- resident autonomy/choice
- transfer/discharge
- staffing
- resident agreements/contracts
- disclosure

For each area, there will be a discussion of ways in which ombudsman strategies and approaches from the nursing home setting apply, what features of assisted living facilities make them different from nursing homes, and strategies ombudsmen can use to help residents within the context of those differences. The specific strategies that are presented are provided as

examples and should not be considered a complete listing of every approach that could be used.

CARE OR SERVICE PLANNING

Care planning is a concept that is used throughout the health care system - from home health services to hospital care. While assisted living facilities may call it by another name, such as a service plan or service agreement, the principle of a care plan usually exists in some form.

Years of nursing home reform advocacy efforts throughout the country have resulted in care planning becoming a common practice for quality care. Advocates, working with others, successfully established that nursing home residents cannot achieve their highest level of well-being if they do not receive individualized care, and individualized care can only stem from a careful care planning process based on a thorough assessment.

Ombudsman work in assisted living builds upon this principle. As a result, many of the nursing home care planning strategies already familiar to ombudsmen can be employed to help residents in the assisted living setting. These include:

- Educating residents and families about what the care planning process is, its importance, their rights pertaining to care plans, and how to participate in a meaningful way.
- Helping residents and families learn how to plan and prepare for a productive care planning meeting. If asked, ombudsmen can attend the conference to provide support and demonstrate to residents and families how to speak out. The role of the ombudsman in such a meeting might be to model to facility staff how to focus on the resident (ex. involving residents, getting resident input and resident agreement, encouraging residents to bring up issues, using language that can be understood, etc.).
- Using the care plan as a tool in problem solving advocacy. Ombudsmen can work with the resident to convene a care plan meeting when there are concerns about the delivery of care; concerns about the type and quantity of services and fees associated with that care; a proposed transfer or discharge that the resident opposes; or any other type of resident complaint that the facility has failed to resolve.¹³

Uniqueness of the assisted living arena in care planning

- There may be no state requirement for individualized care plans, and facility staff may not be familiar with this practice.

¹³ Hunt, S. *Using Resident Assessment and Care Planning As Advocacy Tools: A Guide for Ombudsmen and Other Advocates*. National Citizens' Coalition for Nursing Home Reform. July 1992. p. 23.

- State regulations governing assessments and care plans are rarely as comprehensive as the federal nursing home regulations. Unlike in nursing homes, regulations may only require that assessments/care plan reviews be conducted annually or when there is a significant change in the resident's condition, rather than quarterly.
- There may be no requirements for a care/service plan conference to be held with resident and family participation.
- The care plan is frequently not developed by an interdisciplinary team. In fact, in some facilities, there may only be one caregiver developing the plan.
- The provision of care may be fragmented, resulting in more than one care/service plan being developed by different entities. For instance, personal care assistance may be provided by facility staff, while more complex nursing services may be provided by a home health agency. In such a situation, both the facility and the home health agency would develop a care plan.
- The care/service plan is often linked directly to fees. Consequently, an increase in the services provided to a resident frequently results in an increase in rates. This can create a dynamic where residents and their families are reluctant to ask for or accept more services or where a facility has a strong incentive to determine that a resident "needs" additional care. In other instances, the facility may place a resident into a category or level that includes set services at a pre-established price. The resident may then have to pay for certain services that he or she does not need, while having to pay extra for services not included in that package.

Ombudsman strategies for care planning to address the uniqueness of assisted living

- Using "advocacy by analogy."
 - ⇒ In cases where the care/service planning requirements are minimal or non-existent, ombudsmen can make the case that care planning is not an unusual or rare process. Instead, it is an important tool found in every setting in our society where care is provided (for instance, home care, hospital care, and adult day care), and should be applied in the assisted living arena as well. Ombudsmen can stress how both the resident and the facility benefit from this process.
 - ⇒ In situations where the facility recommends additional services that the resident does not want because they would result in increased costs, the ombudsman can contend that the resident has the right to refuse treatment. Even if this right is not explicitly spelled out in state law or regulations governing assisted living, the ombudsman can argue that the right to refuse treatment is found throughout our health care system and should also apply in assisted living.

- Reframing the issue. Ombudsmen can frame the issue as one of informed consent - the right that we all have in our society, no matter where we live, to be informed about and consent to any care and treatment we might receive. The ombudsman can emphasize that residents are more likely to be satisfied with their care when they actively participate in decision-making.
- Using the care plan concept, but avoiding the term. When there are care issues or concerns, the ombudsman can suggest a “meeting,” attended by all parties, to try to come up with an agreed upon approach to address the concerns. The “agreement” can then be put in writing.
- Serving as broker. In homes where the care/service planning team is not interdisciplinary, ombudsmen can connect the operator to community resources or consultants to cover areas in which the provider needs additional knowledge or expertise.

Systems advocacy for care planning

While ombudsmen are often successful in arguing on a case by case basis for assessments and care planning in assisted living facilities, they have learned from their nursing home experience that advocating for more comprehensive assessment and care planning requirements benefits all residents. Examples of this type of systems advocacy follow.

- North Carolina: The North Carolina Long-Term Care Ombudsman Association worked with other advocacy groups in the state to change the assisted living regulations to require an assessment tool that must be reviewed and signed by a nurse. This was a significant step forward since there had been no such requirement before.
- Washington: The ombudsman program, along with a number of stakeholders in the state, pushed for a standardized assessment instrument to be used in its adult family homes. The effort was successful for Medicaid residents for whom a required “long term care assessment and care planning tool” must now be completed by a “qualified assessor” prior to admission, at least annually, and when there is a significant change (see Appendix 2 for a copy of this instrument). A “qualified assessor” is considered to be a health care professional, such as a doctor, or a state case manager. A standardized form filled out by a qualified assessor has promoted consistency in the assessment process from one facility to another and ended the facility practice of charging for assessments. While this assessment form is only suggested, but not required for private pay residents, the ombudsman program successfully advocated for all residents to have the right to an assessment which must cover 12 specific items (see Appendix 3 for information about what the assessment must include).

In addition, an assessment tool similar to the Minimum Data Set used in nursing homes has been created for assisted living facilities. Developed as part of the Quality Measurement in Residential Care program which is funded by the U.S. DHHS Agency for Healthcare Research and Quality and whose principal investigator is Dr. Catherine Hawes, it is being piloted in Maine

and to a lesser extent in North Carolina. This tool, called the Minimum Data Set Residential Care Assessment (MDS RCA), can be viewed online at <http://www.snfinfo.com/content/MDSForm.pdf>.¹⁴

Ombudsmen can also advocate for a requirement that care plans/service agreements include certain core elements. This has been done in Idaho where regulations mandate that the service agreement address specific areas, such as medication assistance, habilitation/training and behavioral management needs. A copy of Idaho's regulations regarding service agreements can be found in Appendix 4.

PROMOTING RESIDENTS' RIGHTS

Ombudsmen have learned from over 30 years experience in nursing homes that residents' rights are vital to ensuring the welfare of residents. Residents' rights safeguard and promote dignity, choice and self determination; and protect civil, personal and privacy rights including: rights related to health care, due process and life in the nursing home; transfer and discharge rights; rights to information; and the right to be free from abuse and restraints.¹⁵ These rights are no less important for residents in the assisted living setting. In fact, the increasing similarities between residents in assisted living facilities and nursing homes described earlier make a strong set of residents' rights in assisted living even more essential.

Residents' rights, however, are meaningless unless they are implemented. An important role of the ombudsman is to promote residents' rights by educating residents, families, providers and the general public about what rights residents have, how to put them into practice and what should be happening in facilities if rights are truly being respected.

Nursing home ombudsman strategies to promote residents' rights that apply in assisted living include:

- Educating residents and their families about rights directly through presentations, one-on-one visits and consultations, complaint cases, and written information;
- Empowering residents and families to self-advocate when working with a resident or family member on a complaint;
- Working with guardians to ensure they know and promote the rights of their ward;

¹⁴ *New ALF quality tools in the works*. Briefings on Assisted Living – Complementary Issue. HCPro, Inc. 2003.

¹⁵ Clark, L. A. *Georgia Long Term Care Ombudsman Volunteer Trainer's Manual*. Resident's Rights section. p. 1. http://www.ltombudsman.org/ombpublic/49_506_1788.CFM.

- Mediating between residents when the rights of different residents conflict;
- Assisting residents and families to develop and maintain strong, effective resident and family councils;
- Providing inservice training to facility staff on residents' rights and how to work through difficult situations in a way that respects residents' rights;
- Educating the public about rights through presentations, phone consultations, and dissemination of written materials;
- Bringing together representatives with decision-making authority from a corporation to develop solutions to residents' rights problems or find ways to promote rights;
- Approaching a provider trade association to see if its leaders will promote residents' rights improvements and best practices among its members;
- Using and assisting others to use the "Golden Rule" (treating residents as we would want to be treated) as the framework for all work and interaction with residents; and
- Modeling respect for residents' rights when interacting with residents and facility staff.

Uniqueness of the assisted living arena in promoting residents' rights

- Regulations on residents' rights may be very minimal or even nonexistent.
- Since residents in assisted living can be more independent and less frail than many nursing home residents, they may be more likely to comprehend and exercise their rights. This often creates tension between a resident's right to choose and a provider's concern for safety and protection, and requires skillful intervention on the part of the ombudsman.
- Due to the private pay nature of much of assisted living, families may be paying a large portion of a resident's assisted living bill. They may therefore feel justified trying to control a resident's actions. Providers concerned about alienating the source of payment may react to this by following the family's, and not the resident's, wishes.
- In small homes where the operator is the only caregiver or the primary caregiver, the operator may believe that residents must conform to her standards and expectations because they are in her personal home. Raising concerns about rights may therefore be perceived by the operator as criticism of who she is as a person, her family background, ethnicity and culture.¹⁶

¹⁶ Phone conference call with Sally Reisacher Petro, publisher of *Board and Care Quality Forum*. 5/1/02.

- Residents in a small home operated by a single caregiver may view the provider and the other residents as their new family. Residents may feel that voicing concerns about rights is a betrayal of that family and may consequently be reluctant to talk about any problems.¹⁷
- The fear of retaliation may be far greater in small assisted living homes than in nursing homes. This fear is intensified because it may be next to impossible to voice a concern anonymously; there are fewer outside people (families and others, including staff) to observe what is happening in the home; and residents may have very few or no other choices about where to live.
- Difficulty in obtaining or affording liability insurance may make facilities reluctant to permit residents to exercise rights that staff believe might result in resident harm and possibly lead to a lawsuit. In West Virginia, for example, current regulations for residential board and care homes state that “Residents have the right to be free to leave the residential board and care home, however, this does not absolve the home of the responsibility to supervise residents.” Providers, fearful of possible litigation against them for injury to a resident, have limited the freedom of some residents to go to a local convenience store or even take a walk outside a protective fence, despite the fact that these residents have mental and physical capacity.

Ombudsman strategies for residents’ rights to address the uniqueness of assisted living

- Apply constitutional rights, federal laws and state laws. Ombudsmen can remind providers that a resident still has all her rights as a U.S. citizen (e.g. the right to vote). Ombudsmen can also inform the operator that all applicable state and federal laws, such as laws prohibiting the opening of mail, must also be followed.
- Review resident contracts and agreements. Ombudsmen can analyze a resident contract/agreement to see if the provider’s actions are contrary to what these documents require. If contradictions are found, the ombudsman can argue that the operator must adhere to the contract provisions. Conversely, if the contract restricts the rights of residents, the ombudsman can work with the provider to change the contract.

Systems advocacy for promoting residents’ rights

Ombudsmen across the country are drawing upon their nursing home advocacy experience to fight for adequate protections for assisted living residents. Perhaps the best example is the state of Washington, where the ombudsman program advocated for the rights guaranteed to nursing home residents under the Nursing Home Reform Law to be expanded to residents in *all long-term care settings*. In 1994, ombudsman efforts were successful, and legislation was

¹⁷ Ibid.

passed that incorporated federal nursing home residents' rights into assisted living facilities. These residents' rights can be found at <http://www.leg.wa.gov/RCW/index.cfm?fuseaction=chapterdigest&chapter=70.129>.

The Alaska Ombudsman Program is also working to broaden the rights of assisted living facility residents. There, ombudsmen have observed that current regulations governing residents' rights in assisted living are too vague and do not sufficiently safeguard residents. For instance, ombudsman program representatives in Alaska have noted that it is currently easier to restrain residents in assisted living facilities than in nursing homes. The ombudsmen are also concerned about the ability of assisted living facilities to override a resident's decision to refuse treatment. In one case the Alaska Ombudsman Program is aware of, a facility insisted on using a Hoyer lift for a resident despite the adamant refusal of the resident to be transferred in this manner because the procedure terrified her. These situations have led the Alaska Ombudsman Program to advocate for the following rights to be added to assisted living law and regulations: 1) the right to evaluate and choose treatment; 2) the right to refuse treatment; and 3) the right to be free from abuse and neglect. The program is also working for greater protections around restraint use.

Other important systems advocacy efforts are:

- Reviewing state inspection reports to monitor if residents' rights violations are cited and meeting on a regular basis with licensure staff to discuss their understanding, interpretation and citation of rights in assisted living facilities.
- Conducting residents' rights training for state surveyors. In Missouri, the residents' rights portion of the orientation training for new surveyors is presented by the Missouri Ombudsman Program.
- Advocating for state legislation and/or regulation to prohibit facility provisions that permit residents to waive their rights. Both Washington and Oregon successfully fought against such waivers.
- Promoting the adoption by individual assisted living facilities of a trade association's "Bill of Rights" (if such a document exists). In some states, trade associations have developed a model assisted living bill of rights for voluntary use by their members. Ombudsmen can urge assisted living providers to implement these rights in states where there are few to no rights afforded to residents under state law and regulation. Since such a bill of rights is the product of the provider's own association, the provider may be more receptive to putting it into practice.

RESIDENT AUTONOMY/CHOICE

Supporting residents' rights to make their own decisions is central to ombudsman work. This means helping to ensure that residents have control over what they do and how and when they do it, and that their individual needs and preferences are accommodated. In the course of assisting residents to exercise these rights, ombudsmen must struggle with the complex issues around resident protection/safety and resident independence.

Nursing home ombudsman strategies that apply in assisted living include:

- Using fundamental ombudsman principles and approaches. This entails working with the resident to identify what the real issue is, determining what the resident wants done about the problem, making sure that the resident has all the information she needs to make a decision, exploring possible solutions with the resident, and empowering the resident or negotiating on the resident's behalf to arrive at a satisfactory resolution.
- Utilizing the assessment and care planning process. Such an approach is particularly helpful in cases where the resident is acting in a certain way or making certain decisions because: other needs are not being met; the resident has not been provided with information about alternatives; or staff approaches and responses are not appropriate. For example, a facility may be claiming that the resident is "choosing to fall" when the facility has failed to inform the resident about interventions that can be used to prevent falls. Another example is a facility that states it is honoring the resident's right to "choose not to bathe," when the resident's refusal is instead the result of her customary routines and preferences not being followed or the way in which staff interact with her at bath time.

Uniqueness of the assisted living arena in resident autonomy/choice

- The smallness of the home may make exercising choice difficult. A resident may feel forced to participate in activities that she doesn't like because there are no other options and she doesn't want to appear different from everyone else.¹⁸
- Many operators run their homes according to the way in which they were raised and have always lived. In the context of such an intimate and family-like environment, expressing interest in a choice that is different from what is offered may be viewed as a challenge to the provider's personal values.¹⁹
- The concept of "managed risk," "negotiated risk," or "shared responsibility" has arisen in the assisted living setting. Negotiated risk is often defined broadly as "an agreement between a resident and an assisted living facility regarding the services that the resident

¹⁸ Ibid.

¹⁹ Ibid.

requires and the risks that the resident is willing to take.’²⁰ An example is a situation in which a negotiated risk agreement might specify that a resident does not want assistance in dressing, despite the risk that she has of falling.²¹ Such an agreement may or may not release a facility from liability should an injury or negative outcome occur. While the idea of negotiated risk is usually presented as a means of promoting resident autonomy and choice, it may be little more than a way for a facility to limit resident actions, abdicate its responsibility to provide truly individualized care, and avoid the work of finding alternative ways to support a resident’s choice.

Ombudsman strategies for resident autonomy/choice to address the uniqueness of assisted living

- Using “advocacy by analogy.” Ombudsmen can help operators think how they might feel in an analogous situation, thereby increasing the provider’s understanding of the resident’s feelings and position. For instance, a provider may serve the type of food that she grew up with and that she has cooked all her life. However, a resident may come from a completely different cultural and ethnic background and not like or be able to adjust to the operator’s cooking. If the resident expresses her wish for a different type of food, the provider may feel her cooking has been insulted. The ombudsman can talk with the operator about how she might respond if she were in a place where people ate a completely different type of food that she couldn’t get used to, even when the food was wonderfully well cooked.
- Providing one-on-one education and technical assistance. Through direct and personal contact, ombudsmen can talk with providers about how to approach an issue, help brainstorm, share ideas, and assist them in working their way through a problem in a manner that supports resident choices. For example, a provider may be concerned that a resident who is mentally ill is being exploited by unscrupulous salespeople who encourage her to buy expensive items she can’t afford or who overcharge her. To protect the resident, the provider prohibits the resident from going shopping. The resident then becomes upset because she wants to be independent and to continue to shop. The ombudsman can work with the provider to explore how the resident’s rights can be upheld, while possibly putting some protections in place. One solution might be seeing if someone could accompany the resident when she goes shopping.
- Addressing autonomy/choice issues in a care plan rather than a risk agreement. Use of the care planning process avoids certain aspects of risk agreements that can be problematic, such as the unequal bargaining position of residents and families and the opportunity for subtle coercion of residents and families that can arise from their fear of discharge.²²

²⁰ Carlson, E. M. *Long-Term Care Advocacy*. LexisNexis Matthew Bender. July 2002. p. 5-42.

²¹ Ibid.

²² Edelstein, S. op. cit, p. 6.

- Assisting residents for whom a risk agreement is being developed. Ombudsman assistance can ensure that the agreement is individualized, does not limit the resident's choice of actions, and does not release the facility from liability.

Systems advocacy for resident autonomy/choice

- Working for legislation and/or regulations that prohibit waivers of facility liability if negotiated risk agreements or managed risk agreements are used. Ombudsmen in Washington and Oregon advocated successfully for such waivers of liability to be illegal. In addition, the Oregon Ombudsman Program also obtained language mandating that negotiated risk or managed risk agreements could only be made with residents who had mental capacity and not with their family or legal representative. An agreement becomes invalid should the resident lose capacity.
- Reviewing deficiencies written by the regulatory agency to ensure that resident choice and autonomy are being upheld.

TRANSFER/DISCHARGE

A great deal of ombudsman time and energy is spent helping nursing home and assisted living facility residents in involuntary transfer/discharge cases. Ombudsmen have long expressed concern about the traumatic impact on nursing home residents of a forced relocation. Given the increasing frailty of assisted living facility residents, involuntary transfers in this setting can be equally devastating, especially if the facility has promised residents that they can “age in place.”

Most nursing home ombudsman approaches to transfer/discharge cases can be used in the assisted living arena. These include:

- Educating residents and families about their rights relating to transfers, especially with regard to notice and appeal, so that they can seek help if the issue arises;
- Intervening early before notice is issued to address problems that raise the specter of transfer/discharge;
- Working with facility staff in using an assessment/care planning process to identify individualized needs and interventions in transfer cases related to resident needs; and
- Representing residents at a hearing or connecting residents to legal counsel.

Uniqueness of the assisted living arena in transfer/discharge issues

- Regulations may not specify permissible reasons for transfer/discharge. In some states, these reasons may be entirely up to the facility, or not required at all.
- There may be no requirement for the facility to provide a written notice of the proposed relocation.
- There is frequently no right to appeal or contest the proposed transfer.
- *Residents* may have to give notice if they leave. This results in the absurd situation, such as exists in Maryland and Colorado, of residents having to give 30 days advance notice of their own death. If such notice is not given, facilities often tell families that they must pay rent for the remainder of the month.
- In nursing home cases, the majority of proposed transfers are to the *same* level of care (another nursing home). In assisted living, however, many of the cases involve a move to a *higher* level of care (which also happens to be a nursing home). The assisted living philosophy of resident choice and independence, as well as the concept of “aging in place,” has created much debate in many states about whether residents should be forced to move to nursing homes when they need more care. In three states - Texas, Michigan, and Mississippi - legislation has been passed to allow assisted living residents who need more care to remain if the resident, the facility and the resident’s doctor agree.²³ Other states, such as Georgia and West Virginia, have given their regulatory agency the authority to grant a waiver permitting a resident to stay, provided that certain criteria are met.

Ombudsman strategies for transfer/discharge to address the uniqueness of assisted living

- Reviewing the resident contract or agreement and utilizing any relevant provisions.
- Connecting/referring the resident to legal counsel to review her rights and, if appropriate, to demand a court trial under state landlord/tenant laws,²⁴ contract law, and fair business practice law.
- Pursuing any waiver options that might exist within the regulatory agency.
- Applying the Fair Housing Amendments Act of 1988 and the Americans with Disabilities Act prohibiting discrimination on the basis of disability or the perception of disability. Depending on the circumstances of the case, ombudsmen can argue that these laws require providers to make reasonable accommodations or modifications that would allow protected individuals to meet the requirements of residency and therefore remain in the facility.²⁵

²³ Carlson, E. M. op. cit, p. 5-16.

²⁴ Carlson, E. M. op. cit, p. 5-36.

²⁵ *White Paper on Assisted Living*. National Academy of Elder Law Attorneys. Fall 2001. p. 18.

- Enlisting the help of the doctor in situations where the resident immediately needs a higher level of care in another setting, but the assisted living provider requires 30 days prior notice. In Maryland, the Ombudsman Program handled a case where a resident needed therapy after a hospital stay. The resident’s family wanted her to receive care in a nursing home. However, the assisted living facility, which wanted to fill its beds, argued that it could provide the necessary care and that the resident could not leave without giving notice. Invoking an exception to the 30 days prior notice for emergency situations, the ombudsman worked to get a statement from the resident’s doctor saying that the resident’s medical needs were greater than what the assisted living facility could provide. The resident was allowed to move without paying 30 days rent.

Systems advocacy for transfer/discharge

- Advocating for state laws and regulations that give assisted living residents transfer/discharge rights similar to the rights of nursing facility residents. Prior to the Nursing Home Reform Law, residents were often arbitrarily and suddenly evicted from nursing homes and had no recourse. Nursing home reform advocacy resulted in federal law and regulations that protect residents in involuntary relocation situations. Ombudsmen can model their assisted living advocacy efforts on the approach used in the nursing home setting. This is precisely what happened in North Carolina, where the local ombudsman association, in conjunction with a number of advocacy groups, successfully fought for transfer/discharge protections that mirror those in nursing homes. This is also the case in a number of other states as well, including Washington, Oregon, and Indiana.
- Working for state laws and/or regulations that prohibit residents from having to give 30 days notice prior to departure in cases of medical necessity or death.
- Educating prospective residents, their families and the public about the importance of knowing in advance the transfer/discharge criteria for any facility they choose. In general, consumers are not aware that most assisted living facilities require residents to move when they have exhausted their private pay resources or need a higher level of care. Consumers need to learn about a facility’s transfer/discharge policies prior to admission so that they can make an informed decision about assisted living placement.

The Ombudsman Resource Center paper entitled, “Ombudsman Advocacy Challenges in Assisted Living: Outreach and Discharge,” provides additional information about the ways in which ombudsmen can advocate at both the individual and systems level in assisted living facilities. This paper can be accessed at:

<http://www.ltombudsman.org/uploads/SAchallengesinALdischarge.pdf>.

STAFFING

The issue of staffing is just as important in assisted living as it is in nursing homes. Ombudsmen see the same type of problems - insufficient numbers of staff and inadequately trained staff - in both settings. Many of the reasons given for staffing problems are also the same, such as lack of adequate reimbursement and shortage of health care workers. A discussion of nursing home ombudsman strategies that apply in assisted living follows.

When the problem relates to the number of staff, ombudsmen can:

- Focus on the specific needs of an individual resident and develop a plan to meet those needs. For example, if the resident is not receiving her baths three times a week, the ombudsman can advocate that the service or care plan specifically state that such assistance will be provided three days weekly.
- Determine if state staffing standards (if any) are being met.
- Persuade the facility to bring in additional help or adjust staffing schedules to accommodate peak times.
- Work with residents and families to understand staffing issues and file a complaint with the licensing agency, if appropriate.

When the problem involves staff training, ombudsmen can:

- Provide training or arrange for an inservice to address the particular care needs of an individual resident.
- Connect the facility to resources and information. A helpful source of information for providers is the *Board and Care Quality Forum* newsletter.²⁶ Providers can also be great resources to each other. In West Virginia, ombudsmen who discover a facility “best practice” ask the provider if they can suggest that other operators contact her about how to implement such a practice. They also highlight the practice in a quarterly newsletter that is sent to most providers in the state.

Uniqueness of the assisted living arena in staffing

- Far less staff training may be required in assisted living facilities than in nursing homes. In some states, almost no training is required at all. Regulations in Alaska, for instance, mandate that the administrator must have sufficient training, without defining “sufficient.” Alaska rules also fail to require training for anyone other than the administrator.

²⁶ The *Board and Care Quality Forum Newsletter* is published by Reisacher Petro and Associates. 1728 Holly Lane, Pittsburgh, PA 15216. (412) 563-7330. www.bcqf.com.

- While an increasing number of residents in assisted living need nursing home level of care, the facility may not have any nurses or nursing assistants on staff 24 hours a day, nor have any staff that are trained in recognizing symptoms of medical problems, such as pain or medication errors. A local ombudsman in Idaho reports that this creates a dangerous situation because even though a home health agency may be responsible for providing nursing care, no one with nursing knowledge and skills is monitoring - or even available to monitor - a resident around the clock. The consequences of this lack of nursing expertise can be devastating. The same Idaho ombudsman was involved in a case in which a resident experienced severe neglect that stemmed in part from the failure of assisted living facility staff to identify the resident's symptoms of dehydration and infection.
- Attending a training may be difficult or impossible for a provider of a small home. There may be no one else in the home who can supervise and care for the residents in the provider's absence.

Ombudsman strategies for staffing to address the uniqueness of assisted living

- Providing education and technical assistance. In small homes where providers may be less knowledgeable about the regulations than in nursing homes or larger assisted living facilities, this may be the most helpful approach that ombudsmen can use. The ombudsman can research an issue and then share with the operator written information or provide a community contact who can answer questions. For instance, the ombudsman might connect a provider who did not know how to work with a low salt diet to the dietary manager at a senior center that serves meals. In another situation, the ombudsman might educate the provider about the regulations. The Maryland ombudsman program reports that it will sometimes point out issues to the provider in a helpful way in order to resolve a problem. In one case where the ombudsman saw medications lying out in a home, she told the operator that the facility needed to address this matter because the medications were required to be locked away.

After sharing information with a provider, ombudsmen need to vigilantly monitor the situation. Monitoring is essential to ensure that the problem has been addressed in a lasting way.

- Creating a network for providers to share information and best practices and receive education. In Texas, the Tarrant County Ombudsman Program developed training for operators of small assisted living facilities. The training was designed for staff in unregulated homes (1-3 beds) where no training or skills are required of caregivers and in other small facilities (4-6 beds) with minimum training requirements and limited access to training resources. A one-day training session is offered quarterly.²⁷

²⁷ *Best Practices of Regional Ombudsman Programs: Training for Operators of Small Assisted Living Facilities*. National Long-Term Care Ombudsman Resource Center website.
http://www.ltombudsman.org/ombpublic/49_506_1792.cfm

Systems advocacy for staffing

Many years of nursing home advocacy around staffing issues have taught ombudsmen a great deal about how to approach staffing issues in assisted living.

Problems relating to the number of staff

An important lesson from ombudsman nursing home work is that the language “sufficient staffing to meet residents’ needs” does not translate into adequate numbers of staff to care for residents. Consequently, ombudsmen have joined with other advocates to push for minimum nurse staffing standards in nursing homes. Strategies that have been used in nursing home reform work can also be applied to assisted living. Specifically, ombudsmen can:

- Assemble a panel of experts to recommend appropriate staffing standards;
- Document the effects of understaffing on assisted living facility residents;
- Educate and empower residents, families, citizen advocates, and workers about how to push for reform;
- Develop coalitions;
- Focus public attention on the issue.

Problems involving staff training

The similarities between nursing home staff training requirements before the Nursing Home Reform Law and current training requirements in assisted living are quite striking. Some long-time ombudsmen report that assisted living homes are sometimes hiring people with little or no training “off the streets” in a manner reminiscent of what occurred prior to the implementation of the nursing assistant training and certification requirements under the Nursing Home Reform Law.

As with staffing standards, ombudsmen can use the same strategies they have employed in the nursing home arena to push for stronger training requirements in assisted living. Coalition building can be a particularly effective approach. For instance, in North Carolina, the ombudsman program joined with other advocate organizations, including AARP and a citizen advocacy group, to obtain legislation requiring classroom training and competency evaluations.

RESIDENT AGREEMENTS/CONTRACTS

Agreements or contracts are found in both nursing homes and assisted living facilities. The purpose of a contract is to establish the responsibilities and obligations of both the provider and the resident. Ombudsmen can use a combination of contract provisions and regulations in their long-term care advocacy efforts.

However, there is a “continuum” of assisted living regulations nationwide ranging from states with detailed and specific regulations to states with minimal or non-prescriptive rules. The less prescriptive the rules are, the more ombudsmen will need to base their advocacy on the contract requirements. The reverse is also true: the more prescriptive the rules, the less ombudsmen will have to rely on the contract provisions.²⁸

A number of advocacy strategies from the nursing home setting can be transferred to the assisted living arena. These include:

- Reviewing obligations/responsibilities of the provider and rights of residents and using those standards to support advocacy efforts on behalf of residents;
- Helping residents/families understand contract terms/conditions, what those conditions mean for them, and what their options are; and
- Advocating for the consumer’s right to obtain a copy of the contract prior to admission so the consumer can carefully study the contract (or seek assistance in reviewing it). This avoids situations, such as occurred in a Maryland facility, where potential assisted living residents were not provided a copy of the contract until they had made a commitment to move into the facility.
- Seeking opinions from legal counsel to support advocacy in a particular situation
- Connecting residents to legal counsel, if appropriate; and
- Using persuasion skills to argue on residents’ behalf on issues that are not clearly spelled out (the “gray” areas). For instance, in Maryland, the ombudsman helped a resident in a situation where the contract did not address exactly how transportation services would be handled. The resident assumed that transportation would be provided; the operator claimed that the contract did not state that such services would be furnished. The provider said the facility would provide transportation, but was going to charge an exorbitant fee. Through negotiation, the ombudsman was able to establish that the facility would be responsible for *arranging* transportation, but with a service that was far less expensive.
- Analyzing the contract to see if a particular action by a provider is permissible.

Uniqueness of the assisted living arena in contract issues

²⁸ Phone conference call with Meredith Cote, Oregon State Long-Term Care Ombudsman.

- The contract in assisted living facilities is generally far more important than the contract in the nursing home setting, particularly in states with little assisted living regulation.
- The assisted living contract may be the **only** place where residents' rights/provider obligations and responsibilities are spelled out.
- Assisted living contracts may be more individualized (at least in theory).
- Major changes are sometimes made to assisted living contracts with only 30 days notice to the resident. This may happen when a facility is sold to a new owner or simply when the provider wishes to make a change. The new terms of the contract may significantly alter the providers' and residents' obligations to the point where the reasons why the resident originally chose the particular facility no longer exist.
- Contracts can vary greatly from one facility to another.

Ombudsman strategies for contract issues to address the uniqueness of assisted living

- Assisting a resident to renegotiate the contract, if possible. Ombudsmen can advocate for a provider to carve out an exemption or make a change on an individual level for a particular resident. The Oregon Ombudsman Program reports that it has successfully used this strategy to help individual residents when a facility has precipitously and dramatically increased its fees. In Maryland, the Ombudsman Program was able to resolve a case involving a resident with advanced dementia by working with the resident's family and the facility to develop an addendum to the original resident agreement. The facility wanted to transfer the resident because of behavioral issues. The individualized addendum stated the intervention the facility was going to use to address these behavioral symptoms. It also required monthly meetings to assess the situation and periodic review of the plan.
- Analyzing the contract. Ombudsmen can: 1) see if the proposed action is tied to illegal provisions in the contract and point out the illegality to the operator; 2) identify any illegal provisions in the contract (whether they relate to the matter at hand or not) and use those issues as leverage in negotiating on a resident's behalf; and/or 3) determine whether the contract violates *any state law or standard* and then persuade a provider to take certain action in light of those illegalities. For instance, the ombudsman might say to a facility administrator or corporate manager, "You have a contract that may not be enforceable. Given the potential irregularities in the contract, we are asking you to permit the resident to...."

- Using substantiated problems with provider care as leverage in helping a resident with a contract provision. The Alaska Ombudsman Program has taken this approach to assist residents who want to move to another facility because of poor care, but are told that their contract with the original facility obligates them to pay the next month's rent unless another occupant can be found. In this situation, ombudsmen advise residents to move without paying the next month's rent. They then inform providers who wish to pursue action against the resident that the provider certainly has the right to go to small claims court over the matter, but that the program has found quality of care issues in the home and will be sharing information about those problems with the judge.
- Applying the community standard argument. In North Carolina, a regional ombudsman was contacted by a resident who had signed an assisted living facility contract that included a lifetime guarantee controlling her rent. When the facility was sold to a different owner, a new contract was issued that removed this provision. One approach the Ombudsman Program considered was to emphasize to the home that breaking the promise that had been made to the resident would not sit well with the community since the local culture placed great value on honoring commitments.

Systems advocacy for contract issues

To effect change at the systems level, ombudsmen can:

- Develop a “model contract” for assisted living facilities. If the contract is to be mandatory, ombudsmen can work to pass legislation establishing a uniform admission agreement, as California advocates did for nursing homes in 1997. However, the contract could also be voluntary. In this case, advocacy could be patterned after the efforts of the Washington State Ombudsman Program to create a suggested assisted living resident admission agreement. The Ombudsman Program joined with other stakeholders in the state to formulate two model contracts - one for private pay and one for Medicaid-eligible residents. The contracts are now widely used, and the Washington assisted living facility provider association even recommends their use to its members. A copy of the sample agreement for private pay residents can be found in Appendix 5.
- Use “advocacy by analogy” to change regulations regarding contracts. As mentioned in Section IV, the Oregon Ombudsman Program used this approach to eliminate private duration-of-stay contract provisions in assisted living.
- Advocate for state statutes and regulations that specify what must and cannot be included in an assisted living contract.
- Advocate for more detailed regulations to lessen the reliance on contracts. Such regulations give ombudsmen stronger legal tools with which to help residents.

- Educate residents, family members and the public about what to look for in contracts prior to selecting a facility and where to turn for help if they encounter problems once they or a loved one are in a facility. The Colorado Ombudsman Program has developed a consumer handout for this very purpose (see Appendix 6). In Maryland, assisted living ombudsmen counsel callers looking for assisted living facilities to make sure that any particular needs they might have are addressed in the contract.

DISCLOSURE

Any consumer shopping for an assisted living facility quickly learns that very few facilities are alike. Services differ from place to place, as do the fees and the fee structures. All these factors make it almost impossible for consumers to compare “apples to apples” when selecting among homes and to differentiate between the advertising/marketing of a facility and what it truly offers.

To help consumers in assisted living, ombudsmen can draw upon their years of experience in helping residents and families select a nursing home. Such assistance is provided primarily through consumer information, education and consultation. As they have done so well in the nursing home arena, ombudsmen can make public presentations and counsel individuals about how to determine what exactly an assisted living facility offers and how to compare one to another. Ombudsmen can help consumers with this “comparison shopping” in other ways as well. One approach is to develop “worksheets” for consumers to use when trying to distinguish one assisted living facility from another. Ombudsmen can base these worksheets on categories used in disclosure forms from states with a disclosure law. Another way to promote effective comparison shopping is to encourage “truth in advertising.” This approach is used by a local North Carolina ombudsman program which developed a detailed consumer’s guide so that facilities could clearly spell out exactly what services they provide and the costs. A sample of information from this guide is included in Appendix 7.

Uniqueness of the assisted living arena in disclosure

- Unlike nursing home regulations, assisted living regulations in many states do not mandate exactly what services a facility must furnish.
- The services to be provided may be determined by each *individual* facility. Consequently, consumers must carefully research what a facility does and does not provide.
- The services may be misrepresented through marketing materials. An ombudsman in Idaho has observed that assisted living facilities sometimes state that they have a registered nurse on staff. She notes that residents and families may choose the facility for this very reason, believing that the facility will be able to respond to nursing questions and concerns. However, the ombudsman has been contacted by angry and frustrated residents and families who discovered after the fact that the nurse is only there to conduct assessments and care plans and that they must call their doctor if they have any questions.

Ombudsman strategies for disclosure problems to address the uniqueness of assisted living

- Applying consumer deception laws. When a resident is not being provided with a service that a facility has claimed to offer, the ombudsman can gather all pertinent information about the facility (ex. any type of disclosure form, brochures, websites, marketing materials, resident handbook, contract) and use deception laws to persuade the facility to provide the service.
 - ⇒ On the state level, apply state deception laws and work with the State Attorney General's office. In Oregon, the Ombudsman Program has worked with the Oregon Department of Justice to enforce the state's "Unlawful Trade Practices Act" against facilities when their conduct has harmed residents.
 - ⇒ On the federal level, Ombudsmen may want to consider federal laws with regard to deception in advertising and work with the Federal Trade Commission to enhance their efforts to persuade the facility to offer the service or alter its marketing practice.
- Filing a complaint with the state Consumer Protection Division.
- Using state disclosure laws. Ombudsmen can argue that a facility must or cannot take actions depending on what the facility has previously disclosed. For example, in Oregon, an assisted living facility cannot move a resident to a smaller apartment when the resident converts to Medicaid unless that is disclosed in the admission contract. The Oregon State Ombudsman has used this disclosure requirement to block efforts to move some residents.
- Advocating with the individual facility or with the corporation to change inaccurate or misleading information in marketing materials.

Systems advocacy for disclosure

One of the most effective ways to address disclosure issues at a systems level is to advocate for a uniform disclosure law. Such a law requires that each assisted living facility in a state disclose the same information in the same format, usually on a prescribed disclosure form. The information to be provided might include: a description of the services to be furnished to the resident in the base rate; fee schedules outlining costs of additional services; and the criteria used to determine who may continue to reside in the facility. This type of law was passed in Indiana with input from the Indiana Ombudsman Program. The Indiana disclosure law can be accessed at <http://www.in.gov/legislative/ic/code/title12/ar10/ch15.html>.

VI. ETHICAL ISSUES FACED BY OMBUDSMEN IN ASSISTED LIVING

Ombudsmen are frequently faced with ethical issues in their work. They must determine how to proceed when they don't know what an individual resident wants and there is no family or legal representative to speak on her behalf, or decide what to do if advocating for one resident would have a negative impact on other residents. Such dilemmas arise in long-term care ombudsman practice in all settings.

However, given the distinctive features of assisted living facilities that have been described throughout this paper, ombudsman advocacy in assisted living has its own unique ethical issues. Examples of some of the dilemmas that ombudsman programs are facing across the country are described below.

- How do ombudsmen support the need for protection/safety of residents in assisted living while upholding residents' rights and wishes? This issue surfaces in a couple of different ways.

⇒Scenario #1: An ombudsman has substantiated very poor care in an assisted living facility and is not able to persuade the operator to improve conditions. She has exhausted all possible avenues, and regulatory action is the only remaining option. However, many of the residents have said they would prefer to live with substandard care than to move. The majority of residents are on Medicaid, and this is the only facility that takes Medicaid-eligible residents in a 200-mile radius. Should the ombudsman initiate regulatory action that might ultimately result in facility closure?

⇒Scenario #2: A state is writing or rewriting its assisted living regulations and the ombudsman program is at the table. Do ombudsmen push for stringent regulations that would have the result of forcing operators out of business - particularly operators of small homes who care for very low-income, often mentally ill residents, whom no one else will take?

- What should an ombudsman or the ombudsman program do when a resident who has decision-making capacity, but whose care needs exceed what a facility is licensed to provide, asks the ombudsman to assist her in fighting to remain in the facility?

⇒Scenario #1: The ombudsman believes that the facility is capable of meeting the resident's needs or appropriate services can be brought in.

⇒Scenario #2: The ombudsman believes that the provider truly can't meet the resident's needs in this setting.

What if the resident does not have decision-making capacity?

- How do ombudsmen respond when they find an unlicensed facility, however operating in a state that requires licensing, but residents like the home and wish to stay?

Clearly ombudsman assisted living work is complex, and advocacy at the systems level can result in ethical dilemmas at the individual level and vice versa.

There is no “one size fits all” answer in any ethical dilemma. Joan McIver Gibson, Director of the Center for Health, Law and Ethics at the University of New Mexico’s Institute of Public Law, told ombudsmen at a national state ombudsman training conference in 1991 that “there are rarely rights or wrongs - there are actions which are better or worse than others as a result of better or worse thinking. The key is the process used to sort out the options and arrive at a choice.”²⁹

State ombudsmen need to ensure that such a “process” is created for their programs. This is essential since these situations are going to arise as part of day-to-day ombudsman advocacy. Without a framework for working through such situations, decisions might be made that negatively impact an individual resident, all residents in a particular facility or the state, and/or the ombudsman program itself. For instance, in the first example discussed above, choosing to advocate for a resident to stay in a facility in one situation (the ombudsman knows the facility is “good” and will truly provide the services it says it will), but not in another (where the ombudsman knows the facility does not have a history of good care and is concerned that services promised will not be delivered), can open the program to accusations of inconsistency. This claim can jeopardize the program’s credibility.

Each ombudsman program should develop guidelines for addressing ethical issues as a statewide program. Such program guidance should be established through a collective “group think” process involving ombudsman program representatives at every level to promote thoughtful ethical decision-making.

Some of the factors for ombudsmen to consider when crafting program guidance on handling ethical dilemmas in assisted living include:

- What are the short-term, long-term and possible unintended consequences to:
 - ⇒the particular resident involved in the matter?
 - ⇒the other residents at the facility or in the state?
 - ⇒the provider (i.e. will the home close)?
 - ⇒the ombudsman program?

Ombudsmen need to think broadly about the possible results their actions might have, asking if their actions will cause the resident(s) harm or make the situation worse for the resident(s).

²⁹ Hunt, S., and Wood, J. *Ethical Issues in Ombudsman Advocacy*. Ombudsman Reporter. National Center for State Long Term Care Ombudsman Resources. Summer, 1991. p. 1.

- What are the financial resources of the residents in the home? What other facilities are in the area? If a small assisted living facility were to close, are there other homes in the same community? Can the residents afford those facilities? Unlike in nursing homes where Medicaid covers expenses, a number of assisted living residents, particularly in smaller homes, rely solely on their Social Security checks to pay for their room, board and care.
- Is there regular ombudsman presence in a facility? This must be considered since the ombudsman's ability to visit a home frequently can influence whether the program takes action at a certain time or chooses to monitor the situation very closely instead.
- What protections are in place for residents? As noted in the section on transfer/discharge rights, many states do not have laws and regulations that provide residents with any recourse if the facility decides to evict them. There may also be no rights against retaliation. Lack of such standards may lead the ombudsman to select a more cautious course of action.
- What are the options available to the resident(s)?

When an ethical issue arises, working through these questions and applying the ombudsman principles described at the beginning of this paper can guide ombudsmen in making difficult decisions and ensuring that all program representatives are taking the same factors into consideration.

In addition to the above framework, ombudsmen might also consider forming an ethics committee. Such a group could review the types of ethical dilemmas that have already arisen or that might come up in the ombudsman program and give recommendations as to how ombudsmen could handle those cases in the future. The regional Ombudsman Program in West Virginia has taken this approach and created an "Ombudsman Program Multi-Disciplinary Team Committee" comprised of members representing a number of different disciplines. Difficult cases and questions pertaining to the ombudsman program are presented to team members for their input as to how these issues can be addressed. The program reports that feedback from the team has been very helpful.³⁰

A more indepth discussion about addressing ethical issues in ombudsman work in general can be found in "An Ombudsman's Resource Paper for Effective Advocacy: Working Through Ethical Dilemmas in Ombudsman Practice."³¹

³⁰ *Best Practices of Regional Ombudsman Programs: Ombudsman Program Multi-Disciplinary Team Committee*. National Long-Term Care Ombudsman Resource Center website. http://www.ltombudsman.org/ombpublic/49_507_1801.CFM

³¹ Hunt, S. *An Ombudsman's Resource Paper for Effective Advocacy: Working Through Ethical Dilemmas in Ombudsman Practice*. National Center for Long Term Care Ombudsman Resources. 1989.

VII. CONCLUSION

It was stated in the introduction to this paper that ombudsman practice in assisted living is not “a whole new ball game.” As long-term care ombudsmen either begin or continue their assisted living advocacy, they should be constantly considering nursing home advocacy examples and how to translate those examples to the assisted living arena. Sometimes this happens naturally as ombudsmen carry over their basic principles into another setting. At other times, ombudsmen will need to carefully reflect upon the lessons learned from nursing home work and how they might pertain to assisted living facilities. And while, as this paper points out, there are certainly parts of the “ball game” that are indeed new and will require different approaches, it is important that ombudsmen learn from their many years of nursing home experience and not lose precious time covering the same “bases” again.

VIII. RESOURCE LIST

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National Long-Term Care Ombudsman Resource Center. Provides documents developed by the Center including *Ombudsman Advocacy Challenges in Assisted Living: Outreach and Discharge*; and *Translating Nursing Home Ombudsman Skills to Assisted Living: Something Old/Something New*. <http://www.ltombudsman.org>