

**IN-SERVICE TRAINING GUIDE FOR OMBUDSMEN
ETHICAL ISSUES IN CASE ADVOCACY**

by

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We wish to thank all of the ombudsmen who
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PURPOSE AND USE OF THIS TRAINING GUIDE

PURPOSE: To sensitize ombudsmen to some of the ethical issues that arise in the course of case advocacy and provide guidance in resolving these issues.

TEACHING METHODOLOGY: Discussion, including analysis of cases. Some case studies are included with this guide. You may substitute some of your own, using questions similar to the ones in this guide as a framework for analysis.

SUPPLIES AND TEACHING AIDS:

Chalkboard or flipchart

Copies of case study handouts

"Code of Ethics for Ombudsmen" and

"Definitions of Ethical Concepts Pertinent to Decision-Making" are optional handouts

RESOURCES: "Working Through Ethical Dilemmas in Daily Ombudsman Practice" is the primary resource for this training and should be read by the trainer before teaching this session. Other resources that might be utilized are readings, a bibliography is included with the paper, and cases from ombudsman files.

TIME: This session is designed for various time frames. The approximate time for each section of the training outline precedes the section of content. There will be variations in the time according to the amount of discussion generated and the depth with which the content is covered. Some options for using this guide follow.

Two and One-Half Hour Session: Use Sections I - VII, and IX of the training guide.

This will provide basic information for identifying ethical perspectives illustrated by a case and will analyze one case vis-a-vis ethical principles and issues.

Four Hour Session: Use the entire training guide. This expands upon the shorter session by the addition of a second case study for analysis.

Additional Time: Either of the above sessions can be lengthened by taking time to further the application of content by a more full discussion of specific ethical issues that ombudsmen face with their case advocacy. Some appropriate places to extend the discussion of content are indicated in the trainer instructions. No time frames are given for this additional discussion, it is at the discretion of the trainer. A description of one training program that utilized this option follows.

The training extended over a day and a half time period; thus giving the ombudsman participants sufficient time to become familiar with the ethical concepts and begin applying them to cases. The ombudsmen received the "Generic Concepts" section of the ethics paper and a case study, Mrs. Smith, with questions attached, prior to the training.

An hour and a half introduction to ethical issues was given as suggested in Sections I-VI of this guide. Discussion of the Smith case focused only on the roommate issue. Ombudsmen were encouraged to list the methods they use to make decisions regarding someone's decision-making capacity. They were asked

to list a code of ethics for ombudsmen although the code drafted by NASOP was not handed out at this point.

The second session, one hour long, was conducted via small groups working on the Smith case with regard to the medication issue. There were specific questions to guide this discussion. Each group had a recorder/reporter responsible for reporting back to the big group in a later session. Groups were encouraged to acknowledge disagreements among themselves regarding the "right" way to proceed.

The entire group reconvened to report their responses to the medication issue. Ombudsmen were asked to share their personal "standards" for knowing when they've done "the right thing". Ombudsmen were encouraged to evaluate their actions vis-a-vis the ethical principles they had identified, with emphasis upon supporting the autonomy/decision-making capacity of the resident.

Another session used the Vince Jones case. A panel consisting of an administrator, a health department surveyor, a social worker, a protection and advocacy attorney, and an ombudsman, each stated what actions they would take in response to this case. The audience interacted with the panel following the presentations. The total time for this was two hours.

An option for skills building in follow-up to this discussion would be a short session with ombudsmen, maybe including the administrator, to focus on the way ombudsmen would respond to this situation given the realities of their facilities. If the panelists' responses aren't realistic for their facilities, what would be?

A final session summarized the ethical principles regarding decision-making. A comparison of the Code of Ethics for Ombudsmen and the principles identified by the group in the initial session reiterated the foundation for decision-making that is to be the base of ombudsman practice. Ombudsmen were encouraged to remain sensitive to the ethical decisions they routinely make as part of their daily activities.

USE OF THIS GUIDE: Suggestions for what the trainer can say and do to present the information are given in outline format. Specific directions for the instructor are bracketed [] and underlined throughout the outline. Some options for teaching methodology are included.

Some flexibility should be exercised in using this guide. For instance, if discussion leads into issues that come later in the outline, you may decide to focus on those issues as they arise within the group. You may choose to use small groups for the Vince Jones case or for both cases instead of strictly following the suggestions in the outline.

Other factors to consider are the size of the group and the degree of experience of the participants. Essentially, the guide should be tailored to meet the needs of the particular group with whom you are working.

OTHER OPTIONS FOR TEACHING ETHICAL CONTENT: This in-service guide is meant to be simply that, a guide. You may have other ways to effectively teach this content. The purpose of this guide is to present one way of sensitizing ombudsmen to ethical issues. The guide is not intended to be the only way to address ethical decision-making for ombudsmen, nor is it meant to be all-inclusive in terms of its content. Two other approaches to ethical issues are suggested.

1. "A Process for Individual Case Advocacy" in Appendix A of "Working Through Ethical Dilemmas in Ombudsman Practice" can be used as the basis for teaching. (pages 51-60) Discrete sections of that process may be applied to ombudsman cases. The list of "Difficult Questions" can serve as a discussion guide. Then the trainer would be responsible for: a) either bringing appropriate case examples or eliciting such from the ombudsmen and b) guiding the group in working through the hard issues. Points from this section can also be integrated into a training session on complaint investigation and resolution.

2. Another way to approach ethical issues with ombudsmen is to incorporate such content into on-going training or supervisory sessions with ombudsmen. For instance, one hour of each regular training program could be devoted to a review of current ombudsman cases. The review should be designed to focus on any ethical issues related to the cases. The role of the trainer would be to: a) structure discussion to highlight ethical issues and b) guide the discussion to some conclusion that would offer support and direction pertinent to the issue(s) that were discussed.

TRAINER NOTES: ETHICAL ISSUES IN CASE ADVOCACY

(5 minutes)

1. INTRODUCTION TO THE SESSION

- a. In recent years there has been much discussion about ethical issues, particularly in a couple of areas:
 - i. health care
 - ii. government

[Ask participants to give some examples of ethical issues in these areas.]
- b. Today we want to look at some of the ethical issues encountered by ombudsmen. There are two objectives for this session:
 - i. to increase everyone's sensitivity to ethical issues;
 - ii. to discuss approaches to resolving these issues, perhaps arriving at some consensus that can be used as a guide to practice.

(10 minutes)

2. ETHICAL PRINCIPLES

- a. Let's start our discussion by defining ethics. What do we mean by the term ethics? [Allow the group to respond, offering their own definitions. Conclude by stating the definition from the "Glossary" (p.43) of the paper, "The Role of the Ombudsman in Making Ethical Decisions". Ethics is the principles of right and wrong conduct.]
- b. Now that we have a common understanding of the term ethics, let's talk about our own individual principles and values of right and wrong conduct. Who'll share a few of your personal ethical principles with the group? These don't have to be related to your ombudsman work. [Invite responses from various group members. You may have to initiate the sharing by giving two or three of your own principles. Allow some thinking time if necessary. After a few minutes of sharing of principles, summarize some of what you've heard, particularly those that are relevant to a discussion of the other principles to be covered in this session. Comment on the similarity or diversity of personal ethical principles in the group. Thank the group for their contributions.]
- c. Everyone has a "code of ethics" that guides personal decision-making and behavior. In addition, a number of professions have their own code of ethics, statement of ethical principles, that is to guide the practice of each discipline. Examples are: nurses, physicians, social workers. [Ask if anyone in the group has a professional code of ethics by virtue of training or employment. Invite a few individuals to share some of the principles upheld by their professions. Point out to the group some of the principles they mention that relate to healthcare, like autonomy.]

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- d. In ombudsman work, conflicts sometimes arise because of differences in the ethical principles that are guiding residents and caregivers. There may even be clashes between caregivers due to differences in perspective in areas such as autonomy or surrogate decision-making. Questions about a resident's ability to make a decision may be critical to problem resolution. Let's look at some ways decision-making ability is classified.

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(30 minutes)

3. CAPACITY TO MAKE DECISIONS

- a. How do we know if a resident can make a decision? Consider the situation of Mrs. Smith for example. [Pass out the handout containing this case and review it with participants. Then ask the questions that follow.]
 - i. Is there any question about Mrs. Smith's ability to make decisions? If so, what is the question(s)? [If the group needs prompting you might ask, "Is Mrs. Smith's demand for another roommate a statement of her desires or is it symptomatic of her state of chronic dissatisfaction? Does she have dementia?"]
 - ii. Before we proceed any further with Mrs. Smith's case, let's look at some basic approaches to decision-making capacity that ombudsmen typically encounter. We'll start by defining a few terms. [List the terms on the board as they are defined.]

- b. 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.
 - i. Decisional autonomy: The ability and freedom to make decisions without external coercion or restraint.
 - ii. Autonomy of execution: The ability and freedom to act on this decisional autonomy, to carry out and implement personal choices (Collopy, 1988).
 - iii. Autonomy is the American standard, everyone wants to be free to choose. Think about your cases. When do conflicts arise with regard to autonomy?

[You may allow participants to respond, you might list some of the responses on the board. Briefly mention and/or classify these conflicts as "internal" or "external" to the ombudsman according to the framework presented in "Another Framework for Analysis," Section II.B. (p. 21) of the paper. If you want more discussion on the range of issues autonomy presents, you can extend this session by examining the chart in Appendix B, "Polarities Of Autonomy," page 71.]
 - iv. When there is a question about the exercise of autonomy, one of the major points seems to be the determination of the decision-making capacity of the resident. There are some common terms regarding an individual's ability to make decisions.

- c. Competency and decision-making capacity are often used interchangeably; however, they have different meanings. [As time permits, invite group participation by asking for definitions/examples of the terms to follow.]
 - i. Competency: The decision-making capacity of an individual as determined by a court of law. "Competency" and "incompetency"

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are legal terms of art. Legally, until a person has been adjudicated "incompetent" the person is presumed competent to manage his/her own affairs.

- ii. 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. Maybe Mrs. Smith can't balance her checkbook, pay her bills on time, or select color coordinated clothes, but she does know that the pill she takes for the pain in her leg makes her too sluggish to enjoy visiting with friends. She may be very capable of making an informed decision about refusing her medication.

- d. What do you think about Mrs. Smith's ability to exercise autonomy? Can she exercise individual autonomy with regard to a decision about choice of roommate? What about her refusal to take the medication? [Allow some discussion about these questions, emphasizing and focusing on those responses that highlight issues pertinent to decision-making capacity. You might ask what additional information or considerations would be important in making a determination about autonomy.]

- e. What is her capacity to make decisions?
 - i. Do you need/want additional information before you have a sense of her decision-making capacity? If so, what kind of information? [What might affect a resident's clarity of mental functioning?]
 - ii. What position would you, as an ombudsman, take with regard to Mrs. Smith's decision-making ability? [An ombudsman's responsibility is to assume the fullest cognitive capacity, not be guilty of making superficial judgments.]
 - iii. What internal questions/reservations would you have that might give you some feelings of uncertainty? [Refer to Section II.B. of the paper, "Another Framework for Analysis" for some background information.(pp. 21-29) The purpose of this discussion is to put some of the issues and struggles on the table and to get people thinking along these lines. A more full discussion will occur later with the presentation of other cases.]

- f. Once the issue of decision-making capacity has been settled, the next question that usually arises is that of how a decision is made. What principle is the basis for decision-making?

(25 minutes)

4. PRINCIPLES FOR DECISION-MAKING

- a. There are three primary principles that guide decision-making: informed consent, best interests, and substituted judgment. Let's see what we mean by each

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of these. [Continue inviting the interaction of participants, as time permits. Keep writing the terms on the board as each is discussed.]

- b. 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:
- disclosure to the person of information relevant to the proposed treatment or research;
 - the person's freedom of choice in a noncoercive environment;
 - competency [decision-making capacity] of the person to make [and communicate] a decision on his/her own behalf (Stanley et al., 1988).
- i. The determination that someone can exercise informed consent hinges upon the individual's decision-making capacity.
 - ii. Informed consent is obviously supportive of autonomy.
- c. 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 outweigh the burden of treatment. It is acting with beneficence or benevolence. Patient health and welfare are the controlling values (Caplan, 1985).
- i. 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)
 - ii. 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.
- d. 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.
- e. As an ombudsman, what is your reaction to these three principles (B., C., D.)? [The amount of discussion of these questions is flexible, depending upon]

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- the time allocated. At a minimum, prompt participants to start considering their adherence to these three principles in case work.]
- i. Which of these is your "starting point", your goal with your cases? What principle is typically applied by the facility staff with whom you work?
 - ii. What are the barriers, other than decision-making capacity, that cause problems in applying this (ombudsman's starting point) principle (#1 choice, probably informed consent)?
 - iii. What are the questions, doubts, that may "nag" at you regarding the application of this principle?
 - iv. How do you work through these issues?
- f. Referring back to Mrs. Smith's case, what principle(s) should be applied to her decision-making process?
- i. Take the issue of choice of roommate.
 - (1) What principles should guide this decision-making process for Mrs. Smith? [This might be a good place to discuss limitations on autonomy as well as decisional autonomy versus autonomy of execution. (p.5)]
 - (2) What should apply to her roommate?
 - (3) Can anyone give an example when best interest would apply for her roommate?
 - (4) In trying to sort out some of these issues, are there any internal questions that you have regarding your advocacy activities? If so, what are they?
 - ii. What about Mrs. Smith's refusal of medication?
 - (1) Can she make an informed decision?
 - (2) Should the nurse and/or physician be acting in Mrs. Smith's best interest?
 - (3) Should you, as her advocate, be acting in her best interest?
 - (4) Is the principle of substituted judgment even applicable to this situation? If so, how?
 - (5) Are there any misgivings that you have about your role in this situation? Is there anything that causes you to wonder if you're "doing the right thing"? [Entertain brief discussion about these questions. Continue encouraging/enabling participants to get in touch with their own feelings about their judgments and actions.]
- g. Just as principles of decision-making strongly influence both the control an individual has in a given situation and the outcome, attitudes toward decision-making also have an impact.

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(10 minutes)

5. TRADITIONAL ATTITUDES TOWARD MAKING DECISIONS FOR SOMEONE

- a. In advocacy work there are two primary attitudes toward making decisions for someone that ombudsmen may encounter. Each of the two has a definite influence upon the decision-making biases of the professionals who hold them.
- b. 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.
- c. 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.
- d. Can anyone give an example of a situation where you encountered one of these attitudes? What impact did the attitude have on the course of action? Can you think of some examples where either of these attitudes would be desirable? [Have one or two examples ready in case no one can think of an illustration. Generate some discussion about these attitudes, particularly their application to case advocacy.]
- e. Look at Mrs. Smith's case. What relevance do either of these attitudes have to this situation?
- f. Now that we've had a quick overview of some predominant ethical concepts apropos to the health care field, let's move on to the ombudsman arena.

(10 minutes)

6. ETHICAL PRINCIPLES FOR OMBUDSMEN

- a. What are the underlying principles/values that pertain to most situations ombudsmen encounter? [Ask this question and write the group's responses on the board. Compare the group's list to the following set of underlying principles, a Code of Ethics drafted by the National Association of State Long Term Care Ombudsman Programs. (Handout is on page 31 of this guide.)]
 - i. The Ombudsman provides services with respect for human dignity and the individuality of the client unrestricted by considerations of age, social or economic status, personal characteristics or lifestyle choices.
 2. The Ombudsman respects and promotes the client's right to self-

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- 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 opinion.
 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 Ombudsman network.
- b. Although these may seem straightforward, their application in day-to-day situations may not be so clear cut in every case.
- i. Does anyone see any problems with the application of these principles to Mrs. Smith's case? [Allow time for responses the group may have.]
 - ii. Which ones of these will take more "creativity" in exercising with Mrs. Smith? [If relevant, ask how the group rationalizes their actions vis-a-vis the "creative" application of these principles.]

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(45 minutes)

7. CASE STUDY: VINCE JONES [Give each person a copy of this case study or a similar one you have developed.]

- a. Now we want to turn our attention to another case to see what ethical dilemmas exist and how we work with those issues. Let's look at the case of Vince Jones. Please read the case and answer the discussion questions at the end. [Allow time for everyone to read the case and answer the questions. You might ask the group to sit in pairs to jointly answer the questions. Then lead the group in a discussion of the questions. Give some guidance and structure to the discussion as appropriate, using "Working Through Ethical Dilemmas in Ombudsman Practice" as a primary source of information. Refer to the "Glossary of Terms", p. 42, "A Process for Individual Case Advocacy", p. 51, and "Agenda Behavior", p.63, as necessary to give substance and direction to the discussion.]

If the discussion gets stymied at any point you might interject some additional case details to refocus. Allow the group to grapple with the unknown elements of the case before you provide more specific details. Two possibilities are suggested. (1) Mr. Jones's behavior was completely void of malice. Even though he is demented his sexuality remains intact. He misses the closeness of his wife. The episode in his room was a display of jealousy in the only way he could find to express himself. He has always taken walks and used to walk around the yard everyday after work. (2) Mr. Jones has severe cognitive impairments. He has unpredictable bursts of energy, largely unfocused. He is capable of inflicting harm on others. These outbursts have been increasing in frequency. If using either of these, lead the group in a discussion of some of the same questions to see how additional information may change their perspective.]

- b. Ethical Dimensions: What ethical dilemmas, or concerns, do you see in this case? [Some dilemmas that might be among those mentioned are listed.]

- i. Who's the client?
- (1) Mrs. Jones?
 - (2) Vince Jones?
 - (3) Other residents?
 - (4) The facility?
 - (5) More than one of these?
 - (6) Does the definition of the client change as the problem resolution progresses? [Ask the group why determining "who's the client" is sometimes hard?]

- ii. What kind of decision-making capacity can Vince Jones exercise? [Use "Capacity to Make Decisions", Section I.A., pp. 5-9, as resource material for this discussion.]

- (1) Who determines this?
- (2) How is it determined?
- (3) Whose word/authority do you accept regarding Mr. Jones's

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- capacity to make a decision about restraints?
- (4) As an ombudsman, would you have any misgivings about advocating for no restraints for him if that (no restraints) is what he tells you he wants?
 - (a) If so, what are your doubts?
 - (b) Is there anything you can do in working with this complaint to address uncertainties that you have?
- iii. What do you think the perspective is of other people involved in this situation regarding restraining Vince Jones? [What ethical dilemmas confront you as you consider the varying needs of all involved?]
- (1) Other residents?
 - (2) The families of other residents?
 - (3) Facility staff?
 - (4) The facility administrator?
- iv. How should Mr. Jones's rights be balanced with the rights and needs of other residents? [Ask the group to list the rights of other residents pertinent to this case. Lead in a discussion of a range of options for Mr. Jones and other residents. Some points for possible consideration are listed below.]
- (1) What are the rights of other residents vis-a-vis Mr. Jones's behavior?
 - (2) Whose rights can be restricted? For what reasons?
 - (3) Is there a way to meet everyone's needs?
 - (4) What is your responsibility as an ombudsman to be concerned about the safety of the other residents?
 - (5) What are the tradeoffs with each decision or solution that is suggested? [Spend enough time to work through a few of these with the group.]
 - (6) What mechanism/forum exists for resolving these issues?
 - (7) Who determines what's "right"?
- v. How do the principles of informed consent, best interest and substituted judgment apply to this case?
- (1) Who would be applying which principles?
 - (2) How would you apply any of these three principles to your work on the case? [Lead in a discussion of which of these the group would use in trying to resolve the problem. Encourage discussion of any differences of opinion that may exist within the group. For instance, someone may believe that Mr. Jones is capable of exercising informed consent, someone else may believe that the wife should be supported in exercising substituted judgment. Another position could argue that the facility should balance the best interests of Mr. Jones with the best interests of the

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other residents.]

- vi. What resolution are you seeking? [Use this as an opportunity for participants to air more of their internal questions, "nagging doubts" about the position they are proposing. Probe if none of these issues are verbalized.]
- (1) As an ombudsman, what are you proposing?
 - (2) What is reasonable to expect of the facility?
 - (3) Should the facility consider whether the resolution to this problem increases the frustration and concern of a number of other residents and their families? (This could happen if Mr. Jones is not restrained.)
 - (4) How will this resolution affect future decisions the facility might make regarding: staffing, admissions, policies?
 - (5) Should you as an ombudsman be concerned about the facility's realistic capability to implement the resolution goal?
 - (6) Does the resolution leave you feeling uneasy about the quality of care that Mr. Jones will receive? What about any concerns for the other residents? For the facility?
 - (7) Will you have any question about whether you did the "right" thing after the situation is resolved? If so, what will you do about it?
- h. How will you work through any doubts about the facility's ability to handle the situation? How do you handle similar dilemmas on a systemwide basis?

- c. Additional Perspectives: [If time permits and the group is receptive, you could ask what would be different about an ombudsman's actions and feelings if one of the other residents asked the ombudsman to intervene due to intimidation by Mr. Jones. Then work through some of the same questions as above, with particular emphasis upon the internal questions of the ombudsman.

(20 minutes)

- d. Case Summary [Summarize the areas of consensus and point out any areas where disagreement still exists within the group. Consider the following steps as a way to conclude the discussion of this case study.]
- i. Compare the group's collective wisdom about how to proceed with the underlying principles for ombudsmen that were previously discussed. Is any clarification or refinement needed in either? Did the group adhere to the basic set of principles? (VI.A.) If not, why not?
 - ii. How does an ombudsman know if his/her actions have been appropriate? When has an ombudsman made a correct decision? When has an ombudsman done enough? [Consult the section under Another

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Framework for Analysis entitled, "Conflicting Interest Among Clients," especially the list of questions to be asked about case activities. (pp. 23-24)]

- iii. Are there any Ombudsman Program policies or service standards that need to be developed regarding the issues brought out in this discussion? If so, what are they?

[At this point, the training can be concluded, see IX., or another case can be discussed in a similar fashion. Another case is outlined below. An alternative would be to discuss a case from one of the ombudsman's files or one you have prepared. Another option is to focus on one particular topic, such as a resident wants something you feels goes against your best judgment. "A Process for Individual Case Advocacy", pp.51-60, has a number of such topics any of which could be selected.]

(70 minutes)

8. CASE STUDY: MABEL TURNLEY

- a. Please read this case and answer the questions at the end.

[Give each person a copy of this case study or an alternate one. You might divide the class into small groups to work on this case. If using small groups, ask each group to have a reporter to relay information to the entire class and someone to record the main points of discussion, including points of disagreement within the group. Allow the groups to read the case and answer the questions. You might visit the groups to interject some questions or comments as needed. Then have each group report on its conclusions, taking each question individually, discussing it, then going to the next question. Record the significant points of each question on the board. Offer some guidance and substance to the discussion as appropriate for learning purposes. "Working Through Ethical Dilemmas in Daily Ombudsman Practice" is a primary resource. Some points you might want to have discussed are listed under each question.]

- b. What are the ethical issues in this case?
 - i. For Mrs. Turnley?
 - ii. For you as the ombudsman?
 - iii. For Mrs. Turnley's physician?
 - iv. For the nursing facility?
- c. Does Mrs. Turnley have the capacity to make this decision? [Refer to "Capacity to Make Decisions", pp. 5-9.]
 - i. Who can make a decision about her capacity?
 - ii. Is a referral to someone else, or an assessment team, appropriate for this determination?
 - iii. How can her decision-making capacity be determined?
 - iv. How do you determine a resident's decision-making capacity on a routine basis?

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- v. When do you turn to someone else regarding a resident's decision-making capacity? [This question and #4 are designed to get at the "rule of thumb" that ombudsmen are using in their everyday case advocacy. It's an opportunity to discuss issues, to offer guidance, and to see where policies/standards need to be developed.]
- 6. What is the appropriate ombudsman role regarding the determination of her capacity?
- d. Is Mrs. Turnley making an informed decision? Is she deciding on the basis of informed consent?
 - i. What is informed consent?
 - ii. How can you as an ombudsman know if a person has sufficient information to be giving informed consent?
- e. Should this case be referred to adult protective services?
 - i. Yes?
 - ii. No?
 - iii. What is the basis for your response?
 - iv. What happens if the case is referred?
 - v. When is a referral appropriate?
 - vi. If you make a referral, are you taking an "easy out"?
 - vii. If you make a referral, are you reinforcing the facility in not accepting a resident's decision to refuse treatment?
- 8. What internal response, on a feeling level, do you have after making the referral?
- f. How do you proceed as Mrs. Turnley's ombudsman?
 - i. What do you do?
 - ii. Who should be involved in talking with Mrs. Turnley about her decision?
 - iii. How do you know if you've done the "right thing" with regard to this case?
 - iv. How much do you seek to influence Mrs. Turnley's actions? Do you operate on the best interest principle?
 - v. What questions do you have that cause some internal doubts? Is there anything that leaves you feeling uneasy about the results of this case? If so, what do you do about it?

(15 minutes)

- g. Case Summary [Summarize the areas of consensus and point out any areas where there is disagreement within the group. Consider the following steps as a way to conclude the discussion of this case study.]
 - i. Compare the group's collective wisdom about how to proceed with the underlying principles for ombudsmen that were previously discussed. Is any clarification or refinement needed in either? Did the group adhere to the basic set of principles? (VI.A.) If not, why not?

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- ii. How does an ombudsman know if his/her actions have been appropriate? When has an ombudsman made a correct decision? When has an ombudsman done enough? [Consult the section under Another Framework for Analysis entitled, "Conflicting Interest Among Clients," pp.23-24.]
- iii. Are there any Ombudsman Program policies or service standards that need to be developed regarding the issues brought out in this discussion? If so, what are they?

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(5 minutes)

9. CONCLUSION OF TRAINING

- a. Challenge the participants to remain sensitive to ethical issues in the course of their routine ombudsman work.
- b. Remind them that there may not be "easy" answers or just one "right" course of action.
- c. Encourage them to acknowledge their questions and uncertainties, to let ethical issues rise to the surface so that they can be articulated and worked through within the framework of your program.
- d. Offer any support that you can as they face tough situations.
 - i. Do you have program standards or policies that are applicable?
 - ii. Are there structures in place to lend support as ombudsmen struggle with determining the "right" course of action? [Like peer advice, advisors, or advisory boards?]
 - iii. Are there structures to assist when ombudsmen have uneasy feelings after a case has been resolved? If so, how can ombudsmen utilize these resources?
- e. Give participants guidance regarding what is expected of them as they encounter some of these situations that raise internal questions. [What do you expect them to do as part of your program personnel? What principles are to be upheld? What are priority positions for your program's approach to advocacy?]
- f. Adjourn the session.

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DEFINITIONS OF ETHICAL CONCEPTS PERTINENT TO DECISION-MAKING

Ethics: The principles of right and wrong conduct.

CAPACITY TO MAKE DECISIONS

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).

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).

PRINCIPLES FOR DECISION-MAKING

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).

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).

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

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competent. Individual autonomy is a priority value (Caplan, 1985).

ATTITUDES TOWARD MAKING DECISIONS FOR SOMEONE

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. It is strongly paternalistic since the physician defines the patient's best interests.

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.

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CODE OF ETHICS*

1. The Ombudsman provides services with respect for human dignity and the individuality of the client unrestricted by considerations of age, social or economic status, personal characteristics or lifestyle choices.
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 opinion.
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 Ombudsman network.

*From "Standards of Professional Conduct & Code of Ethics" of the National Association of State Long Term Care Ombudsman Programs.

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CASE STUDY: MRS. SMITH

You are visiting in Happy Times Nursing Facility when a resident, Mrs. Smith stops you in the hall. She is dressed in clothing that is too big and the colors of her skirt and blouse clash. You remember her from previous encounters. She always seems to have a series of "problems". No one in the facility takes her seriously.

After asking you if you've been in the facility before, she emphatically tells you that she can't tolerate her roommate. She wants another one, the home will just have to find somewhere else to move the lady who is in Mrs. Smith's room now!

There's one more thing Mrs. Smith wants you to know: the nurse is trying to force her to take drugs that dope her up. She has managed to outsmart the nurse so far, but she doesn't know how much longer she can continue before the nurse starts trying to slip the pill in her food! Mrs. Smith mumbles something about the nurse claims her doctor ordered the pill for the pain in her leg.

Mrs. Smith asks if you can help her with these problems.

CASE STUDY: VINCE JONES

Mr. Vince Jones has resided in this nursing home six months. He has a diagnosis of Alzheimer's type dementia. Mr. Jones is 68 years of age and is very active, often roaming outside or pacing inside the facility. He is calm when his wife visits although her visits are usually followed by outbursts of physical energy upon her departure. Other periods of calmness are when he visits with a female resident from another wing in the facility. The woman comes to Mr. Jones's day room and sits with him several times a week.

The staff is aware that Mr. Jones is oblivious to anything, or anyone, in his path when he is walking. On one of his trips back into the facility after a period of walking in the enclosed outer courtyard, a frail, female resident was blocking the doorway. Mr. Jones burst into the facility, literally running over the resident. The woman fell and sustained some broken bones as a result of this incident. Her family is considering suing the facility.

On another occasion, Vince was in the day room when his female friend from the other wing entered. She chose to sit with a newly admitted resident, another male with dementia who was very outgoing and much taller than Vince. Shortly after her arrival, Mr. Jones entered his room, slamming the door. The loud sounds coming from inside the room indicated that Mr. Jones was throwing objects around, probably demolishing the room.

Mrs. Jones calls you, the ombudsman, for help. The staff is thinking of calling the physician for a restraint order. Mrs. Jones does not want her husband restrained! She believes his mobility is what keeps him alive, it's one thing that he can still "be in charge of". After all, there are such things as resident rights! She contends that her husband is not dangerous if properly supervised and managed.

The use of restraints had been much debated among the staff following the broken bone injury. The possibility of discharging Vince was also discussed. This current episode makes his behavior seem unmanageable and inappropriate. Other families have been heard murmuring fears that their relatives may be Mr. Jones' next victim.

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5. How do the principles of informed consent, best interest and substituted judgment apply to this case? Who would be applying which principles?

6. What resolution are you seeking?

7. List any uneasy feelings you might have about this case.

CASE STUDY: MABLE TURNLEY

Mrs. Turnley is an 88 year old widow with no children. She has resided in this nursing facility for three years. She has a history of diabetes and for years has refused to follow the prescribed treatment for this condition. During the last couple of years, Mable Turnley has developed other disabilities which have restricted her enjoyment of life.

Now, Mrs. Turnley has gangrene in both legs. She has become despondent and apathetic. Although she is usually able to tell people exactly what she wants, she has begun to occasionally lose her train of thought. Her statements aren't always directly relevant to the conversation.

When her physician advises Mable that both legs must be amputated in order to save her life, she refuses the surgery. Mrs. Turnley says that she is tired of living with increasing disabilities and doesn't want to continue without her legs. She says she is ready to die without prolonging the inevitable.

Feeling like no one will listen to her, or respect her wishes, Mrs. Turnley appeals to you, her ombudsman, for assistance. What do you do?

1. What are the ethical issues in this case?

a) for Mrs. Turnley?

b) for you as the ombudsman?

c) for Mrs. Turnley's physician?

d) for the nursing facility?

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2. How do you know if Mrs. Turnley has the capacity to make this decision?

3. Is Mrs. Turnley making an informed decision? Is she choosing on the basis of informed consent?

4. Should this case be referred to adult protective services?

5. How do you proceed as Mrs. Turnley's ombudsman?

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6. How much do you seek to influence Mrs. Turnley's actions?

7. What questions do you have that cause some internal doubts about your approach to the case?

8. List any concerns you would have about the implementation of the "resolution".