NATIONAL ELDERCARE INSTITUTE
ON ELDER ABUSE AND
STATE LONG TERM CARE
OMBUDSMAN SERVICES

APPLYING ETHICAL PRINCIPLES TO INDIVIDUAL ADVOCACY

A Presentation by Joan McGiver Gibson, Ph.D.

Summarized by Sara S. Hunt

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APPLYING ETHICAL PRINCIPLES TO INDIVIDUAL ADVOCACY

Presented by Joan McGiven Gibson

This resource paper* contains a discussion of the ethical dilemmas facing long term care ombudsmen in their daily practice. One of the most problematic issues confronting ombudsmen is assessing the decisional capacity of often frail nursing home residents. This paper promotes the use of a values history as a method for determining an individual's wishes, and provides a description of a process ombudsmen might use for individual case advocacy. Ombudsmen are asked to think differently about the formation and expression of values and about decision-making capacity, and are challenged to:

- ☐ Become familiar with the varied ways in which people learn so that information can be presented in such a way that it will be received.

- ☐ Acknowledge the opportunity conflict presents for helping people express what is important to them.

- ☐ Assist the involved parties to develop their own solutions by really listening to what they say and asking the kinds of questions which empower the persons involved in the conflict, always making sure that the resident's voice is heard.

This paper serves as a companion piece to a series of publications on ethical decisions-making, produced by the National Center for State Long Term Care Ombudsman Resources. **Working Through Ethical Dilemmas in Ombudsman Practice** (1989) includes a resource paper and training guide. The paper provides a detailed discussion regarding approaches ombudsmen might take when a resident's decision-making capacity is questionable, and includes a glossary of ethical terms, a bibliography and selected readings. The training guide which accompanies the paper uses a case study approach to teaching ombudsmen to handle ethical dilemmas. In an article published in the **Ombudsman Reporter** (vol. 3, no. 1) entitled, "Ethical Issues in Ombudsman Practice," an ethical framework ombudsmen might use when handling cases which involve medical decisions and advance directives is described.

We hope that by using these resources, ombudsmen will develop greater insight in recognizing and responding to the ethical dimensions of the serious problems with which they are confronted. It is also our expectation that these resources will form a core of basic information which state ombudsmen can use to develop training for paid and volunteer staff on handling ethical dilemmas.

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* Joan McGiver Gibson, Ph.D., Center for Health Law and Ethics, Institute of Public Law, University of New Mexico School of Law: Excerpts from Presentations made at the Fifth Annual National Training conference for State Long Term Care Ombudsmen, June 1992.

INTRODUCTION

There are several questions ombudsmen face in daily practice such as:

- ☐ what is informed consent?
- ☐ how do you get informed consent when someone's decision-making capacity is questionable?
- ☐ how do you serve an individual whose decision-making capacity is questionable and who has no one to legally make decisions for him/her?

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In many areas we have exhausted the discrete possibilities for absolute certainty in responding to these questions. We know the criteria for informed consent and the state laws regarding decision-making. Although we can't ignore legal and clinical standards, the application of laws and standards to an individual's ability to exercise choice may leave us feeling like something is missing.

These objective criteria - checklists, procedures and legal standards - have limitations. If a legal or clinical decision about an individual's capacity leaves us feeling, "So what does <u>that</u> mean in <u>this</u> case?" that's the nature of the beast. Legal and clinical standards cannot tell us everything we need to know about an individual's ability to express a choice, to make a decision. We must continue to live with ambiguity. Instead of letting legal or clinical definitions be the sole indicator of an individual's ability to make a decision, ombudsmen should consider using a different approach to working through issues of decision-making capacity: that is, enabling an individual within the context of his/her community to express what is important. In doing so, ombudsmen face the following challenges:

To effectively work with individuals we must understand their perspective...we must hear what they say in the way they have to say it.

- ☐ We must pay attention to how people learn.
- ☐ We must acknowledge the opportunity and "joy" that working to resolve conflict presents.
- ☐ We must assist the involved parties in developing their own solutions.

When faced with ethical dilemmas, ombudsmen can benefit from using a primary ombudsman skill: **conflict resolution.** The process of conflict resolution can serve as a vehicle for getting people to talk, to tell their stories, to mediate. **Communication is a major component:** listening as you invite someone to tell her story and learning to understand how individuals obtain information.

In working with families, the conflict resolution process of having each person tell his/her story without interruption is a useful method for obtaining the family history, including the meaning attached to certain kinds of issues and the significance of the decision as seen by each person involved in the process. This process can lead to mediation and facilitate conversation about the essence of the issue. To effectively work with individuals we must understand their perspective, not force our terminology and values system upon them. We must hear what they have to say in the way they have to say it.

Asking a person if she wants a DNR order without realizing there is a life, a person, behind the answer to the question is dangerous.

For example, an older woman's doctor asks if she wants to be resuscitated. She replies that she just wants to be left alone, to sleep. In her mind, she meant that she did not want to be disturbed or awakened if she is able to fall asleep. Her doctor, however, thought she was assenting to a Do Not Resuscitate (DNR) order. Asking a person if she wants a DNR order without realizing there is a life, a person, behind the answer to the questions, is dangerous. It is irresponsible to accept an answer without making sure we fully understand what the answer means to the individual. Otherwise, the results can be horrendous.

We need to know what "does do not resuscitate" mean to this individual? What does this person want? Is she saying that she is exhausted and wants to sleep for three days? Is she saying that she does not want to be resuscitated under any circumstance? Is she saying that her daily life has no meaning? Does she understand what this terminology means in her life? What does the family want? What are the doctor and the staff saying? What is important to each person regarding treatment? What is the root issue?

AUTONOMY

The scientific approach to questions of treatment and medical utility is very narrow. It asks:

⇒ will the treatment achieve what it is supposed to?
⇒ what is the value of treatment (outcome) as assessed by the individuals involved?

This approach leaves unanswered the questions of: who is the client? For whom is benefit or autonomy being sought?

...we must be cautious about using autonomy and confidentiality to further isolate individuals who are already frail and vulnerable.

Sometimes certain rights, and even autonomy, have been imposed on people for whom these are irrelevant. An individual may not want to make a decision in isolation without considering the wishes of her family. As individuals, we often lack total autonomy. It may be more important to see how a person feels about a decision than to determine if the decision is an autonomous one. We might need to broaden the scope of who needs to be involved in talking about benefits and values of specific treatment modalities. Most important, we must be cautious about using autonomy and confidentiality to further isolate individuals who are already frail and vulnerable.

VALUES

Values are both public and community property. They emerge in conversation as part of the creative process. Individuals are not walking repositories of values developed in isolation. Rather, our values

are shaped and refined over a lifetime, within the context of community through a process of communication. Some of our values change as a result of dialog with others.

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To really explore another person's values, we have to engage in conversation with the person and be open to something new. To participate in such a conversation, we cannot separate our own values from the dialogue. We cannot hold our values outside of the communication process. By engaging in an open conversation and really listening to someone else, our values necessarily will be impacted due to the nature of values formation.

One approach to the discussion about values is to use a **values history** as a "jumping-off point".* A values history provides the opportunity to ask the person to teach us what we need to know. Values histories can serve as prompts to invite individuals to talk, to tell us what's important to them. It is important to ask what certain terms or questions mean to each individual. Some physicians have printed a values history on a brochure and bring up some of the questions/issues during on-going conversations with the individual. The values history then becomes a communication tool for understanding the person. We need to create an environment to allow clients to teach us about themselves and what they value.

DECISION-MAKING CAPACITY

Think of decisional capacity as a process, not an end product.

In assessing a person's decision-making capacity, avoid using a checklist. Pay attention if something comes at you from "left field," if something doesn't make sense. Ask yourself why you are uncomfortable with the person's decision. In addition, ask yourself these questions:

- ☐ Does the decision go against your value system?
- ☐ Does the decision fit with the person's story?

* *One version of a values history is avalable from Dr. Joan Gibson.*

- ☐ Are you more concerned with legal liability than with understanding what this person is expressing?

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QUESTIONS TO CONSIDER

A linear approach is not the best way to work through ethical issues. However, there are nine questions ombudsmen might consider in determining if the client is being given a "fair shake".

1. What are the health, legal, social, economic, etc., issues?

2. What are the ethical or value issues? What really matters?

3. What else do you need to know? What additional information or explanation is needed?

4. Who are the stakeholders, the individuals who will be affected by the decision?

5. What are the values of the involved parties?

6. What are the conflicts, the points of tension, of contention?

7. Must a decision be made? Who must make it? How important is it? Can it wait? If there is time to ask the question, there may be time to wait to make a decision. Uncertainties can be dealt with if the stakeholders are involved all along the way. Sometimes the push for a decision is a plea for involvement, for participation in the process.

If there is time to ask the question, there may be time to wait to make a decision.

8. What are the alternatives? The presentation of facts/issues is important. Fancy language or jargon can be used to cloud the values that are important. Reflect on the appeal of one alternative versus another.

9. What are the probable outcomes of the alternatives: short term, mid-term and long term?

Every step that is taken needs to be seen as an opportunity, not as a trap.

CHALLENGES FOR OMBUDSMEN

The breakdown in communication and lack of trust is the root cause of conflicts in institutions. We can help by bringing people together instead of continuing their adversarial positions.

First, we must pay attention to how people learn. We need to keep abreast of neuro-linguistic information and use it in communicating with others. Research is revealing that individuals learn in a variety of ways. Knowing different ways to present information so that it can be readily received by someone else will enhance our communication.

Second, we must acknowledge the opportunity and "joy" that working to resolve conflict presents. Don't avoid one side of the tension. Put it all out there. Do we have to pick one alternative over the other? How can we hold off the adversarial aspects of the problem so that people can express what is important and hear each other? Look at collaborating, at maximizing our interests and that of others.

Third, we must assist the involved parties in developing their own solutions. Is advocacy one-sided or is it helping move through conflict? To assist people in developing their own solutions we need to:

⇒ figure out who should be involved;

⇒ figure out how to get the involved people off their stated positions to move to the underlying issues, the things that matter to them;

⇒ think of the kinds of questions we ask and of the power that the questions we ask have;

⇒ make sure the resident's voice is heard, that there is a balance of power with the stakeholders present;

⇒ really listen. Listening is not waiting to talk.

The goal is to achieve a kind of therapeutic understanding. We need to move away from seeing ourselves as objective questioners to being people who listen and understand, who participate in communication. A quote from Merleau Ponty summarizes therapeutic understanding, "To the extent that I understand, I no longer know who is speaking and who is listening."

The breakdown in communication and lack of trust is the root cause of conflict in institutions. We can help by bringing people together instead of continuing their adversarial positions.

Instead of ombudsmen being experts in applying legal and clinical standards to determine decision-making capacity, we need to use our skills in communication and mediation to advocate for a process that enables the client's voice to be heard regarding what is most important to him/her.

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The National Eldercare Institute on Elder Abuse and State Long Term Care Ombudsman Services is a component of the National Eldercare Campaign -- a nationwide effort spearheaded by the U.S. Administration on Aging to mobilize community action on behalf of older persons, particularly those at risk of losing their independence. The Institute strengthens local, state and national efforts to combat elder abuse in both *domestic* and *institutional* settings. It assists states in the development of effective Long Term Care Ombudsman Programs.

Training, information and technical assistance is provided to Eldercare Coalitions. Policy and trends analysis, program management technical assistance and skills training is provided to state long term care ombudsmen, elder abuse and adult protective service program personnel. The Institute is operated by NASUA, in collaboration with NCCNHR, and APWA.

The National Association of State Units on Aging (NASUA), founded in 1964, is a national public interest organization dedicated to providing general and specialized information, technical assistance and professional development support to State Units on Aging. The membership of the Association is comprised of the 57 state and territorial government units charged with advancing the social and economic agendas of older persons in their respective states. NASUA is the articulating force at the national level through which the State Units on Aging join together to promote social policy responsive to the needs of aging America. For further information contact: NASUA, 1725 I Street, NW, Suite 725, Washington, DC 20005. (202) 898-2578.

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The National Citizens' Coalition for Nursing Home Reform (NCCNHR), founded in 1975, is a consumer-based nonprofit organization of local and state member groups and individuals, working to improve health care and quality of life for nursing home and boarding home residents. NCCNHR operates an information clearinghouse, promotes public policy responsive to the needs of nursing home residents, and promotes full implementation of the Nursing Home Reform Law. For more information, contact: NCCNHR, 1224 M Street, NW, 3rd Floor, Washington, DC 20005. (202) 393-2018.

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American Public Welfare Association (APWA), founded in 1930, is a non-profit organization representing state and local public human service agencies and individuals concerned with human services. The Association advocates for progressive social policy at the national level and provides services to meet the professional development needs of its members including state human service, local public welfare, and adult protective services administrators. Serves as the lead agency for the National Aging Resource Center on Elder Abuse (NARCEA). For further information contact: APWA, 810 First Street, NE, Suite 500, Washington, DC 20002-4205. (202) 682-0100.

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