MODULE 1
THE LONG TERM CARE OMBUDSMAN PROGRAM

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I. History of the Long Term Care Ombudsman Program

A. Nursing Home Care: Historical Background

In the late 1960s and early 1970s, many publications appeared describing abuse, neglect, and substandard conditions in the nation's nursing homes.[1] Several Congressional committees convened to hear testimony, compile data, and propose reforms for the nursing home industry. The ample publicity about poor care and personal profit for nursing home owners created a climate enabling more rigid federal regulations for standards of care to be enacted in the early 1970s.

A 1971 directive from President Richard Nixon led to the establishment of a new office within the Department of Health, Education and Welfare (HEW) to oversee all programs relating to nursing homes. The new Office of Nursing Home Affairs (ONHA) was to be responsible for coordinating efforts by different agencies in HEW to upgrade standards nationwide for the benefit of nursing home residents. Establishment of ONHA and the appointment of Marie Callender as its director provided for the first time the framework for pulling together different HEW nursing home efforts into a single coordinated program. Two hundred and twenty-seven new personnel were added to federal enforcement.

B. President Nixon's Eight Point Directive

President Nixon's 1971 directive also formulated an 8-point nursing home program:

1. Training of 2,000 state nursing home inspectors
2. Complete (100 %) federal support of state inspections under Medicaid
3. Consolidation of enforcement activities
4. Strengthening of federal enforcement standards
5. Short-term training of 41,000 professional and paraprofessional nursing home personnel
6. Assistance for state investigative "Ombudsman" units
7. Comprehensive review of long-term care
8. Crackdown on substandard nursing homes: cut-off of federal funds to them.

In January 1972, HEW awarded more than half a million dollars in contracts to test ombudsman programs for nursing home residents. By January 1974, 5-day registered nurse coverage (but no medical director) was required for Intermediate Care Facilities (ICFs). Then, in December 1974, significant regulations for Skilled Nursing Facilities (SNFs) were approved, including a "patient's bill of rights," a medical director (as of January 1, 1976), a registered nurse seven days a week, and a discharge planning process.

The rapid growth of nursing homes in the 1960s and 1970s and a concern for the quality of care and quality of life experience by the residents of these facilities were in part responsible for the creation of the nursing home ombudsman programs that exist today.

C. Ombudsman Program History

As noted above, The Long-Term Care Ombudsman Program was initiated by President Nixon, who directed HEW "to assist the States in establishing investigative units which would respond in a responsible and constructive way to complaints made by or on behalf of individual nursing home patients." An interdepartmental task force was formed under the direction of the Health Services and Mental Health Administration to develop

[1] See, for example, Mary Adelaide Mendelson, *Tender Loving Greed*, N.Y.: Alfred A. Knopf, 1974, and R.N. Butler, *Why Survive? Being Old in America*, NY: Harler & Row, 1975.

models for investigative/ombudsman units; and in the Supplemental Appropriations Act of December 1971, Congress made funds available for the establishment of nursing home ombudsman demonstration projects.

On June 30, 1972, contracts were awarded to Idaho, Pennsylvania, South Carolina, and Wisconsin to establish a State level long-term care ombudsman office linked to a local unit. A fifth contract was awarded to the National Council of Senior Citizens to test the effectiveness of an independent nursing home ombudsman project operating outside government jurisdiction and to assess the feasibility of linking a national voluntary organization to State and local units. The National Council selected Michigan as the site of its demonstration. Additional projects were started in Massachusetts and Oregon in July, 1973.

An impressive record of complaint resolution was submitted by the demonstration projects in quarterly reports and program assessments provided at the end of the demonstration period. In addition, the projects were successful in (1) identifying problems related to long term care and bringing them to the attention of the public, government agencies, and providers; (2) including the needs and perspectives of residents in the deliberations of policy makers; and (3) designing, organizing, and implementing training programs and informational forums for the public and for nursing home staff.

In 1973, the Health Services and Mental Health administration was re-organized, and the Nursing Home Ombudsman Program was transferred to the Administration on Aging. In May of 1975, former Director of the Administration on Aging, Arthur S. Flemming, invited all State Agencies on Aging to submit proposals for grants "to enable State Agencies to develop the capabilities of the Area Agencies on Aging to promote, coordinate, monitor, and assess nursing home ombudsman activities within their services areas." The primary goal of the grants was to inaugurate in as many areas as possible community action programs dedicated to identifying and dealing with the complaints of older persons, or their family members, regarding the operation of nursing homes. All states except Nebraska and Oklahoma received grants the first year and hired a nursing home ombudsman developmental specialist, generally working out of the State Office on Aging, to develop the State and sub-State programs.

From 1975 through 1978, the ombudsman programs departed from the demonstration projects in two particularly significant ways:

1. Where the demonstration projects had focused on complaint resolution from one (or, in some cases, two or three) central points in the State, the 1975-78 program stressed development of local/area programs throughout the State.
2. Where the directors of the demonstration projects had been called ombudsmen and had worked directly on complaints, the individuals hired under the 1975-78 grants were designated "ombudsman developmental specialists" and were charged by AoA with developing sub-State programs rather than working directly on complaints.

In addition, the early nationwide program stressed reliance on volunteer, rather than paid, ombudsmen.

These changes were made because the demonstration projects had indicated that a small staff operating an ombudsman program from one central location in a State would have great difficulty responding to the volume and variety of complaints voiced by residents and

their families throughout the State. Given the limited funding available, the development of locally-based complaint resolution and resident advocacy programs was seen as the only means of attaining statewide ombudsman coverage. This approach had a significant impact on the direction of the program after passage of the ombudsman legislative mandate in 1978.

D. Ombudsman Program and Advocacy Assistance

In June of 1978, AoA announced its intention to combine ombudsman and legal services efforts into a common framework to "more effectively deal with the concerns of institutionalized and non-institutionalized vulnerable elderly." AoA made available to State Agencies on Aging model project grants to support this advocacy effort by assuring more legal back-up for the ombudsman program, in particular, and for dealing with the problems of the institutionalized elderly, in general, and to encourage the increased use of advocacy by non-lawyers to serve the elderly.

To support the State and Area Agencies on Aging and other community organizations in their advocacy functions, AoA awarded contracts in 1979 and 1980 for five Bi-Regional Advocacy Assistance Resource and Support Centers and a national center. Under these awards, the contractor has provided training for State and local advocacy programs and technical assistance in the design and implementation of advocacy delivery systems, including statewide ombudsman programs and resource and support services on legislative and administrative advocacy and litigation.

Also in 1979, AoA awarded a grant to the National Citizens' Coalition for Nursing Home Reform to promote and organize citizen involvement to improve the quality of life for nursing home residents. One of the objectives of the grant was to strengthen and maintain the Coalition's linkages with the ombudsman network through its provision of information, training, and technical assistance to those involved in the Ombudsman Program at both the State and local levels. The Coalition continues to support Ombudsman Programs nationwide through its development and operation of the National Ombudsman Resource Center, its sponsorship of annual national conferences, and its advocacy efforts on the national level on behalf of nursing home residents.

E. Ombudsman Program Under The Older Americans Act (OAA)

The 1978 Amendments to the Older Americans Act, passed in October 1978, considerably strengthened the Ombudsman Program. Title III, Section 307(a)(12) required every State to have a program and specifically defined ombudsman functions and responsibilities. The 1978 Amendments also elevated the Ombudsman Program to a statutory level and required all State Agencies on Aging to establish an ombudsman program that would carry out the following activities:

- Investigate and resolve long term care facility residents' complaints;
- Promote the development of citizens' organizations and train volunteers;
- Identify significant problems by establishing a statewide reporting system for complaints and work to resolve these problems by bringing them to the attention of appropriate public agencies;
- Monitor the development and implementation of federal, state, and local long term care laws and policies;
- Gain access to long term care facilities and to residents' records;
- Protect the confidentiality of residents' records, complainants' identities, and ombudsman files.

These regulatory provisions set the framework for the development of State Ombudsman Programs that included both the complaint investigation focus of the demonstration projects and sub-State program focus on establishing local/area resident advocacy units throughout each State. These provisions also enabled the States to develop and work for the enactment of State ombudsman program legislation.

The 1981 reauthorization of the Older Americans Act resulted in further expansion of ombudsman duties. Personal care homes,[2] in addition to nursing homes, were to be the monitored by ombudsmen, and the title of Nursing Home Ombudsman was changed to Long Term Care Ombudsman (LTCO) to reflect this change.

The 1987 Amendments to the OAA made substantive changes to the Long Term Care Ombudsman Program that resulted in a significant improvement in the program's ability to advocate on behalf of residents of LTC facilities. The changes required States to provide for:

- Ombudsman access to residents and residents' records;
- Legal immunity to ombudsmen for the good faith performance of their duties;
- Prohibitions against the willful interference with the official duties of an ombudsman and/or retaliation against an ombudsman, resident, or other individual for assisting the Ombudsman Program in the performance of its duties.

From President Nixon's directives in 1971 to the Ombudsman Program's reauthorization in 1987 and the subsequent amendments to the Older American Act, the purpose of the program has remained constant: to represent the needs and interests of present and potential long term care facility residents.

F. The D.C. Long-Term Care Ombudsman Program

In order to assist long term care residents in the assertion of their civil and human rights, the District of Columbia Council specifically defined the powers and duties of the D.C. Long-Term Care Ombudsman Program in legislation that took effect in 1989. The powers granted to the Ombudsman Program in this legislation are intended to emphasize the primary role of investigating and resolving complaints made by or on behalf of long term care residents. The rights given to the Ombudsman Program include:

- Access to nursing homes
- Access to nursing home residents
- Access to records concerning nursing home residents
- Immunity from liability
- Confidentiality
- Civil penalties for willful interference with Ombudsman Program activities

The services provided by the Ombudsman Program on behalf of long-term care residents include:

- Receiving, investigating, and attempting to resolve complaints;
- Helping residents with individual personal problems;
- Assisting in forming and strengthening family councils;
- Linking residents to outside services or activities;
- Attending meetings with facility staff to explain the Ombudsman Program or seek resolution to an individual or widespread problem;

[2] Also known as board and care homes, adult group homes, adult congregate living residences, etc.

- Serving as the representative for residents who have not designated someone to represent them and/or do not have a court appointed representative;
- Providing legal representation for residents;
- Advocating for the rights and quality of life for long-term care residents.

(**Note**: A copy of the D.C. Long Term Care Ombudsman Program Act of 1988 is included in this manual as Appendix A.)

The District of Columbia Long Term Care Ombudsman Program

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Nursing Homes Monitored:

Northwest Health Care Center

Washington Home

Thomas House

Rock Creek Manor

J.B. Johnson

Knollwood

Sibley Hospital Rehab.Unit

Methodist Home

Ingleside Presbyterian Home

Lisner Louise

Stoddard Baptist

Howard University Hospital, Skilled Nursing Home Unit

2. Charles Marquardt, Local Ombudsman

United Planning Organization
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Nursing Homes Monitored:

Health Care Institute

Washington Nursing Facility

MedLINK Nursing & Rehab Center

Hadley Hospital Skilled Nursing Facility

Washington Center for Aging Services

Grant Park

Little Sisters of the Poor

Carroll Manor

II. Functions/Roles Of Ombudsmen

A. Introduction to the Ombudsman Role

1. <u>Long-Term Care Ombudsman Role</u>

In the case of long term care, an ombudsman helps the public (usually residents) get answers to questions about the services received from agencies and facilities. The long term care ombudsman should be:

- independent politically and administratively of the facility or agency involved;
- impartial, serving the administration as well as the residents or service recipients;
- accessible to all parties concerned;
- knowledgeable about long term care and concerns of the elderly.

The long term care ombudsman does not have the power to make or alter administrative decisions, but he/she does have the power to investigate and to recommend courses of action. While an ombudsman's primary role is to help residents to help themselves, at times he/she may be asked to speak on behalf of the resident or family. This usually occurs when the resident or resident's family does not know how to access resources within the home or community, when family or legal problems arise, or when there is fear of causing tension in resident-staff relationships.

The ombudsman hears about concerns from many sources: from residents, families, friends, personnel, the administrator, and others. The subject of most of these concerns will be related to nursing care, food, finances, sanitation, activities, and physician services. The resident may need assistance in obtaining legal aid, especially in regard to property, wills and guardianships. If they have no relatives, residents may need to locate services to assist in shopping for clothing and personal items. Thus, the ombudsman must work with the administrator to identify appropriate community resources.

There are four basic reasons why many residents are unable to address problems on their own.

1. They are unaware of their rights or of what facilities are required to do.

2. They lack of knowledge, have physical or mental limitations, or have situational circumstances that make them unable to work through the complexities of the complaint process.

3. The whole process of working to resolve a complaint is overwhelming.

4. Institutional factors, such as isolation, lack of power, and resistance to change,

make it difficult for a resident to resolve the problem without outside assistance.

Since an ombudsman does not have any authority to compel a facility or agency to take actions necessary to resolve a complaint, he/she must utilize a number of different roles in order to influence decision-makers to act in a manner that will resolve the complaint. As a

result of these different roles, there are a number of terms that can be used to describe the roles played by ombudsmen to resolve complaints: companion, mediator, broker, educator, and advocate. However, the roles available to the ombudsman should not overlap with the legitimate roles of others, (e.g., inspectors, facility, staff, doctors).

The following is an outline of the different roles an ombudsman might assume to resolve problems:

COMPANION - An ombudsman may provide simple companionship or social activity to a resident. The friendly visiting function is often an important and necessary step in getting to know residents and establishing trust. Most ombudsmen find that friendly visiting is only the first step they take as ombudsmen. When trust is established, residents can feel comfortable in presenting problems to ombudsmen, who can then offer planning suggestions or other assistance to resolve complaints.

ADVOCATE – Advocacy is often used as a generic term for what ombudsmen do, but in looking at roles, it has a very different meaning and function from other roles. As an advocate, the ombudsman works on behalf of a resident to resolve complaints that have been substantiated and develop specific strategies to alleviate the problem. Advocacy may take the form of negotiating with an administrator or other staffperson, filing a complaint on behalf of the resident, working with a resident council, or getting a group of residents who have similar concerns together and working to resolve the problem as a group.

EDUCATOR - An ombudsman works to educate residents, families, friends or potential consumers about their rights and responsibilities in a facility. Ombudsmen need to have a working knowledge of current federal and state residents' rights in order to answer questions. Ombudsmen also provide information to concerned individuals who wish to advocate for themselves, but don't know how to go about it. Materials on topics such as "How to Select a Nursing Home" or "Resident Rights" can be used to provide supplementary information to residents, family members, and others.

MEDIATOR - The Ombudsman may serve as a mediator between resident and staff, resident and community or local government agency, resident and other residents, or resident and family. In this role the ombudsman may be a spokesperson for the resident, communicating his/her concerns to the appropriate staff, agency or family member in an effort to see the grievance or problem resolved. At times the response may be immediate and satisfactory. The agency or individual may be unaware of the problem until it surfaces through the efforts of the ombudsman, and the resolution may be relatively simple. Many problems result from misunderstandings or breakdowns in communication. Clarification by the ombudsman may be all that is necessary.

A mediator helps the parties find an acceptable solution by following a complaint or grievance through to resolution. In this role, ombudsmen do not impose their own solution but help those involved to find and agree upon their own acceptable solution.

BROKER - A broker's role is essentially that of a referral agent. When an ombudsman investigates a problem and finds that another agency could better resolve it or is essential to the process, a referral should be made. Referrals will often be made to many of the same resources used in carrying out education and advocacy duties.

After making a referral to an agency, the ombudsman should remain in contact with the agency, checking on progress and reporting back to the complainant. The ombudsman may not have the power to ensure prompt service, but his/her conscientious follow-up may help "oil the wheels."

2. The Role of the Volunteer Resident Advocate

To be effective as a volunteer resident advocate with the Ombudsman Program, one must be a problem-solver. The Ombudsman Program exists to empower nursing home residents, with a special emphasis of advocacy**. The client for whom the volunteer advocates is always the resident.**

3. Inappropriate Roles for the Volunteer Resident Advocate

Some roles are not appropriate for the volunteer advocate:

- **Friendly Visitor**

All nursing home residents need a friend - someone to remember their birthday, bring them home for Thanksgiving dinner, take them cards, cookies and flowers. However, this valuable role is not appropriate for the volunteer resident advocate with the Ombudsman Program.

- **Objectivity**

A person should not be a volunteer advocate in a nursing home where he/she is visiting relatives. Objectivity usually is not possible; fear of retaliation against the relative may keep him/her from being an advocate; a perception of favoritism may develop; and his/her role in the nursing home may be misunderstood by the staff. Even more important, other residents in the facility may be neglected, or feel neglected, if the volunteer resident advocate's time is concentrated on meeting the social needs of a few residents.

- **Facility Helper**

Family members, volunteers of the facility, and/or friendly visitors are often asked to help facility staff with residents' needs. However, feeding residents, helping with recreational activities, helping residents walk, and providing transportation are responsibilities of the facility staff. Volunteer advocates are there to help residents get the care and services they need and are entitled to-- not to perform these tasks.

- **Special Interest Visitor**

Many special interest groups (religious, political, and charitable) want to work with nursing home residents. However, it is unacceptable to use the position of volunteer resident advocate with the Ombudsman Program to gain access to residents and/or their families to further the goals of a religious, political, nutritional, medical, or other special interest group.

- **Volunteers Should Not be Vigilantes**

Persons who are “out to get” nursing homes, who want to “settle an old score,” or who have hostile or negative attitudes about nursing homes cannot be reasonable about solving problems in nursing homes and thus are ineligible to serve as Ombudsman Program volunteers. People who are on power trips and like to throw their weight around are seldom attracted to this program and are asked to leave immediately.

B. Confidentiality

Confidentiality is of the highest importance in the Ombudsman Program. The resident is the one who suffers from a broken confidence, and the resident has every right to say what information can be released and to whom. **The need for confidentiality cannot be stressed enough.** Nursing home residents are often afraid to complain for fear of reprisal or retaliation, so often the only way that they will voice their complaints is if they can be assured that they will be allowed to remain anonymous. This desire for anonymity may make it difficult to resolve complaints, but it is the absolute right of residents to keep their complaints confidential.

A volunteer resident advocate must respect confidentiality, utterly and completely. Whatever he/she knows about a resident is under no circumstances to be discussed with anyone outside the Ombudsman Program. Violations of confidence are not only highly unethical and illegal, but also a sure way to destroy a relationship with a resident.

C. Advocacy Issues

Advocacy in the Ombudsman Program exists primarily to represent the expressed concerns of nursing home residents who are relatively without influence or representation within a facility. By extension, the Program will represent the concerns of the relatives and/or friends of nursing home residents, taking care to determine the degree to which such concerns reflect the concern of the residents.

Case advocacy assumes a partisan stance on behalf of a person or a group of people who cannot negotiate their demands alone, find redress for grievances, or cut through bureaucratic red tape.

D. The Do’s And Don’ts Of Advocacy

The Do’s of Advocacy

1. Respect the confidentiality of all complaints made to you.
2. Be a good listener.
3. Assure the residents that you are there to listen to their problems.
4. Speak clearly and slowly so the resident can understand you.
5. Try to talk to the resident in a quiet, private area.
6. Explain things in a few words, rather than in long paragraphs.
7. Be objective, yet understanding.
8. Try to provide an accurate picture to the residents of what they can expect.

9. Attempt to make the residents feel that you care and are there to help them.
10. Work with residents, the staff, and the administration in solving problems.
11. Keep accurate records (e.g.: complaint forms, consultation forms, complaint referral forms, ledger of on-going activities, etc.) of problems as requested for evaluation of the program.
12. Remember that it may take questions and perseverance to get to the problem.
13. Make an attempt to understand the total situation regarding the problem by seeking out as many sources of information as possible.
14. Remember that some residents, as well as some staff and administrators, may distort or exaggerate; therefore, an accurate and reliable assessment of the problem is necessary.
15. Be patient -- remember that the resident may tire easily, have a short attention span, digress during conversations, or simply become confused.

The Don'ts of Advocacy

1. Do not provide physical or nursing care. This is the responsibility of the trained nursing staff in the facility.
2. Do not bring unauthorized articles into the home such as food, drugs, prescriptions, tobacco, alcoholic beverages, or matches.
3. Never treat the residents as children. They have had a lifetime of experience.
4. Do not diagnose or prescribe for a resident.
5. Do not make promises (they may be impossible to keep).
6. Do not advise residents on business or legal matters.
7. Do not be critical of the residents or the nursing home.
8. Do not engage in arguments, but stick to the question or problem at hand.
9. You are an inspector of the facility. You are there to listen to individual complaints and try to resolve them.

E. Services Offered By The Ombudsman Program

Investigative Services.. The program receives, investigates and resolves complaints made by or on behalf of older persons who are residents of long term care facilities or their representatives relating to action, inaction, or decisions of providers, of public agencies, or of social service agencies, which may adversely affect the health, safety, welfare, or rights of such residents. A complaint is defined as a problem, concern, or issue reported to, or observed by, an ombudsman on which the ombudsman takes action on behalf of the resident(s) to intervene in or alter the outcome of the situation or solve the problem.

Public Information And Education. The Ombudsman Program provides information and training to assist individual residents, or individuals requesting information on behalf of a resident, concerning the long term care system, the rights and benefits of residents of long term care facilities, and services available to residents including the activities of the ombudsman program. Public education activities include public speaking engagements, sponsoring or conducting workshops, promoting the development of community organizations to participate in the ombudsman program, developing and distributing written materials, and promoting media coverage of long term care issues.

Issue Advocacy. In accordance with federal law, the Long Term Care Ombudsman Program monitors the development and implementation of federal, state, and local laws, regulations, and policies that relate to long term care facilities. Often, ombudsmen are involved in initiating changes in legislation or policy.