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# Chapter 5

# Safety, Self-Determination, and Choice in Long-Term Care: The Consumer and Ombudsman Experience

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Professional caregivers, administrators, policy makers, and advocates have learned much from research and literature about the balance between protection against harm, on one hand, and consumer rights and autonomy to make decisions, on the other. This chapter reports some outcomes of that learning, through exploration of the experiences of long-term care ombudsmen in applying knowledge and skills to real situations.

For thirty years, long-term care ombudsmen have been helping resolve problems with and for residents of nursing homes and other long-term care consumers. (Although some state ombudsman programs have authority to assist home care consumers, the term "residents" will be used here for consistency.) After a period of demonstration in selected states, the Older Americans Act (hereafter, the Act) was amended in 1978 to require that states receiving Older Americans Act funds establish and operate long-term care ombudsman programs. In the years since its inception, the authority of the ombudsman program has evolved and the ombudsman's role as an advocate has grown. Consequently, the Office of the State

Ombudsman in every state has a well-defined and visible presence in long-term care. That presence ranges from broad systems-level advocacy for public policy benefiting long-term care consumers, to individualized advocacy for one nursing home or residential facility resident at a time. It is primarily the individual day-to-day ombudsman experiences that will be explored here in the context of the safety and self-determination of those residents.

The Office of the State Long-Term Care Ombudsman is charged with many responsibilities under the Act and, for context, a listing of those responsibilities is warranted. Long-Term Care Ombudsmen (hereafter Ombudsmen) are responsible for: identifying, investigating, and resolving complaints; providing services to assist residents in protecting their health, safety, welfare, and rights; informing residents about the means of obtaining services from providers or agencies; ensuring that residents have regular and timely access to the services provided through the Office of the State Long-Term Care Ombudsman; representing the interest of residents before governmental agencies; seeking administrative, legal, and other remedies to protect the health, safety, welfare, and rights of residents; analyzing, commenting on, and monitoring the development and implementation of federal, state, and local statutes and regulations and other governmental policies and actions that pertain to the health, safety, welfare, and rights of residents with respect to the adequacy of long-term care facilities and services in the state; recommending changes to any such laws, regulations, policies, and actions as appropriate; facilitating public comment on the laws, regulations, policies, and actions; providing training to representatives of the office; promoting the development of citizen organizations; and providing technical support for the development of resident and family councils to protect the well-being and rights of residents (Older Americans Act, as amended, 2000).

There are three recognized types of ombudsman entities. After extensive review and discussion, in January 2002 the American Bar Association released standards for ombuds (ABA term) offices. This landmark work recognizes the similarities and differences among classical, organizational, and advocate ombuds roles. It clarifies that ombudsmen investigate complaints with impartiality but that the advocate ombudsman, such as the long-term care ombudsman, is not precluded from advocating on behalf of a subject population. Classical and organizational ombuds focus on advocating for change within the entity (American Bar Association, 2002). For the long-term care population, this advocacy role is especially important because of the inherent and increasing acuity of nursing home residents (Harrington, Carrillo, Wellin, & Shemirani, 2002). They might or might not be able to make decisions for themselves. In 2001, nearly 43% of nursing home residents had a dementia diagnosis (Harrington et al., 2002). Although many residents with dementia are still able to make day-to-day choices, experience has demonstrated that a dementia diagnosis or symptoms cause others to doubt capacity. Even if residents are able to make decisions for themselves, they might not be able to execute their choices because of the confines of institutional living and regi-

mentation. The ombudsman helps to balance the power between the resident and the long-term care provider to resolve a complaint using a number of strategies—empowerment through education and informational support, education of caregivers and administrators, negotiation, brokering with other agencies such as the regulatory agency, and referral.

Obviously then, the ombudsman is not a regulator and has no power to enforce standards of care. In that sense, the ombudsman has no stick with which to guarantee cooperation. It is not unusual for consumers, particularly family members, to say that the ombudsman needs more power (Ohio Department of Aging, 2001). However, it is the nonregulatory nature of the ombudsman wherein the power really lies to resolve problems as an advocate. The ombudsman is not constrained by the need to identify a regulation that applies to a complaint, but uses regulations as a resource in a tool kit. The ombudsman has the flexibility to be an advocate for process, an advocate for adherence to and application of the law when indicated, and an advocate for common sense. This flexibility can contribute to a greater sense of trust and cooperation with long-term care provider staff. Additionally, residents can feel more comfortable talking with the ombudsman about their concerns because they are less likely to get the home into trouble, something that residents are sometimes hesitant to do.

Ombudsmen are not legal surrogates for consumers who can no longer make decisions for themselves. They are taught that decisions based on best interest should be left for legal surrogates, such as court-appointed guardians. In fact, ombudsmen really are not decision-makers at all in the process of problem resolution. They serve as resources and educators for decision-makers and as facilitators for decision-making processes.

Ombudsmen also are not law enforcement officers or attorneys practicing law who must adhere to strict standards of evidence to determine that a complaint is verified. The definition of "verified" used by ombudsmen throughout the country is, "It is determined after work (interviews, record review, observation, etc.) that the circumstances described in the complaint are substantiated or generally accurate." (Administration on Aging, 2001)

The role of the advocate is not always clear. For a variety of reasons, there are circumstances under which an ombudsman may struggle over the best path to take and how far down a path he or she should tread. In addition to training, a Code of Ethics adopted by the National Association of State Ombudsman Programs provides helpful guidance. The ombudsman:

- Provides services with respect for human dignity and the individuality of the client unrestricted by considerations of age, social or economic status, personal characteristics or lifestyle choices.
- Respects and promotes the client's right to self-determination.
- Makes every reasonable effort to ascertain and act in accordance with the client's wishes.

- Acts to protect vulnerable individuals from abuse and neglect.
- Safeguards the client's right to privacy by protecting confidential information.
- Will provide professional advocacy services unrestricted by his/her personal belief or opinion. (National Association of State Long-Term Care Ombudsman Programs, n.d.)

Several questions arise in considering the issue of the ombudsman's role in matters of health and safety and a consumer's right to make decisions affecting his or her own life. The two do not have to be in conflict and it is often the ombudsman's role to help others see safety and self-determination as congruent. "The choice between autonomy and well-being…requires not simply choosing right from wrong, but choosing right from right, choosing one value over another." (Collopy, 1990, p. 9)

Case examples are described below to illustrate ombudsman application of principles and tenets of practice. The authors and many ombudsmen throughout the country rely on the work of Sara Hunt, Consultant to the National Long-Term Care Ombudsman Resource Center, who compiled the best of the best thinking on issues of capacity, self-determination, autonomy, and related ombudsman practice (Hunt, 1989). These illustrations are based on actual cases, but are generalized and modified slightly for confidentiality.

### Case Example 1: Resident Choice in Involuntary Nursing Home Closure

A nursing facility with a four-year history of poor performance and negative resident outcomes was terminated from the Medicare and Medicaid programs by the Centers for Medicare and Medicaid Services. The state survey agency also issued an order revoking the operating license of the home, providing the opportunity for the home to appeal. At the time of termination, there were approximately 78 residents in the 100–bed home. The state and local Medicaid agencies and the ombudsman followed previously established guidelines for notification of residents, families, and legal representatives about the status of the facility, and that they would have to move to a certified nursing home in order to continue receiving Medicaid or Medicare coverage for their care. A complicating factor in the process was that, on the day of termination, the nursing home applied for restoration of its certification. The ombudsman spoke with residents and family members individually during a coordinated visit to the nursing home and explained that Medicaid would continue to pay for their care for thirty days for purposes of relocation. The ombudsman and Medicaid officials also explained that the nursing home had applied for restoration of certification and that, if they became recertified within the thirty-day period, it would not be necessary for the residents to move. So there *were* options for the residents and their surrogate

decision-makers. They could move as soon as another nursing home with available space was identified. They could take a chance that the nursing home would become certified again and stay. Additionally, they could stay and pay privately under arrangement with the nursing home as long as the nursing home retained its license. The reaction of residents and family members varied, but the author's experience was that the majority did not want to move. Many felt that the nursing home had been targeted by the state survey agency based on a complaint from a former disgruntled employee. The ombudsman's experience with this home was consistent with the survey agency's findings, specifically that double-digit numbers of complaints had been received including, but not limited to, allegations of neglectful conditions such as pressure sores and physical plant problems such as a leaking roof. Additionally, the surveyors found that a staff member, against whom the nursing home itself had verified abuse, was rehired and assigned to care for residents on the night shift.

In termination and closure, the ombudsman has several roles, all focused on advocacy for and protection of resident rights, quality care, and quality of life. It is the ombudsman who is best able to assist a resident with selection of another home, due to the ombudsman's knowledge of the community (Murtiashaw, 2000). The ombudsman usually knows the facility management and staff since, by the time a home is terminated, he or she has handled complaints and made numerous visits. The ombudsman is trained to manage the conflict that will inevitably occur in situations involving the termination or closure of a home.

The ombudsman's dilemma in this case centered on the conflict between resident wishes and the facts of poor facility performance, with the resulting concern for resident well-being. Residents did not want to move. Although there are varying views on transfer trauma, it is clear that adequate preparation is essential to minimize the risk to residents of physical and psychological problems as much as possible (Wood, 2002). Another issue was that the ombudsman had seen multiple-care problems in the home and agreed with the survey agency that, after years of intermediate sanctions and attempts by the agency to give the nursing home chances to correct the problems, the time had come for termination. Additionally, the homeowner owned another facility in the vicinity that had occupancy at 51% of licensed capacity, so the homeowner planned to encourage several residents to relocate there. That home had an above-average number of deficiencies cited on its most recent state survey; problems with inadequate space in resident living areas were alleviated only because the census was low.

After considering these issues, and in keeping with the ombudsman Code of Ethics, the ombudsman made every reasonable effort to ascertain and act in accordance with the clients' wishes, acted to protect residents from abuse and neglect, promoted the clients' right to self-determination, and provided

professional advocacy services unrestricted by her personal opinion. She first focused on empowering residents and family members to make informed choices. She assembled a notebook for every resident, containing the statement of deficiencies, compliance and family satisfaction information about other nursing homes in the state, and information about the ombudsman program. Another ombudsman scheduled time to be in the nursing home and notified family members of the opportunity to discuss the situation and request assistance. Many of the residents and families decided to wait out the recertification process, but eventually moved when the survey agency identified continued deficiencies and could not recertify. Most of the private-pay residents decided to stay at the home as long as the license was intact. A few Medicaid-eligible residents worked out payment with the nursing home so they could stay, including one who initially relocated and then returned. In total, ten residents remained at the nursing home. The ombudsman continued to visit and monitor care. She communicated with the survey agency about the status of the home from her perspective, as well as following up with residents who relocated to other homes. The nursing home owner hired a new administrator with experience in turning around troubled nursing homes and the ombudsman developed a relationship with him for ongoing communication.

Armed with the experience of this situation and the reactive nature of ombudsman involvement, the ombudsman can be an important part of prevention and proactive approaches to quality problems. It was clear in this example that resident preference was for the home to remain open and that residents not have to move; yet there were serious concerns about resident health and safety.

As an advocate for both resident self-determination and safety, the ombudsman can promote the more aggressive use of intermediate sanctions that are underused, such as temporary management (Wood, 2002). The ombudsman can establish more frequent communication with the survey agency in order to identify problems before they escalate to high levels of scope and severity, encourage the development of temporary management, provide residents and family members with information to raise expectations for quality as well as information for contacting facility owners or corporation leadership about problems, empower resident and family councils to communicate with facility administration on a regular basis, and speak to community groups to raise awareness of issues in long-term care facilities (Murtiashaw, 2000).

### Case Example 2: Due Process Rights, Client Choice, and Safety of Others

A nursing home proposed to discharge a resident based on behavioral manifestations of his mental illness. The resident was breaking furniture and acting in other ways that posed a danger to other residents. He was transferred to an acute care hospital for evaluation and treatment, and then upon hospital dis-

charge the nursing home refused to allow him to return. All residents have a right to due process prior to nursing home discharge, including proper notice and an opportunity for appeal, 42 C.F.R. §483.12. The nursing home had a duty to appropriately assess the resident's needs and plan care to meet those needs, 42 C.F.R. §483.20. As a practical matter, the ombudsman believed that it was not appropriate simply to move the problem to another nursing home and knew that adequate home care resources were not available in the resident's particular community. In addition, the ombudsman was concerned about the safety of other residents. In this case, a family member with legal authority acted as the resident's surrogate after the ombudsman visited the resident and determined that he did not have capacity to express his wishes. The family member expressed a desire on the resident's behalf to have him remain at the home so that he could have family members visit more conveniently.

The goal for the ombudsman intervention was multifaceted. In order to balance the interests of the resident who needed appropriate care for his illness with the interest of safety for other residents in the living environment, the ombudsman advocated for due process for the resident and requested a hearing. At the same time, he educated himself about the accountability and responsibilities of the public mental health system in order to identify available resources that could help the nursing home meet the resident's needs so that he could remain there without placing other residents at risk of harm. He additionally contacted the regulatory agency with a complaint about improper discharge. The agency opted not to cite the nursing home for improper discharge because the serious nature of the resident's behavior presented potential harm to others in the living environment. At a systemic level, the ombudsman looked at the holes in preadmission screening regulations and processes that the resident had slipped through on his way to admission to the nursing home. The state ombudsman formed a work group to evaluate preadmission screening rules.

A tangential question arises in this case about the ombudsman, involving the regulatory agency. The ombudsman feared that the surveyors' decision not to cite the home for improper discharge would send a message to the nursing home administrator that he could "dump" residents with difficult behaviors without providing adequate notice. In negotiations, the negotiator strives for a substantive agreement while building a relationship with the other party (Fisher & Ury, 1991). Since the ombudsman's goals, based on the request of the client's surrogate, were to have the resident return to the nursing home and to keep other residents safe, should the ombudsman have attempted to work the problem out between the resident and the nursing home before contacting regulators, or could the involvement of the regulators impair the ability to build a relationship and achieve an agreement?

### Case Example 3: Self-Determination Under Guardianship

A nursing home resident wrote to the ombudsman, emphatically expressing her desire to go home and live independently. She explained that she had a court-appointed guardian who would not allow her to leave the nursing home. The letter was coherent and caused the ombudsman to question why the resident even had a guardian. The ombudsman visited the resident to discuss the request and learned that a guardian had been appointed because she had abused alcohol. The guardian had determined that, when the woman lived independently, she was a danger to herself. The guardian said he would consider assisted living, but not independent living, because she needed supervision to prevent alcohol consumption. The guardianship had been reviewed a few months earlier and the judge suggested that the client identify someone to be her guardian other than the attorney whom the court had appointed.

The ombudsman, grounded in her commitment to the client's right to self-determination, presented the client with options that included seeking to remove the guardianship and moving to assisted living as a step toward independence. The ombudsman explained the adult protective services (APS) system and the likelihood that the facility would contact APS if the resident left the home against the wishes of the guardian.

The options were not acceptable to the resident. She did not want to try to fight the guardianship again, but said that when she was ready she would suggest that the court appoint her son. In this case, the ombudsman became frustrated, not because she struggled with the concern for resident safety, but because the choice seemed so clear but the resident was not willing to execute her autonomous choice.

In another case with similar facts, a resident's son, who had been appointed as her guardian, raised objections to the client executing her choice to leave the nursing home. She was a Native American and wanted to return to her Native American community. Her son had never been connected to that culture and did not fully understand what it meant to her. The ombudsman talked to him on multiple occasions to discuss his fears about his mother's safety. She discussed the quality of his mother's life, the importance of cultural connection near the end of her life, and resources that were available for her in the community. Eventually, the resident's son felt comfortable with assisting his mother to carry out the decision she made, and the ombudsman facilitated the relocation.

### Case Example 4: Promoting Self-Determination Through Provider Consultation

Some of the ombudsman's most important work in promoting environments that allow for self-determination of consumers does not involve handling

complaints, but consulting with and educating care providers. In this example, a nursing home owner contacted the ombudsman when a family member obtained guardianship and requested that the resident's gastric feeding tube be removed. The resident had depended on the feeding tube for nine years and her husband/guardian had recently died, leaving the son to become guardian. Soon after the son's appointment, he directed the nursing home to have the tube removed. The resident's living will had been executed after the date the tube feeding began and before the resident lost decision-making capacity related to dementia.

The facility administrator was concerned because the resident had a living will indicating desire for continuation of nutrition and hydration. The administrator asked the ombudsman to help. The ombudsman recommended that the staff contact the probate court judge about the administrator's concerns with the directive of the new guardian. The nursing home requested a review and the home's medical director convinced the attending physician to delay removal of the tube pending the court's review. However, the judge agreed with the guardian and the physician removed the feeding tube. The ombudsman advised the nursing home to implement a care plan to attend to the needs of the resident, including allowing family members to visit as much as they wanted and providing grief support to staff members who were upset about the decision after they had cared for the resident for ten years. The resident died eleven days after discontinuation of artificial nutrition.

In this case, the ombudsman did not have a complaint from a client, so did not conduct an investigation or have a client goal for resolution. The issue of whether the guardian or the living will should take precedence was a legal question, which led to the suggestion that the nursing home legal counsel submit the issue to the probate court.

One of the American Bar Association standards (2002) for ombudsman practice sets out limitations on the ombudsman's authority, by stating that an ombudsman should not "conduct an investigation that substitutes for administrative or judicial proceedings." With that in mind, the ombudsman advocated for a process to be followed by the nursing home administrator, and served as a facilitator for an appropriate decision-making process.

### Case Example 5: Self-Determination and Staff Perceptions of Safety

In this case, the ombudsman received a complaint about conjugal privacy of a married couple in a nursing home. The complainant reported that a nurse entered a resident room after knocking on the door but had not waited for a response. The nurse found the married couple engaging in sexual activity in which one of their hands and feet were tied with neckties. The nurse immediately assumed that she was witnessing abuse and contacted the physician, who ordered that the residents be separated. The physician also ordered a

psychiatric evaluation of the residents. Based on the assumption of abuse, the staff expressed concern about their license to practice nursing if they were to allow sexual activity between these residents to continue.

The ombudsman's first approach to investigation and resolution was to meet with the residents together and separately to discuss their desires. Although the residents reported being embarrassed about the revelation of their activity, they emphasized that the activity was consensual. In this case, there was no question about the decision-making capacity of either resident. The ombudsman had worked with them on other matters previously and engaged in discussion to assure that both could express their wishes autonomously. She discussed concern about safety to assure that the couple understood the consequences of their choices. Given the very sensitive nature of the problem, the ombudsman was especially careful to map a resolution strategy that was directed by the couple. She assembled a manual with information about sexuality in the geriatric population and conducted training for nursing home staff to help them become comfortable with their own values and social mores. Through negotiation, she worked out protocols for administration of medication and other care. First, staff committed to respect the privacy of the residents by knocking on the door and waiting for a response before entering. Second, staff agreed to call the residents on their phone from the nursing station to alert them that medications were due to be delivered.

In this case, the ombudsman simply could have referred the nursing staff to the law that affords residents the right to privacy, 42 C.F.R. §483.10. However, she was concerned that perceptions of impaired safety would override the ongoing respect for resident dignity and choice. So she met with nursing home staff and educated them about rights, dignity, resident choice, and sexuality. After her intervention, the line of communication between the residents and staff was opened so they could work together to allow residents to make informed choices based on information about their medical conditions in the future. With regard to the psychiatric evaluation, the ombudsman informed the residents of their right to refuse the evaluation, but, after discussion, the residents decided to go through with the appointment in order to appease the nursing home physician. In the end, the residents benefited emotionally from the psychiatrist's validation of their private conduct and the increased understanding of the staff.

## CONCLUSION

The authority of the Ombudsman program has grown in the thirty years since it first became a part of the Older Americans Act. As the program has grown, so, too, has its reputation. Ombudsmen are generally well respected within long-term care

for their ability to investigate and listen to all aspects of an issue and assist with resolution by putting the client first and balancing right with right.

The case illustrations presented demonstrate that ombudsmen are sometimes clear about the desires of their clients and, quite naturally, sometimes have their own concerns about the decisions of the clients for whom they advocate. The most ombudsmen advocates can do under such circumstances is to help ensure that the residents or their surrogates have enough information to make informed choices. Grounded in the Code of Ethics, the ombudsman must put the client first. Ombudsman skills should be based on continuous learning that should include initial training in principles of self-determination. Ombudsmen need to keep this in the forefront as they pursue their day-to-day activities as advocates.

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