

WORKING THROUGH ETHICAL DILEMMAS IN DAILY OMBUDSMAN PRACTICE

by
Sara S. Hunt
National Citizens' Coalition for Nursing Home Reform

Prepared for
National Ombudsman Resource Center
1828 L Street NW, Suite 801
Washington, DC 20036
(202) 332-2275
www.ltombudsman.org

TABLE OF CONTENTS

Introduction.....	2
Section I. Generic Concepts in Ethical Decision-Making.....	4
A. Capacity to Make Decisions.....	5
B. Principles for Decision-Making.....	10
C. Traditional Attitudes Toward Making Decisions for Someone.....	13
D. Values History: A Process to Assist with Decision-Making.....	14
E. Application of Generic Concepts to a Case.....	17
Section II. Ombudsman Responsibilities in Ethical Decision-Making.....	19
A. Underlying Principles.....	19
B. Another Framework for Analysis.....	21
C. Application of Ombudsman Responsibilities.....	30
D. Summary of Ethics and Ombudsman Responsibilities.....	33
Section III. Management of Ethical Issues in Statewide Programs.....	34
Section IV. Areas for Facility Advocacy by Ombudsmen.....	38
Glossary of Terms.....	42
Bibliography: References and Selected Readings.....	44
A Resource List for Additional Information.....	49
Appendix A: Guidelines for Practice.....	50
A Process for Individual Case Advocacy.....	51
Guidelines for Substate Ombudsmen.....	61
State Laws vs. OAA Confidentiality.....	62
Agenda Behavior.....	63
Appendix B: Additional Perspectives Pertinent to Ethical Issues.....	68
Guidelines for Hospital Discharge Planners.....	69
Components of a Valued Life.....	70
Polarities of Autonomy.....	71
Medical Treatment Guardian Program.....	72
Appendix C: Ethical Positions of Selected Organizations.....	74
National Association of State Ombudsman Programs.....	75
American College of Health Care Administrators.....	76
American Medical Association.....	77
American Academy of Neurology.....	78
American Hospital Association.....	83
Appendix D: Selected Readings.....	86
"Let Wisdom Find a Way," Arthur L. Caplan.....	87
"Decision-Making Strategy for Clinical-Ethical Problems in Medicine," Mark Siegler.....	92
"An Ethical Framework for Terminal Care Decisions: A New Classification of Patients," Robert M. Veatch.....	94
"The Many Faces of Competency," James F. Drane.....	99

WORKING THROUGH ETHICAL DILEMMAS IN DAILY OMBUDSMAN PRACTICE

Everyone has a set of ethics, principles of right and wrong conduct. Ethical issues arise when there are questions, or uncertainties, about the "right" thing to do in a given situation. An ethical issue can become a "dilemma" when an individual, or group of individuals, must choose between two or more plans/actions when no one choice is clearly satisfactory. Ethical conflicts are present when values, ethics, are in opposition to one another. An individual can experience an ethical conflict, feelings of being torn in more than one direction due to an incompatibility in values regarding a choice. The person has opposing feelings about what should be done. Ethical conflicts can also be between, or among, individuals who have opposing values.

In recent years ethical issues in health care such as the use, or removal, of life-sustaining treatment have received much attention. Various professional disciplines, in addition to provider organizations, have been forced to re-examine their ethical guidelines for making treatment decisions. Ombudsmen, likewise, make ethical decisions and find themselves in positions of ethical conflict.

While ombudsmen are well acquainted with ethical dilemmas that typically arise, guidance for working through some of these has been lacking. For instance, what is the "right" thing to do when an ombudsman is representing one resident whose resolution goal will cause problems for other residents? Who's the ombudsman's "client" when a family member of a resident with significant impairments in memory calls with a complaint? By necessity, ombudsmen have found their own ways of working through ethical dilemmas such as these.

There are four purposes of this paper:

1. To increase ombudsman sensitivity to ethical dimensions in daily practice;
2. To suggest questions for self-analysis, and a process to be followed, that can offer reassurance to ombudsmen that they have asked the "right" questions regarding how to proceed in determining a course of action;
3. To offer resources and supplementary information to augment ethical decision-making processes for ombudsmen;
4. To increase ombudsman knowledge of the ethical positions of healthcare providers and other caregivers, positions that ombudsmen frequently encounter in the course of complaint resolution.

This paper describes some of the various ethical dilemmas that ombudsmen encounter. Neither specific solutions nor prescriptive guidelines are given to resolve the dilemmas. To set the stage for a discussion of ombudsman work, explanations and summaries of basic ethical concepts and guidelines are given. Following the background section on ethical perspectives in the healthcare field is a section on ombudsman responsibilities. Ways that ombudsmen can analyze situations to determine a course of action are discussed.

Management issues and concerns pertinent to the administration of a statewide program are also included. This section addresses ways to offer substate ombudsmen guidance, support and review in their work on ethical issues. A list of questions regarding program structures and

processes is included as a discussion guide. Although not part of the body of this paper, an in-service trainer's guide, "Ethical Issues in Case Advocacy", is a companion resource.

A final section of this paper presents additional areas for institutional advocacy pertinent to the ombudsman role: a) the linkages among assessment, care planning and services provided; b) the development of facility policies and c) the development of ethics committees. These three areas present options that facilities have for developing positive ways of addressing ethical issues.

SECTION I: GENERIC CONCEPTS IN ETHICAL DECISION-MAKING

There is a growing body of literature regarding ethics, the principles of right and wrong conduct. In the medical field each profession has its own ethical guidelines. Recently the discussion of life-sustaining treatment has brought a number of ethical issues into the public arena. The judicial system has been called upon to resolve tough dilemmas, cases in which the alternatives for action present difficult choices. Trying to decide where ombudsmen fit within the spectrum of ethical approaches in long term care settings is no small task.

Before looking at how ombudsmen work through ethical dilemmas, it might be helpful to see the way other professionals approach issues that center around decision-making. These issues encompass concepts such as autonomy, informed consent, and best interest. These ethical concepts are applied whenever someone decides if a resident can choose for herself, or if someone else makes decisions for the resident, with or without legal authority. The application of these concepts also influences how much information individuals are given to assist with decision-making. Since a resident's ability to make decisions is often at the core of how an ombudsman approaches a case, this paper's discussion of ethical issues will focus on concepts pertinent to decision-making.

Conflicts arise when there is disagreement among caregivers, both formal and informal, or between caregivers and a resident about which concept applies. For instance, a resident may believe that she is able to make decisions about her medical treatment, she is autonomous. Her physician and her daughter may believe the resident's decision-making capacity is too impaired to enable her to make such a decision. Who's right? Who ultimately has the power to decide? What indicators are the physician and the daughter using to conclude that the resident is not capable of making decisions about her treatment? What is the ethical basis for their decisions?

An ombudsman needs to know what ethical concepts form the basis for each person's beliefs and actions. Although a nurse or a family member may not say, "I'm using substituted judgment to decide what Mrs. Smith/Mom wants," an ombudsman might be able to identify the caregivers' underlying principle that is governing their actions. By understanding each person's position, an ombudsman will be better able to work toward a resolution to the conflict.

To frame the discussion of ombudsmen and ethical decision-making, some primary concepts from the broad base of ethical literature will be defined and briefly discussed. Three dimensions of decision-making capacity are related to the autonomy of the individual, the right of the resident to make basic decisions.

These dimensions of decision-making are:

- A. Capacity to make decisions;
- B. Principles for decision-making;
- C. Attitudes toward making decisions for someone.

Each of these dimensions contains concepts that ombudsmen encounter in their interactions with other professionals. These three dimensions include some principles that ombudsmen adhere to; others that conflict with such basic ombudsman precepts as resident empowerment and focusing on what the resident wants. Ombudsmen need to be knowledgeable about these principles in

order to clarify the ethical positions of their own practice and to increase their problem solving skills.

A fourth content area will be discussed related to decision-making: tools/skills to assist in determining what someone wants. This area is included to describe a resource that is emerging as a positive way to support the decision-making process of an individual. The process is designed to support individual autonomy.

A. CAPACITY TO MAKE DECISIONS

Competency is frequently one of the first issues that is raised when there is conflict over decision-making. Who can make decisions? Is the resident capable of choosing? If not, who makes the determination of incapacity outside of the judicial arena? How is that decision made? What does it take to demonstrate that one has the capacity to make a decision? Some key definitions regarding capacity are necessary.

1. Autonomy: Self-rule, the right of an individual to make decisions for self. Individuals have the right to self-determination so long as their exercise of that right does not violate the rights of others.

Decisional autonomy: The ability and freedom to make decisions without external coercion or restraint.

Autonomy of execution: The ability and freedom to act on this decisional autonomy, to carry out and implement personal choices (Collopy, 1988).

The sub-categories of decisional autonomy and autonomy of execution were developed to acknowledge that the capacity to make a decision and the ability to implement the decision may differ. The implementation of a decision may require the cooperation and participation of others. To say that a person has autonomy of choice may not always include the freedom or ability to act upon that choice.

Autonomy can be inappropriately taken to an extreme, to the point where it leaves the individual bereft of care providers or without the possibility of making a different decision at a later time. With regard to medical care, the exercise of autonomy in an individual's refusing treatment DOES NOT give the physician permission to abandon the patient. The physician has the responsibility to continue discussing treatment choices with the patient throughout the course of the illness/condition.

****One area that ombudsmen need to be particularly sensitive to is autonomy of execution. Maybe a resident is capable of making a choice, but can/will that choice be implemented? Are there barriers to the resident's exercising autonomy? Is it sufficient to grant choice without enabling someone to act upon that choice?*****

In addition to the polarity of decisional versus executional autonomy, there are other polarities with regard to autonomy that can present ethical issues. These have been delineated in a chart by Collopy which is in Appendix B. The concepts clarify some of the decision points surrounding the exercise of autonomy, the inherent ethical risks each creates, and possible responses of

caregivers.

2. Competency: The decision-making capacity of an individual as determined by a court of law. "Competency" and "incompetency" are legal terms of art. Legally, until a person has been adjudicated "incompetent" the person is presumed competent to manage his/her own affairs.

3. Decision-Making Capacity: Describes an individual's ability to make an informed decision, sometimes referred to as "functional competence" or "health care decision-making". These terms have no legal meaning and are clinical judgments. An individual who is exercising decision-making capacity is acting with autonomy. Capacity isn't an "all or nothing" proposition. (Drane, 1985) A person may be capable of making a decision about a course of treatment but incapable of managing her finances. Therefore a person may be autonomous with regard to certain types of decisions but may not have unrestricted autonomy in all areas of life.

In The Hastings Center's Guidelines on the Termination of Life- Sustaining Treatment and the Care of the Dying (1987) decision-making capacity is defined as: (a) the ability to comprehend information relevant to the decision; (b) the ability to deliberate about the choices in accordance with personal values and goals; and (c) the ability to communicate (verbally or nonverbally) with caregivers. Six standards, identified by Stanley and others (1988), that clinicians commonly use for judging functional competence are:

1) evidencing a choice;

-Can the individual make a decision consistent with his/her values?

-There is no consideration given to understanding the treatment/research and potential outcomes.

2) factual comprehension;

-Does the individual understand the information relevant to the treatment: risks, benefits, alternatives?

-There is no consideration of the reasonableness of the decision or of the rationality of the thought processes. This is also biased against individuals with poorer verbal ability. (Appelbaum & Roth, 1984)

3) quality of reasoning;

-Can the individual understand the nature of the procedure, weigh the risks and benefits, and reach a decision for rational reasons?

-The application of this standard may reflect a bias toward a particular type of reasoning. Sometimes it is difficult to distinguish rational from irrational reasons, verbalized from unstated/underlying reasons, and real reasons from false ones. (Roth et al., 1977)

4) appreciation of the nature of the situation;

-Does the individual understand the consequences of consenting or not consenting and the implications of acceptance/refusal of the procedure?

-This standard places high demands on the individual for being able to understand information and to demonstrate reasoning ability.

5) reasonable outcome of choice;

-Does the individual make the choice that a reasonable person would make?

-This protective standard allows the reviewer to determine if the individual's decision is that which a "reasonable" person would make. It does not rely on the verbal skills of the individual as does #3 and provides more of an assessment than #1, evidencing a choice. (Stanley et al., 1981)

6) status competence:

-If the individual belongs to a certain group of individuals, like the mentally retarded, mentally ill, or very old, he/she is considered functionally incompetent due to that status.

-This is the most protective standard of all because decision-making incapacity is assumed rather than evaluated by examining functional abilities. (Lawton, 1980; Vestal 1980)

There is another method for determining an individual's decision-making capacity: a sliding-scale model. This model, as developed by James Drane (1985), posits three general categories of medical situations. In each category, as the consequences of patient decisions become more serious, competency standards for valid consent become more stringent. (Refer to Appendix D for the article discussing this model.) Essentially, the criteria for declaring someone incapable of exercising autonomy in making healthcare decisions become more or less rigorous proportionate to the severity of the medical consequences of the decision.

The determination of decision-making capacity is not easy. Questions regarding functional competence usually do not arise as long as a person does or says nothing strange and agrees to the treatment or services recommended by professionals. (Drane, 1985) Some of the major difficulties in making the determination of functional competence are cited in the following list.

-Frequently used mental status exams measure factors that may have little relevance to an individual's ability to make a health care decision. An exam that depends heavily on the ability to remember lists of words and numbers and to count backwards calls for a different type of mental ability than is necessary to understand treatment options and their ramifications.

-The results of competency tests are strongly influenced by the appropriateness of the skills and expertise of the practitioners administering the tests (OTA,1986). Beyond the necessity for basic skills in using a particular test, the practitioner's ability to communicate with geriatric residents or with residents with a variety of communication impairments can strongly influence the outcome of the test.

-Decision-making capacity can be a function of setting, resources and social contact. It may "wax and wane depending on mood, time of day and physiological health." (Caplan, 1985) There can be great variation in an individual's functioning, including recall ability, from morning to night. The physiological and psychological stress of an illness can also impair a person's functioning. A number of older individuals may seem very competent in their own familiar environment while seeming questionably competent in a clinical setting. Numerous factors influence the measurement of functional competence. Trying to ascertain someone's decision-making capacity is far more difficult than simply administering and scoring an instrument.

4. Application by Ombudsmen: For ombudsmen, the crucial aspects in determining an individual's decision-making capacity might center upon:

- (a) what and how information is given to the individual to assist with decision-making;
- (b) what standard(s) is used in making the determination; and
- (c) who makes the determination.

The following are some questions ombudsmen might consider when someone decides that a resident is capable/incapable of health care decision-making.

- How are the choices, alternatives and implications presented?
- Does the discussion occur in a setting that is comfortable for the resident?
- Are the full range of choices and implications presented?
- Are they fairly described and discussed?
- How is the resident assisted to understand the various implications?
- How much time is the resident given to make a decision?
- Is there anyone else the resident would normally ask to assist with working through this type of decision?
- Does the resident have any more questions?
- Is the individual presenting the information seeking to influence the resident in one direction?
- Why is the individual making the choice that he/she is? This gets at background information and values.

B. PRINCIPLES FOR DECISION-MAKING

There are three primary principles that guide decision-making: (1) informed consent, (2) best interest, and (3) substituted judgment. If a person has decision-making capacity, the doctrine of informed consent applies. Someone who is unable to give informed consent may have decisions made by someone else on his/her behalf according to the principles of best interest or of substituted judgment. There is frequently a history of group decision-making: medical personnel, family members and the resident decide what is to be done. Sometimes these decisions are made without the resident's full participation, even if the person is competent. Such group processes can exert undue influence upon the resident.

****How does an ombudsman determine informed consent for the purpose of pursuing an investigation or resolution? Which of these forms of decision-making should an ombudsman support? What does an ombudsman use to support his/her actions?*****

1. Informed Consent: The intent of this doctrine is to safeguard the autonomy of an individual's decision-making in both treatment and research settings. There are three general components:

- a) disclosure to the person of information relevant to the proposed treatment or research;
- b) the person's freedom of choice in a noncoercive environment;
- c) competency of the person to make [and communicate] a decision on his/her own behalf (Stanley et al., 1988).

Of course, the determination that someone can exercise informed consent hinges upon the individual's decision-making capacity. Other influential factors are: the environment, who explains the alternatives, how the options are presented, who determines that a reasoned decision in fact has been made. (These are discussed in A.3. Decision-Making Capacity, page 6.)

2. Best Interest: A principle of acting in the interests of someone's well-being, health and welfare. This principle has its origins in the judicial system as cases have been litigated regarding treatment for patients who are incompetent. In the medical field, it implies that the benefits of treatment are weighed with the burden of treatment in order to determine what best interest is. It is acting with beneficence or benevolence. Patient health and welfare are the controlling values (Caplan, 1985).

If someone were applying this principle, the "reasonable person" standard would be used. The patient's interests are promoted as they would probably be conceived by a reasonable person in the patient's circumstances, selecting from within the range of choices that reasonable people would make. (The Hastings Center, 1987)

The outcome of this principle depends upon the way best interest is determined. The person making the decision about best interest, a surrogate decision-maker, plays a critical role in what happens.

Key questions are:

-Who is making this decision: family members? physician?

- If there's more than one physician, which one(s) decides? -Are decisions made according to the best interest of the patient/resident or for the family/caregiver?
- Is best interest determined on the basis of allocation of health care resources?
- Does ageism influence the decision-making process?

3. Substituted Judgment: Clinicians, or other decision-makers, attempt to decide about the acceptability of medical interventions as the patient would have decided had he or she been fully competent. Individual autonomy, following what the individual wants or would choose, is a priority value (Caplan, 1985). This takes into primary consideration what is known about the person's values and preferences. It usually requires some reflection about statements the individual made, actions which indicate personal values, preferences the individual expressed, talking with the individual's closest family members or friends, and looking at the individual's lifestyle and enduring characteristics.

4. Comparison of These Three Principles: By definition these three principles, informed consent, best interest and substituted judgment, are quite distinct. The principle of informed consent presumes that the individual can make a decision for himself/herself. In the case of best interest or substituted judgment, someone else is making a decision for the person.

If the best interest standard is used, the decision-maker uses his/her own values, knowledge, and expertise regarding treatment/services to make a decision for someone else. The underlying assumption is that the decision will be for the individual's "good", will support their well-being and health.

In the case of substituted judgment, decision-makers ask, "What would this person choose, if he/she were able to express a choice?" An attempt is made to identify what is known of the values and preferences of that individual. Then a decision is made according to that knowledge. At least one research study has shown a significant congruence between the decisions generated by this approach and what elderly individuals would choose for themselves. (Tomlinson, 1987)

For individuals who cannot exercise informed consent as a decision-making process, it seems that the principle of substituted judgment is more compatible with the principle of individual autonomy than best interest. The beginning point for this principle is trying to determine what the individual might choose were he/she able; thus upholding the concept of self-rule, autonomy.

**Ombudsmen should seek to assure that informed consent is utilized to the greatest extent possible. When the principle of informed consent isn't applicable, ombudsmen may choose to advocate for the use of substituted judgment as a decision-making principle. Undoubtedly it may be more time consuming and difficult than using best interest as the decision-making principle. There may be situations where best interest may either be appropriate or the only recourse.

Other cases may call for a combination of substituted judgment and best interest, with neither being applied to the exclusion of the other. Ombudsmen must consider a resident's decision-making capacity and ways to reinforce the resident's autonomy when choosing which decision-making principle would be applicable to a case.**

A set of guidelines has been proposed for use by hospital caregivers involved in discharge planning and concerned about protecting the autonomy and best interest of patients (Dubler, 1987). These guidelines are included in Appendix B. These guidelines may be helpful in suggesting principles ombudsmen could adapt for use in long term care settings. They seem compatible with ombudsman principles and strongly support the autonomy and participation of the patient (resident).

C. TRADITIONAL ATTITUDES TOWARD MAKING DECISIONS FOR SOMEONE

Paternalism and beneficence are two concepts which translate into attitudes toward decision-making and the delivery of care. Although they have long been associated with the medical profession, other professionals also let these attitudes affect the way care is provided. There is inherent tension between these attitudes of paternalism and beneficence and the principle of individual autonomy.

Paternalism: The intentional coercive overriding of the free choice of others for their own good. It is a refusal to acquiesce in a person's wishes, choices, and actions for that person's own benefit.

Beneficence/Benevolence: Acting to promote and protect the best interests of the patient by seeking the greater balance of good over harm in treatment and care. This is the dominant framework of moral responsibility within the Hippocratic tradition, its origins are in philosophy and theology. It is strongly paternalistic since the physician defines the patient's best interests.

Both of these attitudes have the same result: someone other than the individual being treated, or for whom decisions are being made, is deciding on a course of action based on what the decision-maker determines best interest to be. There are subtle differences in these two but they yield similar outcomes. Ideally, these attitudes would be present only if the individual does not have decision-making capacity in the area in question and only in the absence of substituted judgment information or advance directives.

****Can ombudsmen support either of these? Are there times when beneficence is appropriate for ombudsman consideration in weighing alternatives? Are ombudsman actions influenced by one of these attitudes? Ombudsmen need to be aware of personal attitudes about decision-making that influence their advocacy efforts on behalf of residents.****

D. VALUES HISTORY: A PROCESS TO ASSIST WITH DECISION-MAKING

Within the past few years, a process and/or tool has been emerging to assist with clarifying an individual's values for the purpose of guiding long term care decisions. This process is referred to as a values history. Although it is still in a very developmental stage, it can be an important resource for older individuals and their families. For obvious reasons, a values history needs to be developed by an individual who has decision-making capacity in the relevant areas.

There seem to be two key uses of a values history. One is to assist an individual in identifying specific values pertinent to care options. Then decisions about care can be made. There is no question about the individual's mental capacity. The values history is a means of sorting out an individual's values in order to rank choices about care.

A second use of this tool is in times when it is difficult to know if a person has the capacity to make health care decisions, the ability to exercise informed consent. One test for decision-making capacity is to ask if the decision is consistent with the individual's core values. If an individual has lost the capacity to make a specific health care decision and the standard of substituted judgment is to be used, how does one know what that individual would have chosen for herself/himself? If an individual has a values history that was developed for health care decisions, such a document might be considered as part of a substituted judgment decision-making process.

**Ombudsmen need to:

- know that a values history process exists;
- understand its utility;
- be able to suggest that it be used whenever appropriate.**

Values History: A process for ascertaining a person's wishes, of collecting information about a person's preferences, goals and values. The information collected via this process is also referred to as a values history. Once collected, such a history may be useful in guiding decision-making if the individual becomes incapable of stating his/her own preferences.

This process is being used in a variety of settings to assist individuals in stating their wishes and priorities.¹ Values histories typically go beyond the blunt questions, such as "Do you want to be

¹There are two primary sources of information on values histories. One emanates from

resuscitated?", to core values and desires. An individual is guided through a logical sequence of stating personal perspectives; treatment decisions/preferences then flow from the stated values.

To identify the values most pertinent to long term care decision-making, the areas listed below might be discussed, preferably between the resident and his/her physician. (Agree et al, 1988)

These values should also be shared with family members.

- Length versus Quality of Life: Which is more important? If quality of life is most important, what does this mean to the individual? How does this differ from maintaining independence or other particular interests of the person?

- Maximizing the Independence of the Older Person: How does this rank in comparison to other values? Is it more important than safety, prolongation of life?

The statement "I'm old and tired and want someone else to take care of me" may represent a valid value of the patient or may be an acceptance of society's ageism, assuming that the elderly cannot be independent. (Agree et al, 1988)

- Values Regarding the Interests of the Patient/Resident: This set of values includes interests such as privacy, being treated with dignity, physical and emotional comfort, safety, security and the availability of needed personal and medical care. Which is most important to the individual? How does each one rank? How do these rank in comparison to other values?

- Interpersonal Concerns: What concern does the resident have for other people? Such

research conducted by Laurence B. McCullough and Beth J. Soldo, principal investigators. With their colleagues, they have discussed their work via presentations and written materials. Some of these works are cited in the bibliography of this paper. Much of this section of content comes from the pertinent sections of their work as referenced. The second source is the Values History Project conducted by the Institute of Public Law, Albuquerque, New Mexico. Joan McIver Gibson is the Project Director, a description of the project is in Appendix B.

concerns might include the avoidance of "unfair" physical, emotional, or financial impact on one or more parties.

Once these values are identified they must be integrated with the resident's functioning. What needs, functional deficits or disabilities, must be met? Which ones will be accepted, "lived with" because they aren't as important as others? For instance, elderly individuals frequently rank independence or maintenance of good family relationships higher than purely medical needs. The next step is to ask the individual to rank the care options according to which ones are most supportive of his/her values.

After the process described in the preceding paragraph has been completed, the resident and involved family members should share with each other their values and the preferences based on them. Similarities and differences in values and rankings of values should be pointed out and explored. "Respect for autonomy requires each party to recognize that he or she has no absolute right or 'trump' to override another." (Agree et al, 1988) This open decision-making can reduce guilt, hostility and stress among the involved parties.

This type of values identification, or values counseling, process is best suited to instances where the individual has an on-going relationship to a health care worker. It may take more than one session to address all of the relevant areas. This process should also be on-going, it should be open to refinement and change as the individual's condition or circumstances change. (McCullough & Soldo, 1988)

Once an individual has worked through the values history process, the information, the values history document, can be maintained as part of that individual's medical history. (Gibson, 1988) For individuals whose autonomy may be at risk in subsequent health care decisions, the values history is a record to guide surrogate decision-makers.

E. APPLICATION OF GENERIC CONCEPTS TO A CASE

The way that the dimensions of decision-making: capacity to make decisions; principles for decision-making; and attitudes toward making decisions for someone, might affect a resident are illustrated in the following case description.

Case Description: Mrs. Ross is an eighty-two year old resident of a nursing facility. She has been constantly begging to return to her apartment since her admission three weeks ago.

Her physician says she must live in a nursing facility because she doesn't eat properly in her apartment. After all, this is the third time in the last eighteen months that he's had to see her in the emergency room due to malnutrition and dehydration. She also has a chronic heart condition and arthritis which sporadically makes movement difficult. Mrs. Ross refuses to take care of herself, so she must have someone to make sure she eats and follows the necessary regime to manage her chronic conditions. The doctor tells Mrs. Ross that he is acting in her best interest by insisting that she live in a nursing facility. He truly believes that he is acting with beneficence.

The facility staff agree with the physician about Mrs. Ross's need for nursing facility care. They have doubts about Mrs. Ross's decision-making capacity. She has been observed muttering to herself and has angry confrontations with the staff at bath time. The social services staff learned that Mrs. Ross refused to let a home health nurse into her apartment and that she quit paying the agency. Her ability to manage finances seems questionable. Mrs. Ross's capacity to make reasonable choices also seems impaired since she disregards her doctor's instructions and lets herself get so run down. Any talk of other options such as a board and care home only increases Mrs. Ross's anger. She seems to be on one track: returning to her apartment to live independently.

The staff concludes that Mrs. Ross cannot act as an autonomous individual, capable of exercising informed consent with regard to decisions about living arrangements or daily care routines.

When Mrs. Ross's nephew, Mr. Johnson, was contacted by the facility staff, he reinforced everyone's ideas about his aunt. He has grown tired of getting calls from neighbors, social services and health care agencies, and the hospital about Mrs. Ross. The agreements he made with her in the past--extractions of promises to follow her doctor's orders and to eat properly, weren't kept. She's incapable of following through with the decisions she makes. Although she has always been an independent woman who cherishes solitude, she has obviously exceeded her ability to live alone this time.

Mr. Johnson lives out-of-state and relies on the doctor's opinion about what is in Mrs. Ross's best interest. After all, Mr. Johnson loves Mrs. Ross and wants whatever is best for his aunt.

Case Analysis: Everyone, the physician, facility staff, and the nephew, is acting out of genuine concern for Mrs. Ross. Each person is acting according to what is perceived to be for Mrs. Ross's welfare. No maliciousness is intended. Even though each of these persons may not be

consciously aware of the ethical principles that are guiding their judgments and actions, the influence of ethical principles relative to decision-making is definitely present.

Before the ombudsman approach to this case and its ethical dimensions is explored, there will be a discussion of ethical principles for ombudsmen. This discussion follows in the next section, Section II.

SECTION II. OMBUDSMAN RESPONSIBILITIES IN ETHICAL DECISION-MAKING

In view of the various approaches to making ethical decisions, what is the role of the ombudsman? What are underlying principles/values that pertain to most situations? Is there a core role that will be constant regardless of whether the decision centers on life and death matters or on issues more typical of the daily life of a resident? Is there anything unique that the ombudsman brings to a situation?

There is a basic set of principles which all ombudsmen can bring into every situation. They stem from the Older Americans Act provisions that define the responsibilities of the Ombudsman Program. The principles set forth below are consistent with the "Code of Ethics" being finalized by the National Association of State Long Term Care Ombudsman Programs. The draft of this code is in Appendix C, page 75.

A. UNDERLYING PRINCIPLES

1. Services are provided with respect for human dignity and the individuality of the resident.
2. The resident's right to self-determination is respected and supported. (The compatible ethical principles previously mentioned are: autonomy of the individual and informed consent.)
3. Every reasonable effort is made to ascertain and act in accordance with the resident's wishes.
4. The resident's right to privacy is upheld by protecting confidential information.
5. Services are provided unrestricted by the ombudsman's own personal belief and opinion.
6. Competence in areas relevant to the long term care system, especially regulatory and legislative information and long term care service options is maintained.
7. The ombudsman acts in accordance with the standards and practices of the Long Term Care Ombudsman Program.
8. The ombudsman conducts him/herself in a manner which will strengthen the statewide and national ombudsman network.

By the statutory authority of the Older Americans Act, the Ombudsman Program maintains a unique role with regard to long term care facilities. The law states that ombudsmen work to investigate and resolve complaints made by or on behalf of residents. Given that foundation it follows that the role of the ombudsman vis-a-vis ethical dilemmas is to represent the resident to the greatest extent possible. The ombudsman is not charged with making decisions for residents but with representing residents' needs and wishes.

Ombudsmen generally have little quarrel with accepting these principles and roles: they flow from the very foundation and structure of the program. The difficulties, the "sticky" situations, arise in the course of daily practice. How can these principles be translated into action when the issues in a case do not have clear answers? The standard ombudsman problem solving model's approach to such questions as, "Who's the client?" or "What do I do when the desires of one resident may create problems for other residents?" does not offer relevant guidance in all situations.² How can ombudsmen work through ethical issues--whether the issue is one of

²"A Process For Individual Case Advocacy" in Appendix A is a delineation of the usual ombudsman problem-solving process with some of the more difficult questions listed in a

individual case advocacy or one of broader scope like legislative, or systems, advocacy?

parallel column. Thus, the specific steps in complaint investigation and resolution will not be discussed in this section.

B. ANOTHER FRAMEWORK FOR ANALYSIS

In addition to the basic ombudsman approach to problem-solving, what other framework might be helpful in structuring discussion about ethical issues for ombudsmen? Are there similarities in dilemmas that lend themselves to classification? Can guidelines and/or processes for addressing these issues be developed?

The ethical decisions facing ombudsmen seem diverse, ranging from individual case advocacy issues to legislative ones.

One way to approach these situations is to see what categories might exist for classifying similar types of problems. There seem to be four categories of situations which encompass the majority of ethical dilemmas ombudsmen face. These categories are not mutually exclusive. The four are:

1. conflicting interest among potential clients;
2. individual resident wishes versus facility rules or societal good;
3. long term goals and principles versus the immediate reality;
4. biomedical decisions.

The following section, beginning on page 23, lays out the categories of ethical dilemmas faced by ombudsmen. Each of the four categories is immediately followed by a list of questions ombudsmen might ask, based upon the internal/external framework described below. These lists are not mutually exclusive nor all inclusive. This structure is offered to facilitate discussion and to assist with developing consensus regarding guidelines for ombudsman practice.

Another approach that may prove useful as a tool for framing a discussion regarding ethical dilemmas is classification according to their impact on the individual ombudsman. Is the dilemma internal or external to the ombudsman? An internal dilemma is one in which the conflicts exist within the individual ombudsman. The situation generates conflicting feelings regarding what the ombudsman "should" do, it leads to self-analysis. Are there conflicts between the ombudsman's values and what the resident wants? Has the ombudsman done "enough", or the "right thing", in this situation? How does an ombudsman know he has made appropriate decisions?

Alternately, does the dilemma exist outside of the ombudsman, is it an external one? Are other people experiencing ethical conflict and the ombudsman is involved in the decision-making process? An external conflict involves other actors in the case. It is not a conflict within the ombudsman. The ombudsman may be clear about her role and principles, but there may be opposing views about what actions will be taken on behalf of a resident. If the conflict is external to the ombudsman, what role should the ombudsman assume? What response should the ombudsman make?

There may be times when the ombudsman is experiencing both types of conflict. The ombudsman may have some internal questions to ask of herself, while being involved in the external process of working through ethical decisions with other people. These are not mutually exclusive processes. They are suggested as a way to consider guidelines for ombudsman action.

This internal/external rubric lends itself to generating questions that are process oriented. These questions can become check points for ombudsmen, a tool for assessing their decision-making process. Have I covered all the bases in this situation? Have I been true to ombudsman principles? These questions may lay the foundation for developing guidelines for action, a type of check list, for ombudsmen to follow when involved in ethical dilemmas.

1. Conflicting Interest Among Potential Clients: These situations are probably the most frequently encountered ethical dilemmas for ombudsmen whose primary work is complaint resolution. This category gets at the root of the manner by which an ombudsman engages in advocacy: those times when it is hard to determine, or act upon, what a resident wants. It also includes the issues of: who's the client, the resident's right to confidentiality, and conflicting laws. Some examples of this type of ethical dilemma follow.

A resident has asked the ombudsman to proceed with complaint resolution on her behalf.

The resident's family pleads with the ombudsman to drop the complaint because they fear retaliation will occur. This is the only facility within 80 miles that would accept their mother. Whose request prevails?

A husband and wife share a room in a board and care home. Their previous pattern of spouse abuse continues in this facility. Neither will admit that there is a problem. What is the ombudsman's responsibility?

A resident is capable of physical violence and has already injured one resident. The family does not want the resident to be restrained. What is the role of the ombudsman?

Internal Questions About Conflicting Interest: Cases in which it's hard to determine, or to act upon, what a resident wants. What questions might an ombudsman ask of himself/herself when there is some inner turmoil, uncertainty, about sorting through the issues?

1. What internal conflict am I feeling?
2. What is the basis of the conflict?
3. Whose interests am I representing?
4. Am I seeking to balance the needs of various parties? If so, why? What needs? For whom?
5. Have I taken reasonable actions to:
 - a) respect and maintain the confidentiality of the resident;
 - b) ascertain what the resident wants;
 - c) identify the underlying issue/problem;
 - d) verify the complaint;
 - e) identify as many solutions as possible;
 - f) seek the assistance of other resources as appropriate;
 - g) consult with the resident throughout the process;
 - h) follow the resident's desires, not my determination of the best interest of the resident;
 - i) encourage the resident to exercise self-advocacy;
 - j) discuss with the resident the potential ramifications of this course of action, or of taking no action;
 - k) engage in advocacy, not just accept the explanations of others as to what "has to be"?
6. Have my actions been in accordance with Ombudsman Program policies? or with applicable laws?
7. Will my actions impair the credibility of the Ombudsman Program if other people find out about them?

8. Have I used my influence to persuade the resident to pursue my agenda to the detriment of her own agenda?
9. Am I asking too much of the resident?
10. Have I been honest with the resident?

2. Individual Resident Wishes Versus Facility Rules Or Societal Good: What should an ombudsman do when the wishes of a resident conflict with appropriate/good facility rules, with laws, regulations, or with the interest of society? The resident's immediate needs, or desires, are in opposition to the good of a community. What is the "right" thing to do? What is the primary obligation? To what extent are residents allowed to take risks, to choose a set of circumstances, when their choice affects a number of other people? For example:

A resident lives on the second floor of a board and care home, she can't evacuate by herself in case of an emergency. The home is chronically understaffed, leaving serious doubt that this resident would receive timely assistance in case of a fire. The resident asks the ombudsman not to report the home.

A nursing facility resident wants a change in her care routine that will require a significant increase in staff time with her. You know that although the facility is a little above the minimum staffing requirements now, there are problems in providing adequate care for all of the residents. If this resident has her way, other residents will have even less assistance from the staff. Also the frustration of the staff will probably increase regarding the resident needs they see and their limited capacity to respond.

Residents in a boarding home have "aged in place" and their care needs exceed the boarding home's service capacity as well as licensure standards. The residents are adamant about not wanting to relocate to another facility.

Internal Questions About Individual Resident Wishes Versus Facility Rules Or Societal Good: The questions in the previous section regarding individual case advocacy are applicable in order to ensure that the ombudsman has represented the needs of the individual. When the issue involves larger groups of residents or systems, other questions may provide further direction. How can an ombudsman work through any internal conflicts regarding the ombudsman's responsibility to act?

1. Whose interests am I representing? Who's the client?
2. Does anyone else need to be brought into the situation?
3. Will the resident permit anyone else to be involved?
4. Have I fairly presented all of the options to the resident? (Am I offering the resident the opportunity to make an informed decision?)
5. How can I adhere to the principles of the client's right to self-determination and confidentiality and also be responsive to the needs of other residents?
6. Are the residents' needs actually in conflict? Is there a way to meet the needs of one resident

(client) while respecting the needs/rights of others?

7. What's the "worse case" scenario?
8. Who will be affected by this decision?
9. Are there other ways to address this problem?
10. Are there any Ombudsman Program policies that apply in this case?
11. Are there laws that compel me to take a certain course of action? If so, what is my responsibility to the resident?
12. Is there a time factor to be considered?
13. What is the short term impact of (insert various alternatives) course of action? What is the long term impact?
14. What action will lead to a positive outcome?
15. If I find a way to pursue action, what is the probability that corrective, and positive, change will occur?
16. If I don't act and my knowledge of this situation becomes public, what impact will that information have on the Ombudsman Program?

3. Long Term Goals And Principles Versus The Immediate Reality:

In these situations the issues may be how far one goes on principles versus accepting the immediate reality of the situation. Ombudsmen may have to make a judgment call regarding what is possible. How can ombudsmen know where the limits are? How far should the limits be pushed? What compromises might be made in the short term in order to move toward achieving long term goals? What is feasible, or practical to achieve considering the realities of the situation? A few examples follow.

A bill to improve facility conditions is in the legislative process. It may be enacted if the Ombudsman Program will negotiate with the industry/providers. The State Ombudsman yields on some provisions but safeguards as much as possible for consumers. Local advocates feel that the State Ombudsman has "sold out" to providers.

The Director of Nursing tells the ombudsman that the facility's physician, who is the attending M.D. for most of the residents, bills residents for services not rendered although the documentation is in the charts. She asks the ombudsman not to pursue this problem because this is the only physician in the county who will agree to accept these residents. If the facility loses his services, the facility will not be able to maintain its license.

The State Ombudsman finds the regulatory system lax in enforcing standards and regulation. The ombudsman is vocal and assertive about the deficits in enforcement, to a point. To be more forceful about the lack of effectiveness would likely result in the loss of the ombudsman's job. Does the ombudsman stay in the system in order to continue to fight for change? Does the ombudsman continue attacking the system, be removed from that position, knowing that it will be months or longer before another ombudsman can

acquire the same level of expertise? Does the ombudsman put the enforcement problems "on hold" and focus on other areas where there's a greater probability of achieving results?

Internal Questions About Long Term Goals And Principles Versus The Immediate Reality:

These cases require a judgment call by the ombudsman about what is possible. How far does one go on principles? When does the "real world" factor into decision-making? When an ombudsman feels tugged in different directions due to internal conflict, what questions can be asked? How does the ombudsman know that her decision is true to the ombudsman function and not being made primarily due to self-interest motivations?

1. Whose interests am I representing?
2. Are there any Ombudsman Program policies that apply in this case?
3. Is there a time factor to be considered? Is there a long term approach that can be taken to address some aspect of this problem?
4. What are all the possible approaches to this situation?
 - Is there a creative solution, or resource, that will offer additional options for resolution?
 - Is there a solution whose consequences will have a less severe impact on residents than the obvious choices?
5. How can these approaches be rank-ordered, which is optimal?
6. Who else might be a resource? (individuals, agencies, or organizations)
7. What is the short term impact of X course of action? What is the long term impact?
8. If I find a way to pursue X action, what is the probability that corrective, and positive, change will occur?
9. What is likely to be the impact of my actions upon residents?
10. Can other systems, resources, be put in place so that a positive outcome occurs?
11. Can this situation be measured in terms of the "benefit versus burden" standard of beneficence?
12. Will this action strengthen the Ombudsman Program's ability to represent long term care facility residents? Will it have an adverse impact?

4. Biomedical Decisions³: These issues revolve around life-sustaining treatment and medical treatment decision-making. Often there are questions about the decision-making capacity of the resident, the resident's wishes, best interest, liability, and conflicting ethics among professional caregivers. Sometimes a resident can express his wishes; sometimes others are called upon to

³ This section is intended to introduce discussion about the role of the ombudsman in the biomedical area. It is not a comprehensive examination of the breadth or complexity of bio-medical issues vis-a-vis the ombudsmen. For more information on bio-medical issues refer to the bibliography of this paper.

assist with making decisions. When faced with cases regarding treatment decisions, what is the role of the ombudsman? What does an ombudsman have to offer in these situations?

A resident is in a life-threatening situation, medically. Both her guardian and her attending physician refuse to treat her or to attend to her needs because there is a "No Code" order on the chart. The resident can't express her wishes. The ombudsman is brought into the situation.

A resident continually attempts to pull out her feeding tube, so she is restrained. There is no living will or advance directives and the resident cannot make her wishes known.

Questions And Process For External Conflicts About Biomedical Issues: Many of these situations arise, or become more complicated, due to the resident's inability to clearly express himself/herself. The questions in this section apply to such cases where the resident cannot communicate his/her wishes. When there are conflicting perspectives among caregivers, family, and/or the resident, who makes the decisions? What role should the ombudsman assume? Are there unique perspectives that an ombudsman brings into situations where there is conflict about medical treatment? Although the ombudsman may have some internal conflict regarding a course of action, usually an external conflict exists in these cases.

There seems to be a process that ombudsmen can advocate for to ensure that the decision-making is resident focused and upholds the autonomy and dignity of the resident to the greatest extent possible. This process is similar to the one often used for everyday complaint resolution. It involves much discussion; care plan meetings may be an appropriate context for such dialogue.

1. Maintain the focus on the resident. This may involve asking questions of other sources, such as relatives, friends, roommates, staff, if the resident is unable to express his/her own views. Ask each person interviewed for specific information to support their perspectives.

- a) Are there any written or oral expressions of the resident's wishes? (If pertinent.)
- b) Is the principle of substituted judgment applicable to this case?
- c) Did the resident have any conversations with anyone regarding this subject?
- d) What actions/behaviors on the part of the resident offer clues as to the resident's feelings or values?
- e) Who knows the resident best?
- f) Who knew the resident well in the community?
- g) Who else might offer some insight regarding the resident's perspective?
- h) Are these (d,e,f) involved in this process? What are their views?

2. Attempt to get the parties involved in the decision-making process to meet together for the purposes of:

- a) stating their views, hopes, and fears;
- b) identifying common goals and concerns;
- c) focusing on what is known about the resident's values and wishes;
- d) listing as many alternatives as possible to this dilemma;

- e) identifying one or more solutions that are acceptable and consistent with any applicable laws.
3. Seek to ensure that any policies that the facility has pertinent to this issue are followed throughout the process.
 4. Bring in other resources as necessary. If the facility has an ethics committee, it might be helpful in clarifying the positions and possible courses of action. Clergy, other medical professionals, and other service personnel might offer additional alternatives for resolution.

Questions And Process For External Conflicts In Non-Life Threatening Treatment Issues

If the issue falls into categories such as the use of restraints, moving the resident to another room, transferring a resident out of the facility, other questions might substitute for some of the ones in the preceding list. For example:

- What prompted this decision?
- What might be causing the resident's reaction/behavior?
- What is the resident trying to express?
- What is the meaning of this behavior? (Refer to Appendix A for information on agenda behavior.)
- What interventions have been tried? What was the response to these?
- Is another medical evaluation needed?
- Is an interdisciplinary assessment needed?
- What risks would an individual in a comparable situation in the community be permitted to assume?

**In summary, the task of the ombudsman with regard to biomedical treatment decisions seems to be:

- a) representing the resident;
- b) asking questions about background information, proposed interventions, expected outcomes, and other alternatives;
- c) seeking to get the pertinent parties, such as family members, direct care personnel, medical personnel, clergy, or friends, involved in discussing the situation;
- d) bringing in outside resources as necessary;
- e) maintaining the focus on the RESIDENT.**

In reviewing the preceding four categories of ethical problems encountered by ombudsmen, some basic roles and challenges for ombudsmen emerge. These are:

- balancing conflicting needs, rights, and interests;
- deciphering best interest, or what "good" prevails;
- distinguishing what's feasible from what is most desirable if the two are incompatible;
- asking pertinent questions and/or rallying outside resources.

C. APPLICATION OF OMBUDSMAN RESPONSIBILITIES IN ETHICAL DECISION-MAKING

A case description of Mrs. Ross was given in Section I. E., page 17. A re-examination of that case will focus on the ethical issues Mrs. Ross's ombudsman might encounter and how the ombudsman can work through such issues.

Additional Case Information: During a visit in the nursing facility, an ombudsman encounters Mrs. Ross. She grabs the ombudsman by the arm and asks, "Can you get me out of here?! Will you please help me? Being here is like being in prison, I want to return to my apartment. I can live alone no matter what my nephew and doctor think!"

The Investigation: An initial step for the ombudsman is to determine whether Mrs. Ross has decision-making capacity regarding her desire to return to her apartment. Does she know what she's talking about? Can she act with autonomy regarding choice of living arrangements? Another issue is Mrs. Ross's decision-making capacity relevant to nutrition and medical care. Is she capable of making an informed decision about following/not following her physician's advice? Based on conversations with Mrs. Ross and observations of her behavior, the ombudsman concludes that Mrs. Ross does know what she wants. She does have the decision-making capacity to consent to the ombudsman working on her case.

After receiving Mrs. Ross's permission to work on this case, the ombudsman interviews the staff and looks at Mrs. Ross's chart. All reports confirm the earlier information on this case. The staff asks the ombudsman not to create false hope in Mrs. Ross and above all else, not to alienate her physician. After all, the woman has impaired mental abilities and no one to care for her in the community. There is even a direct request from administration for the ombudsman to discontinue the case; otherwise if Mrs. Ross returns to her apartment and anything happens to her, the ombudsman will have to accept responsibility.

The ombudsman continues to work on this case by gathering additional information and keeping Mrs. Ross informed about the steps that are being taken. Although the nephew has expressed his disapproval of a return to apartment life and skepticism about Mrs. Ross's abilities to manage, he is too busy to become involved. The ombudsman uncovers legitimate explanations for Mrs. Ross's angry confrontations at bath time, her refusal to let the home health nurse enter her apartment, and her nonpayment of the home health agency bill. From the ombudsman's perspective, these behaviors seem "reasonable" reactions to Mrs. Ross's circumstances. Mrs. Ross is capable of acting as an autonomous individual and of making decisions based on informed consent.

Resolution: With Mrs. Ross's permission, the ombudsman contacts the physician's office. The doctor has his nurse talk to the ombudsman about Mrs. Ross's case. When the ombudsman mentions a values history, the nurse agrees that knowing Mrs. Ross's values might help everyone sort through their concerns about supporting her return to the apartment. The process could also help Mrs. Ross take another look at the importance of various care options for herself. The

values history does lead Mrs. Ross and her physician into a more full discussion of her health care needs and her desire to live in her apartment.

A care plan conference is convened at the facility to address her goal of discharge to the apartment. The social service staff assists Mrs. Ross in making the necessary plans and arrangements to meet her needs in the community. Mrs. Ross returns to her apartment with supportive services.

Internal Questions of the Ombudsman: During this process of investigation and problem solving the ombudsman had some internal questions about her role and how to proceed. Some questions that she had to work through before the case could be closed are listed below.

1. Does Mrs. Ross really have the ability to make a decision about returning to her apartment?
2. Is she capable of exercising informed consent about her medical regime?
 - a) Who has discussed her physical condition with her?
 - b) When and where did the discussion take place?
 - c) Was the information presented in a way that she could understand?
 - d) Does she understand the regime she is to follow?
 - e) Does she understand the consequences of not following that regime?
 - f) Are there other alternatives that were not discussed?
3. Am I "off base" with my conclusion that Mrs. Ross can exercise autonomy in making these two decisions?
4. Am I overreacting to everyone's paternalism by too zealously advocating for Mrs. Ross's autonomy in making the decision to leave the facility? Have I lost my objectivity?
5. Am I encouraging Mrs. Ross to take risks which are beyond her capacity to evaluate or understand?
6. Am I setting Mrs. Ross up for a major disappointment if the return to her apartment doesn't work? Am I reinforcing her unrealistic goal because I want her to be happy, "free"?
7. How much responsibility do I accept for her decision? for what happens to her once she returns to her apartment?

The ombudsman worked through these internal questions by:

- a) discovering the facts of the case which kept pointing in the direction of Mrs. Ross's decision-making capacity; thus confirming the ombudsman's judgment based upon observation of Mrs. Ross's behavior and direct contact with her;
- b) talking with other ombudsmen who'd had similar cases to see how they sorted through the issues and internal questions;
- c) reviewing resident's rights;
- d) reviewing the list of ethical principles for ombudsmen to assess the ombudsman's actions and decisions;

e) remembering that the ombudsman had involved appropriate resources to share the decision-making process as well as to rally more support for Mrs. Ross's decision; therefore the ombudsman wasn't exerting undue influence to get Mrs. Ross out of the facility.

Ethical Principles for Ombudsmen Applicable to This Case: In working with this case, the ombudsman's actions were consistent with a number of the ethical principles for ombudsmen. Ombudsmen can conduct a self-analysis to see if their actions have been consistent with the role and ethics of their profession by examining their actions in light of these principles. The principles most applicable to Mrs. Ross's case are:

- a) services are provided with respect for human dignity and the individuality of the resident;
- b) the resident's right to self-determination is respected and supported;
- c) knowledge of applicable state and federal laws provides further guidance for the conduct of ombudsman activities.

D. SUMMARY OF ETHICS AND OMBUDSMAN RESPONSIBILITIES

Ethical issues are inherent in ombudsman case work. The questions that such issues pose need to be expressed, ombudsmen need to be comfortable acknowledging their internal questions about their own actions. To do so is one way to remain sensitive to the existence of ethical dimensions of daily practice. Articulating questions, especially about the "rightness" of one's own actions also helps ombudsmen remain open to validation and improvement of their ombudsman skills.

The lists of internal and external questions as well as the ethical principles for ombudsmen are included to offer assistance in working through some ethical dilemmas faced by ombudsmen. Although they do not supply concrete answers, they can serve as indicators of movement, of decision-making, in a direction that is consistent with the charge given to the Ombudsman Program.

SECTION III. MANAGEMENT OF ETHICAL ISSUES IN STATEWIDE OMBUDSMAN PROGRAMS

Both state and substate ombudsmen are very familiar with ethical issues arising from daily situations. Listing several of these issues, "sticky wickets", is easy; developing mechanisms to formulate policy, support and guide substate ombudsmen, and offer some measure of quality assurance is much more difficult and time consuming. In many programs, ethical issues have not been clearly articulated. There may be an absence of consistent guidance and training regarding how to respond to the full range of issues. Some basic considerations for management are discussed followed by a list of questions for review of existing mechanisms.

Ethics Committee or Advisory Panel:

An ethics committee for an Ombudsman Program could serve the same function as one in a health care setting. It could assist with policy development, education, offer guidance and clarification on tough cases, and conduct retrospective case review for educational purposes. Similar functions could also be carried out by an advisory panel. In either case, the membership of such a group might differ in expertise from that of any existing boards or committees currently relating to an Ombudsman Program. Such a group would be very focused on ethical issues.

Program Guidelines:

Written policies and standards addressing some of the key ethical dilemmas faced by ombudsmen could be developed. These should allow for flexibility in problem-solving and resolution while providing basic guidance regarding how to proceed in certain difficult situations. For instance, policies or service standards could help ombudsmen decide when to refer a case to another agency. They might also offer guidance about how to proceed when one resident's desires and rights conflict with those of another resident. When to refer problems to the State Ombudsman, or even when to alert the State Ombudsman to an issue, might be covered in written guidelines. Appendix A contains a description of some standards/criteria that a few State Ombudsman Programs are considering incorporating into their policies.

Along with the guidelines pertinent to ombudsman actions, should be some guidelines for case review and action if an ombudsman violates ethical standards. An appeals process would be a companion piece for development.

Education:

An awareness of ethical issues can be cultivated by education: training, reading and "real world" experiences. The ombudsman may not always be the "good guy" just because that individual is an ombudsman. In addition to the usual training prerequisite to becoming an ombudsman, some specific information regarding ethical issues needs to be imparted. This paper, or some sections of it, may be useful to introduce such concepts.

Initial training for new ombudsmen needs to be conducted as well as periodic sessions for everyone on particular ethical questions. Sometimes the challenge may be reminding ombudsmen that certain situations do pose ethical questions. Training can be a means of

maintaining an ombudsman's sensitivity to these issues. A trainer's guide to an in-service on ethical issues in case advocacy is a companion piece to this paper.

Resources:

At least at the state level certain resources pertinent to ethical concerns should be maintained. These might include the codes of ethics for the various professions interacting with ombudsmen, selected readings on ethical issues, and a list of resource people available for consultation on certain topics. Certain laws, regulations, and forms might be maintained at both the state and substate level. These could be documents such as statutes on:

- living wills,
- power of attorney for health care decisions,
- health care consent,
- declaration of death, and
- guardianship or conservatorship.

Model forms for the applicable declarations should also be maintained.

Support:

Support for ombudsmen who are encountering ethical dilemmas is essential to maintaining personnel. In addition to the various types of support already in place, a type of peer review or case conference may be helpful to substate ombudsmen. This could be conducted locally or at periodic meetings of ombudsmen from different areas. The purpose of such a session would be to discuss specific ethical issues and resolution strategies pertinent to recent cases. The outcome might be guidance for resolution, additional alternatives, reinforcement for a course of action, or increased knowledge about the aspects of the case.

Substate ombudsmen might also benefit from having someone with whom a case could be discussed as issues are emerging. Outside consultants, members of an ombudsman ethics committee, or other ombudsmen might be utilized in this capacity. There should be a clear course for an ombudsman to follow when case consultation is needed.

State Ombudsmen might be able to use an advisory panel to provide guidance regarding specific cases or actions. There might be a need for peer consultation or review among State Ombudsmen.

MANAGEMENT CONSIDERATIONS

The following enumeration of questions is included to:

- a) serve as a framework for reviewing what is in place with regard to ethics in the statewide Ombudsman Program and
- b) prompt some decisions about options for offering guidance, support and some measure of quality assurance in the recognition and handling of ethical issues.

Program Structure:

1. What is available to guide policy development and serve an educational purpose related to ethical dilemmas?
2. What guidelines or procedures exist to address ethical issues facing ombudsmen? Are these written or oral?
3. What is the potential for substate ombudsmen to find themselves in situations where there are conflicting laws?
 - What policies exist to provide direction in these cases?
 - What structures are in place for supporting ombudsmen after a course of action has been followed?
4. What structure exists for an ombudsman who violates Ombudsman policies regarding ethical actions?

Process For Action:

1. What are the professional code(s) of ethics that substate ombudsmen bring to the position by virtue of their educational training or professional license?
 - Are these professional codes consistent with the philosophy and ethics of the Ombudsman Program?
2. How do substate ombudsmen express their ethical dilemmas? Who hears the internal questions they have regarding ethical issues they've been working through with specific cases?
3. Who should be the first person to supply guidance to substate ombudsmen in situations where dilemmas arise?
4. What ethical issues should be brought to the attention of the State Ombudsman?
 - How?
 - When?
 - For what purpose?
5. What happens at the state level when an ethical issue is received from a substate program? To whom does the State Ombudsman go for guidance, support, direction, review?

Support And Review

1. What kind of support systems exist for substate ombudsmen who are struggling with, or making decisions that pose ethical conflicts?
2. Are there case review processes to provide support and serve as quality assurance monitors? If not, what kind might be developed?
3. How can substate ombudsmen be sensitized to ethical dilemmas that are not as obvious as life-sustaining treatment decisions?
 - How can they become aware of their own values and ethics that influence their work?
4. What kind of support can be developed to prevent "burn-out" among substate ombudsmen who become overwhelmed with ethical dilemmas?

SECTION IV. AREAS FOR FACILITY ADVOCACY BY OMBUDSMEN

There are some other areas, focused on facility change or functioning, where ombudsman activity might be helpful. Three of these are briefly mentioned: assessment and care planning; development of facility policies; ethics committees. All pertain to facility actions and may present opportunities for ombudsmen to work with facilities. If these are not in place, or working well, ombudsmen might advocate for their development or improvement.

These areas can be resources pertinent for ombudsmen vis-a-vis ethical issues. For example in a case where a resident's decision-making capacity is in dispute or one where there's disagreement over the facility's response to a resident's behavior, an interdisciplinary assessment and another care planning process might eliminate some of the ethical concerns. Good facility policies can guide the staff in appropriate ways of responding to ethical issues such as refusal of treatment. Of course ethics committees could be a helpful resource for a resident whose specific situation needs some clarifying of alternatives and some focus upon the ethical dimensions.

The initial step for everyone is to be sure that there is an assessment and care planning process in place, one that works well. A thorough assessment will: identify the resident's strengths, discover the resident's preferences and usual routines, spot areas of concern for observation, and identify potential problems. Some questions typically asked as part of a values history may be appropriately included in sections of the assessment. It will be conducted by an interdisciplinary team of individuals, each of whom interacts with the resident during the assessment.

This assessment process leads to the development of a care plan with the participation of the resident. The care plan is essentially the product of an assessment. It should be a specific "blueprint" to ensure that coordinated, consistent and therapeutic care is delivered to meet the individualized needs of each resident. The care plan translates directly into the care each resident receives.

There should be definite linkages among assessment, care planning, and the daily life of each resident. The care planning process is a vehicle for getting everyone, caregivers, resident, and family members, to talk to each other about goals and approaches. Whenever there is a major change in the resident's condition, the care plan is to be revised to reflect the current condition and care needs of the resident. Thus, the care planning process can be an appropriate forum to discuss some ethical issues such as conflicting needs among residents or situations where one resident's needs conflict with the facility's policies. The care planning process could also be used to ask about the resident's treatment preferences.

A second area for advocacy is the development of facility policies regarding a range of topics from wandering to roommate selection to advance directives. Obviously, any policy development in these areas must be well conceived and then translated into action via staff education. Some policies may be substantive, for instance: what constitutes death. Others may be more procedural, like the process a facility will follow if a resident wanders off the property. A few good models for policies on such topics as wandering behaviors and advance directives are emerging. They are respectful of resident's rights and autonomy. There is a need for facility

policies regarding the resolution of conflicts among residents or grievance procedures for residents.

In the area of advance directives: such as living wills, do not resuscitate orders, power of attorney for health care, there has been some discussion about when and how to proceed. The time of admission generally is so stressful that it is not the best time to ask for advance directives information or decisions. How long the facility should wait to initiate discussion about advance directives and who should discuss the options with the resident and/or family are still questions with ambiguous answers. Facilities need to have a clearly defined process for obtaining such information. The process must be respectful of resident's rights and of the needs of each individual resident. A natural time to broach such topics is during care plan conferences when a change in the resident's condition is either occurring or expected to occur. At each turn in the resident's condition advance directives decisions should be discussed to offer an opportunity for the resident to change or reconsider previous decisions. The advance directives decisions can't be separated from ongoing care decisions.

A third area is the development of an ethics committee for the facility. Institutional ethics committees can perform a number of functions. Among the functions that an ethics committee may assume are the following:

- initiate educational programs within the institution;
- formulate institutional policies and guidelines in ethically sensitive areas such as the ones identified in the
- monitor compliance with those policies;
- undertake needed policy revision;
- advise on particular cases;
- serve as a forum for discussing and resolving disagreement about treatment decisions.

(The Hastings Center, 1987)

Ethics committees do not make decisions on case-by-case issues that arise, they may offer guidance in tough cases. The committee may review cases retrospectively and make judgments at that point.

Although not every facility will have an ethics committee, the facility may have another mechanism for performing some of the same functions that a committee would. Sometimes a team or a consultant is used. A clergy or chaplain might also be used by other facilities. Whatever the process, there is a need for someone or group to fulfill the functions of: education, policy formulation and revision, and case review as part of ethical decision-making in an institution.

The membership of an ethics committee should be large enough to represent diverse viewpoints. Specific membership might include:

- representatives from many areas of the facility such as physicians, nurses, social workers, administrators, lawyers, clergy, and someone familiar with medical ethics;
- at least one person from outside the facility;
- at least one person who represents the resident's perspective.

"The institution's legal counsel should not be a member of the committee, but rather should be available to the board of directors, medical staff, or committee for consultation on legal issues.

This frees the committee to explore ethical issues without being unduly concerned with legal matters and risk assessment, and provides assurance that IEC [institutional ethics committee] recommendations can be reviewed for their legal implications by some other office." (The Hastings Center, 1987)

The Hastings Center's publication, Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying contains some clear reference information on ethics committees. It includes a list of some of the issues that should be resolved in setting the rules for the committee's functions.

For most ombudsmen ethics committees in facilities may be a new experience. Ombudsmen need to be aware of the existence of such committees, or comparable mechanism, and of their functions. If a facility doesn't have a sound mechanism for addressing ethical issues, the ombudsman might suggest that one be developed.

If an ombudsman is asked to serve on a facility's ethics committee, there are some questions the ombudsman might wish to consider in making a decision.

- What are the functions of this ethics committee?
- What are the committee's policies regarding confidentiality?
- Why am I being asked to serve, are there underlying motivations?
- How will my participation be used by the facility?
- How will residents, family members, and facility personnel view my participation?
- Are there some non-negotiable items that must be agreed upon before I join the committee? If so, what are they?

- How will my participation affect my ability to fulfill my ombudsman responsibilities?
- Will there be conflicts with my serving on the committee and my case advocacy?

Regardless of the decision that an ombudsman makes about participating on an ethics committee, it is important for ombudsmen to be knowledgeable about committees that do exist and how they can be used to benefit residents.

GLOSSARY OF TERMS

Advance Directive: A document in which a person gives advance directions about medical care, or designates who should make medical decisions for the person if he/she should lose decision-making capacity. (The Hastings Center, 1987)

Proxy directive: an individual's written designation of another person to act on behalf of the designating individual in the event he/she becomes incapable of making decisions.

Treatment directive: a written statement prepared by an individual directing what forms of medical treatment the individual wishes to receive/forgo should he/she be in stated medical conditions (such as irreversible unconsciousness, terminal illness) and lack decision-making capacity.

Advocacy: Working on behalf of someone to argue his/her case. The advocate takes a partisan stance.

Autonomy: Self-rule, the right of an individual to make decisions for self. Individuals have the right to self-determination so long as their exercise of that right does not infringe the rights of others.

Decisional autonomy: The ability and freedom to make decisions without external coercion or restraint.

Autonomy of execution: The ability and freedom to act on this decisional autonomy, to carry out and implement personal choices (Collopy, 1988).

Benevolence/Benevolence: Acting to promote and protect the best interests of the patient by seeking the greater balance of good over harm in treatment and care. This is the dominant framework of moral responsibility within the Hippocratic tradition. It is strongly paternalistic since the physician defines the patient's best interests.

Best Interest: A principle of acting in the interests of someone's well-being, health and welfare. In the medical field, it implies that the benefits of treatment outweigh the burden of treatment. Patient health and welfare are the controlling values (Caplan, 1985).

Competency: The decision-making capacity of an individual as determined by a court of law. "Competency" and "incompetency" are legal terms of art. Legally, until a person has been adjudicated "incompetent" the person is presumed competent to manage his/her own affairs.

Decision-Making Capacity: is used to describe an individual's ability to make an informed decision, sometimes referred to as "functional competence" or "health care decision-making". These terms have no legal meaning and are clinical judgments.

Six standards that clinicians commonly use for judging competence are:

- 1) evidencing a choice;
- 2) factual comprehension;

- 3) quality of reasoning; 4) appreciation of the nature of the situation; 5) reasonable outcome of choice; and
- 6) status competence (i.e. competence based on class characteristics such as age or mental status) (Stanley, et al., 1988).

Ethics: The principles of right and wrong conduct.

Informed Consent: The intent of this doctrine is to safeguard the autonomy of an individual's decision-making in both treatment and research settings. There are three general components:

- 1) disclosure to the patient of information relevant to the proposed treatment or research;
- 2) the patient's freedom of choice in a noncoercive environment; 3) competency of the patient to make a decision on his/her own behalf (Stanley et al., 1988).

Mediation: Working with opposing sides to bring them together for resolving a dispute. The mediator doesn't take sides but facilitates discussion and exchange of information to settle the conflict. The focus is on problem solving, not on the behavioral or personality issues of participants. This process promotes reconciliation, settlement, compromise, or understanding.

Paternalism: The intentional coercive overriding of the free choice of others for their own good. It is a refusal to acquiesce in a person's wishes, choices, and actions for that person's own benefit.

Substituted Judgment: Clinicians, or other decision-makers, attempt to decide about the acceptability of medical interventions as the patient would have decided had he or she been fully competent. Individual autonomy is a priority value (Caplan, 1985).

Values History: A process and a tool for ascertaining a person's wishes, of collecting information about a person's preferences, goals and values. Such a history may be useful in guiding decision-making if the individual is incapable of stating his/her own preferences.

BIBLIOGRAPHY: REFERENCES AND SELECTED READINGS

HEALTH CARE DECISION-MAKING

- Agree, E., Lipson, S., McCullough, L., & Soldo, B. (1988). Long-Term Care Decision Making. Clinical Aspects of Aging, 10, 1-10.
- American Association of Homes for the Aging. (1988). AAHA Task Force on Ethics: White Paper. Washington, DC: American Association of Homes for the Aging.
- American Association of Retired Persons. (1986). A Matter of Choice: Planning Ahead for Health Care Decision Making. Washington, DC: American Association of Retired Persons.
- American Health Care Association. (1986). Health Care Decisionmaking in Long Term Care Facilities. Washington, DC: American Health Care Association.
- American Hospital Association. (1985). The Patient's Choice of Treatment Options. Chicago, IL: American Hospital Association.
- Alschuler, J., Bach, S., Froemming, R., Glowacki, T., Greenley, D. & Newton, J. The Guardian ad Litem Handbook. Chicago, IL: American Hospital Association.
- Collopy, B. (1988). Autonomy in Long Term Care: Some Crucial Distinctions. The Gerontologist, 28, 10-17.
- Dubler, N. (1987). Coercive Placement of Elders: Protection or Choice? Introduction. Generations, 11, 54-56.
- Dubler, N. (1988). Improving the Discharge Planning Process: Distinguishing Between Coercion and Choice. The Gerontologist, 28, 18-22.
- Dubler, N. (1987). The Dependent Elderly: Legal Rights and Responsibilities in Agent Custody. Philosophy and Public Affairs, 16, 1-14.
- Dubler, N. & Bayer, R. (1987). Final Report: Ethical and Legal Issues in Long-Term Care Placement and Imposition. Washington, DC: American Hospital Association.
- Froemming, R. & Streit, K. (1985). Guardianship of Adults: A Decision-Making Guide For Family Members, Friends, and Professionals. Chicago, IL: American Hospital Association.
- Gibson, J. (1988). Final Report: Medical Treatment Guardian Program. Albuquerque, NM: Institute of Public Law and Ethics.
- Macklin, R. (1982). The Geriatric Patient: Ethical Issues in Care and Treatment. Value Conflicts in Health Care. Washington, DC: American Hospital Association.
- McCullough, L. & Lipson, S. (1989). A Framework for Geriatric Ethics. Clinical Aspects of Aging, Third Edition. Washington, DC: American Hospital Association.
- McCullough, L. & Soldo, B. (1988). Final Report: Enhancing Choice and Resolution Autonomy of the Frail Elderly. Washington, DC: American Hospital Association.
- Parsons, R. & Cox, E. (1989). Family Mediation in Elder Caregiving Decisions: An Empowerment Intervention. Journal of Aging and Health, 1, 1-10.
- Subcommittee on Housing and Consumer Interests, House Select Committee on Aging. (1988). Surrogate Decision Making. Washington, DC: U.S. Government Printing Office.
- Tobin, S., ed. (1988). Autonomy and Long Term Care. The Gerontologist, 28, 1-17.

Gerontologist, 28.

Tomlinson, T. (1987). Final Report: Proxy Consent for the Elderly. East Lansing, MI: Michigan State University

COMPETENCY/DECISION-MAKING CAPACITY

American Health Care Association. (1982). Questionably Competent Long Term Care Residents' Problems and Possible Solutions. Washington: American Health Care Association.

Applebaum, P., & Roth, L. (1982). Competency to Consent to Research: A Psychiatric Overview. Archives of G

Caplan, A. (1985). Let Wisdom Find a Way. Generations, 10-14.

Drane, J. (1985). The Many Faces of Competency. The HastingsCenter Report, (15:2), 17-21.

Kapp, M. (1988). Decision Making by and for Nursing Home Residents: A Legal View. Clinics in Geriatric Med

Lawton, M. (1980). Psychological Vulnerability. Institutional Review Board, 2, 5-6.

President's Commission for the Study of Ethical Problems in Biomedical and Behavioral Research. (1983). Mak

Roth, L.H., Meisel, A., & Lidz, C.W. (1977). Tests of Competency to Consent to Treatment. American Journal o

Stanley, B., Stanley, M., Guido, J., & Garvin, L. (1988). The Functional Competency of Elderly at Risk. The Ge

Stanley, B., Stanley, M., Haelen, R., Lautin, A., Schwartz, N., & Shortell, D. (1981, August). Hospitalization as a

Vestal, R. (1980). Physical Vulnerability. Institutional ReviewBoard. 2, 5.

LIFE-SUSTAINING TREATMENT

Bopp, J., Jr., ed. (1986). Issues in Law & Medicine: Ethics Issue. Terre Haute, Indiana: National Legal Center f

Lynn, J., ed. (1986). By No Extraordinary Means: The Choice To Forgo Life-Sustaining Food and Water. Bloom

Miles, S., Gomez, C., Zweibel, N., & Cassel, C. (1988). Nursing Home Policies Addressing the Use or Withdraw

President's Commission for the Study of Ethical Problems in Biomedical and Behavioral Research. (1983). Deci

The Hastings Center. (1987). Guidelines on the Termination of Life-Sustaining Treatment and the Care of the D

The Office of Technology Assessment. (1987). Life-Sustaining Technologies and the Elderly. Washington, D.C

Vogel, A. (1985). Supportive Care Only: Guidelines for making a major ethical decision. Consultant. January 3

Wanzer, S., Federman, D., Adelstein, S., Cassel, C., Cassem, E., Cranford, R., Hook, E., Lo, B., Moertel, C., Sar

PRACTICE GUIDELINES AND APPLICATION

Craig, R., Middleton, C. & O'Donnell, L. (1986). Ethics Committees: A Practical Approach. St. Louis, Missouri.

Henderson, M. & McConnell, E. (1988). Ethical Considerations. Gerontological Nursing: Concepts and Practice

Kane, R. & Caplan, A., eds. (fall publication, 1989). Everyday Ethics: Resolving Dilemmas in Nursing Homes.

McCormick, R. (1984). Ethics Committees: Promise or Peril? Law Med Healthcare. Sept., 150-152.

Sachs, G. & Cassel, C. (in press). Ethical Aspects of Dementia. Neurologic Clinics: Ethical Issues in Neurology.

Sachs, G. & Riesenber, D. (1989). The Physician and the Care of the Nursing Home Resident. Geriatric Medicine

INTERPRETING AND RESPONDING TO RESIDENT BEHAVIORS

Aronson, M., Bennett, R., & Gurland, B. (1983). The Acting-Out Elderly. New York, N.Y.: The Haworth Press

Blakeslee, J. (1988). Speaking Out: Untie The Elderly. American Journal of Nursing, June, 833-834.

Block, C., Boczkowski, J., Hansen, N. & Vanderbeck, M. (1987). Nursing Home Consultation: Difficult Resid

Demitrack, L. & Tourigny, A. (1988). Wandering Behavior And Long-Term Care: An Action Guide. Alexandri

Feil, N. (1982). Validation: The Feil Method. Cleveland, Ohio:Edward Feil Productions.

Goldenberg, B. & Chiveton, P. (1984). Assessing Behavior: the Nurse's Mental Status Exam. Geriatric Nursing

Hussian, R. & Davis, R. (1985). Responsive Care: Behavioral Interventions With Elderly Persons. Champaign,

Mitchell-Pedersen, L., Edmund, L., Fingerote, E. & Powell, C. (1985). Let's Untie The Elderly. Quarterly: A Jou

Rader, J. (1987). A Comprehensive Staff Approach to Problem Wandering. The Gerontologist., (27:6), 756-759.

Rader, J., Doan, J. & Schwab, M. (1985). How to Decrease Wandering, a Form of Agenda Behavior. Geriatric M
July/August, 196-199.

Robinson, A., Spencer, B. & White, L. (1988). Understanding Difficult Behaviors: Some Practical Suggestions

Williams, C. (1989). The Experience of Long Term Care in the Future. Journal of Gerontological Social Work.

A RESOURCE LIST FOR ADDITIONAL INFORMATION

Long-Term Care Decision Making: A Handbook For Social Workers And Case Managers: This manual discusses the role of values in long-term care decision making and provides procedures for administering the Values Identification and Values Negotiation.

contact: Steve Lipson M.D., M.P.H.
 Medical Director
 Hebrew Home of Greater Washington
 6121 Montrose Road
 Rockville, MD 20852
 (301) 770-8377

The Directory of the American Geriatrics Society: This lists the American Geriatrics Society membership and may be useful for ombudsmen who are seeking the opinion or services of a geriatrician. It will be available in December, 1989, and there will be a charge for this publication.

contact: American Geriatrics Society
 770 Lexington Avenue, Suite 400
 New York, New York 10021
 (212) 308-1414

Society for Bio-Ethics Consultation
 Park Ridge Center
 676 North St. Clair, Suite 450
 Chicago, Illinois 60611

The Hastings Center Report: a bimonthly journal publication of The Hastings Center which covers a variety of ethical issues and seeks to present both sides of each issue.

contact: The Hastings Center
 255 Elm Road
 Briarcliff Manor, New York 10510
 (914) 762-8500
 rates: individual \$42 institution/library \$55
 Rates will increase in January, 1990. Prepayment is required. Subscriptions are for six issues.

Ombudsman Technical Assistance Manual, Administration on Aging.
 Chapter XV, "Complaint Management Issues" by Brian Clapham, is a good resource for the ombudsman approach to problem solving techniques for individual case advocacy.

APPENDIX A: GUIDELINES FOR PRACTICE

A PROCESS FOR INDIVIDUAL CASE ADVOCACY

A basic process for individual case advocacy has been set forth in the Administration on Aging's Ombudsman Technical Assistance Manual, Chapter XV, "Complaint Management Issues" by Brian Clapham. However, ombudsmen frequently face situations that the basic approach to problem solving doesn't address. Some tough questions arise which stretch the applicability, or at least the interpretation, of this basic problem solving process.

The following pages present a delineation of the usual process with some of the more difficult questions listed in a parallel column. These "sticky" questions are not meant to be overwhelming; they are included as a tool to focus discussion, to maintain ombudsman sensitivity to ethical issues arising during problem resolution.

The questions in the outline are quite familiar to experienced ombudsmen. The process and accompanying questions do not address every issue that ombudsmen face in individual case advocacy. The questions are listed without answers: there can be no one prescriptive course of action or resolution that fits every situation.

In lieu of supplying answers, the dilemmas regarding the application of the basic problem solving model are included to stimulate discussion about ethical issues ombudsmen face. Perhaps consideration of some of the hard questions on the list will serve to refine ombudsman practice and guide the development of policy or service standards. This framework might also be used as an in-service guide by taking different sections of the problem solving outline, discussing the issues, and reviewing cases that are applicable. This paper, with its discussion of ethical principles and listing of internal questions that ombudsman experience, can be a resource in obtaining answers to some of the tough questions in the outline.

THE PROBLEM SOLVING PROCESS

THE BASIC PROCESS

1. Clearly define who is the client and maintain a client centered focus. Ask:

-Who is the client? For the ombudsman, the RESIDENT must be the client unless the resident is deceased or has a guardian.

(For problems with guardians, see 3e.)

If the ombudsman feels tugged in competing directions, return to the central question, "Who is the client? On whose behalf am I working? What is the basis for my actions as stipulated in the Older Americans Act?"

2. Determine what the resident wants.

-Ask the resident to state the problem(s). What does the resident want/expect as an outcome? What would be an acceptable resolution?

Residents may need assistance in clearly stating problems and prioritizing them. They may also need some guidance regarding realistic outcomes.

DIFFICULT QUESTIONS

1. Who is the client when:

-There are conflicting desires among residents?

-The resident can't communicate and a relative seeks your help?

What if no one seeks your help? Can the ombudsman initiate problem solving independent of residents' wishes?

Is the ombudsman only an instrument of the resident or does the ombudsman look after the best interest of the resident?

If the ombudsman can do both, how does the ombudsman decide when to assume either role?

2. When does an ombudsman know that a statement of the REAL problem has been obtained?

What if the resident doesn't know what he/she wants?

What if the resident refuses to set/accept realistic outcomes? How far does the ombudsman go in seeking an unrealistic resolution?

If the resident wants to refuse treatment, should the ombudsman insist that the resident get medical advice before pursuing?

-LISTEN to the resident. It is the resident's life; hence, it is up to the resident to label something as a problem. The ombudsman may have a different opinion about the situation, what constitutes a problem or an acceptable outcome.

-What is the resident actually expressing? Is there an underlying problem or fear that has not been articulated?

Example: The resident says, "I want to go home." Does she mean for a visit? Does she want to move back home? If returning to her previous house is not an alternative, what might be acceptable? Would a personal care home be more satisfactory? Is there a way to create a more "homelike" environment for her in the facility? What exactly is she missing in her current residence that makes her say, "I want to go home?"

Always seek to understand the meaning behind the words. Remember to attend to the resident's body language as well as the verbal communication. Are there other fears, ambivalent feelings, uncertainties that are not being stated? (Refer to Appendix A, Agenda Behavior, p. 63.)

How much influence should the ombudsman exert in the process to get the resident to accept a realistic goal?

What if what the resident wants poses an ethical dilemma for the ombudsman?

What if there are conflicting needs, or goals, among residents who are seeking the ombudsman's assistance?

When, if ever, does an ombudsman refuse to work on behalf of a resident?

What does an ombudsman do when a resident is cognitively impaired? How can the ombudsman understand what the resident wants?

What does the ombudsman do when no one expresses any problems due to fear or intimidation?

What is the ombudsman's responsibility when the resident's statement of goals is restricted by not knowing that other options exist?

How does an ombudsman interpret resident behaviors such as pulling out feeding tubes or wrestling with restraints?

What guidelines apply to the preceding situations?³

Some potential problem areas exist that can generate pressure and possibly some conflicting feelings for ombudsmen. It is imperative to go back to Steps 1 and 2 above in every circumstance. A few of these situations are listed below.

a) Relatives' wishes run counter to those of the resident. Maybe the family is urging an investigation and the resident denies that there is a problem. Perhaps the resident wants one outcome and the relatives are pushing for another solution.

- The resident **MUST** be informed **BEFORE** any action is taken on his/her behalf.
- The resident decides whether any action will be taken.

b) The complainant wants an investigation but does not want the resident informed of the details.

- The resident must be informed and involved in the complaint investigation process.
- The ombudsman may make some observations and report back to the complainant but cannot conduct an investigation without the resident's permission.

a) What if the ombudsman suspects intimidation or abuse of the resident by the family? The resident consents to action, but very reluctantly?

What if the resident tells the ombudsman one thing but tells the family something different?

What if the family threatens to sue the ombudsman for unduly influencing, or even visiting, the resident?

Can the ombudsman make any comments about the resident to the complainant without the resident's permission? About the complainant to the resident without the complainant's permission? If so, what types of comments?

What if the complainant alleges abuse but doesn't want the ombudsman to mention this to the resident? If the resident claims abuse and says, "Don't report"?

c) The resident's wishes run counter to the family's.

-The ombudsman is bound to act on behalf of the resident. The ombudsman's primary responsibility is to the resident, not to the family or the facility.

-If seeking, or attaining, what the resident wants can create negative repercussions, the ombudsman should point these out to the resident before the course of action is pursued. Examples of these might be incurring the wrath of the family if the resident chooses to move, or increasing health problems if the resident refuses to adhere to dietary restrictions.

How "heavy handed" should the ombudsman be in listing the potential negative outcomes?

When is the ombudsman giving a realistic portrayal of the results of a course of action and when is the ombudsman subtly trying to promote a specific decision?

Whose definition of best interest is being followed?

Is the ombudsman really supporting the autonomy of the resident?

d) The resident has some mental impairment and there has not been an adjudication of incompetence.

-Using all of the ombudsman's senses and reasoning capacity, try to determine if there is a valid problem. If so, what does the resident want?

(Some information on interpreting behaviors is in Appendix A, agenda behavior.)

e) The resident has a guardian.

-Work through the guardian and with the resident unless:

1. The complaint is about the issue of whether a guardian is needed;
2. The complaint is about the actions/inactions of the guardian;
3. The interdiction is a limited one, work directly with the resident regarding those areas where the resident maintains control.

d) Who determines the resident's competence regarding day-to-day decisions?

How can the ombudsman know when a resident has given permission to act on a problem?

What, if any, protection does the ombudsman need before proceeding with problem resolution on behalf of a resident with significant memory impairments?

What kind of documentation is needed? Is written permission necessary, or always required?

What is the ombudsman's basis for acting on behalf of a resident who cannot clearly express his/her wishes due to cognitive impairments? What can be done if the ombudsman believes the facility is misinterpreting the resident's behaviors and thus not adequately meeting the resident's needs?

e) What is the ombudsman's responsibility to the resident?

How can the ombudsman determine what the resident wants?

Can the ombudsman see that the resident's wishes are respected?

f) One resident's wishes conflict with those of other residents.

-Resolution strategies may call for education or mediation regarding the rights of every resident.

-Resident councils may be excellent resources for resolution in these situations.

What kind of structure or process can be put in place to resolve grievances between residents?

f) What happens when one resident refuses to be "reasonable"?

What if one or both residents have mental impairments; thus making mediation difficult and remembering the resolution virtually impossible?

What if both residents have valid positions?

What if there is not an effective resident council that addresses such issues?

4. The resident guides the complaint investigation and resolution process and can stop it at any point.

-The ombudsman follows the doctrine of informed consent.

a) Confidentiality is explained, the resident's permission is given before ANY identifying information is related to someone else.

b) Promises are not made which can't be kept. The ombudsman's communication with the resident is honest.

- If the ombudsman can't guarantee that no retaliation will occur, the ombudsman cannot promise that there will be no repercussions.
- If the ombudsman is required by state law to report abuse, neglect, exploitation, the ombudsman informs the resident of actions the ombudsman will take.

c) The ombudsman informs the resident of the possible consequences, positive and negative, of each strategy/decision before action is taken.

4. What happens if once the process is set in motion, it can't be stopped--a referral to another agency and follow-up on the complaint is begun?

Once the facility staff has been interviewed, they begin their own investigation and the situation is out of the resident's or ombudsman's control.

a) In the absence of a court order to divulge confidential information, are there other involuntary ways in which confidentiality can be breached?

Are there ever any ethical reasons that justify violating confidentiality?

How does the ombudsman handle the issue of conflicting laws: the confidentiality of the resident's communication and any requirements to report abuse, neglect?
(Refer to Appendix A for the Bonker/Glenn letter responding to this question. The federal law protecting confidentiality takes precedence over state laws, page 62.)

c) What happens when the resident isn't capable of understanding the possible repercussions?

-The ombudsman encourages the resident to engage in self-advocacy, representing himself/herself. Even if the resident declines and asks the ombudsman to act, the ombudsman encourages the resident to take some actions and remains open to the time when the resident may assume the self-advocate role.

-The resident must be informed about each step in the problem solving process. This not only gives the resident the option of stopping or redirecting the process at any point but it also demonstrates the tools to be used in seeking resolution for any problem. Checking with the resident regarding findings and subsequent steps provides the resident with control. This process is one aspect of building empowerment.

What does the ombudsman do when something unforeseen happens, something the ombudsman didn't discuss with the resident?

What does the ombudsman do if the "worse" happens? Does the ombudsman have any responsibility for the consequences?

What is the ombudsman's responsibility with a resident whose obnoxious behavior will work against achieving the resident's goals?

What if the everyone's perception of the resident's "competence" lessens the probability of successful resolution if the resident represents herself?

What if the resident has very poor judgment, makes poor decisions? How can the ombudsman keep the resident involved without taking over?

Are there circumstances when the ombudsman should act in the best interest of a resident?
-If yes, what are they?

-Who/what determines that such action is needed and isn't chosen to serve the ombudsman's desire for efficiency? -If the resident insists upon no action, or no further action, regarding a complaint, the ombudsman must comply with the resident's wishes.

- a) The door should be left open in case the resident chooses to pursue the complaint at a later time.
- b) The ombudsman may see if other residents are experiencing the same problem. Perhaps someone else will pursue the issue or action can be taken on behalf of a group of residents; thus protecting specific individuals.

5. If an ombudsman's personal values, ethics, relationships, or business interests interfere with the ombudsman's ability to represent the RESIDENT'S goals, the ombudsman should remove himself/herself from the case and make some other provisions for the resident.

b) What is the ombudsman's responsibility if no one in the facility will agree to pursue action on complaints due to fear of reprisal?

-How can the ombudsman act without worsening the situation for those residents?

-If no one resident will agree to pursue the issue to resolution, how much evidence/how many residents are needed to build a case that won't divulge the identity of specific residents?

5. The Code of Ethics for Ombudsmen being finalized by the National Association of State Ombudsman Programs addresses the issue of personal conduct and conflict of interest.

GUIDELINES FOR SUBSTATE OMBUDSMEN: THE CASE OF CONFLICTING LAWS

What happens when an ombudsman is caught between laws safeguarding the confidentiality of complainants and laws requiring the reporting of abuse, neglect, exploitation? The Older Americans Act prohibits an ombudsman from revealing the identities of residents and complainants without their consent. A number of state laws require ombudsmen, or categories of individuals which include ombudsmen, to report abuse or neglect. If a resident/complainant alleges abuse and refuses to consent to reporting by the ombudsman, what does the ombudsman do?

How can a program develop guidelines or structures to share the decision-making responsibility and to offer support to that substate ombudsman?

The following guidelines are a compilation of some that are being considered for adoption by various state Ombudsman Programs. This issue is addressed by Congressman Don Bonker and Senator John Glenn, authors of the 1987 ombudsman provisions of Amendments to the Older Americans Act. Their statement follows these guidelines.

Laying Out The Case

The substate ombudsman collects the facts of the situation and presents them to his/her immediate supervisor:

- allegations made by the complainant;
- the reasons the ombudsman has cause to believe that abuse, neglect, or exploitation has occurred;
- the reasons why the complainant refuses to authorize the reporting of abuse to state officials in accordance with state laws.

Considerations For Action

The ombudsman's supervisor will consult with the State Ombudsman to decide whether to report the abuse without complainant authorization. Factors to be considered are:

- the severity of the alleged abuse, neglect, or exploitation;
- the likelihood of the incident being repeated;
- whether or not the complainant is the victim;
- whether other residents are in danger;
- the likelihood of investigation by other agencies;
- the integrity of the Ombudsman Program if it does not report the alleged abuse, neglect, or exploitation.

If the State Ombudsman does not honor the complainant's request for confidentiality and no reporting, the State Ombudsman will report the allegations to state officials. A report of the action taken and the rationale will be immediately given to the supervisor, the substate ombudsman, and the complainant.

STATE MANDATED REPORTING LAWS VERSUS OAA CONFIDENTIALITY**QUESTIONS ON THE 1987 AMENDMENTS TO THE OLDER AMERICANS ACT AND
THE OFFICE OF THE LONG-TERM CARE OMBUDSMAN**

The following is a response to questions on the 1987 Amendments to the Older Americans Act by Congressman Don Bonker and Senator John Glenn, authors of the ombudsman provisions of those Amendments. It is excerpted from "Best Practice NOTES On Delivery of Legal Assistance to Older Persons," Volume 2, Number 4, published by The Center For Social Gerontology, Inc., Ann Arbor, Michigan, page 7.

QUESTION THREE:

Our state has a law which mandates that various health and human service providers report instances of abuse and neglect. The requirement to report extends to ombudsmen. Does this create a conflict with the Older Americans Act requirement that ombudsmen keep identities of nursing home complainants and residents confidential?

BONKER/GLENN RESPONSE:

Yes. The Older Americans Act (OAA) is clear on this point. Section 307(a)(12)(D) of the OAA clearly prohibits an ombudsman from disclosing the identities of nursing home residents and complainants. It would also violate the spirit of the law to provide other information that would serve to help identify a resident or complainant without specifically naming them. The federal law, therefore, takes precedence over a state law that is in conflict with it.

Moreover, beyond the particular identities of individuals, Section 307(a)(12)(D) limits disclosure of information in the ombudsman program files. It gives to the ombudsman the sole discretion over whether to reveal any information in program files; thus state law cannot force disclosure of such information. The law does not, however preclude ombudsmen from encouraging residents or complainants who allege abuse, or are the subject of an abuse allegation, to consent to disclosure of their identities.

AGENDA BEHAVIOR: DECIPHERING NONVERBAL COMMUNICATION

This section on agenda behavior is included in this paper because many of the problems that arise around the management of resident behaviors are fraught with ethical issues. For ombudsmen to skillfully advocate on behalf of a resident who cannot verbally express him/herself, an elementary knowledge of ways to interpret behavior is necessary.

In most nursing facilities some of the following scenes can be witnessed on a daily basis.

- A resident is pacing the halls, trying every doorknob.
- A resident is walking into various rooms as if searching for something, occasionally opening closets or rummaging through drawers.
- A resident makes hostile gestures toward any other resident who approaches.
- A resident is straining against the vest restraint, trying to unfasten it.
- A resident's hands are restrained. Staff report that the resident has continually tried to remove the nasogastric tube ordered by her physician.
- A resident is repetitively calling out, "Help me, someone please help me!"

Different facilities have different responses to such behaviors. Some facilities tolerate a wide range of "difficult", or "disruptive" behaviors, others have less tolerance for behaviors that present management challenges.

Ombudsmen may feel awkward approaching residents who exhibit these behaviors or similar ones. Trying to determine what a resident wants, or needs, is complicated by behaviors that are hard to understand. Yet, knowing how to proceed with deciphering such behaviors can be a real asset when it's time to represent the needs of residents.

Ethical dilemmas may arise when there is ambiguity regarding the meaning of a resident's behavior. To use a couple of examples from the list above: a resident continually pulls the tubes out. What does this behavior mean? What is the resident trying to say? How far do the physician and staff go to keep the tubes in? When a resident is roaming into other residents' rooms, whose rights should be violated? Should the interloper be restrained? Should the other residents have their privacy infringed?

BEHAVIOR IS CAUSED

A body of literature is emerging which discusses ways to understand the underlying message in such behaviors. Then the development of management strategies can flow from that understanding of the core meaning of the behavior. The goal is to accommodate the needs of individual residents with minimal, if any, restraints and infringement of individual freedom. This approach is best described as individualized, person centered care. (Refer to C. Williams, 1989, for more on this approach.)

Behavior is caused by feelings and/or experiences; something precipitates behavior. Even among confused, cognitively impaired individuals behaviors have causal factors. Thus the term, agenda behavior, was coined by Joanne Rader (1985).

Agenda behavior is the planning and behavior which the cognitively impaired clients use in an attempt to meet their felt social, emotional or physical needs at a given time.

Accepting that behaviors, even in demented individuals, stem from attempts to have their needs met changes the focus of how others respond to the behaviors. A demented person may need to have her feelings validated. (Feil, 1982) Instead of seeing a "problematic" behavior and trying to either extinguish it or cajole/coerce the resident into conformity with more acceptable behavior standards, another approach is being successfully used. It is this alternate approach that ombudsmen need to know because it directly relates to assessment, care planning, and resident rights.

ANALYZING BEHAVIOR

Deciphering agenda behavior, getting to the root of the behavior is the driving force behind this alternative approach. The focus shifts to the resident. The strategy then becomes one of finding ways to meet the resident's needs while protecting the safety, privacy, welfare, of that individual resident and also of other residents. Initially, this approach may take more caregiver time. In the long run, it can result in a more calm and contented resident and in less staff time spent dealing with the problems arising from more traditional responses to such behaviors.

If a resident's agenda for wandering is discovered and an intervention, like increased sensory stimulation, is found, that takes less time than restraining the resident. The documentation that goes with restraints, the staff time spent in releasing and repositioning the resident, and the time consumed if pressure sores, loss of muscle tone, or combativeness result can be quite taxing on staff resources.

This approach also has enormous benefits in terms of resident autonomy, dignity, and preservation of freedom in general. The payoff is meeting the underlying needs of the resident who is incapable of clearly articulating those needs. Needs encompasses psychological, emotional, needs as well as physical needs.

An analytical process is required to determine the resident's agenda underlying behavior. To be thorough, thus increasing the probability of success, everyone who relates to the resident must be involved. Even housekeeping staff may have relevant observations. Family members, friends, roommates, as well as others should be included in the process. The process centers around answering the basic five questions: Who? What? When? Where? and How? Take a specific behavior for one resident and work through these questions.

Who: Who is involved in this behavior? Which resident? Anyone else? Who participates in the behavior? Who intervenes? Who witnesses the behavior? Who saw this behavior prior to admission?

What: What is the behavior? (a very specific factual description of the behavior) What happens immediately before this behavior? What immediately follows this behavior?

(on the part of the resident, other residents and staff) What else is going on in the environment when this behavior occurs? What else does anyone know about this behavior? What is gained by this behavior? What is the resident seeking?

When: When does this behavior occur? (time of day, day of week, on whose shift, for how long, etc.)

Where: Where does this behavior occur? Is it always in the same place? Where else has this happened?

Why: Why is this behavior occurring? Why is the resident doing this? Why is this behavior problematic? Why does this behavior need to be altered?

How: How can the resident's needs be met? How can this behavior be understood? How can the root cause of this behavior be uncovered and eliminated? How can this behavior be channeled into a more acceptable place, time, or manner? How can resident's rights be maintained? How can the resident's needs be met? How can staff, and others, constructively respond to the needs the resident is expressing?

Discovering the underlying cause of behaviors is a challenge. Answering these questions may take days, or be an on-going process for awhile. It is usually helpful to keep a log documenting observations and specific times, dates, and circumstances, surrounding the behavior. Such documentation aids in identifying patterns of major significance in determining underlying causes. A log can also be written in by staff on all shifts.

RESIDENT ASSESSMENT

The resident assessment process can be an invaluable tool in gaining insight regarding "disruptive" behaviors. A thorough assessment, conducted by an interdisciplinary team, can discover a wealth of information to utilize in analyzing behaviors. Sometimes the assessment can be proactive in discovering these behaviors and in determining the underlying cause.

Sometimes problematic behaviors are caused by physical conditions such as infections, untreated illnesses, drug interactions, side effects of medication, nutritional deficiencies, as well as a host of others. Therefore, the analytical process may lead to a referral to a physician or to a team for an assessment. At other times, the assessment process may detect the root of a problem and provide care plan recommendations for alleviating the condition.

Catherine Hawes, of the Research Triangle Institute, gave an example of how this process can work.⁴ A nursing facility had some residents who screamed. The screaming caused problems

⁴In a presentation given May 2, 1989, at the National Training Conference for State Long

for other residents who heard the noise as well as for the staff who provided care for the "screamers". The staff couldn't decipher any patterns, the screaming seemed random, unpredictable. Some anthropology students from a nearby college were invited to observe and record the screaming episodes of two residents. The students kept documentation for a period of time.

They discovered that one resident screamed only when food got lodged between her dentures and her gums. The screaming stopped when the food was removed. This did not occur at every meal. The other resident screamed only when someone turned off her television while she was watching a program. Thus they discovered logical reasons for the screaming which led to simple solutions. This analysis of behaviors generated positive results for both the residents and the staff.

CARE PLANNING

Once there are some "educated guesses" regarding the root of the behavior, a care plan conference can be held to develop strategies for intervention. EVERYONE, resident, aides, housekeepers, professional caregivers, and family members/friends, needs to have input into this process. The same type of questioning process can be followed.

Who is going to do what piece of the intervention?

What will be tried? What is the expected outcome? (for the resident? for the staff?)

When will this be tried?

Where will this be implemented?

Why are we doing this?

How will this be implemented? How will we know if this works?

In cases like the example with the nasogastric tube, the same process can be followed. The process will need to be expanded to include some of the additional questions discussed in the body of this paper on biomedical treatment issues.

More than one intervention may have to be tried. If one works for awhile and then is no longer effective, the analytical process needs to begin anew. Thus calling for another care planning conference, or at least an update on the care plan.

OMBUDSMAN ROLE

The ombudsman role vis-a-vis agenda behaviors is that of **observation** and **questioning**.

-Has the facility tried to determine the underlying cause of the behavior?

-Has that need been met for the resident?

-Has the facility considered a range of options for meeting the resident's needs?

Term Care Ombudsmen, Chicago, Illinois.

- Has the facility been respectful of the rights of all residents affected by this behavior?
- Does the ombudsman have any knowledge to contribute to the facility's process of addressing the behavior?

This approach of deciphering the cause of problem behaviors can assist with working through ethical dilemmas. A residents' behaviors that present problems for other residents may disappear when that individual's needs are met. Thus the ethical issues around balancing the needs of one resident with the needs of others may not be relevant. Taking the time to understand the meaning of behaviors is consistent with the ombudsman ethical principle of respecting the dignity and individuality of each resident.

APPENDIX B: ADDITIONAL PERSPECTIVES PERTINENT TO ETHICAL ISSUES

GUIDELINES FOR HOSPITAL DISCHARGE PLANNING

From: "Ethical and Legal Issues In Long-Term Care Placement And Imposed Financial Management: Advocacy, Autonomy And The `Best Interests" Of The Elderly" a final report to the Retirement Research Foundation by Nancy Dubler and Ronald Bayer. Bronx, N.Y.: Montefiore Medical Center, Briarcliff Manor, N.Y.: The Hastings Center, 1987.

1. Elderly patients who are decisionally capable must be presented with the available discharge options and must be afforded the opportunity to either consent to or refuse the various alternatives.
2. Decisionally capable elderly patients have the right to assume personal risks to themselves, even if those risks may place them in a situation of potential harm. Opting to expose oneself to risks does not negate the presumption that the patient is decisionally capable.
3. Caregivers have the responsibility to discuss with decisionally capable patients what discharge alternative is considered in the patient's "best medical interest" and which is realistically feasible, given family and community supports.
4. Patients of diminished, uncertain or fluctuating decisional capacity may still be able to participate in discharge planning and may be able to select a discharge option according to their own personal desires and values. Caregivers should discuss discharge options with such patients at times when the patient's decision-making capability is most intact.
5. Given the variety of factors that must coalesce in order to develop a discharge plan, family members or other close individuals should be encouraged (after the consent of the patient has been obtained) to participate in the discharge planning process and to assist the patient in selecting a discharge option. It should be made clear to all participants, however, that the choice is first and foremost that of the patient.
6. All efforts should be made to educate family members regarding the availability of community supports and reimbursement mechanisms that could ease the obligations or burdens which they may face as a result of the discharge plan.

COMPONENTS OF A "VALUED" LIFE

The following list provides one way of looking at the essential components of what most people in our society would consider a worthwhile life. In any real-life situation, there will be conflict and overlap. For example, supporting an individual in making choices may result in that individual choosing to live in unsanitary conditions. Sometimes trying to achieve a good balance among these components poses a dilemma: there are trade-offs, as with almost every other aspect of life.

- Being healthy, safe, and comfortable: physical and mental health and safety; comfortable clothing, good food, and pleasant surroundings
- Making choices: having control over choices affecting one's life
- Being part of a community: most people choose to live, shop, work, and enjoy themselves in ordinary neighborhoods and communities
- Sharing relationships: family ties, close friendships; relationships with a wide variety of people as neighbors, service providers, and fellow members of the community
- Learning and having the opportunity to be self-sufficient, active, and productive: being independent, learning and using skills; having interesting work and leisure activities
- Having continuity in relationships, environment, and experiences: maintaining family ties and friendships; having a stable home and community; building new skills on ones previously learned

These concepts come from the "normalization" approach utilized in human services. This particular list comes from:

The Guardian ad Litem Handbook, J. Alschuler, S. Bach,
R. Froemming, T. Glowacki, D. Greenley, & J. Newton. Madison, WI: State Bar of
Wisconsin, ATS-CLE Division.

APPENDIX C: ETHICAL POSITIONS OF SELECTED ORGANIZATIONS

CODE OF ETHICS*

- 1.The Ombudsman provides services with respect for human dignity and the individuality of the client and family.
 - 2.The Ombudsman respects and promotes the client's right to self-determination.
 - 3.The Ombudsman makes every reasonable effort to ascertain and act in accordance with the client's wishes.
 - 4.The Ombudsman acts to protect vulnerable individuals from abuse and neglect.
 - 5.The Ombudsman safeguards the client's right to privacy by protecting confidential information.
 - 6.The Ombudsman maintains competence in areas relevant to the long term care system, especially regulatory and legislative information, and long term care service options.
 - 7.The Ombudsman acts in accordance with the standards and practices of the Long Term Care Ombudsman Program, and with respect for the policies of the sponsoring (contract) organization.
 - 8.The Ombudsman will provide professional advocacy services unrestricted by his/her personal belief or bias.
 - 9.The Ombudsman participates in efforts to promote a quality long term care system.
 - 10.The Ombudsman participates in efforts to maintain and promote the integrity of the Long Term Care Ombudsman Program.
 - 11.The Ombudsman supports a strict conflict of interest standard which prohibits any financial interest in the delivery or provision of nursing home, board and care services, or other long term care services which are within their scope of involvement.
 - 12.The Ombudsman shall conduct him/herself in a manner which will strengthen the statewide and national Long Term Care Ombudsman Programs.
- *From "Standards of Professional Conduct & Code of Ethics" of the National Association of State Long Term Care Ombudsman Programs.

APPENDIX D: SELECTED READINGS

.....