



# OMBUDSMAN REPORTER

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## ETHICAL ISSUES IN OMBUDSMAN ADVOCACY

by Sara S. Hunt and Jean Wood

At the Center's 1991 annual State Long Term Care Ombudsman Training Conference, one morning was devoted to discussing ethical issues pertinent to ombudsman advocacy. This article contains highlights of the presentations and discussions from those sessions and references other relevant resources. There are three sections of content:

- 1) an ethical framework for ombudsmen;
- 2) ombudsman responsibilities with advance directive issues;
- 3) ombudsman responsibilities with residents who cannot consent.

It is hoped that this information will contribute to the ongoing discussions about the application of ethical principles to the daily work of ombudsmen.

### 1. AN ETHICAL FRAMEWORK FOR OMBUDSMEN

In the opening plenary session, Joan McIver Gibson offered guidance to ombudsmen regarding ethical dilemmas. Joan is the Senior Program Director of the Center for Health Law and Ethics, at the University of New Mexico's Institute of Public Law. A synopsis of her remarks follows.

#### ✓ Develop a Way of Thinking

To work through ethical dilemmas is to develop a way of thinking and to become comfortable with discussing the issues. 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. Conflicts usually arise over the application of values rather than over values.

It is important to ask:

- what "harm" are we preventing?
- what "good" are we doing?
- what's the real issue?
- what do we need to know to make this decision?
- what are client's questions/concerns?

A good grounding in alternative dispute resolution may be helpful in working through issues. If your ability to discern an autonomy issue still leaves you asking yourself what you should do, you're absolutely "right on". Ombudsmen need to be able to tolerate ambiguity.

#### ✓ Values Emerge From Relationships

Values come out of relationships, and are articulated in conversation. They may evolve and change depending upon who's

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involved in the conversation. For example, a resident may say one thing by herself and something else with her family present. Is either statement less valid? Isn't that what happens to us on a daily basis? No one holds us to consistent expressions of our decisions as a way of judging our decisional capacity. Ombudsmen need to be identifying individuals to be involved in the conversation with the resident when conflicts arise.

Ombudsmen need to consider the communal aspect of values and relationships when adhering to strict confidentiality policies. In honoring resident rights and the values of someone else, we need to avoid separating the individual even more. The rules and principles of autonomy, beneficence and justice are less fundamental than **roles and relationships** in deciding what we should do and in discerning which values are important to us. Everyone of us is an individual only in so far as we see ourselves both in relationship to and as separate from each other.

✓ Consider Autonomy and Community

Given that values develop within the context of relationships, the worship of autonomy can be destructive. In its extreme we turn ourselves into living life all alone. The nursing facility or a board and care home setting has already separated residents from those persons and places which are their most important connections. By pursuing a philosophy of extreme individualism, we are increasing the separation of people who are already vulnerable. We may be separating them even more from people and places they may need. Therefore our emphasis upon autonomy should not be at the expense of valued relationships or presented in such a way that we threaten the potential to foster positive community connections. We

need to think about our advocacy in ways that enhance connections rather than exacerbate distances between people. For example, ombudsmen need to take seriously the interests of all the stakeholders when trying to decide how to proceed in working through a conflict. The stakeholders include the resident, family members, the caregivers, the community in which the resident resides, and the ombudsman. To work through dilemmas, ombudsmen need to find ways to honor the connections that exist and learn to develop conversations among the stakeholders.

✓ Ask Questions of Facilities About Advance Directives and Medical Treatment Decisions

There are five questions ombudsmen might want to ask facilities:

- 1) What are your policies regarding advance directives?
- 2) What are your policies regarding decisional incapacity? How is decisional incapacity determined? Is it based on a diagnosis? How is a decision about decisional incapacity reviewed?
- 3) What do you know about the state's laws concerning proxy consent, durable powers of attorney, living wills, family consent? How well informed are the people in your facility about these issues?
- 4) What are your policies for resolving disputes?
- 5) Is a values history available in the facility? (A values history is a tool to assist an individual in stating his/her wishes, preferences, goals and values. It can be useful in guiding treatment decisions.)

✓ Ask Questions About Ombudsman Cases

In ombudsman advocacy, consider these questions when working with a case.

- 1) What really are the issues? Are they legal? medical? psychosocial? economic?
- 2) How can I use resources to help me sort this out? Are there professionals in the community I need to consult? Who are the stakeholders in this case?
- 3) What values or beliefs are important to the resident?
- 4) What is my role as an ombudsman?

✓ Learn by Doing

A recurring theme was "there is no *they*" with ethical issues. The best way to become more comfortable with these issues is to practice discussions about our values and desires regarding medical treatment with our families and friends. Notice whether what you say differs with the setting and the people who are present. Decisions about ordinary, day-to-day issues may be harder than these about end-of-life treatment. For example, it may be easier to talk with mother about whether she wants a nasogastric tube than about when and how to decide she can no longer drive. It's the little issues that lay the groundwork for decision-making. Ombudsmen need to develop a way of thinking about, discussing, and working through ethical dilemmas by practicing with personal discussions.

This framework of ethical principles and ways of thinking about ethical issues was then applied to ombudsman work with regard to two issues:

- 1) the role of the ombudsman with advance directives issues, particularly the Patient Self-Determination Act, and;
- 2) the role of the ombudsman regarding clients/residents who cannot give consent for the ombudsman to act on their behalf and who have no legal representative to grant consent.

Each of these was the focus of a concurrent workshop to discuss the ombudsman role. Some areas of consensus emerged as well as further clarification of ethical concepts applied to these situations.

**2. OMBUDSMAN RESPONSIBILITIES WITH ADVANCE DIRECTIVES ISSUES**

Ombudsmen encounter these issues in individual client advocacy and with regard to facility-wide practices. Some examples are:

- An ombudsman is called by a facility because the family of a resident who can't communicate, and whose wishes aren't known, refuses the treatment that the physician and facility want for the resident. The facility is planning to discharge the resident.
- A resident in a nursing facility executes a living will and some of the directives in that document conflict with the facility's policies. The resident calls the ombudsman.
- Ombudsmen are being asked to serve as witnesses to advance directives documents or to serve on the ethics committees of facilities.
- In preparing to implement the Patient Self-Determination Act, some facilities are asking residents to sign Do Not Resuscitate and Do

Not Transfer orders. Ombudsmen have questions about their role and responsibilities regarding facility implementation of this law.

Joan Gibson set the stage for ombudsmen to discuss their role with regard to the Patient Self-Determination Act and advance directives as follows:

✓ Basic Premises in the Patient Self-Determination Act

- 1) Each of us has a right to accept and refuse medical treatment. We need to develop our own concept of medical treatment. Is it a medicine? Is it the goal of something? What are the mechanisms that people are given to accept or refuse treatment?
- 2) Facilities must inform people of their rights in their state to make decisions. Avoid using advance directives as a term. Instead say that laws exist to allow people to plan ahead for decision-making. Discuss proxy decision-making laws first, then discuss living wills.
- 3) Facilities must inform residents about policies and procedures they've developed internally. Do corporations require all of their facilities to use a uniform policy or do they use policies specific to each state's laws? Have corporate/chain facilities adopted the most conservative laws of the states in which they do business? Are their policies consistent with the laws of the state in which the facility is located?
- 4) Facilities must find out if an individual has some decision-making directive and get a copy of it.

- 5) Facilities must have a form for complying with this Act if the resident is interested in it.
- 6) Facilities must provide training for staff and the community.

✓ Key Aspects for Implementation of the Act and for Execution of Advance Directives

One key to implementation of the Patient Self-determination Act is **how information is presented and discussed** in the nursing home. Ombudsmen might consider:

- educating and counseling residents and families to help them see what the real questions are.
- guiding people to talk about what they **do want** instead of what they **don't want**. Have people talk about how they feel about pain, and function, for example, rather than about tubes.
- focusing on goals **NOT** on treatments. Treatments serve or deserve goals; they are instruments to an end, not the end in themselves. If the end is to relieve pain, then evaluate treatment options to see how they meet the goal. If it's life at any cost, then decide what will further life. Take the talk away from medical treatment to values.

✓ A Range of Roles for Ombudsmen

During the discussion in this workshop ombudsmen identified a number of roles that could be assumed in relation to the implementation of the Patient Self-Determination Act and with other opportunities for decision-making. Their ideas are in the following list.

- Convene a meeting at a nursing home, or for nursing homes in the community, to discuss how to inform residents and/or discuss issues with residents.
- Convene, or participate in, statewide planning meetings for developing the written materials, the actual text to be distributed, and for planning and carrying out educational programs for staff and consumers.
- Convene discussions with resident and family councils about how this should be implemented in their nursing home: what information they need and how they would want the issues discussed in individual situations.
- Monitor whether nursing homes are following residents' wishes, including a residents' wish not to write anything down and residents' right to change their minds.
- Advocate for self-determination in everyday decisions, not just advance directives.
- Don't take away a resident's autonomy and right to exercise choice about these daily or end-of-life decisions by labeling these as issues for ethics committees. There are several legitimate avenues for resolving disagreements or issues such as care planning meetings, resident councils, grievance processes, without sending all controversial issues or questionable decisions to an ethics committee.
- Protect residents from being evicted if the nursing home disagrees with

their choices about either the end-of-life decisions or everyday decisions.

- Monitor nursing home development of admissions criteria such as not admitting someone with an NG tube.
- Be involved in legislative developments for enactment of advance directive laws.
- Monitor what other groups, including the industry and public agencies, are doing to implement the law.
- Advocate for institutions to talk across institutional lines so that if a resident expresses wishes in the nursing home, her wishes go with her to the hospital.
- Conduct training for staff on proper implementation.

### **3. OMBUDSMAN RESPONSIBILITIES WITH RESIDENTS WHO CANNOT CONSENT**

The application of ethical principles to ombudsman advocacy on behalf of residents who cannot give consent was also the focus of a workshop, facilitated by Jean Wood. Protecting the rights of residents who cannot consent may conflict with the confidentiality provision in the Older Americans Act (OAA). The Older Americans Act states that the "identity of a complainant or resident will not be disclosed without the written consent of such complainant or resident..."[OAA 307(a)(12)(B)]. This provision exists to (1) assure the ombudsman consults with the resident and handles the problem according to the resident's direction, and

(2) address concerns about retaliation against the resident or complainant. The dilemma arises when the most vulnerable residents, those unable to speak or consent for themselves, have a problem that needs resolution. Often, due to the specificity of the complaint, the ombudsman will need to reveal the identity of the resident while handling the problem. The session made use of a case study that concerned a resident who could neither give nor deny consent and who had no guardian or other representative to give or deny consent. In the case scenarios, harm to the resident was probable and the type of harm increased as the case study progressed. The discussion focused on alternative problem-solving processes and potential protocols or guidelines ombudsmen could use when working with residents who cannot consent and who have no one authorized to act on their behalf.

#### ✓ Alternative Courses of Action

The alternative problem-solving processes discussed included the ombudsman:

- investigating to see if the resident's problem is shared by other residents, or is part of a facility-wide problem, in which case the problem can be pursued by the ombudsman without singling out the individual.
- observing the problem and acting as the complainant, sometimes referred to as an ombudsman-generated complaint.
- referring the problem or acting collaboratively with another agency. Such referrals may include an understanding that the other agency will conduct the investigation without revealing the individual resident's identity. In

some states, laws create an obligation for reciprocal confidentiality.

#### ✓ Single and Joint Decision-making Processes

Protocols for decision-making to guide individual ombudsmen could include the following:

- assessment of the client by the ombudsman. Such assessment should include analyzing the possible causes for the resident's nonresponsiveness; and exploring whether further interviewing, more sensitive interviewing, or interviewing at a different time of day would be productive.
- examination of alternative courses of action, as outlined in the previous section.
- assessment of potential harm to the resident if the ombudsman does not intervene;
- assessment of the risk of retaliation or other harm to the resident if the ombudsman does intervene;
- use of professional judgement.

Offices also should develop protocols for a joint decision-making process between the ombudsman handling the complaint and the state program. The joint process would encompass a joint local and state ombudsman review, usually by telephone, of the above steps. More than likely, they would analyze the information gathered by the responding ombudsman, discuss potential courses of action, and decide on the actions to take.

States favored using the single decision-making process when the responding ombudsman was comfortable deciding and

- Are local ombudsmen involved in developing and revising program policy?

✓ Conduct Training

- Conduct training to enable local ombudsmen to discuss their ethical dilemmas and to equip them to work with residents and facilities.
- Conduct training to address some of the issues and topics identified as areas of need by local ombudsmen.

RESOURCES RELATED TO ETHICS

A values history instrument is available from Joan Gibson. Contact Joan at the Institute of Public Law, 1117 Stanford NE, Albuquerque, NM 87131, (505) 277-5006.

A resource for training is "Working Through Ethical Dilemmas In Ombudsman Practice", developed by the National Center for State Long Term Care Ombudsman Resources in 1989. It consists of a paper discussing the topic and a training guide for in-service use with local ombudsmen. Copies of the resource paper and guide were provided to all state ombudsman Offices by the Center. Additional copies can be ordered from: the National Citizens' Coalition For Nursing Home Reform, 1224 M Street NW, Suite 301, Washington, DC 20005-5183, (202) 393-2018.

Generations, the Journal of the American Society on Aging, has published a supplement to its 1990 issues, "Autonomy and Long Term Care Practice," Volume XIV. This issue includes articles by national experts such as Bart Collopy, Charles Sabatino, Nancy Dubler, Joan McIver Gibson, Rosalie and Robert Kane, and Iris Freeman, on the issues of autonomy in long term care facilities as well as in home care, including discussions

of client rights, guardianship, nursing home admissions, restraints, and an article by Janet Tulloch, "From Inside a Nursing Home: A Resident Writes About Autonomy." The issue can be ordered from ASA for \$8.00. Write to: American Society on Aging, 833 Market Street, Suite 512, San Francisco, CA 94103.

"Ethics Committees: Allies in Long Term Care," a video program produced by AARP and AAHA, is available for free loan to advocacy organizations, members of the aging network, and long term care administrators, and can be purchased for \$20.00. The video is accompanied by a facilitator's manual and a guidebook. To preview, write to: AARP Dept/ER, Program Scheduling Office, 601 E Street, N.W., Washington, DC 20049. Refer to Ethics Committee Program Kit - D14172.

Kane, R.A. and Caplan, A.L., eds. 1990. Everyday Ethics: Resolving Dilemmas in Nursing Home Life. New York: Springer.

Patient Self-Determination Act State Law Guide, American Bar Association Commission on Legal Problems of the Elderly, Washington, DC, August, 1991. This booklet is designed to assist states in implementing the requirement of the Patient Self-Determination Act that states develop a written description of the law of the state regarding advance directives. It includes a discussion of the requirements of the Patient Self-Determination Act; a process for states to follow in developing their written description; some guiding principles for the process; and a series of questions to be addressed in a states' written description. Copies of the guide will be sent by ABA to all state ombudsmen. Others can order the guide for \$5.00 from the American Bar Association, Commission on Legal Problems of the Elderly, 1800 M Street, N.W. Washington, D.C. 20036, (202) 331-2297.

## **NEWS FROM THE CENTER**

This newsletter departs from its usual format so that we can bring you a special lead article, based upon sessions at the recent national training conference which we knew would be of interest to all of you...We want to acknowledge that Ann Lordeman, former Center Director, has left NASUA to join the staff of the Congressional Research Service, and that Mary McKenna, former Center staff person, has returned to Massachusetts as a state long term care ombudsman. We wish them both well in their new endeavors... Some of you have asked about the ombudsman program promotional video being produced by the Center. It has experienced some delays, but will be completed this fall and distributed to all state ombudsman offices...

## **NEWS FROM THE STATES**

### **MISSOURI AND WEST VIRGINIA ENACT OMBUDSMAN LEGISLATION**

Both Missouri and West Virginia enacted ombudsman enabling legislation for the first time during their most recent legislative sessions. In addition to fairly standard provisions which implement requirements of the Older Americans Act, each of the states' law includes some unique features.

#### **Missouri's law:**

○ In addition to addressing access to residents' records, grants the ombudsman or representative authority to "make the necessary inquiries and review such information and records as the ombudsman or representative deems necessary to accomplish the objective of verifying these complaints."

○ requires the Office to "prepare and distribute to each facility written notices

which set forth the address and telephone number of the office, a brief explanation of the function of the office, the procedure to follow in filing a complaint and other pertinent information." The facility is then required to give this notice to every resident or her guardian upon admission or already in residence, as well as post the written notice in a manner set forth by regulation to be adopted.

○ requires the Office to "inform residents, their guardians or their families of their rights and entitlements under state and federal laws and rules and regulations by means of the distribution of education materials and group meetings."

○ makes the unauthorized disclosure by a representative of the Office of the identity of a witness or any information obtained from a witness pursuant to a complaint examination a class A misdemeanor.

#### **West Virginia's legislation:**

○ sets forth detailed qualifications for the state and regional ombudsmen, including a prohibition against their or any member of their immediate family having, or having had within the two years preceding their employment, any pecuniary interest in the provision of long term care.

○ prohibits ombudsmen from having been employed by a long term care facility, association of facilities, or by an organization or corporation that directly or indirectly regulates, owns, or operates a long term care facility, within two years of ombudsman employment.

○ restricts ombudsman volunteers to activities which do not involve "access to confidential resident or facility records...complaint investigation other than information gathering to ascertain the nature and facts of a complaint, [or]...the initiation or pursuit of legal proceedings, actions, or remedies."



○ permits state and regional ombudsmen to institute actions on behalf of residents to obtain injunctive and declaratory relief, but not damages. To enable such actions the Secretary of the state's Department of Health and Human Resources shall either: establish an administrative process to be available to state or regional ombudsmen bringing an action on behalf of a resident against a long term care facility or governmental agency, or ensure that state and regional ombudsmen have sufficient access to legal counsel to bring actions on behalf of residents in civil court.

○ permits state or regional long term care ombudsmen access to all records of long term care facilities that are "reasonably necessary" for the investigation of a complaint, including incident reports, dietary records, policies and procedures required under state and federal law, admission agreements, staffing schedules, "any document depicting the actual staffing pattern of the facility" and resident council and grievance committee minutes.

○ Authorizes the state ombudsman or designee to in the course of any investigation apply to the appropriate circuit court for the issuance of a subpoena to compel the appearance of a person, documents, or other evidence which the ombudsman reasonably believes may relate to a matter under investigation.

Copies of the Missouri and the West Virginia legislation are available from the Center.

### **OHIO PROMULGATES ADMINISTRATIVE RULES**

Last year, Ohio passed ombudsman enabling legislation which required that administrative rules be written. Because a process of open deliberation and input created good enabling legislation with

broad ownership, it was determined that a similar process would result in realistic and effective rules.

A rule writing committee was established by the State Ombudsman. Members included the State Ombudsman and state staff; regional ombudsmen appointed by the Ohio Association of Regional Long Term Care Ombudsmen (OARLTCO); and representatives of Area Agencies on Aging appointed by the Ohio Association of Area Agencies on Aging (OAAAA). An Ohio Department of Aging (ODA) attorney who would put the rules into final formal language was involved in all meetings and discussions to gain an understanding of the subject matter. To facilitate the rule writing process a consultant with significant experience working in the long term care ombudsman program was hired.

A regular schedule of meeting every three weeks was established. The first meeting was used to establish ground rules of the committee, review areas of the law specifically requiring rules, and organize the schedule of topics and set time frames for the completion of each step in the process including rule filing. Subsequent meetings were spent in reviewing rule language provided by the consultant based on prior discussions, followed by exploration of the next topic on the agenda. Because the consultant took responsibility for writing language, committee members were free to discuss and debate issues. To a significant extent this consisted of fully verbalizing established ombudsman practice in Ohio. The process was also very effective at addressing new requirements, their impact on involved parties, developing agreeable solutions and eliminating potential conflicts.

In addition to the topic by topic review, the committee was provided the opportunity to review and comment on the final draft of rules upon its conversion from layman's terms to formal legal language. Comments

were then discussed and incorporated. This draft was then circulated to a broader group of interested parties including other divisions within ODA, other state agencies, members of the long term care provider community and legislative sponsors. As required by ODA rules, a public hearing was held. Resulting comments were reviewed and incorporated into the final draft which was submitted to Ohio's Joint Committee on Agency Rules Review, leading to approval by Ohio's General Assembly within the one year deadline.

An open process such as this one requires a great deal of work and commitment on the part of each of the participants. Positive outcomes include:

- rules based on realistic practice
- acceptance/ownership of the product
- further establishment of positive working relationships
- facilitation of acceptance by lawmakers
- enhanced credibility
- timely accomplishment of goals

The rules include sections regarding: types of ombudsman representatives; duties of representatives; professional development and certification of representatives, including content and administration of certification exams; separation of representatives from the Office; continuing education requirements; staffing requirements and qualifications for regional programs; conflicts of interest; complaint-handling protocol, including referral to the standards for designation of existing and new regional programs; program review; provisional designation, involuntary withdrawal, and voluntary separation of regional programs; and notice rights and hearing requirements. Copies of the rules in their entirety, or of sections as described above may be obtained from the Resource Center. *Thanks to Jo Ellen Walley, Assistant State Long Term Care Ombudsman in Ohio, for developing this piece.*

## **RESOURCES**

**PASARR** - "Making Choices: Challenges for Advocates and Nursing Home Residents with Mental Illness," focuses on advocacy through sample cases for clients undergoing PASARR review. Single copies are free to AoA-funded attorneys and advocacy organizations. Contact: Mental Health Law Project, Elders Project, 1101 15th Street, N.W., Suite 1212, Washington, DC 20005, or call (202) 467-5730.

**Alzheimer's Disease** - "Special Care for Alzheimer's Disease Patients: an Exploratory Study of Dementia Specific Care Units," addresses research conducted in Florida in an attempt to find common features that could be combined to create guidelines for the design, operation, and staffing of "Alzheimer's units." For copies, contact: Lilia Alexander, State Liaison, National Resource Center on Alzheimer's Disease, 12901 Bruce B. Downs Blvd., MDC-Box 50, Tampa, FL 33612-4799, or call (813) 974-4355.

**Health Data - Reforming the Health Care System, State Profiles 1990** highlights the major health care characteristics of each state - demographics, health status, coverage, utilization, resources, expenditures and financing, cost containment/reform measures, and AARP membership and state legislative committee priorities for 1991 - and compares state data to national averages. Contact: AARP, Public Policy Institute, 601 E Street, NW, Washington, DC 20049, or call (202) 434-2277.

**Nursing Home Life - Borders of Time** is a collaboration between writer, Walter and photographer, Rob Crandall, who spent two years visiting a nursing home in Oregon. The book is an eloquent chronicle of life in a nursing home. It can be ordered from Springer Publishing, 536 Broadway, NY, NY 10012, for \$30.70.