

Coordination Between Long-Term Care Ombudsman and Adult Protective Services Programs and Related Issues

Report on a Meeting Sponsored by the Administration on Aging on October 25-26, 1993 in Washington, D.C.

Introduction

During the past ten to fifteen years, two programs with statewide networks have developed in most States to assist and serve as advocates for disabled and vulnerable adults:

The Long Term Care Ombudsman Program, which is charged under the Older Americans Act with advocating on behalf of older residents of long-term care facilities, and

Adult Protective Services (APS) programs, which typically, though not always, are charged under State and/or county mandates with protecting vulnerable adults of any age, living in any setting.

Both networks are responsible for receiving and investigating complaints involving mistreatment, neglect, abuse and exploitation of individuals who are vulnerable due to disability and often lack the means and capacity to protect themselves from harm.

The two programs share important overall objectives and functions. Both programs seek to improve the quality of care and life of their clients; individuals working in both programs consider themselves to be *advocates* for the vulnerable people they serve; both programs seek to honor and protect the individual preferences and right to self-determination of those they serve. However, there are significant differences and distinctions in their history, stated missions, and statutory mandates. Also, staff of the two programs have distinct and different roles. As the ombudsman and APS networks have matured, program staff have realized that these issues of missions and roles require attention, understanding and "sorting through" in order to insure the maximum efficiency and effectiveness of both programs. The attached paper by the Coordinator of the Long-Term Care Advocacy Program of Pima County, Arizona, illustrates the need for increased clarity about the roles of local APS workers and ombudsmen. (Attachment A)

With the enactment in 1992 of Title VII of the Older Americans Act, the need to examine the similarities and differences between the two programs/networks has become urgent. Title VII authorizes funding for four State advocacy programs, all of which previously were under Title III of the Act in varying degrees of definition and development. (See Title VII Fact Sheet, Attachment B). Chapter 2 outlines requirements for State Long-Term Care Ombudsman Programs; and Chapter 3 requires States to develop and enhance programs for the prevention and treatment of elder abuse, neglect and exploitation. Chapter 3 does not envision that the State Agency on Aging would establish a State protective services system. Rather, the State Agency is expected to work to support, enhance and improve the State's overall system for the prevention and treatment of elder abuse, neglect and exploitation, in alliance with the State APS agency.

The need for clarity regarding roles of ombudsmen and APS workers is heightened by the growing number of State Agencies on Aging which also serve as the State Adult Protective

Services agency: as of 1992 approximately twenty-two State agencies administered the APS program in their State.

In order to facilitate a dialogue to generate increased understanding about the similarities, differences and interface between adult protection and ombudsman services and programs, AoA, which administers the Long-Term Care Ombudsman Program at the Federal level, outlined the specific issues involved and raised a series of questions for discussion. We invited representatives of the Long-Term Care Ombudsman, Adult Protective Services and Elder Legal Services networks who had particular knowledge and specifically identified experience in the designated topic areas to a meeting held on October 25-26, 1993 at the Omni Shoreham Hotel in Washington, D.C. The agenda, discussion questions, and list of the participants are attached. (Attachment C)

The Meeting

The one-and-one half day meeting provided for an in-depth discussion of the issues among the participants in three small groups with equal numbers of ombudsman, APS and legal representatives in each group, and, on the second day, among all of the participants meeting together. AoA asked the invitees to debate among themselves the specific issues contained in the ten questions and arrive at:

- a group response to the questions and
- recommendations on Federal policies and program guidance which might be required to improve program operations at the State and local levels.

In his opening remarks, Deputy Assistant Secretary for Aging William Benson underscored the need for clarifying the roles of ombudsmen and APS workers. In describing how there can be a conflict of interest between these two roles, he provided the following example:

An APS worker investigates a report of abuse, neglect or exploitation and concludes that the alleged victim needs protective services and successfully moves to have the older person placed under a guardianship. Once under the guardianship, the guardian, who is the APS worker who investigated originally, places the ward (i.e., the older person) in a nursing home. Once in the nursing home, the ward is unhappy and wants to file a complaint (e.g., about being placed under a guardianship, about being placed in a nursing home, about the behavior of the guardian) with the ombudsman. An ombudsman comes to investigate and she/he turns out to be the very same person who is the guardian and investigating APS worker, or is from the same office as the guardian and APS worker.

Mr. Benson said that when he used this example in a recent speech, the audience responded that it was not an "extreme hypothetical"; that there were inherent conflicts between the roles of ombudsman and adult protective services workers which often surfaced in real-life situations similar to that in the example. He exhorted the group to fully examine the core issues around such potential conflicts of interest.

Summary of Considerations, Findings and Recommendations

In response to the discussion questions posited by AoA, the participants provided the responses and recommendations outlined in the six parts which follow. Since there was overlap in their responses to the questions, the conclusions below are presented by topic area, rather than in the question format used at the meeting. Additional thoughts and suggestions were provided by individual participants, as a result of their review of the first draft of this report. These additional comments were inserted at appropriate places in the text of the report.

I. Roles and Functions of APS and Ombudsman Programs

The two programs must work together to better serve their clients. They often serve the same individuals. These individuals may need the services of either or both programs. By coordinating their efforts the two programs can assure that the people who turn to them receive the assistance they need.

There are variations among the States in the degree to which the similarities and differences discussed below apply due to differences in authorizing legislation, operational structures, resources, and philosophy. Nevertheless, the conclusions in this section apply in many, if not most, States and provide a framework for understanding the history, philosophy, mission, roles and functions of the two programs and networks.

Similarities Between APS and Ombudsman Programs

There are some basic and important similarities in the overall objectives and functions of Adult Protective Services and Long Term Care Ombudsman Programs:

- Both programs seek to improve the quality of care and life of their clients.
- Individuals working in both programs consider themselves to be *advocates* for the vulnerable people they serve.
- Both programs seek to honor and protect the individual preferences and right to self-determination of those they serve.
- Some key functions and approaches of the two programs are similar: both programs receive, investigate, and act on reports and complaints concerning care and treatment of vulnerable adults.

Differences and Distinctions Between APS and Ombudsman Programs

The participants agreed that there are, however, important distinctions and differences in the history, legal underpinnings, mandates and development of the two programs and in the roles of ombudsmen and APS workers. While there was a lack of consensus in defining the philosophical approaches and specific roles of each program, the chart below reflects the conclusions reached by a large majority of the participants regarding distinctions between the two programs. To some degree, the lack of consensus reflects the variations in programs and working relationships within the States represented and underscores the need for similar discussions to occur within every State.

Differences in History, Philosophy, Mandates, Authorities:

APS	Ombudsman
In many States, organizationally linked to child protective services.	Linked to network on aging, with mission to advocate for older people.
Based on a <i>parens patriae</i> legal philosophy: the State's responsibility to protect the health and welfare of citizens; but supports philosophy of client autonomy as long as client retains decisional capacity.	Based on philosophy of being watchdog and advocate for rights of individuals and supporting resident's autonomy and expressed preferences
Established by State legislation and funded with combination of State and Federal block grant funding; therefore only nationally uniform philosophy or definition is that provided by the National Association of Adult Protective Services Administrators.	Established and defined by Federal legislation and receives designated Federal funding; therefore, there is a nationally uniform philosophy and set of program mandates.
Mandate is usually limited to focus on individual client rather than systems change, although some APS agencies do work for systems change.	Mandate is to focus on individual client and changes in system to benefit large numbers of individuals.
In most States, not restricted by age: typically serves all adults who are vulnerable due to disability.	Serves older residents of long-term care facilities, although may respond to younger residents.
Intervention triggered by crisis and is often relatively short-term (weeks or months).	Relatively long-term (months or years) ombudsman presence in facilities improves quality of life and, in addition, can prevent crisis from developing.
May be mandated to report abuse, neglect and exploitation to other agencies or officials and/or take action under conditions set forth in law.	Restrained by Federal law from reporting or otherwise breaching resident's confidentiality without consent of resident, except in certain circumstances.
Usually authorized to obtain access to clients and clients' records without their consent, if necessary, as permitted by law.	Access to resident only with resident's consent; restrained from access to resident's records without consent of resident or resident's representative, or unless approved by State Ombudsman.
May petition the courts for guardianship or emergency protective order and sometimes serves as temporary guardian.	It is outside of ombudsman mandate to seek or serve as guardian or temporary custodian; such authority would present conflict-of-interest with mandate to serve as advocate.

APS	Ombudsman
Differences in Roles:	
Serves as agent of the State to act in best interest of client; staff are investigators and caseworkers.	Serves as agent of and advocate for residents.
Develops service plan and arranges for placement or other services to meet the client's needs.	Advocates for services to be provided; monitors availability and quality of services to residents.
Uses long-term care facilities as a resource for client placement, when needed.	Monitors long-term care facilities and often advocates for facilities to change their practices.
Acts as an agent of consumer protection; at the point that intervention becomes necessary, APS intervenes.	Acts as an agent of consumer protection; at the point that intervention becomes necessary, advocates for intervention and monitors the intervention.
Respects and guards client autonomy as long as client retains decisional capacity.	Empowers residents and guards their autonomy, usually in a more unrestricted way than APS.

Barriers to Cooperation and Collaboration

There are several factors which can impede cooperation and collaboration between the APS and Ombudsman programs. These barriers will vary from State to State, depending upon legislated mandates, program philosophy, resources, and the inter-relationships which have developed.

- Lack of specific knowledge about the other program: its mandates, scope of responsibility, skill and knowledge base, constraints, and approach to cases;
- Over-stretched resources in both programs;
- Placement in different agencies can contribute to poor communication and lack of sharing of information;
- In some States, lack of APS responsibility for residents of long-term care facilities (in some States, cases of abuse and exploitation in long-term care facilities are handled by the facility licensing agency);
- Misunderstanding of the Federal ombudsman client confidentiality requirement; unclear policies, requirements, practices vis-a-vis client consent and mandatory reporting and/or sharing of case information;

- In some States, differences in program philosophy and/or misunderstanding on the part of ombudsmen of the APS role and philosophy vis-a-vis client autonomy.
- Differences in definition of terms, e.g. both programs consider themselves *advocates* but may define the term differently; they may define "abuse, neglect and exploitation" differently;
- Confusion about, or blurring of, roles regarding:
 - when a case should be referred to APS by ombudsmen or to ombudsmen from APS;
 - when there are roles for both ombudsmen and APS in working with the same client;
 - when and how to share confidential information; and
 - when an ombudsman provides services and acts more as a caseworker than as an advocate;
- The difficulty of the two programs working cooperatively if they have criticized or advocated for changes in the approach and/or operation of one another's programs; and
- Lack of understanding about when to call in other agencies/entities in addition to APS or ombudsmen, like law enforcement or licensing and certification.

Additional Barrier Provided in Comments Following Meeting:

- Lack of clarity and/or agreement about the intent of Older Americans Act Title VII, Chapter 3, "Programs for Prevention of Elder Abuse, Neglect and Exploitation" and the expenditure of funds appropriated for activities under this chapter.

Recommendations to AoA

- Emphasize the Ombudsman Program's advocacy role to resolve individual cases and systems issues.
- Issue guidance to States which discusses similarities and differences in roles between APS and Ombudsmen. In the guidance materials, stress that the vulnerable individuals these programs are designed to serve need access to both ombudsman **and** protective services.
- Emphasize in guidance to States that Title VII is not a directive to State Agencies on Aging to administer State APS programs. The role of the State agency is to advocate for a statewide APS system that is available and effective by helping to build, support and strengthen the existing system and link it to agencies and individuals who have a role in preventing and treating abuse, philosophy and exploitation.
- Convene meetings through the AoA Regional Offices to bring State leaders together to discuss Elder Rights issues. These would serve as a model and a springboard for similar discussions to be conducted in each State, as described below under recommendations to States.

- ❑ Encourage States to conduct a discussion under their Title VII mandate similar to this one held at the national level and to develop memoranda of understanding and protocols for coordination between State agencies with responsibilities related to Title VII, especially ombudsman and APS programs. (See the recommendations to the States.)

Recommendations to State Agencies on Aging and State Adult Protective Services Agencies

- ❑ Convene meetings at both the State and the regional/local levels to discuss and clarify the roles and functions of APS and the Ombudsman Program and explore ways that the two programs can work together and be mutually supportive.
 - Involve : APS, ombudsmen, legal services, law enforcement, licensing and certification, public guardians, Attorney General, and any other entities which need to participate due to the relevance of their role.
 - Focus on: resolving confusion about definitions, roles, referrals; program priorities; avoiding conflicts of interest; confidentiality and reporting requirements; and client empowerment issues.
 - Use case scenarios from recent cases to determine how they could have been addressed more effectively through improved collaboration.
 - Develop written memoranda of understanding and protocols, based upon areas of agreement.
- ❑ Keep the roles of APS and Ombudsmen separate and distinct, recognizing that each is important to undergirding Elder Rights.

Additional Recommendations Provided Following Meeting:

- ❑ AoA should foster and be involved in continuing communication and meetings between national agencies and organizations involved in Elder Rights issues, such as the National Association of Adult Protective Services Administrators (NAAPSA), the National Association of State Units on Aging (NASUA), the National Association of State Long-Term Care Ombudsman (NASOP), the National Citizens Coalition for Nursing Home Reform and others.
- ❑ States should foster in any way possible on-going communication and meetings at both State and local levels so that genuine working relationships and meaningful collaboration will develop between key agencies and individuals.
- ❑ States should develop training curriculum which utilizes staff perspective and expertise of the various agencies and programs involved; provide training and technical assistance so that "hoped for" results occur at the local level.

II. APS and Ombudsman Services: Separate Roles; Separate People

Distinct Functions

While they often share a similar philosophy of respect for client wishes and preferences, similar long-term objectives for the well being of the vulnerable individuals they serve and similar functions and approaches in their work, adult protective services and ombudsman services are separate and distinct, as outlined in the preceding chart. Each role has its own inherent conflicts that arise in serving clients/residents, working with facilities and systems, and working within legal mandates. To ask one person to do both jobs is to ask that person to serve in conflicting roles in working with clients/residents, and to perform both roles with equal skill.

A few States have combined the APS and ombudsman roles; others allow one individual to serve in both jobs, each on a part-time basis. Due to budgetary constraints other States may be considering, or may consider at some future point, combining these functions. *In spite of this, there was consensus among the participants that combining the roles means that one job will not be done.* If one person is trying to be both APS worker and ombudsman, the following consequences are very likely to occur:

- One function will be favored more than the other, as both cannot be performed adequately. In particular, the ombudsman would spend all of his/her time on cases involving abuse, gross neglect and exploitation and not be able to address other types of complaints or undertake other ombudsman functions which help to prevent or reduce the incidence of abuse, neglect and exploitation in long-term care facilities.
- Clients will lose the services and representation that is available by keeping APS and ombudsman programs separate. An example of is that provided by Deputy Assistant Secretary Benson on page 2.
- It will not be possible to develop procedures, safeguards or boundaries to adequately address the conflict-of-interest issues that would arise.

There are times when a *team* approach to investigating cases is beneficial. However, this approach should be used judiciously to avoid overwhelming the client with too many people or compromising the role of the ombudsman from the client's perspective.

Recommendations to AoA

- ❑ Issue a regulation which prohibits an ombudsman from also being an APS worker; reflect this policy in AoA correspondence and all other pertinent policy issuances.
- ❑ State the principles by which ombudsman programs operate with integrity. Ask State and local programs to operate in line with these principles and monitor them by these principles.

Recommendations to State Units on Aging

- ❑ If there is not enough money to fund both programs, acknowledge this reality, and do not claim both are being done.

Additional Recommendation Provided Following Meeting:

- ❑ Where State Adult Protective Services agencies are not currently investigating abuse, neglect and exploitation in long-term care facilities, work for changes in law, regulations, and/or policy, as needed, to designate APS to perform this function; and advocate for funding for APS adequate to carrying out this responsibility.

III. Administration of APS and Ombudsman Programs by the Same Agency

In approximately twenty-two States, the State Agency on Aging and the State Adult Protective Services program are combined in the same agency. The participants agreed that, for ombudsman and APS program operations, there are both advantages and disadvantages to such consolidation.

Advantages

- There is increased potential for the agency to see the “big picture” of client needs and advocacy.
- There could be equal access to resources and decision-makers.
- Joint training and program coordination are easier to achieve.
- Both programs will be as strong as the agency to which they are attached. To place them in the same agency could strengthen both programs if the overall agency is strong.

Disadvantages

- At the direct service level, there are conflicts of interests if both programs are in the same agency. There may not be enough staff to separate the functions.
- The ability of both the Ombudsman Program and APS to assess and, when necessary, to criticize each other's programs could be weakened.
- An administrator might emphasize one program to the detriment of the other by favoring one with more resources.
- The ease of communication and coordination could encourage breaches of confidentiality.
- Both programs will only be as strong as the agency to which they are attached. To place them in the same agency could weaken both programs.

Recommendation to AoA

Issue guidance to States which reiterates the importance of States insuring that the Ombudsman Program has a high level of autonomy and full ability to effectively advocate for needed systems changes. Placement of the program in any agency, at the State or local

level, which impairs that ability is inappropriate and contrary to the program's purpose, as envisioned in the Older Americans Act.

Additional Recommendation from Comments Following Meeting

If APS and Ombudsman programs are housed in the same agency, the State Agency should be required to explain how the Ombudsman Program meetings its responsibilities.

IV. Conflicts for Ombudsmen Between Older Americans Act Confidentiality Requirements and State Mandatory Abuse Reporting Requirements

Legal Provisions and Other Considerations

There are both Federal and State laws regarding confidentiality and mandatory reporting of abuse.

The Older Americans Act [Section 712(d)(2)] prohibits disclosure of the identity of any complainant or resident by the ombudsman unless the complainant/resident or resident's legal representative consents or a court orders the disclosure. The Act [Sections 705(a)(6)(C) and 721(e)(2)(B)] also requires that elder abuse prevention programs funded under Title VII, Chapter 3 keep information pertinent to a report or referral of elder abuse, neglect or exploitation confidential. Exceptions include: consent by all parties to such complaint or report; release of such information to a law enforcement agency, public protective service agency, licensing or certification agency, ombudsman program, or protection or advocacy system; and upon court order.

In contrast to, and sometimes in conflict with, the Federal law, a number of States have mandatory reporting requirements for individuals — including ombudsmen - who know of or suspect adult abuse, neglect, or exploitation. These provisions create confusion and misunderstanding about the responsibility of ombudsmen regarding cases of abuse, neglect, or exploitation and client/resident confidentiality. Sometimes ombudsmen, particularly those working at the local level, feel caught between these conflicting State and Federal statutory requirements and the philosophies they represent.

In discussing confidentiality, several participants mentioned tangential issues regarding to access to residents and records. These comments are reflect in the last two recommendations, below.

Reporting/Handling Information About Abuse

Conflicts between mandatory reporting and protecting resident confidentiality arise when a resident tells an ombudsman about abuse/neglect/exploitation, refuses to report the incident to anyone but the ombudsman, and asks the ombudsman not to tell anyone.

General Consensus

- The Federal requirement regarding the ombudsman duty to protect the identity of complainants/residents supersedes State reporting requirements. Disclosing information provided by the resident only with the resident's permission is essential to a trust relationship between an ombudsman and a resident. It is akin to the physician or attorney privilege.
- If the ombudsman thinks the situation should be reported because of danger to the resident and/or others, the ombudsman should: counsel the resident about the risk of repeated abuse and abuse to other, more impaired residents; explain the reporting and investigation process and possible outcomes; and attempt to obtain consent to report.

Ombudsmen should commit necessary resources to support a resident who will be reporting grave allegations of abuse to APS, law enforcement agencies and regulatory agencies.

- Even if a resident refuses to report or to give the ombudsman permission to report, the ombudsman can take some actions to support the resident and to try to safeguard other residents if they might also be at risk of being harmed. *It is not permissible for the ombudsman to abandon a resident who refuses to report or to have the case reported, or to abandon the abusive situation and thus other residents who have not spoken out but may also be at risk. Work must continue to resolve the issue.*
- The ombudsman should report the case with or without the resident's permission if the perpetrator of the abuse confesses or if an offense is about to be committed.

Lack of Consensus

Notwithstanding the last sentence above, there was prolonged discussion and lack of a clear consensus regarding whether there should be *any* exceptions to the confidentiality provisions in the Ombudsman Program section of the Act. Some participants expressed the strong opinion that there may be sufficient reasons for ombudsmen to violate the Federal confidentiality requirement under certain circumstances. They pointed out that even physician and attorney confidentiality can be ethically and legally breached in specific situations. The following protocol was recommended in such circumstances:

In situations where failure to report may result in *imminent, extreme, or life-threatening harm to a resident or third party*, the ombudsman should:

- first, explore the fears of the resident in depth and follow the approach recommended above, under general consensus;
- second, if the resident and/or the resident's representative is not willing or able to give consent, inform the resident or the representative, if applicable, that the ombudsman is going to report and explain again what reporting means;
- take steps to assure protection of the resident to the greatest extent possible; and
- report to whichever authority - APS, licensing or law enforcement - has jurisdiction for protective services in the facility and/or will provide the most quick, effective response.

Recommendations to AoA

- ❑ Do not change the OAA provisions related to ombudsman protection of confidentiality.
- ❑ Issue program guidance which states that:
 - The confidentiality provisions in the Federal law supersede State mandatory reporting requirements;
 - Ombudsmen are obligated to know their State's definition of abuse, neglect and exploitation and upon recognizing these situations, to specifically ask the resident's permission to call in whichever agency is authorized in the State to respond to such situations;
 - Ombudsmen should never abandon the client/resident; and
 - States should address these confidentiality issues in interagency discussions and develop, as part of the memoranda of agreement discussed under Part I, a protocol which:
 - 1) incorporates the confidentiality requirements in Sections 712(d)(2), 705(a)(6)(C) and 721(e)(2) of the Older Americans Act;
 - 2) outlines steps for reporting and responding to cases involving abuse, neglect and exploitation, including those cases where residents or their representatives are not able or willing to consent to disclosure to anyone other than the ombudsman and there is risk to the resident and other residents, and
 - 3) specifies how ombudsman data can be incorporated into other State data to accurately reflect the incidence of abuse, neglect and exploitation in the State.
- ❑ Issue program guidance to clarify what some may view as inconsistency between the ombudsman confidentiality requirement in Title VII, Chapter 2, Section 712(d)(2) of the Act and Sections 705(a)(6)(C) and 721(e)(2)(b) of the Act, pertaining to confidentiality of information gathered by programs for the prevention of elder abuse, neglect and exploitation under Title VII, Chapter 3.
- ❑ Issue clear guidance which states that ombudsmen have the authority to see the client/resident, unless the resident refuses, even if the resident has a guardian.
- ❑ Make it clear that States are to develop procedures for ombudsmen to have access to resident records, even residents who have legal representatives/guardians, in accordance with the provisions in the OAA.

Additional Consideration in Comments Following Meeting:

In addition to the confidentiality considerations, there is also the need for:

sanctions and corrective actions when abuse and exploitation occur in long-term care facilities and

State and national data to adequately reflect the incidence of elder abuse, neglect and exploitation.

These factors should be included in the equation when discussing reporting of abuse, neglect and exploitation.

V. Balancing Protection and Self-Determination for Residents

For Residents/Clients With Decision-Making Capacity

For individuals *with decision-making capacity* the principle of self-determination should guide both the APS worker and the ombudsman. Differences in the approach of each program may occur in responding to questions of an individual's right to assume risk versus that person's decision-making capacity, but each program should promote the empowerment of the individual in his or her decision-making.

In discussing this topic, one participant pointed out that in some States APS laws evolved from the child protection model and stated that a better model for adults might be one based on *empowerment* rather than *protection*. It was proposed that under Title VII a national meeting and/or regional conferences involving people with a variety of perspectives might be held to examine the underlying principles of protective services and their applicability to adults, similarities and differences between child and adult protective services, experiences of the States in implementing adult protection laws, and consideration of other models as a legal basis for adults.

Situations of Conflict

For both APS workers and ombudsmen there are times when conflicts arise between protecting the health, safety and welfare of a client/resident, or of other residents, and respecting or protecting that individual's right to self-determination. These situations sometimes occur in cases where:

- a resident or client is engaging in, or threatening to engage in, criminal behavior;
- residents' wishes and/or facility actions are in conflict with the Federal Civil Rights or Americans With Disabilities laws; or
- the facility is the resident's guardian/conservator.

Recommendation to AoA

Highlight for States their Title VII responsibility to inform seniors and the public about the Americans With Disabilities Act and the Civil Rights Act and provide information to assist the States to fulfill this educational/advocacy role.

Recommendation to States

Encourage ombudsmen and APS workers at both the State and local levels to be sensitive to both individual life choices and cultural practices when assessing situations where an individual's decision-making capacity is questioned due to the personal risk an individual is accepting.

Working with Questions About an Individual's Decision-Making

Many dilemmas arise for both ombudsmen and APS workers when a resident's/client's decision-making capacity is questionable or when a resident/client clearly lacks the capacity to evidence his/her preference.

• Situations Involving Abuse, Neglect, or Exploitation

Both APS and ombudsmen should look for any *glimmer of capacity* in an individual. If this can be found, the individual preference should be followed. Determining a person's preference requires patience and spending time with that individual, as well as asking the questions a variety of different ways and offering the individual all possible options. The person may not express in words, but may express in actions or mood, his/her feelings and wishes about a situation. Two tools which can help with this determination in nursing facilities are the resident assessment instrument and the Pre-Admission Screening and Annual Resident Review process. These, or other documents, may provide an indication of Any indications of the individual's wishes should be well documented.

When an individual clearly lacks decision-making capacity and neither past nor present indications of preference can be discerned, both the APS worker and the ombudsman should act to meet the evident needs and serve what they believe to be the best interests of the individual.

• Situations Involving Medical Decisions

State laws are rapidly changing to ensure that family members are legally empowered to make decisions for an incapacitated individual without an authorizing document or court order. Examples of problem areas which will continue, even with this change, are situations when:

- there is conflict among family members;
 - there is a blanket Do Not Resuscitate (DNR) policy for all residents in a facility;
 - the resident has no family;

- instructions left by the resident do not provide sufficient information for the specific situation;
- the facility is the guardian or conservator; or
- abuse is involved and the guardian is the abuser.

General Consensus:

- Because it would compromise the ombudsman's ability to be an advocate for the resident, an ombudsman should never serve as a resident's agent or medical decision-maker or surrogate. However, an appropriate ombudsman role would be petitioning the court to appoint a surrogate decision-maker. (In written comments following the meeting one participant stated that APS, not the ombudsman, should petition the court.)
- Ombudsmen should advocate that an APS worker not be a permanent guardian for individual decision-making if another alternative is available.
- *Neither* ombudsmen nor APS workers should be identified as the *only* witness for DNR orders or other medical directives.
- Ombudsmen may provide information to a facility's ethics committee but should not be a member of any committee which makes medical decisions for residents who lack the capacity to evidence their preference. This role would also compromise the ombudsman's ability to be an advocate for the resident.
- Ombudsmen and legal services providers need to collaborate in determining ways to serve clients regarding these issues.
- There needs to be much more discussion about these issues, including the one below where there was a lack of consensus. The discussion needs to involve ombudsmen, APS, legal services, and perhaps some others. Title VII provides a good framework for such discussion.

Lack of Consensus

There were various perspectives regarding whether APS workers and/or ombudsmen should be among those listed in state law as individuals authorized, along with others, to witness medical directives, including DNR orders. No group consensus was reached. The following points were considered in the discussion:

- Including them as witnesses might be appropriate because the APS worker or ombudsman already has a relationship with the client/resident and has an understanding of the context in which the decision is being made.
- If present when medical decisions are made, the APS worker or ombudsman can provide assurance that the document truly represents an informed choice by the resident or any wishes expressed by the resident are honored.

- Serving as a witness should be voluntary, not mandated, and dependent upon the relationship with the resident.
- There should be detailed protocols to follow if an APS worker or ombudsman serves as a witness.

A minority of participants believed that ombudsmen should not be witnesses or have any formal role because such role prevents them from being free enough of conflict to monitor the situation.

Recommendation to AoA

Encourage States to address these issues by:

- ❑ examining State laws and regulatory oversight practices to see if an individual's rights are protected and what rights are retained under guardianship or power of attorney;
- ❑ analyzing the need for educating consumers, ombudsmen, APS workers, and facility staff about issues such as DNR orders, the implications of DNR orders, and facility and/or physician practices regarding these decisions;
- ❑ clarifying that the ombudsman's role is to advocate for the resident's voice and perspective to be heard and honored in medical decision-making;
- ❑ understanding the rights an individual retains even when there is a power of attorney or guardianship.

VI. Ombudsman Reporting and Definitions of Abuse

Background

The proposed new ombudsman reporting system on complaints received by the Ombudsman Program offers the opportunity to collect uniform, national data on abuse, neglect and exploitation. Since there are multiple definitions of abuse, neglect, and exploitation, participants were asked if they thought AoA should ask States to use their own definitions or provide national definitions to be used by all States for ombudsman reporting purposes.

Lack of Consensus

The majority of participants thought that, for ombudsman reporting purposes, the national definitions provided in the Older Americans Act and Health Care Financing Administration survey guidelines for facilities participating in Medicare and Medicaid would be most appropriate. They made the following points:

- Since there may be different definitions of abuse used within a State, it makes more sense to use a national definition for ombudsman reporting.
- This would yield nationally consistent data from the Ombudsman Program.
- There could be some advantages in the Ombudsman Program's use of HCFA's surveyor definitions in that ombudsmen, surveyors, and facilities would be "speaking the same language" when discussing abuse.

- More examples need to be included with the definitions given in the instructions to the proposed Ombudsman Reporting System.

The minority view was that it would be more beneficial to advocacy purposes and data collection if each ombudsman program coordinated its definition of abuse with that used in its own State, as defined in State APS statute and/or policies. They pointed out that:

- Since there are multiple sources of abuse data, a consistent definition for ombudsman reporting nationally will not make a significant impact on the national data.
- It would be more useful for Ombudsman Programs if they use the definitions applicable in their states. They will be better able to contribute to state discussions and to speak a common language with APS workers if they use the state definition.

Conclusion

In concluding the meeting, Deputy Assistant Secretary for Aging John F. McCarthy thanked the participants for the long, intense hours they had dedicated to consideration of these complex issues. He assured them that AoA would give full consideration to their views and recommendations as it developed policies and guidelines for implementing Title VII of the Older Americans Act.