

*Equipping Long-Term Care Ombudsmen for Effective Advocacy:
A Basic Curriculum*

RESIDENTS' RIGHTS

*Curriculum Resource Material for
Local Long-Term Care Ombudsmen*

Developed by Sara S. Hunt, Consultant

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I. INTRODUCTION

As an ombudsman, you not only have an obligation to provide information about residents' rights, but also a further obligation to assist residents in exercising those rights. This module provides an understanding of residents' rights and the role of Long-Term Care Ombudsman (LTCO) in supporting residents in exercising their rights. It provides a way of thinking about residents' rights and an approach for ombudsman work regardless of the specific issue. Topics covered include:

- empowerment as a basic LTCO approach,
- the principles underlying residents' rights,
- specific residents' rights provisions,
- how residents can be encouraged and supported in exercising their rights, and
- the role of LTCO.

The appendices contain a variety of resources. **Appendix A** has the federal residents' rights provisions for nursing facilities. Specific resources on resident assessment and care planning and on freedom from restraints are in the **Appendices B and C**. A list of resources on residents' rights topics for further information and for use in training is in **Appendix D**. An excellent resource for more specific information on many of the federal residents' rights provisions is *An Ombudsman's Guide to the Nursing Home Reform Amendments of OBRA '87*. A revised version is due in 2005 from the National Long-Term Care Ombudsman Resource Center at the National Citizens' Coalition of Nursing Home Reform.

NOTE: While the ombudsman process and approach is very much the same regardless of where a resident lives, the tools that are available in terms of law and regulation are not. Much of this module references federal law and regulation, but it is important to note that these laws and regulations are applicable only to nursing facilities that accept Medicaid or Medicare. There is no comparable federal law or regulation for adult residential care settings, such as assisted living facilities. You must rely solely on state law and regulation for adult residential care settings and for nursing homes that do not accept Medicaid or Medicare.

II. EMPOWERMENT

What It Is

*"Empowerment means to give power to another or to take it for oneself. The dictionary definition is 'to give authority to, to authorize.' This concept includes an advocate's conscious decision to enable a disadvantaged person or group to become capable of self-advocacy."*¹

As an ombudsman, empowerment needs to be your primary way of relating to individuals. Empowerment is the foundation of your work. You are always seeking to enable others to speak up on their own behalf and to have direct, responsive communication with other residents, family members, and staff.

As an ombudsman, empowerment needs to be your primary way of relating to individuals.

This section discusses dimensions of empowerment and your role in empowering others.

The Need for Empowerment²

All of us have our own way of expressing ourselves, of participating in a community of people, and of dealing with the problems of everyday life. These are all situations in which we develop our own way of living in the world. How we go about this depends a lot on how we perceive and exercise our power in a given situation. When we feel at a disadvantage, we may approach matters with that disadvantage in mind.

In long-term care, there are many factors that affect each resident's own sense of empowerment. Personal factors include his or her individual history or life experience, current health, and current support system. The facility's size, culture, and physical environment also have an impact. For example, the size and shared living areas of a smaller, assisted living home may make standing up for oneself more difficult. The interpersonal dynamics are also more deeply rooted in a smaller place.

The experience of living in a facility can considerably dampen an individual's sense of self and of his/her capabilities. It often engenders a sense of *powerlessness* in people. Long-term care facility residents find themselves thrust into a new environment with new rules and new social codes. One researcher found that residents of one long-term care facility thought they were not supposed to talk because they did not see any other residents talking with each other.³

Residents often do not know how things work in the facility. The very experience of living in an institutional setting can "dis-empower" residents. They don't want to upset their caregivers and may not have the energy, health, or mobility to figure out how to get

¹ Excerpt from training manual, *The Advocacy Spectrum*, July 1979, Washington, DC: National Public Law Training Center.

² The sections on empowerment, resident councils, and family councils, were developed by former LTCO, Cathie Brady, Connecticut, and Barbara Frank, Massachusetts.

³ Kaakinen, JR. Living With Silence. *The Gerontologist*. 1992. Apr; 32(2):258-64.

help. Regular conversations and interactions with people residents know, interactions that strengthen their sense of self, might not continue. These losses can contribute to a sense of powerlessness, disorientation, and despair.

It is important to remember that generational, gender and ethnic differences can affect a resident's sense of empowerment. Most of today's nursing home and assisted living facility residents are women over the age of seventy. They may have a different approach to making things work than men or younger individuals. Traditionally, they have either depended on others to speak up for them or have accepted the status quo.

Generational, gender, and ethnic differences can affect a resident's sense of empowerment.

The Role of the Ombudsman

Ombudsmen can play an important role in helping people restore their own sense of themselves and regain their sense of personal power and voice. Residents who have always felt it easy to speak up may merely need to be pointed in the right direction and be given a little assurance that they are within their rights. Others may need a lot more encouragement; they may need you to go for them or with them. If people are sick, weak, immobile, or alone, you may have to carry more of the load for them; they may have limits on what they want to take on for themselves. They may want to address their problems but will need you to work with their condition.

The first step in this process of empowering residents is simply to have genuine meaningful connection with residents, to get to know them as individuals. Real human connection can be immensely restorative. In the course of that connection, residents may share concerns about their day-to-day experience. How ombudsmen respond and work with these concerns can go a long way in "empowering" residents and restoring their sense of self. It is important throughout such a process to relate honestly and authentically to the resident and to the situation.

Resident Directed

It is also important to take the resident's experience and viewpoint very seriously and proceed at a pace and in a direction in which the resident is comfortable. You must temper your urge to make things better. If you rush to problem solve and take over, it can be just as disempowering as the rest of the resident's experience. If you take your lead from the resident and see yourself as the carrier of the resident's message, you can help the resident regain control of his or her life.

The goal is to foster an environment in which residents, families and staff can talk with each other and make life work well for those living and working in the facility.

By establishing meaningful relationships with residents, taking their experiences and concerns seriously, and creating avenues for communication with staff who can resolve problems, you are able to address problems at the earliest stages before they become major complaints. If residents feel they can tell their problems to staff and have those problems addressed, they are truly empowered. Getting to know residents, their living dynamics, and

establishing rapport are essential in learning how to go about whatever problem solving is needed, in a way that works for residents.

Setting

Be aware of the setting and how it impacts your role in empowering residents. In a smaller assisted living facility for example, you are walking into a living room. Everyone sees you. Everyone knows the purpose of your visit. Smaller spaces magnify everything; therefore, a small intervention can have a big impact. Larger settings may have layers to move through to find out how a problem can be resolved. It may require a more formal approach to bringing the problem to the people with authority to address it.

Problem Solving by Empowerment

When ombudsmen are able to engage in a problem-resolution process with one resident, everyone learns more about addressing issues. The resident can feel more comfortable and confident about bringing up concerns in the future. Facility staff can feel more comfortable about being open to what residents have to say. As an ombudsman, you can build on the rapport you have established and use it for the next problem-solving situation. Working out a channel for solving problems can open the door for future communication between the resident and the staff, once they have learned how to do it.

Some facilities may be more open to hearing and addressing residents' concerns. Others may be more resistant or defensive. In bringing problems forward, you are teaching everyone how to work them out. Often the facility staff is more comfortable making all the decisions. They have to learn how to listen better to residents and how to be responsive to residents' needs.

There are times when your presence as an ombudsman can help "level the field" and add balance for residents. Sometimes just being in a facilitated dialogue between residents and staff helps solve the problem. When this happens, you have just assisted in starting an empowerment process. Each time a resident is successful, he/she feels stronger and is more likely to bring forward concerns in the future.

Assisting residents in the process of becoming empowered is hard work. Ombudsmen must remember that at the end of a visit, you return to your home, but the resident stays in his/her home. Change can at times be so slow that you get frustrated; however, you can go no faster in facilitating change than the comfort level of the resident or residents.

Remember that you can go no faster in facilitating change than the comfort level of the resident or residents.

Proceed in a way that is respectful of inter-personal dynamics and gradually find an approach that is comfortable for residents.

III. NURSING HOME RESIDENTS' RIGHTS UNDER THE NURSING HOME REFORM LAW

Introduction

Certain rights are set forth in the United States Constitution for all citizens. Individuals who live in long-term care facilities do not lose these rights when they enter a congregate living environment. In fact, they are guaranteed *additional rights* under state and federal laws specific to their status as residents! These rights are provided for primarily in the following sources:

- Federal Nursing Home Reform Law: *The Omnibus Budget Reconciliation Act of 1987 (OBRA '87)*, as amended, Medicaid Provisions (§1396r), and Medicare Provisions (§1395i-3)
- Federal regulation: *Medicare and Medicaid Requirements for Long Term Care Facilities*, September 26, 1991, 42 U.S. Code of Federal Regulations, (§483).
- State laws

For your information, the residents' rights excerpts from the Medicaid provision of the federal law is included in Appendix A. While many of the rights guaranteed by each of these sources are very similar, it is important that you be familiar with all of them.

A very useful resource for understanding residents' rights is the *Guidance to Surveyors for Long Term Care Facilities*. These guidelines are part of the *Centers for Medicare & Medicaid Services (CMS) State Operations Manual*⁴, the document that surveyors use to determine whether a facility has met the federal requirements. Another useful resource is *An Ombudsman's Guide to the Nursing Home Reform Amendments of OBRA '87* by the National Long-Term Care Ombudsman Resource Center.

Resources:

- *Guidance to Surveyors*
- *LTCO Guide to OBRA '87*

Key Provisions

There are two key provisions in the federal law (Nursing Home Reform Amendments⁵ of the Omnibus Budget Reconciliation Act of 1987 or OBRA '87) that establish the foundation for all the other provisions: *Quality of Care* and *Quality of Life*.

- **Quality of Care** says a nursing facility must provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial

⁴ The full title of this document is the *State Operations Manual, Appendix PP, Guidance to Surveyors for Long Term Care Facilities*, Rev. 5, 11-19-04. The section that covers the survey protocols is, *Appendix P, Survey Protocol for Long Term Care Facilities*, Rev. 1, 05-21-04. In this resource document, the survey protocols are referred to as the State Operations Manual. http://www.cms.hhs.gov/manuals/107_som/som107_appendixtoc.asp

⁵ The Nursing Home Reform Amendments is also referred to as the Nursing Home Reform Law or as OBRA '87.

well-being of each resident in accordance with a written plan of care.

- **Quality of Life** says a nursing facility must care for its residents in such a manner and in such an environment as will promote maintenance or enhancement of the quality of life of each resident.

There is the same underlying theme in each of these provisions: facilities must be responsive to the particular preferences and needs of each individual resident. Building on that premise, the residents' rights provisions follow the Quality of Life section in the law. Residents' rights are like the directions for achieving quality of life. If facilities follow these directions and fully implement residents' rights, they will be promoting quality of life for each resident.



Residents' rights also have implications for quality of care requirements. Since residents' rights and quality of life are related, what factors do residents consider important for quality? In 1985, the National Citizens' Coalition for Nursing Home Reform asked 450 residents in 15 cities across the country what quality meant to them. Studies since then continue to support the importance of these same factors to residents.⁶ A few central issues were poignantly and consistently identified. Many of these were incorporated as provisions in the Nursing Home Reform Law. They include the following:

- Kind treatment by staff,
- Respect for residents' dignity and being treated as adults,
- Opportunities for choice and input in care and services, particularly related to food, activities, and personal schedules,
- Privacy.

Basic Themes

The residents' rights listed in the federal law, and therefore all of the regulations that follow from them, embody four basic themes. If you learn and remember these four themes, you will understand how to work on the specific rights. You soon will learn many of the specific residents' rights because you will be looking up the exact language of the provisions that apply to an issue you are asked to resolve. The role of the ombudsman is to help residents, their families, and facility personnel understand what these themes mean and how they can be achieved.

The four themes are:

- 1. Communication**
- 2. Choice**

⁶ Kane, R. *Good (or Better) Quality of Life for Nursing Home Residents: Roles for Social Workers & Social Work Programs*. Presentation for Evaluating Social Work Services in Nursing Homes: Toward Quality Psychosocial Care and its Measurement, Institute for the Advancement of Social Work Research, Washington, DC. December 2-3, 2004.

3. Decision-making

4. Participation

The following examples illustrate how these four themes encompass residents' rights.

1. Communication

Effective, on-going communication between residents and staff is essential to fulfilling residents' rights. A resident may say, "*I don't want this food.*" What does this mean? It could mean that the resident is refusing a special diet, or it could be the resident's way of saying that the food is unpalatable because it is cold, bland, or is food that the resident has never liked. There may be a different, unrelated problem behind the refusal of the food. When residents exercise their right to say, "*No,*" staff need to ask questions and observe until they fully understand what the resident is really expressing. Even residents who are not very articulate or who have some degree of memory impairment can express choices.

Specific examples of rights pertinent to communication include residents' rights to:

- be fully informed of his or her rights and all rules and regulations governing resident conduct and responsibilities, orally and in writing, in a language the resident understands;
- participate in planning his or her care and treatment; and
- voice grievances without discrimination or reprisal AND have prompt efforts by the facility to resolve these.

2. Choice

Each resident has the right to exercise choice and have those choices respected. The introduction to residents' rights in the federal regulations says, *The resident has a right to a dignified existence, self-determination, and communication with and access to persons and services inside and outside the facility.* A primary example is the right to reside and receive services with reasonable accommodation of individual needs and preferences. From the **resident's perspective**, this right means that the facility and staff must allow each resident to direct the patterns of his/her daily life, as well as treatment methods and goals.

From the **staff's perspective**, resident choice means that the staff needs to think creatively, to see life from the resident's viewpoint when a request is made or a preference is stated. Instead of saying, "*No,*" or, "*We can't do that because. . .,*" the staff should say, "*Let's see what we can do.*" Staff and residents can brainstorm together and then take action. Exercising choice means considering ways to accommodate residents' preferences and decisions. Staff have a responsibility to help residents exercise their rights, even when staff feel that helping is not their duty. Examples are staff helping a resident to smoke or not interfering when a resident visits with persons whom the staff feel are not appropriate choices of friends. The law challenges the facility to focus on meeting the needs and desires of each individual resident, not on maintaining the customary routines of the institution.

There are some other important dimensions of exercising choice. Making a choice is not a time-limited event. If a resident says she does not care what clothing she wears that day, the person's choice does not mean that she will never have a clothing preference. An individual's choice and preferences may change. After a person has been in the facility awhile, or if her condition changes, she may make different choices than the ones previously stated. *Exercising choice is a continual process.*

3. Decision Making

Each resident has the ability to exercise his/her own rights unless that individual has been adjudicated incompetent according to state law. To exercise decision-making, residents need full information to be able to make a truly informed decision. They need accurate information about alternatives and the consequences, short- and long-term, of the decisions they are considering. Decision making is the implementation of exercising choice.

Another aspect of resident decision making is being in an environment that is truly encouraging and supportive. Residents need to feel free to make their own decisions without fearing that they will be declared incompetent or discharged if their decisions differ from what professionals recommend or from what their family wants. Once a decision is made, residents need to know that their choice will be respected. One of the requirements of the Nursing Home Reform Law is that nursing homes must protect and promote the rights of each resident.

A few specific examples of rights in this area are a resident's right to:

- manage his or her financial affairs;
- work or not work; and
- choose a personal attending physician.

4. Participation

Residents are to participate in planning their care and treatment and to participate in:

- resident groups if they so choose;
- social, religious, and community activities;
- the survey process; and
- the administration of the facility.

Even residents with a diagnosis of dementia can participate in planning care and exercising choice. If a resident's preference cannot be honored, the staff needs to engage in problem solving with him/her to find a solution that is as close as possible to what the resident wants. Residents need to be familiar with the grievance process in the facility and have confidence that the process will work. Facilities are required to assure resident and advocate participation in the administration of the home.

Honoring, upholding, residents' rights is a process; it is not something that is done once, checked off a list, and forgotten because it is a standard that has been met.

These four themes—communication, choice, decision making, and participation—embody the approach, attitude, and philosophy of implementing residents' rights. They have to be continuously exhibited. As an ombudsman, you may be the facility's best model and teacher for implementing residents' rights.

IV. SUMMARY LISTING OF RIGHTS

The following is a summary listing of the provisions of residents' rights for individuals living in nursing facilities certified for Medicare or Medicaid. Although they are often mirrored in state law, the rights presented here are based on federal law and regulation. Their purpose is to safeguard and promote dignity, choice, and self-determination of residents. The citations refer to the federal Requirements for Long-Term Care Facilities.



As with all specific provisions of the law or regulations, it is always advisable to verify any information you rely on in developing or presenting a case by checking the source document.

Rights Regarding Health Care

- To be free of physical restraints not documented as medically necessary [§483.13]
- To have his/her choice of physician [§483.10 (d)]
- To be transferred or discharged only after reasonable notice is given; and only for medical reasons, the safety or welfare of other residents, or for non-payment [§483.12]
- To be protected from transfer or discharge from a Medicaid or Medicare certified facility solely because the resident becomes eligible for Medicaid or Medicare payment [§483.12 (d)]

Right to Exercise Individual Liberties

- To exercise his/her rights as a resident and a citizen [§483.10 (a)]
- To complain and make suggestions without fear of retaliation [§483.10 (f)]
- To a dignified existence and self-determination [§483.10]
- To be free of verbal, sexual, physical, and mental abuse [§483.13 (b)]
- To participate in social, religious, and community activities [§483.15 (f)]
- To have his/her and use own clothing and possessions, including some furnishings

[§483.10 (l), §483.15 (h)(1)]

- To manage his/her personal affairs, or if this is delegated to the facility, to receive an accounting report every three months and on request [§483.10 (c)]
- To have access for visits with family, friends, and representatives of certain agencies, including the ombudsman [§483.10 (j)]
- To share a room with his/her spouse, if he/she is a resident of the same nursing home and they both consent [§483.10 (m)]

Rights to Information

- To be informed of his/her rights, the rules and regulations of the nursing home [§483.10 (b)]
- To receive prompt efforts to resolve grievances [§483.10 (f)]
- To have any significant change in his/her health status reported to him/her

[§483.10 (b)(10)(B)]

- To be informed of his/her condition and planned medical treatment, and to participate in planning or refusing that treatment [§483.10 (b)(3) and (4)(d)(3)]
- To examine the results of the most recent survey conducted by state or federal surveyors of the facility [§483.10 (g)]
- To be informed of the bed reservation policy for hospitalization [§483.10 (b)(2)]
- To be told of all services available and all costs, including charges covered or not covered by Medicare, Medicaid or the basic per diem rate [§483.10 (b)(6)]

Rights to Privacy

- To personal privacy in medical treatment and personal care [§483.10 (e)(1)]
- To send and receive unopened mail [§483.10 (i)]
- To receive visitors in privacy [§483.10 (e)(1)]
- To have his/her personal and medical records treated confidentially [§483.10 (e)]
- To have reasonable access to use of a telephone where calls can be made without being overheard [§483.10 (k)]

Rights for Families or Legal Representatives⁷

- To be notified within 24 hours of an accident resulting in injury, a significant change in the resident's physical, mental, or psychosocial status, a need to alter treatment significantly, or a decision to transfer the resident [§483.10 (11)]
- To be notified of appeal rights [§483.12 (a) (6) (iv)]
- To be notified promptly if change in room or roommate or in resident's rights provisions [§483.10 (b) (11) (i) (D) (ii) (A) and (B)]
- To be notified if the facility receives a waiver of licensed nurse staffing requirements [§483.30 (c) (7), (d) (1) (B) (v)]
- To participate in the care planning process [§483.20 (d) (2) (ii)]
- To have immediate access to the resident, subject to the resident's rights to deny/withdraw consent at any time [§483.10 (j) (1) (vii)]

⁷ An Ombudsman's Guide to the Nursing Home Reform Amendments Of OBRA '87. revised by S. G. Burger, National Long-Term Care Ombudsman Resource Center, National Citizens' Coalition for Nursing Home Reform. 2005.

- To participate in a family council which may meet privately in space provided by the facility and receive the facility's cooperation in its activities [§483.15 (c) (2)]
- To make recommendations to the facility, and the facility is required to "listen to the views and act upon grievances and recommendations of residents and families concerning proposed policy and operational decisions affecting resident care and life in the facility." [§483.15 (c) (6)]

Rights Regarding Incompetent Residents

When an individual is judged by a court to be incompetent in accordance with state law, the resident's rights "shall devolve upon, and, to the extent judged necessary by a court of competent jurisdiction, be exercised by the person appointed under state law to act on the resident's behalf." [§483.10 (3)]

V. DISCUSSION OF SELECTED RIGHTS⁸

This section contains a detailed discussion of some of the residents' rights that are frequently problematic. In some instances, the discussion includes tips for ombudsman practice. Be sure to check the exact language of the applicable law before providing specific information or pursuing complaints. The citations refer to the federal Requirements for Long-Term Care Facilities.

Privacy

Private Telephone Conversations [§483.10 (k)]

Private telephone conversations are included in the federal law. Residents may face a number of problems using the telephone in a facility. The law and the *Guidance to Surveyors* say that residents must have *reasonable access to the use of a telephone where calls can be made without being overheard*. That includes placing telephones at a height accessible to residents in wheelchairs and adapting telephones for use by the hearing impaired.

Privacy [§483.10 (e), §483.15 (c)]

Privacy also includes the rights to privacy with whomever the resident wishes to be private. Private space may be created in a number of ways; it must be accomplished in a way that does not infringe upon the rights of other residents. Privacy extends to medical treatments and bathing. It also includes visual privacy and for visits or other activities, auditory privacy to the extent desired.

Self-Determination

There are several rights that underscore the self-determination and individuality principles that are so clearly stated in the Nursing Home Reform Law's Quality of Care and Quality of Life provisions. A few of these rights are listed here because they counter the institutional approach that often exists. These rights require the facility to adapt to each *resident's* routines and preferences instead of expecting the resident to adjust to the facility's schedule.

Facilities must adapt to each resident's routines and preferences instead of expecting the resident to adjust to the facility's schedule.

- Residents can choose activities, schedules, and health care consistent with their interests, assessments, and plans of care. Staff is required to make adjustments to allow residents to exercise choice. [§483.10 (b)(3) and (4), §483.15 (b)]
- Residents are to reside and receive services with reasonable accommodations by the

⁸ Much of this section is from: B. Frank, *An Ombudsman's Guide to the Nursing Home Reform Amendments of OBRA '87*, The National Center for State Long-Term Care Resources, National Citizens' Coalition for Nursing Home Reform, February 1992.

facility of individual needs and preferences. [§483.15 (e)] The *Guidance to Surveyors* says the facility's physical environment and staff behaviors are to assist residents in maintaining and/or achieving independent functioning, dignity, and well-being. Facilities are directed to adapt such things as schedules, call systems, and room arrangements to accommodate the resident's preferences, desires, and unique needs. Facilities must learn each resident's preferences and take them into account when discussing changes of room or roommates and the timing of such change.

TIPS FOR OMBUDSMAN PRACTICE

You may need to help staff, residents, and their families understand what these rights mean in everyday life. You can do this by modeling, observing, and asking questions.

- Be willing to assist staff and residents in listening to each other and working out solutions that are acceptable to both.
 - Be alert for opportunities to suggest that residents can exercise choice and have their choices respected.
 - Help staff think in terms of "*How can we. . .*" instead of "*We can't do that because...*"
 - Help staff and residents brainstorm about a range of ways to accommodate individual needs and preferences.
 - Encourage residents to express their preferences. When residents are unable to do this, encourage family members to tell staff about the resident's preferences and routines.
 - Share ideas and/or approaches that have worked in other facilities.
 - Use care planning as a problem-solving vehicle to focus everyone's attention on the resident's needs, routines, and preferences. Advocate for care plans that build on the resident's schedules and strengths.
-

Participation in Planning and Treatment

Right to Be Informed [§483.10 (b)(3),(4), and (11)]

Residents are to be fully informed in advance about care and treatment and of any changes in care or treatment that may affect the resident's well-being. This means that a resident receives the information necessary to make a health care decision.

To determine whether this right is being upheld, surveyors might ask residents questions like:

- *How are you involved in planning your care?*
- *If your care plan is changed, how do you find out about it?*
- *Does staff explain how these changes will affect you?*

These three questions might also be appropriate for you to routinely ask residents when helping them identify strategies for good care.

Residents are to participate in planning and making any changes in their care and treatment. [§483.10 (d)(3)] According to the *Guidance to Surveyors*, this means that the resident has an opportunity to select from alternative treatments. Even if a resident's ability to make decisions about care and treatment is impaired or if the resident has been adjudicated incompetent, the resident should be kept informed and be consulted on personal preferences. A handout for you to use in helping residents and families understand and use this process, "Assessment And Care Planning: The Key To Good Care," is in **Appendix B**.

The comprehensive care plan is to include measurable objectives and timetables to meet a resident's medical, nursing, mental, and psychosocial needs that are identified in the comprehensive assessment. [§483.20(d)(1)]

In practice, many residents and family members do not play an active role in the care planning process. Often the conference is short and pre-emptive; selected staff report on the resident and their anticipated treatment objectives. Staff members are usually too busy to really involve the resident (and/or family) in advance to work together toward goals and choices. Yet the resident has the right to "*choose activities, schedules, and health care consistent with his or her interests, assessments, and plans of care,*" and to "*make choices about aspects of his or her life in the facility that are significant to the resident.*" [§483.15(b)] The assessment and care planning process are often the keys to good care and, typically, are areas where improvement is needed.

TIPS FOR OMBUDSMAN PRACTICE

In order to fully participate in planning care and treatment, residents may need information and support. Ombudsmen can be helpful to residents and their families in a number of ways.⁹

- Encourage residents to attend their care-planning meeting.
- Help them prepare by identifying their needs and goals as well as potential strategies and options. If necessary, help them get the information they need before the meeting such as their current care plan or medication orders.
- Let them know that a family member or you may be present during the meeting, and that they can request a care-planning time that allows the family to attend.
- Advocate for care planning to be conducive to resident participation.
- Ask questions if professional jargon is used instead of language that everyone understands.
- Be sure the resident's voice is solicited, heard, and respected.
- If necessary, direct the staff to talk with the resident instead of speaking about the resident in the third person as if the resident were not present.
- Ask for options, alternatives, and/or more information if there are differences that need to be resolved.
- Ask whether the resident understands and agrees with the care plan.
- Be sure the care plan is specific enough to know if it is being followed and who is responsible for implementing each section.

⁹ More information can be found in: S. Hunt and S. Burger, *Using Resident Assessment and Care Planning As Advocacy Tools: A Guide for Ombudsmen and Other Advocates*, National Citizens' Coalition for Nursing Home Reform, July 1992, updated November 1995.

Freedom from Restraints

“While restraints are rarely the best care option available, they are often the most familiar method to resolve situations such as ‘wandering,’ ‘falling,’ and ‘behavior problems.’ Facilities commonly use restraints, presuming they ensure safety, in fear of litigation should a resident fall.”¹⁰

Residents are injured by improperly applied and infrequently checked restraints or injure themselves attempting to get free of them. In the worst case, physical restraints result in death when a resident becomes entangled in the restraint. Restraints are the most obvious substitute for sufficient numbers of staff, but staff shortages make it more difficult to monitor restraints. Moreover, poor training of staff leaves them unable to apply restraints properly and/or recognize signs that harm is being done.

Although restraints can be “enablers,” they are more often used to restrict movement. A chart on the impact of physical and chemical restraints and alternatives can be found in **Appendix C** at the end of this chapter.

The Nursing Home Reform Law provides protections from restraints:

- Freedom from Restraints is “the right to be free from physical or mental abuse, corporal punishment, involuntary seclusion, and any physical or chemical restraints imposed for purposes of discipline or convenience and not required to treat the resident's medical symptoms. [§483.13 (a)(b)] Restraints may only be imposed:
 - To ensure the physical safety of the resident or other residents; and
 - Only upon the written order of a physician that specifies the duration and circumstances under which the restraints are to be used (except in emergency circumstances specified by the Secretary [HHS]) until such an order could reasonably be obtained.”

Restraints are defined in the following way in the *Guidance to Surveyors*:

- “Chemical restraint means a psychopharmacologic drug that is used for discipline or convenience and not required to treat medical symptoms. Psychopharmacologic drugs may be administered only:
 - On the orders of a physician, and
 - As part of a plan designed to eliminate or modify the symptoms for which the drugs are prescribed, and
 - If, at least annually, an independent, external consultant reviews the appropriateness of the drug plan of each resident receiving such drugs.

¹⁰ S.G. Burger, *Inappropriate Use of Chemical and Physical Restraints*, Washington, DC: The National Center for State Long-Term Care Ombudsman Resources, National Citizens' Coalition for Nursing Home Reform, 1989, pp. 3-4.

- Physical restraints include, but are not limited to, leg restraints, arm restraints, hand mitts, soft ties or vests, and lap cushions and lap trays the resident cannot remove. Also included as restraints are facility practices which meet the definition of a restraint, such as tucking in a sheet so tightly that a bed-bound resident cannot move, bedrails, or chairs that prevent rising, or placing a wheelchair-bound resident so close to a wall that the wall prevents the resident from rising.”¹¹

The *Guidance to Surveyors* discusses the use of restraints in depth. Some key provisions from that document regarding using restraints in nursing homes follow.

- If the restraint is used to enable the resident to attain or maintain his or her highest practicable level of functioning, a facility must have evidence of consultation with appropriate health professionals, such as occupational or physical therapists. This consultation should consider the use of less restrictive therapeutic intervention prior to using restraints as defined in this guideline for such purposes.
- If a resident chooses to include a restraint as part of care and treatment, the device may be used for specific periods for which it has been determined to be a therapeutic intervention (e.g. a bedrail used by a resident for turning).
 - For a resident to make an informed choice about the use of a restraint, the facility should explain to the resident the potential negative outcomes of restraint use.
 - The resident’s right to refuse treatment includes the right to refuse restraints.
- Restraints may NOT be used to permit staff to administer treatment to which the resident has not consented.
- If the resident needs emergency care, restraints may be used for brief periods to permit medical treatment to proceed unless the facility has noticed that the resident has previously made a valid refusal of the treatment in question.
- The decision to apply physical restraints should be based on:
 - The assessment of each resident’s capabilities.
 - An evaluation of less restrictive alternatives and the ruling out of their use.
 - The plan of care should contain a plan of rehabilitative training to enable the progressive removal of restraints or the progressive use of less-restrictive means.
- Guidelines are established for checking and releasing residents from restraints. Federal guidelines require that residents in restraints be checked and released from restraints every two hours.
- The use of restraints is to be documented in the resident’s clinical record on each tour of duty during which the restraints are in use.

¹¹ *Guidance to Surveyors* (The Interpretive Guidelines) for Long-Term Care Facilities, *State Operations Manual*. Centers for Medicare & Medicaid Services. Baltimore, Maryland. Section revision 06-95, PP-45.

Progressive nursing homes have been able to drastically reduce the use of restraints through alternative care programs. For information about restraints, ways to reduce or eliminate restraints, and reports from nursing homes about their restraint-reduction successes, consult the following resources.

- *Untie the Elderly* - www.ute.kendal.org. Read their Newsletter, and access the steps toward a successful restraint-reduction program prepared by the Pennsylvania Restraint Reduction Training Team.
- Nursing Home Compare – www.medicare.gov. From this site, access facility specific information regarding the use of physical restraints by facility. The information is based on the Minimum Data Set information submitted by the facility.
- Additional resources are listed in Tips for Ombudsmen section that follows.

TIPS FOR OMBUDSMAN PRACTICE

If there is evidence of a problem with the use of physical or chemical restraints, consider the following actions. Be sure to follow ombudsman policies regarding complaint handling and encourage the complainant to engage in self-advocacy.

- Determine how the decision to use the restraint was made.
 - Was the decision an informed decision made by the resident or by the individual with the legal authority to authorize medical treatment for the resident? Does the resident understand the potential detrimental effects of the restraint?
 - Were other options presented?
 - Does the facility know what the resident wants or needs?
 - Is the restraint being used to treat a symptom instead of the root cause of the symptom?

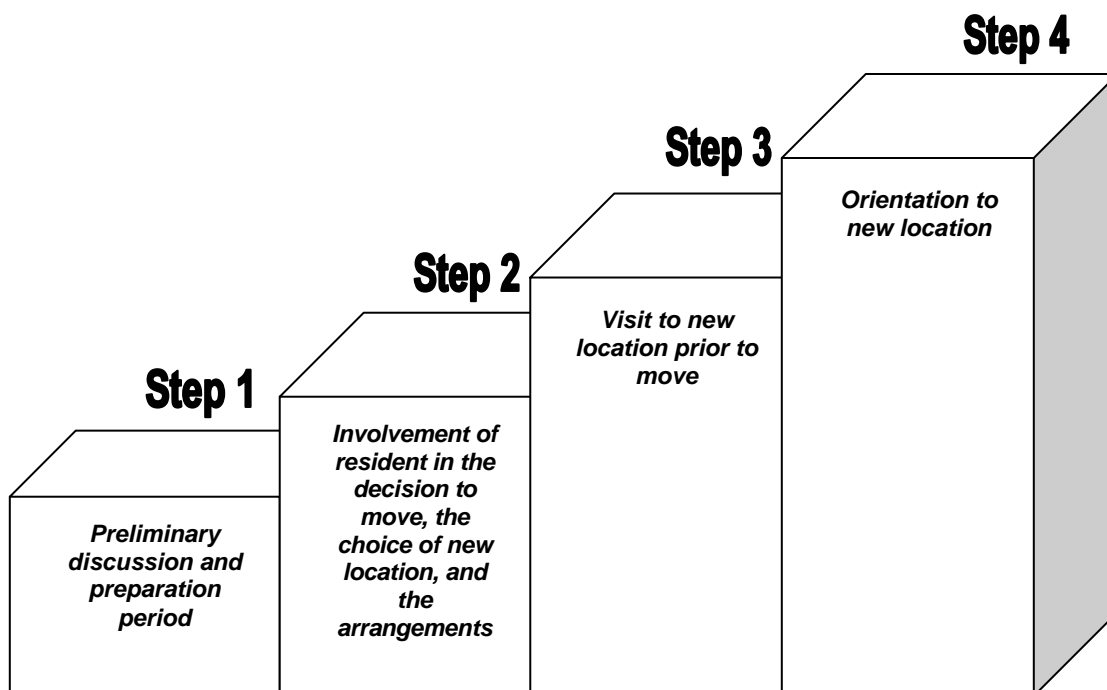
- Consider using the following resources in your review and preparation for resolution in addition to federal and state laws and regulations:
 - The *Guidance to Surveyors* regarding restraints and pertinent care issues.
 - Resident Assessment Protocols (RAPs) of the Resident Assessment Instrument on physical restraints, psychotropic drug use, and others that might be relevant.
 - The chart in **Appendix C**, “Context For Freedom From Physical Or Chemical Restraints Used For Discipline or Convenience.”
 - “Good Care is Restraint Free,” *Nursing Homes: Getting Good Care There*. Burger, SG. Fraser, V. Hunt, S. and Frank, B. Impact Publisher, 1996, revised 1999. Also available from the National Citizens’ Coalition for Nursing Home Reform, 1828 L Street, NW, Suite 801, Washington, DC 20036. (202)-332-2275; www.nursinghomeaction.org

- Ask for a care plan review to:
 - Determine the reason the restraint is being used.
 - Determine what alternatives have been tried
 - Consider other approaches to meeting the resident's need.

Protection Related to Transfer/Discharge

Residents come to view the nursing home and even their room in the facility as their own home. Moving out of the facility can be traumatic for the resident. In one landmark case, a New York State court ruled that a resident should not be made to go because the damage to her health would be greater if she were moved against her will than it would be if she remained in the facility with a lower level of service.

To minimize transfer trauma, residents need to be involved in decisions surrounding the relocation and be given time to adapt to the change. Studies of transfer have identified important steps that can be taken to mitigate the negative impact of relocation. The steps include:



Reasons for Transfer/Discharge from a Facility

The Nursing Home Reform Law and federal regulations specify **permissible reasons for transfer** and establish protections such as advance notice, the right to appeal a transfer, and the right to return to the nursing home if appropriate. [§483.12] Some of these protections are outlined below.

Nursing homes must not transfer or discharge a resident unless the:

- facility is unable to meet the resident's medical needs;
- resident's health has improved such that he/she no longer needs nursing home care;
- safety of other individuals is endangered;
- health of other individuals would be endangered;
- resident has failed, after reasonable notice, to pay for his/her stay in the facility; or
- the facility ceases to operate.

A resident's refusal of treatment is not a reason for transfer unless the facility is unable to meet the needs of the resident or protect the health and safety of others.¹²

Notice to Residents and Their Representatives before Transfer/Discharge from a Facility

Timing

The notice must be given at least 30 days in advance with these **exceptions**:

- The health or safety of individuals in the facility would be endangered;
- The resident's health has improved such that he/she no longer needs nursing home care;
- An immediate transfer/discharge is required by the resident's urgent medical needs; or
- A resident has not resided in the facility for 30 days.

Content

The notice of discharge or transfer must include:

- the reasons for transfer;
- the effective date of transfer;
- the location to which the resident is to be transferred or discharged;
- the resident's right to appeal the transfer;
- the name and address of the State Long-Term Care Ombudsman; and
- the address and telephone number of Protection and Advocacy Services if the resident has a mental illness or a developmental disability.

Individuals Who Receive Notice

The notice must go to:

- the resident;
- a family member if known;
- the resident's legal representative and legal guardian, if known; and
- the regional office of the division of mental health for residents who are developmentally disabled.

In some states, notice must be given to the State or Local Long-Term Care Ombudsman.

¹² *Guidance to Surveyors, State Operations Manual*. Centers for Medicare & Medicaid Services, Baltimore MD, 06-95. PP.32-40.

Orientation before Transfer/Discharge from a Facility [§483.12 (7)]

A facility must prepare and orient residents to ensure a safe and orderly transfer from the facility. The *Guidance to Surveyors* states that:

“Sufficient preparation” means the facility informs the resident where he or she is going and takes steps under its control to assure safe transportation. The facility should actively involve, to the extent possible, the resident and the resident’s family in selecting the new residence. Some examples of orientation may include trial visits, if possible, by the resident to a new location; working with family to ask their assistance in assuring the resident that valued possessions are not left behind or lost; orienting staff in the receiving facility to resident’s daily patterns; and reviewing with staff routines for handling transfers and discharges in a manner that minimizes unnecessary and avoidable anxiety or depression and recognizes characteristic resident reactions identified by the resident assessment and care plan.

Refusal of Certain Transfers [§483.10 (o)]

Transfer to a portion of the facility (a distinct part) with a separate certification under Medicare or Medicaid is considered transfer to another facility and entitles a resident to all the protections (notice and appeal rights) of such a transfer.

Residents have the right to refuse a transfer to another room within the facility if the purpose of the transfer is to relocate the resident from a part of the facility that is a skilled nursing facility to a part to the facility that is not skilled, or vice versa. However, there may be financial consequences attached to the decision.

Good Provider Practice Before Deciding to Transfer or Discharge

Often the basis for a transfer or discharge can be eliminated by close attention to medical problems, changes in the environment, or alterations in the staff interventions. If the transfer or discharge is due to a significant change in the resident’s condition, “then prior to any action, the facility must conduct the appropriate assessment unless the change is an emergency requiring an immediate transfer.” *Guidance to Surveyors* at F-201, F-287.

TIPS FOR OMBUDSMAN PRACTICE

When issues arise regarding transfer or discharge from a facility, consult federal and state laws and regulations for their exact requirements. The *Guidance to Surveyors* describes in more detail factors facilities must consider in making the decision to transfer a resident. It also discusses a facility's obligations to meet the needs of residents according to the quality of care and quality of life requirements. Although there can be great variation in cases, there are some general actions you might consider on behalf of a resident.

- Examine the notice to ensure that it complies with all of the requirements. If it does not comply with all of the requirements, it is not a valid discharge notice and the 30-day time period has not started.
- Focus on the stated reason for transfer/discharge and begin problem resolution.
 - What is the real problem or issue?
 - What approaches has the facility tried to resolve the problem?
 - Has the facility used outside resources when appropriate?
 - What is the resident's role in resolving the problem?
 - Is this an issue where a care-planning conference might be useful?
- Contact the SLTCO if the resident wishes to file an appeal or if the resident is unable to file an appeal.

Notice Before Change in Room or Roommate

Transfer from one room to another can be traumatic. In 1990, the Nursing Home Reform Law was amended to give residents the right to refuse to be transferred from a Medicare/Medicaid bed to a Medicaid only bed. This amendment was adopted in order to address the problem of transfer trauma from frequent room transfers based not on care needs but on reimbursement rates. The law now provides that the resident has:

The right to refuse a transfer to another room within the facility, if a purpose of the transfer is to relocate the resident from a portion of the facility that is a skilled nursing facility [i.e., Medicare certified] to a portion of the facility that is not such a skilled nursing facility. 42 USC 1395i-3(c)(1)(A)(x)

There are other provisions regarding intra-facility transfer from a Medicare bed. If you encounter an issue with this type of transfer, read the exact language in the law and requirements and talk with an experienced ombudsman or with your State Long-Term Care Ombudsman.

Nursing homes move residents around regularly in order to respond to their care needs or those of other residents. Residents have very little opportunity to participate in a decision to move, nor do they often have their choice of where to move or of whom their roommate will be. Only a few states protect residents in cases of intra-facility transfer.

There is no specific federal guidance to facilities regarding the process, timing, or content of a notice before there is a change in room or roommate. Unfortunately, residents cannot appeal intra-facility transfers. They do, however, have the right to file a grievance with the facility. Also, ombudsmen have sometimes been successful in arguing that the move would be or has been detrimental to the resident's health or well being.

Notice of Bed-Hold Policy and Readmission [§483.12 (b)]

- Before a facility transfers a resident to a hospital or allows a resident to go on therapeutic leave, the nursing facility must provide written information to a family member that specifies the duration of the bed-hold policy under the State plan and the facility policies regarding bed-hold. Notice must be given at the time of the transfer.
- The facility must also allow a Medicaid recipient to be readmitted to the first available bed in a semi-private room. This provision might affect the decision to hold a bed.

Protection Against Medicaid Discrimination

Discrimination against Medicaid beneficiaries occurs in admissions, transfers, and the provision of services. Some of the practices clearly violate the Social Security Act and Medicaid regulations, while others require development of further protections.

The Nursing Home Reform Amendments **prohibit discrimination** in treatment of residents and protect residents from fraudulent activities at admission.

Facility Requirements [§483.12 (c) and (d)]

A nursing facility must:

- Have identical policies and practices regarding the provision of services required for all individuals regardless of source of payment.
- Provide information on how to apply for Medicaid and how to receive refunds for previous payments covered by such benefits.
- Not request, require, nor encourage residents to waive their rights to Medicaid.
- Not transfer nor discharge residents solely because they have changed their payment source from private pay to Medicaid.
- Not require another person (commonly known as a "responsible party") to guarantee payment as a condition of a resident's admission or continued stay.
- Not "charge, solicit, accept or receive gifts, money, donations, or other considerations" as a precondition for admission or continued stay for persons eligible for Medicaid.

Problem Areas

- The acceptance of contributions as a condition of residency in a facility still occurs,

- particularly among religious nursing homes. Medicaid Fraud Units in several states have prosecuted nursing homes that have solicited donations.
- Financial screening, the practice of requiring potential residents to disclose their financial records as a condition of admission, has been a source of contention. Facilities that have this requirement are using it to ensure that residents will remain private pay for a certain length of time. This discriminatory practice is clearly prohibited by the Nursing Home Reform Law.
 - One of the most difficult Medicaid discrimination issues to resolve is the requirement that facilities have identical policies and practices regarding the provision of services mandated under the state plan for all individuals regardless of source of payment. The scope of this provision has yet to be defined or tested. Only a few states have developed regulations to address the problem.
 - Nursing homes are required to provide a variety of services to residents, such as nursing, medical, pharmaceutical, dietary, activities, and social services. These services must be of good quality and must meet residents' needs. In order to attract private pay residents and justify the higher basic rate charged to them, some nursing homes offer more variety and better quality services to private-pay residents, such as different menus, activities, room choices, and amenities.
 - Current federal law and regulations require that services be provided to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident. . . . This does not set a basic level of services nor define quality. Trying to distinguish what services (including scope and quality) must be provided to meet the standard set in the law from those that are considered “enhancements”, is an issue that must be resolved.

Protection From Abuse, Neglect, and Exploitation¹³ [§483.13]

All residents in nursing homes are entitled to receive quality care and to live in an environment that improves or maintains the quality of their physical and mental health. This entitlement includes freedom from neglect, abuse, and misappropriation of funds. Neglect and abuse are criminal acts whether they occur inside or outside a nursing home. Residents do not surrender their rights to protection from criminal acts when they enter a facility.

Nursing facilities are required to:

- develop and implement written policies and procedures that prohibit mistreatment, neglect, and abuse of residents and misappropriation of resident property;
- not employ individuals who have been found guilty of abusing, neglecting, or mistreating residents by a court of law; or have had a finding entered into the State

¹³ The content in this section is from “Abuse and Neglect,” a fact sheet by the National Citizens’ Coalition for Nursing Home Reform. www.nursinghomeaction.org

- nurse aide registry concerning abuse, neglect, mistreatment, or misappropriation of residents' property;
- thoroughly investigate all alleged violations of mistreatment, neglect, or abuse of residents and misappropriation of property; prevent further potential abuse during the investigation; and report all alleged violations and the results of all investigations to other officials according to state law.

Abuse

Abuse means causing intentional pain or harm. This includes physical, mental, verbal, psychological, and sexual abuse, corporal punishment, unreasonable seclusion, and intimidation. Examples include:

- Physical abuse from a staff member or an intruder or visitor from outside the facility — including hitting, pinching, shoving, force-feeding, scratching, slapping, and spitting;
- Psychological or emotional abuse —including berating, ignoring, ridiculing, or cursing a resident; threats of punishment or deprivation;
- Sexual abuse — including improper touching or coercion to perform sexual acts;
- Sub-standard care which often results in one or more of the following conditions: immobilization, incontinence, dehydration, pressure sores, and/or depression;
- Rough handling during care giving, medicine administration, or moving a resident.

Neglect

Neglect is the failure to care for a person in a manner, which would avoid harm and pain, or the failure to react to a situation which may be harmful. Neglect may or may not be intentional. For example, a caring aide who is poorly trained may not know how to provide proper care. Examples include:

- Incorrect body positioning — which leads to limb contractures and skin breakdown;
- Lack of toileting or changing of disposable briefs — which causes incontinence and results in residents sitting in urine and feces, increased falls and agitation, indignity and skin breakdown;
- Lack of assistance with eating and drinking—which leads to malnutrition and dehydration;
- Lack of assistance with walking —which leads to lack of mobility;
- Lack of bathing — which leads to indignity and poor hygiene;
- Poor hand washing techniques — which leads to infection;
- Lack of assistance with participating in activities of interest — which leads to withdrawal and isolation;
- Ignoring call bells or cries for help.

Exploitation of Property/Funds

This means the deliberate misplacement or misuse of a resident's belongings or money without the resident's consent. Examples include:

- Not placing resident funds in separate interest-bearing accounts where required;
- Stealing or embezzling a resident's money or personal property, such as jewelry or clothing.

TIPS FOR OMBUDSMAN PRACTICE

- Be alert for potential indicators of abuse, neglect, or exploitation of resident property as you visit residents.
 - If there are issues that need investigation or follow-up, proceed as you do with other complaints.
 - If you receive an abuse or neglect complaint, use your best efforts to ensure protection of the resident from further abuse or neglect in accordance with the LTCOP policies and procedures in your state.
-

VI. ENFORCEMENT OF RESIDENTS' RIGHTS

This section discusses some alternatives available to enforce residents' rights in nursing homes.

Federal Survey and Certification Process

The federal survey and certification process under Medicaid is the primary mechanism established for the enforcement of residents' rights. Having residents' rights as part of the federal law gives new emphasis to the rights in enforcement.

However, enforcement is hampered by a lack of understanding and sensitivity to residents' rights by surveyors. Even when surveyors are sensitive to residents' rights, they find them hard to quantify compared with other regulations. Violations are hard to document and hard to prove, and surveyors often fail to understand their seriousness. Correction is difficult to monitor.

The use of resident interviews in the survey process helps sensitize surveyors to residents' rights issues and provides more opportunities for them to observe, learn about, and document violations. Some LTCO Programs have developed brochures for residents and families on how to participate in the survey process. These contain an explanation of the process, how to contact surveyors, and preparing for an interview with a surveyor.

Residents' Rights Specific Penalties

Some states have incorporated nursing home residents' rights into the monetary penalties systems and levy fines for violations. The fine amounts vary and the violations can be difficult to prove. Collecting fines can also be difficult because of a lack of legal support for such actions and because of overwhelming appeal rights given to facilities in most states.

Other Use of the Courts

Advocates have gone to court successfully for restraining orders and injunctions to prevent transfers. Residents have also brought nursing homes to small claims court over lost or stolen possessions and won monetary awards based on facilities' negligence in failing to protect items. The downside is that legal recourse requires proof of damages. It also requires resources and stamina; however, it can be quite effective.

VII. STRENGTHENING RESIDENTS' RIGHTS

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

- Many residents are unaware of their rights or are unaware of what facilities are required to do.
- Even if they know their rights, many residents are unable to work through the complexities of a problem-solving process because of physical and/or mental limitations or because of a lack of support.
- The process of solving a problem may seem overwhelming.
- Institutional factors, such as isolation, lack of power, and resistance to change can make it difficult for a resident to resolve a problem without assistance.

Three measures that are especially useful in helping residents exercise their rights are discussed in this section: empowering the individual resident, working with resident councils, and working with family councils. The tables on the following pages can be used with each of these groups to help explain some common impediments to exercising residents' rights and to find ways to overcome them.

Table 1 lists a number of the reasons residents are reluctant to assert their rights on their own behalf.

Table 2 lists other obstacles that further impede implementation of residents' rights.

Table 3 lists a number of measures that nursing homes can take to promote and strengthen residents' rights.

A discussion of the role of the ombudsman in empowering individuals and in assisting with resident and family councils follows the three tables. Keep reading for inspiration and very useful tools!

TABLE 1

**REASONS RESIDENTS DO NOT
ROUTINELY EXERCISE THEIR RIGHTS**

1. Residents are intimidated by the idea of appearing in any way to criticize the nursing home.
2. Most residents do not know that they have specified rights and do not know what their rights are in a nursing home.
3. Most residents do not even think about their problems and concerns in any context related to their "rights."
4. Residents have very few opportunities to exercise control over their lives or to have intellectual discussions.
5. Residents have few relationships in which to practice interactive or assertiveness skills or negotiate their rights.
6. Even residents who are aware of their rights must choose their "battles" and often put up with daily violations of their individuality and dignity because:
(a) it requires too much strength to challenge each encounter; (b) they are easily labeled troublemakers; (c) they are dependent for their basic care on those very people and, therefore, hesitant to criticize, and, often, (d) they experience a sense of defeatism.
7. Most residents have come to accept that many of their rights are violated as a part of the daily nursing home routine and, therefore, would never articulate them as problems about which anything can be done.
8. Many residents face a tension between their desire for independence and their need for assistance.
9. Residents often feel more comfortable championing another's problem than asking for help for themselves.
10. Residents face physical, emotional, psychological, social, and/or mental disabilities that make it difficult for them to voice their concerns.
11. Residents' autonomy is undermined from the start by the very fact that most residents would rather not be in a nursing home; many did not have much of a role or choice in the decision to be there, and most have no other options.

Source: National Citizens' Coalition for Nursing Home Reform, Nursing Home Residents' Rights Project, 1828 L Street, NW, Suite 801, Washington, DC 20036

TABLE 2**OBSTACLES TO IMPLEMENTING RESIDENTS' RIGHTS**

1. Many residents do not know about or understand their rights.
2. Most residents feel that asserting rights is a negative thing to do.
3. To exercise their rights, residents need the physical care necessary to promote self-reliance and renewed strength, such as: appetizing food to suit their nutritional needs, rehabilitative and restorative therapy, meaningful activities, and freedom from over-medication and over-restraint.
4. Residents who do assert their rights often face tremendous resistance from every level of staff, which discourages them and makes it nearly impossible for them to succeed.
5. Most residents do not have many social supports inside or outside the home to encourage or assist them to live to their fullest.
6. Most resident councils do not receive the leadership development they need to function effectively.
7. Many resident councils meet resistance from staff when they voice concerns.
8. Few families understand residents' rights or know how to empower their relatives to maintain self-determination.
9. Most nursing homes are run in a very regimented, institutional fashion, which leaves little room for individuality, free expression, personal autonomy, or choice.
10. Most nursing homes provide few opportunities to foster relationships.
11. Many staff do not know about nor understand residents' rights.
12. Very few supervisory and managerial personnel understand residents' rights.
13. Sometimes staff feel threatened by "residents' rights."
14. Staff is often poorly trained in residents' rights.
15. Often, staff is not treated in a manner respectful of their own rights.
16. Short staffing prevents staff from taking the time necessary to treat residents respectfully in routine care and treatment.
17. Staff is used to "caring for" residents and do not know how to empower and enable residents to care for themselves.
18. It takes longer to help someone do something for himself/herself than to do it for him/her.
19. Many staff perceive residents' concerns and recommendations as too bothersome and another demand on an already burdensome schedule.
20. Most staff and others see residents' disabilities instead of their abilities.

Source: National Citizens' Coalition for Nursing Home Reform, Nursing Home Residents' Rights Project, 1828 L Street, NW, Suite 801, Washington, DC 20036

TABLE 3

**HOW FACILITIES CAN PROMOTE AND
IMPLEMENT RESIDENTS' RIGHTS**

- Educate residents and their families about their rights
- Educate and sensitize every level of staff about residents' rights.
- Incorporate resident participation and self-determination into every aspect of nursing home services (e.g., resident advisory committees for food services, activities, housekeeping)
 - Provide more support to workers, including sufficient staffing ratios, training, better supervision, dignified working conditions, and increased salaries and benefits.
 - Orient nursing assistants to the residents they will work with, and promote relationship building between staff and aides
 - Utilize the information and wisdom of residents and their representatives to help develop and conduct training programs for staff.
 - Help staff, residents, and families overcome the tension between dependence and empowerment. Residents need assistance, but the help they receive should increase their ability to help themselves.
 - Establish a grievance committee comprised of residents, family, staff, and administration.
 - Encourage and promote an open exchange of ideas, recommendations, and concerns throughout the facility among residents, families, staff, and administration.
 - Build more private rooms for individual residents and public rooms for private use by residents as needed.
 - Promote a sense of community within the nursing home. For example, organize activities for each wing and each floor or design activities that promote interaction and intellectual and emotional stimulation.

Source: National Citizens' Coalition for Nursing Home Reform, Nursing Home Residents' Rights Project, 1828 L Street, NW, Suite 801, Washington, DC 20036

Resident Councils

Resident councils are organizations within the nursing home or assisted living facility whose members are residents of the home. All residents of the home can participate just by the fact that they reside within the facility. Usually, residents who are able, speak up for those who cannot. Every resident council is different, due to differences in both the residents who participate and in the level of support and responsiveness from the facility.

Resident councils provide a vehicle for resident participation in decision-making and for residents to voice grievances and resolve differences. The Nursing Home Reform Law and federal regulations [§483.15(c)] give strong support and direction for staff in nursing homes to assist in the development and organization of resident councils. No comparable federal law exists for assisted living facilities.

The resident council has grown into a vital force where it has had support. Resident councils have made valuable contributions to decisions within facilities as well as at the state and national policy level. This is particularly true where coalitions of resident councils have helped individual facility councils to function more effectively and have provided a voice for residents on policy issues.

Importance of Resident Councils

Resident councils are important for many reasons. They have become more recognized by facility staff and residents for the important contribution that residents make when given the opportunity to speak for themselves. They provide a forum for residents to:

- Voice their concerns directly to staff.
- Hold the facility accountable.
- Identify problems and their solutions from the residents' perspective.
- Allow residents to recognize staff they feel deserving of recognition.
- Open up discussions on topics of interest to residents.
- Contribute to shaping their world.

In long-term care settings, whether they are large or small communities, resident councils can be a way to foster a feeling of connection to the community. They are a forum for sharing information and being a part of the world in which the resident lives. If the facility sees the value of residents participating in their own world, then the resident council can be a valuable vehicle—not just for improving life in the facility collectively, but also for assisting residents to feel alive individually and in relation to each other.

The Role of the Ombudsman

As an ombudsman, your role is to help develop or support existing resident councils. How you do this will vary with the setting. You may have to begin your work by educating both residents and facility owners to the benefit of having a resident council. You may have to offer assistance with organization and procedures. Ultimately, it will be

important for you to treat the resident council as the “go to” place in the facility for addressing community concerns and establishing community connections.

Resident councils vary greatly from home to home. You may find a strong resident council where residents set the agenda and the staff respond to their concerns. A strong resident council is easily recognized; it has broad participation, and residents freely bring up concerns or suggestions for improving the home.

Unfortunately, there are homes that comply with the letter of the law in that they have a resident council, but in reality it is not a true resident council. Some are staff-run and controlled. Residents who attend are wheeled in, read the recreational calendar, fed juice and cookies, then returned to their rooms. In such a home, you will have your work cut out for you!

As an ombudsman visiting in your assigned facility, you will want to learn all you can about the home’s resident council.

- Does one exist?
- Is it effective?
- How often does it meet?
- How is it run?
- Who is the president?
- How many residents attend?

One way to begin is to meet with the president of the council and ask permission to attend. Discuss with the president ways that you might be supportive. It is usually best to start out slowly, observing how the group works before offering to help.

Once you have become an invited guest and accepted by the group, you can start to promote the idea of the council as a tool in problem-solving. You will have information to share with residents, but your presence may change the dynamic in the group. Be aware of this, be careful not to overstep. Remember, **a resident council is for residents**, ombudsmen must always be respectful of this.

Avoid over-stepping the council if you attend a meeting.

Developing a good relationship with the resident council officers will be helpful. As part of your routine, check in with them whenever you are in the facility, and consider them your primary contacts. Ask what they are working on and how you can be helpful. By taking the resident council seriously, you will demonstrate how seriously it should be taken – by residents, families, and staff.

Resident councils in small, assisted living facilities may be less formally arranged than at larger facilities. In smaller homes, residents may meet informally on a regular basis, yet may not recognize the importance of having a forum such as a resident council to air their

concerns. You may spend a great deal of time in the beginning, letting people know why this kind of format works. It is extremely important to enlist the support of the administration and to show how both residents and staff benefit from having this kind of forum.

The dynamics of a small setting require a different approach than in a larger facility. Since people get together so often, it may be helpful to encourage residents to have a regular gathering time—perhaps even weekly—that is set aside for formal discussion of issues, experiences, and concerns, with a formal agenda and process for the discussion. Otherwise, it might be hard to distinguish the resident council meeting from any other gathering in the living room. Helping residents take their own council seriously and set aside the time for a real meeting may be a big boost in helping their council work effectively.

Keep in mind that a resident council is an organization that requires organizational skills and structures, as well as leadership skills to function. As we all know, running a meeting is not easy; and if it is done poorly, the meeting can feel like a real bore. No one wants to “waste their time” going to something boring or unproductive. Helping resident council leaders develop their organizational skills can help make the council meetings more productive. Any organization also has an organizing element to it—ways of generating and maintaining interest and involvement are a mainstay to any successful organization.

Some ombudsman programs have helped resident council leaders receive technical assistance in organizational leadership; sometimes through regional meetings of resident council presidents. Of course some people are natural leaders—they will be a great resource to other councils, either at regional gatherings or through visits to each other's homes.

There is a wide selection of written information and videos on resident councils available through your State Ombudsman and other sources. A few excellent resources follow.

Resident Council Resources

Resident Councils Resource Materials

The National Long-Term Care Ombudsman
Resource Center
The National Citizens' Coalition for Nursing
Home Reform
1828 L Street, Suite 801
Washington, DC 20036
202-332-2275; Fax: 202-332-2949
www.nursinghomeaction.org
www.ltcombudsman.org

Elder Care Rights Alliance

2626 East 82nd Street
Suite 220
Bloomington MN 55425-1381
Phone: 952-854-7304; Fax: 952-854-8535
www.eldercarerights.org

Resident Councils of Washington

220 E. Canyon View Rd.
Belfair, WA 98528-9597
(360) 275-8000
www.residentcouncil.org

How to Organize and Direct an Effective Resident Council

Emmelene W. Kerr, March, 1992
Missouri Long-Term Care Ombudsman
Program
Missouri Division of Aging
P.O. Box 570
Jefferson City, MO 65102
1-800-309-3282; (573) 526-0727
www.dhss.mo.gov

Coalition for the Institutionalized Aged & Disabled

Brookdale Center on Aging
425 E. 25th Street, Room 818
New York, NY 10010
Phone: 212-481-4348; Fax: 212-481-5069
www.ciadny.org

TIPS FOR OMBUDSMAN PRACTICE

- Help stimulate and support the development of resident councils in facilities without councils.
 - Where a resident council exists, strengthen the functioning of the council if appropriate.
 - Provide information and education on a variety of topics at the request of the council.
 - Meet with the council regarding problems within the facility.
 - Encourage attendance by:
 - *Talking it up.* Some residents do not routinely go to council meetings for many different reasons. As you visit, ask residents if they attend the council meeting. Encourage them to use the council as a way to bring forward concerns. If they are reluctant to do so, find out why. Once you know what the barriers are, you can work with the president to make a plan for overcoming them.
 - *Attending the resident council meeting yourself.* After suggesting to residents that this can be a means to solve problems, let them know that you will attend with them. Many residents will welcome this support. Attend only if invited.
 - *Coming early.* Arrive at the facility at least a half-hour before the meeting begins. Visit with residents who have told you that they would like to attend. They may initially need this kind of reminder. In some facilities, you may find that staff has not helped them get ready, and your presence is the prompt that is needed.
 - *Suggesting that residents put it in writing.* Some residents will feel more comfortable bringing concerns forward if they have listed their concerns in writing before the meeting. Then at the meeting, they can choose to voice their concerns or read from their list.
 - Remember that the council is the **residents'** group and should meet their needs, not be shaped to serve the ombudsman's needs.
-

Family Councils

Family councils are groups that meet regularly and whose membership includes family and friends of residents. Like resident councils, there is language in federal law that mandates that the facility provide support and assistance to family councils. [§483.10] However, even with the federal nursing home law supporting family councils, the reality is that few facilities have active family councils. This may be changing. More facilities are seeking Joint Commission on Accreditation of Healthcare Organization accreditation, which requires more active support and encouragement of family councils from the facility.

Family councils provide a needed link to the world outside of the facility for residents. They are especially valuable in the small, assisted living facilities where residents may be hesitant to voice concerns. They can be a buffer for residents having problems with the homes' administration and can provide an oversight from the community that is invaluable.

One of the reasons that family councils do not develop is that family members and friends have limited time and may not be able to both visit their loved one and attend a family council meeting. Unless there is a pressing need, many family members and friends understandably would rather spend their time visiting.

Importance of Family Councils

Family councils can be a vehicle for breaking the isolation of residents and family members. Additionally, they can provide needed validation for family members and residents. Sometimes family members feel as though they are "causing trouble" if they bring forward a complaint. In isolation, a family member may believe that they are the only family experiencing problems. Complaints are far less likely to be brushed aside or blamed on the resident when brought forth by a family council. It is easy to ignore a complaint when the administrator hears from a lone family member; but when the concern is brought forth in a group setting, there is the public relations need, if nothing else, that will propel the concern forward to resolution. It is true that there is "strength in numbers".

There is strength in numbers when voicing complaints or concerns to facility management.

Some facilities hold information-sharing sessions or support groups such as an Alzheimer's support group and label them as a family council. Although they may be very helpful to family members, they are not what is meant by a family council. Family councils are regular meetings run by family and friends of residents with the support of facility staff. Family councils can be very powerful. Some are completely run by family and friends of residents. Staff can come to their meetings by invitation only!

One family council member felt that the greatest benefit to her was the fact that through the council she had developed friendships with other family members. When she could not visit with her mom, she could call another family member and ask them to look in on her mom. This shared "looking out" for each other contributes to her feeling that her mother is all right even on the rare evening she cannot visit.

The Role of the Ombudsman

Your role as an ombudsman is to provide support and encouragement as well as educational information to family members. To do this effectively, you need to know what is already in place in the facility. As you begin to visit, ask questions about the family council. Some questions you might ask are:

- Is there currently a family council?
- If not, has there ever been one, or have there been attempts to start one?
- If so, how often does it meet?
- Who is the president?
- How well attended is it?
- What kind of issues does it deal with?
- Has it been effective?

If there is a family council, you should introduce yourself to the president and offer your services. If you are invited to attend meetings, remember that, just as with resident councils, you are an invited guest and must be respectful of their process.

If the facility you are visiting does not have a family council, you can be instrumental in assisting family members to start one. You can start by informing family members of the benefits of joining together. Some of these benefits include:

- Identifying problems and offering solutions from the resident's perspective.
- Opening up the dialogue between staff and residents and their family members.
- Having input in facility policies that better meet resident needs and desires.
- Providing a buffer for residents who do not feel comfortable identifying problems.
- Providing family members a forum for identifying shared concerns.
- Turning reactive frustration into proactive energy.
- Enhancing a sense of community for both residents and family members.

Just as with resident councils, family councils may need assistance in developing good organizational and leadership skills. Taking on an organizational responsibility on top of their other responsibilities in life can be overwhelming for family members; therefore, family members are likely to participate only if the council seems worthwhile. If a particular incident draws family members' interest (like the change of ownership, key staff, or in how something works at the home), you as ombudsman can play an important role in helping family members stay involved after the initial energy wanes. You do this by working with them on their particular concern in a way that helps them see the long term value of their continued involvement.

Often family members have a very focused view on their own family situation but do not have a larger context for understanding how the facility and the system work. As

an ombudsman, you can help family members see connections between their concerns and concerns of others; between their concerns and general issues about the facility; or about the system. For example, a family member may be very concerned when a resident's needs are not met. You may know that this is a problem faced by other family members, that it is a function of under-staffing or poor training, or how the management operates. You can explain some of what you know about why the problem exists and the extent of it in a way that helps family members see that they have a common interest in addressing the concern collectively with the facility leadership.

Joint Family Councils

Sometimes family members may want to join together with family members from another facility because there are too few family members from just one facility. At other times, family councils join together because some problems are too large for one family council to tackle. As an ombudsman, you will have knowledge of the concerns of not only one home but of others in the area. If you hear the same concerns voiced by family members from different homes, it most likely surrounds an issue that needs to be addressed at a higher level. You can be instrumental in bringing people together. You can let people know that they are not alone, that others have voiced similar concerns. You can ask them if they have any interest in getting together with others who are concerned. With their permission, you can share their name with others; or if you know that there is enough interest, you can hold open forums where people can come together to voice concerns.

*Ombudsmen
help bring
people together.*

As effective as a family council in a given home can be, joint family councils can be a powerful voice for change. They can affect change in large ways, such as impacting the legislative process to address concerns systemically, or to change policy in the Medicaid office. For example, perhaps a number of family councils are concerned about under-staffing. They can each address this problem at their own facility. But they may also want to bring the problem of under-staffing throughout the area to the attention of state officials. They might want to become engaged in an effort to increase the minimum staffing level in facilities. Another big concern for many residents and families is the need for privacy. This, too, would need to be tackled on a system level. Perhaps a coalition of family groups would want to advocate for passage of a law requiring all newly-built facilities to have more single rooms.

Joint family groups can become even more powerful by joining other citizen action groups to form coalitions that support needed change. A few excellent resources on family councils follow.

Family Council Resources

Family Education & Outreach: Final Report

The National Citizens' Coalition for
Nursing Home Reform
1828 L Street, Suite 801
Washington, DC 20036
Phone: 202-332-2275; Fax: 202-332-2949
www.nursinghomeaction.org

Long Term Care Ombudsman Guide To Developing And Supporting Family Councils and the Family Guide To Effective Family Councils

Robyn Grant, Consultant
The Legal Assistance Foundation of
Metropolitan Chicago
111 W. Jackson Boulevard, 3rd Floor
Chicago, IL 60604
Phone: 312-341-1071, ext. 8341
Fax: 312-612-1441
www.lafchicago.org

Nursing Home Family Council Manual

Texas Advocates for Nursing Home
Residents
P.O. Box 68
DeSoto, TX 75123
Phone: 972-572-6330; Fax: 972-572-7954
www.tanhr.org

Elder Care Rights Alliance

2626 East 82nd Street, Suite 220
Bloomington MN 55425-1381
Phone: 952-854-7304; Fax: 952-854-8535
www.eldercarerights.org

Friends & Relatives of the Institutionalized Aged, Inc.

18 John Street, Suite 905
New York, NY 10038
Phone: 212-732-4455; Fax: 212-732-6945
www.fria.org

VIII. LEGAL PROTECTION: DECISION-MAKING MECHANISMS

Advances in health care and unprecedented growth in the number of Americans living to very old age continue to create important new challenges for our society. Principal among these is that modern medical care can extend some individuals' lives beyond the point where they are capable of making decisions or expressing their needs and desires. This section discusses various legal mechanisms to protect an individual's self-determination to the greatest extent possible.

All of the mechanisms discussed are created in state statutes, except for representative payee and the Patient Self-Determination Act. Therefore, mechanisms for establishing power of attorney and guardianship may function differently from state to state.

Presumption

Even when an individual resides in a long-term care facility, relatives and professional caregivers do not have the legal authority to make decisions for him or her unless that authority has been specifically granted. This is true regardless of how incapacitated an individual is. Residents are presumed to be legally capable of making decisions about their care in a long-term care facility.

Advance Directives

A specific way to promote continuing control over decisions is to write advance directives. The directives may specify medical treatment the individual consents to or refuses and may designate a surrogate decision-maker.

Advance directives are written instructions from a decisionally-capable individual regarding future health care decisions in the event that he/she becomes incapacitated.

Living Will

A living will is a legal document through which a person expresses his/her wishes about medical treatment in the event he/she is unable to make those wishes known. It is effective only when an individual is facing a terminal condition and is unable to provide directives to his physician. A living will can be changed or revoked at any time.

A long-term care facility cannot be forced to comply with the terms of a living will. It is obligated, however, to make a reasonable attempt to locate another facility that will comply with an individual's living will.

Power of Attorney¹⁴

A power of attorney is a legal device that permits one individual the authority to act on behalf of another individual (the principal). The designated person (agent) may be authorized to handle some or all aspects of an individual's life. Common examples of activities a power of attorney might conduct are: banking, buying and selling real estate, incurring expenses, or paying bills. A principal can only develop a power of attorney when the principal is legally competent and capable of expressing her desires regarding this tool.

Power of attorney is a shared decision-making tool.

A power of attorney may:

- restrict duties of the agent by specifying the areas of responsibility/authority;
- be granted for a specified or unspecified length of time;
- be revoked or changed at any time by the individual granting the power of attorney, (the principal.)

Any third party (such as a bank or long-term care facility) who recognizes the power of attorney is not obligated to ask the principal what his or her wishes may be in an area covered by the power of attorney. It is therefore incumbent upon the resident to make his wishes known to the facility or other third party if they differ from that of the agent.

However, in the case of nursing facilities, the *Guidance to Surveyors* states that:

The rights of the resident that may be exercised by the surrogate or representative include the right to make health care decisions. However, the facility may seek a health care decision (or any other decision or authorization) from a surrogate or representative only when the resident is unable to make the decision. If there is a question as to whether the resident is able to make a health care decision, staff should discuss the matter with the resident at a suitable time and judge how well the resident understands the information. [Guidelines: §483.10 (a) (3) and (4)]

A power of attorney may be written so that it becomes effective only if, and when, an individual (principal) becomes disabled or mentally incompetent, depending upon the way it is written. Called durable powers of attorney, these documents are more flexible than a living will and can be applied to more situations. The fact that the power of attorney is "durable" means it cannot be revoked once the person becomes incapacitated.

There is no court supervision or any other monitoring of the agent. Therefore there are some risks associated with granting a power of attorney. This is particularly true if a power of attorney is used on behalf of an incapacitated person.

¹⁴ Much of this section is adapted from: *The Alaska Guardianship System*. Prepared for: AK Division of Senior Services, Dept. of Administration, by The McDowell Group. Juneau, AK. September 1998.

Powers of attorney are often misunderstood—by residents, families, and facilities. It is critical to remember that an individual does NOT give up their rights when a power of attorney is executed. It is intended to be a convenience for an individual. As an ombudsman, you may find yourself advocating for what a resident wants when a facility has relied inappropriately upon a power of attorney. For example, a daughter who holds a financial power of attorney may instruct a facility to restrict visitation with a brother against a resident's wishes.

Patient Self-Determination Act¹⁵

The Patient Self-Determination Act, passed in 1990 as part of the Congressional Omnibus Budget Reconciliation Act, was an attempt to ensure that health care providers know whether a resident/patient has any advance directives and that consumers are given information about their ability to make such decisions. This law requires Medicare and/or Medicaid provider organizations (hospitals, nursing facilities, home health agencies, hospices, and prepaid health care organizations) to:

- provide written information to patients at the time of admission concerning an individual's rights under state law to make decisions concerning medical care, including the right to accept/refuse treatment and the right to formulate advance directives.
- maintain written policies and procedures with respect to advance directives and to provide written information to patients about such policies.
- document in the individual's medical record whether the individual has an advance directive (the law does NOT require individuals to have advance directives).
- ensure compliance with the requirements of state law respecting advance directives.
- provide education for staff and the community on issues concerning advance directives.

It is important to remember that the law does not require an individual to execute a living will. If they are interested, there are a number of basic forms that are readily available that can be used. However, these forms can contain certain common provisions that may not apply to the individual. Ombudsmen should encourage individuals who express an interest in living wills to think about what they do want as well as what they do not want. It is very important for an individual to be sure that the living will document reflects the person's individual wishes.

Representative Payee

The Social Security Administration uses "representative payee" to mean an individual who agrees to accept Social Security payments on another person's behalf. The payee must agree to use the funds to meet the basic needs of the person entitled to the benefit.

¹⁵ This section is from the Louisiana LTCOP Manual.

There is a potential for abuse and exploitation due to a lack of regulations, oversight, or independent monitoring.

Often referred to as simply “payee,” the representative payee may also collect the individual’s public assistance, dividends from Native American corporations, veteran’s benefits, and other wages or retirement funds if the beneficiary agrees to the arrangement. The funding agencies have forms that must be completed in order to designate someone as representative payee. The individual designated as representative payee can be changed whenever the individual receiving the payment/benefit chooses. For convenience, facilities are often named as representative payee.

Payees have certain reporting requirements depending upon the benefit(s) they collect on behalf of the client. The Social Security Administration requires a yearly report outlining how the payee spent the individual’s benefits and the amount of funds remaining. The Veteran’s Administration requires similar reports.

Guardianship

Guardianship is the process of legally *taking away rights* from a person who is unable to make decisions for him/herself. The person who is appointed by a court to make those decisions is called a “guardian.” A person who has a guardian who makes decisions for him/her is called a “ward.”

The process of getting a guardianship of another person is difficult. There are legal protections afforded to the allegedly incapacitated person (the respondent), such as the right to legal representation at the hearing. Another protection is a requirement that the court consider alternatives to guardianship. Hence, guardianship is used as the last resort to promote and protect the well-being of an incapacitated person.

Guardianship can be full or limited. A full guardianship is sometimes called “legal death” because it means that all decisions are left to the guardian. A limited guardianship may give the guardian control over only certain areas, such as financial decisions. Guardianships can also be granted on a temporary or emergency basis if a court is convinced that the individual is at immediate risk.

A guardianship can be terminated by the court if there is evidence that no guardianship or a less-restrictive guardianship is needed. If a guardian is not acting in the best interest of the ward, the court can choose to appoint a different individual as guardian.

Guardians are required to file reports with the court at specified times. Guardians are also required to report to the court when there are significant changes in the ward’s situation.

Even if an individual is under full guardianship, their wishes, if they are able to state them, must still be considered. The *Guidance to Surveyors* states that:

In the case of a resident who has been formally declared incompetent by a court, lack of capacity is presumed. Notwithstanding the above, if such a resident can understand

the situation and express a preference, the resident should be informed and his/her wishes respected to the degree practicable. [Guidelines: §483.10 (a) (3) and (4)]

Tips for Ombudsman Practice

As a LTCO, it is important for you to know the differences in the various types of decision-making mechanisms available in your state. Your role is to model residents' rights. One primary way is to support each resident's right to make decisions and to participate in planning their care and treatment. More information about how to do this is discussed in the problem-solving section of the curriculum materials. Ombudsman skills in this area will be continually refined through working on cases and additional training. A few basic tips for practice follow.

TIPS FOR OMBUDSMAN PRACTICE

- ❑ Help support a resident's decision-making.
- ❑ Provide information about the range of decision-making mechanisms that are available and refer individuals to the appropriate resources for assistance.
- ❑ Be alert in situations where terms like "resident representative," "power of attorney," or "guardian" may be used interchangeably. Verify what mechanism, if any, exists and the extent of what that mechanism covers if necessary to address a resident's concerns.
- ❑ If a case arises with a resident who has a guardian, as an ombudsman, you will work with or through the guardian in most situations. There are three exceptions:
 1. The complaint is about the guardian or some action of the guardian.
 2. The complaint is about the issues of whether the guardian is needed.
 3. The guardianship is a limited one (the resident retains the right to make some decisions).

With these types of cases, it may be advisable to seek legal advice from an appropriate agency.
- ❑ Remember that residents may be able to clearly communicate what they want through behavior. The law, regulations, and *Guidance to Surveyors* support involving the resident in making decisions about their care and life to the extent that is practicable.
- ❑ As an ombudsman, you are the primary model many individuals will have for supporting and encouraging residents in exercising decision-making in their daily lives. Be vigilant about checking with the resident as an initial step in working on a case. Then either empower and assist the resident in resolving the issue, or take your direction from the resident.

APPENDIX A
FEDERAL RESIDENTS' RIGHTS PROVISIONS

**Federal Law – Regulation of Nursing Facilities
Residents' Rights Excerpt from 42 USC Sec. 1396r***

TITLE 42 - THE PUBLIC HEALTH AND WELFARE

CHAPTER 7 - SOCIAL SECURITY

**SUBCHAPTER XIX - GRANTS TO STATES FOR MEDICAL ASSISTANCE
PROGRAMS**

Sec. 1396r. Requirements for Nursing Facilities

(c) Requirements relating to residents' rights

(1) General rights

(A) Specified rights

A nursing facility must protect and promote the rights of each resident, including each of the following rights:

(i) Free choice

The right to choose a personal attending physician, to be fully informed in advance about care and treatment, to be fully informed in advance of any changes in care or treatment that may affect the resident's well-being, and (except with respect to a resident adjudged incompetent) to participate in planning care and treatment or changes in care and treatment.

(ii) Free from restraints

The right to be free from physical or mental abuse, corporal punishment, involuntary seclusion, and any physical or chemical restraints imposed for purposes of discipline or convenience and not required to treat the resident's medical symptoms. Restraints may only be imposed -

(I) to ensure the physical safety of the resident or other residents, and

* Excerpted from a formatted version of the law developed by Leigh Ann Clark in the Georgia Long Term Care Ombudsman Program Manual.

(II) only upon the written order of a physician that specifies the duration and circumstances under which the restraints are to be used (except in emergency circumstances specified by the Secretary until such an order could reasonably be obtained).

(iii) Privacy

The right to privacy with regard to accommodations, medical treatment, written and telephonic communications, visits, and meetings of family and of resident groups.

(iv) Confidentiality

The right to confidentiality of personal and clinical records and to access to current clinical records of the resident upon request by the resident or the resident's legal representative, within 24 hours (excluding hours occurring during a weekend or holiday) after making such a request.

(v) Accommodation of needs

The right -

(I) to reside and receive services with reasonable accommodation of individual needs and preferences, except where the health or safety of the individual or other residents would be endangered, and

(II) to receive notice before the room or roommate of the resident in the facility is changed.

(vi) Grievances

The right to voice grievances with respect to treatment or care that is (or fails to be) furnished, without discrimination or reprisal for voicing the grievances and the right to prompt efforts by the facility to resolve grievances the resident may have, including those with respect to the behavior of other residents.

(vii) Participation in resident and family groups

The right of the resident to organize and participate in resident groups in the facility and the right of the resident's family to meet in the facility with the families of other residents in the facility.

(viii) Participation in other activities

The right of the resident to participate in social, religious, and community activities that do not interfere with the rights of other residents in the facility.

(ix) Examination of survey results

The right to examine, upon reasonable request, the results of the most recent survey of the facility conducted by the Secretary or a State with respect to the facility and any plan of correction in effect with respect to the facility.

(x) Refusal of certain transfers

The right to refuse a transfer to another room within the facility, if a purpose of the transfer is to relocate the resident from a portion of the facility that is not a skilled nursing facility (for purposes of subchapter XVIII of this chapter) to a portion of the facility that is such a skilled nursing facility.

(xi) Other rights

Any other right established by the Secretary. Clause (iii) shall not be construed as requiring the provision of a private room. A resident's exercise of a right to refuse transfer under clause (x) shall not affect the resident's eligibility or entitlement to medical assistance under this subchapter or a State's entitlement to Federal medical assistance under this subchapter with respect to services furnished to such a resident.

(B) Notice of rights

A nursing facility must -

(i) inform each resident, orally and in writing at the time of admission to the facility, of the resident's legal rights during the stay at the facility and of the requirements and procedures for establishing eligibility for medical assistance under this subchapter, including the right to request an assessment under section 1396r-5(c)(1)(B) of this title;

(ii) make available to each resident, upon reasonable request, a written statement of such rights (which statement is updated upon changes in such rights) including the notice (if any) of the State developed under subsection (e)(6) of this section;

(iii) inform each resident who is entitled to medical assistance under this subchapter -

(I) at the time of admission to the facility or, if later, at the time the resident becomes eligible for such assistance, of the items and services (including those specified under section 1396a(a)(28)(B) of this title) that are included in nursing facility services under the State plan and for which the resident may not be charged (except as permitted in section 1396o of this title), and of those other items and services that the facility offers and for which the resident may be charged and the amount of the charges for such items and services, and

(II) of changes in the items and services described in subclause (I) and of changes in the charges imposed for items and services described in that subclause; and

(iv) inform each other resident, in writing before or at the time of admission and periodically during the resident's stay, of services available in the facility and of related charges for such services, including any charges for services not covered under subchapter XVIII of this chapter or by the facility's basic per diem charge.

The written description of legal rights under this subparagraph shall include a description of the protection of personal funds under paragraph (6) and a statement that a resident may file a complaint with a State survey and certification agency respecting resident abuse and neglect and misappropriation of resident property in the facility.

(C) Rights of incompetent residents

In the case of a resident adjudged incompetent under the laws of a State, the rights of the resident under this subchapter shall devolve upon, and, to the extent judged necessary by a court of competent jurisdiction, be exercised by, the person appointed under State law to act on the resident's behalf.

(D) Use of psychopharmacologic drugs

Psychopharmacologic drugs may be administered only on the orders of a physician and only as part of a plan (included in the written plan of care described in paragraph (2)) designed to eliminate or modify the symptoms for which the drugs are prescribed and only if, at least annually an independent, external consultant reviews the appropriateness of the drug plan of each resident receiving such drugs.

(2) Transfer and discharge rights

(A) In general

A nursing facility must permit each resident to remain in the facility and must not transfer or discharge the resident from the facility unless -

(i) the transfer or discharge is necessary to meet the resident's welfare and the resident's welfare cannot be met in the facility;

(ii) the transfer or discharge is appropriate because the resident's health has improved sufficiently so the resident no longer needs the services provided by the facility;

(iii) the safety of individuals in the facility is endangered;

(iv) the health of individuals in the facility would otherwise be endangered;

(v) the resident has failed, after reasonable and appropriate notice, to pay (or to have paid under this subchapter or subchapter XVIII of this chapter on the resident's behalf) for a stay at the facility; or

(vi) the facility ceases to operate.

In each of the cases described in clauses (i) through (iv), the basis for the transfer or discharge must be documented in the resident's clinical record. In the cases described in clauses (i) and (ii), the documentation must be made by the resident's physician, and in the case described in clause (iv) the documentation must be made by a physician. For purposes of clause (v), in the case of a resident who becomes eligible for assistance under this subchapter after admission to the facility, only charges which may be imposed under this subchapter shall be considered to be allowable.

(B) Pre-transfer and pre-discharge notice

(i) In general

Before effecting a transfer or discharge of a resident, a nursing facility must -

(I) notify the resident (and, if known, an immediate family member of the resident or legal representative) of the transfer or discharge and the reasons therefor,

(II) record the reasons in the resident's clinical record (including any documentation required under subparagraph

(A)), and

(III) include in the notice the items described in clause (iii).

(ii) Timing of notice

The notice under clause (i)(I) must be made at least 30 days in advance of the resident's transfer or discharge except -

(I) in a case described in clause (iii) or (iv) of subparagraph (A);

(II) in a case described in clause (ii) of subparagraph (A), where the resident's health improves sufficiently to allow a more immediate transfer or discharge;

(III) in a case described in clause (i) of subparagraph (A), where a more immediate transfer or discharge is necessitated by the resident's urgent medical needs; or

(IV) in a case where a resident has not resided in the facility for 30 days.

In the case of such exceptions, notice must be given as many days before the date of the transfer or discharge as is practicable.

(iii) Items included in notice

Each notice under clause (i) must include -

(I) for transfers or discharges effected on or after October 1, 1989, notice of the resident's right to appeal the transfer or discharge under the State process established under subsection (e)(3) of this section;

(II) the name, mailing address, and telephone number of the State long-term care ombudsman (established under title III or VII of the Older Americans Act of 1965 (42 U.S.C. 3021 et seq., 3058 et seq.) in accordance with section 712 of the Act (42 U.S.C. 3058g));

(III) in the case of residents with developmental disabilities, the mailing address and telephone number of the agency responsible for the protection and advocacy system for developmentally disabled individuals established under part C of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6041 et seq.); and

(IV) in the case of mentally ill residents (as defined in subsection (e)(7)(G)(i) of this section), the mailing address and telephone number of the agency responsible for the protection and advocacy system for mentally ill individuals established under the Protection and Advocacy for Mentally Ill Individuals Act (42 U.S.C. 10801 et seq.).

(C) Orientation

A nursing facility must provide sufficient preparation and orientation to residents to ensure safe and orderly transfer or discharge from the facility.

(D) Notice on bed-hold policy and readmission

(i) Notice before transfer

Before a resident of a nursing facility is transferred for hospitalization or therapeutic leave, a nursing facility must provide written information to the resident and an immediate family member or legal representative concerning -

(I) the provisions of the State plan under this subchapter regarding the period (if any) during which the resident will be permitted under the State plan to return and resume residence in the facility, and

(II) the policies of the facility regarding such a period, which policies must be consistent with clause (iii).

(ii) Notice upon transfer

At the time of transfer of a resident to a hospital or for therapeutic leave, a nursing facility must provide written notice to the resident and an immediate family member or legal representative of the duration of any period described in clause (i).

(iii) Permitting resident to return

A nursing facility must establish and follow a written policy under which a resident -

(I) who is eligible for medical assistance for nursing facility services under a State plan,

(II) who is transferred from the facility for hospitalization or therapeutic leave, and

(III) whose hospitalization or therapeutic leave exceeds a period paid for under the State plan for the holding of a bed in the facility for the resident, will be permitted to be readmitted to the facility immediately upon the first availability of a bed in a semiprivate room in the facility if, at the time of readmission, the resident requires the services provided by the facility.

(E) Information respecting advance directives

A nursing facility must comply with the requirement of section 1396a(w) of this title (relating to maintaining written policies and procedures respecting advance directives).

(3) Access and visitation rights

A nursing facility must -

(A) permit immediate access to any resident by any representative of the Secretary, by any representative of the State, by an ombudsman or agency described in subclause (II), (III), or (IV) of paragraph (2)(B)(iii), or by the resident's individual physician;

(B) permit immediate access to a resident, subject to the resident's right to deny or withdraw consent at any time, by immediate family or other relatives of the resident;

(C) permit immediate access to a resident, subject to reasonable restrictions and the resident's right to deny or withdraw consent at any time, by others who are visiting with the consent of the resident;

(D) permit reasonable access to a resident by any entity or individual that provides health, social, legal, or other services to the resident, subject to the resident's right to deny or withdraw consent at any time; and

(E) permit representatives of the State ombudsman (described in paragraph (2)(B)(iii)(II)), with the permission of the resident (or the resident's legal representative) and consistent with State law, to examine a resident's clinical records.

(4) Equal access to quality care

(A) In general

A nursing facility must establish and maintain identical policies and practices regarding transfer, discharge, and the provision of services required under the State plan for all individuals regardless of source of payment.

(B) Construction

(i) Nothing prohibiting any charges for non-Medicaid patients

Subparagraph (A) shall not be construed as prohibiting a nursing facility from charging any amount for services furnished, consistent with the notice in paragraph (1)(B) describing such charges.

(ii) No additional services required

Subparagraph (A) shall not be construed as requiring a State to offer additional services on behalf of a resident than are otherwise provided under the State plan.

(5) Admissions policy

(A) Admissions

With respect to admissions practices, a nursing facility must –

(i) (I) not require individuals applying to reside or residing in the facility to waive their rights to benefits under this subchapter or subchapter XVIII of this chapter, (II) not require oral or written assurance that such individuals are not eligible for, or will not apply for, benefits under this subchapter or subchapter XVIII of this chapter, and (III) prominently display in the facility written information, and provide to such individuals oral and written information, about how to apply for and use such benefits and how to receive refunds for previous payments covered by such benefits;

(ii) not require a third party guarantee of payment to the facility as a condition of admission (or expedited admission) to, or continued stay in, the facility; and

(iii) in the case of an individual who is entitled to medical assistance for nursing facility services, not charge, solicit, accept, or receive, in addition to any amount otherwise required to be paid under the State plan under this subchapter, any gift, money, donation, or other consideration as a precondition of admitting (or expediting the admission of) the individual to the facility or as a requirement for the individual's continued stay in the facility.

(B) Construction

(i) No preemption of stricter standards

Subparagraph (A) shall not be construed as preventing States or political subdivisions therein from prohibiting, under State or local law, the discrimination against individuals who are entitled to medical assistance under the State plan with respect to admissions practices of nursing facilities.

(ii) Contracts with legal representatives

Subparagraph (A)(ii) shall not be construed as preventing a facility from requiring an individual, who has legal access to a resident's income or resources available to pay for care in the facility, to sign a contract (without incurring personal financial liability) to provide payment from the resident's income or resources for such care.

(iii) Charges for additional services requested

Subparagraph (A)(iii) shall not be construed as preventing a facility from charging a resident, eligible for medical assistance under the State plan, for items or services the resident has requested and received and that are not specified in the State plan as included in the term "nursing facility services".

(iv) Bona fide contributions

Subparagraph (A)(iii) shall not be construed as prohibiting a nursing facility from soliciting, accepting, or receiving a charitable, religious, or philanthropic contribution from an organization or from a person unrelated to the resident (or potential resident), but only to the extent that such contribution is not a condition of admission, expediting admission, or continued stay in the facility.

(6) Protection of resident funds

(A) In general

The nursing facility -

(i) may not require residents to deposit their personal funds with the facility, and

(ii) upon the written authorization of the resident, must hold, safeguard, and account for such personal funds under a system established and maintained by the facility in accordance with this paragraph.

(B) Management of personal funds

Upon written authorization of a resident under subparagraph (A)(ii), the facility must manage and account for the personal funds of the resident deposited with the facility as follows:

(i) Deposit

The facility must deposit any amount of personal funds in excess of \$50 with respect to a resident in an interest bearing account (or accounts) that is separate from any of the facility's operating accounts and credits all interest earned on such separate account to such account. With respect to any other personal funds, the facility must maintain such funds in a non-interest bearing account or petty cash fund.

(ii) Accounting and records

The facility must assure a full and complete separate accounting of each such resident's personal funds, maintain a written record of all financial transactions involving the personal funds of a resident deposited with the facility, and afford the resident (or a legal representative of the resident) reasonable access to such record.

(iii) Notice of certain balances

The facility must notify each resident receiving medical assistance under the State plan under this subchapter when the amount in the resident's account reaches \$200 less than the dollar amount determined under section 1382(a)(3)(B) of this title and the fact that if the amount in the account (in addition to the value of the resident's other nonexempt resources) reaches the amount determined under such section the resident may lose eligibility for such medical assistance or for benefits under subchapter XVI of this chapter.

(iv) Conveyance upon death

Upon the death of a resident with such an account, the facility must convey promptly the resident's personal funds (and a final accounting of such funds) to the individual administering the resident's estate.

(C) Assurance of financial security

The facility must purchase a surety bond, or otherwise provide assurance satisfactory to the Secretary, to assure the security of all personal funds of residents deposited with the facility.

(D) Limitation on charges to personal funds

The facility may not impose a charge against the personal funds of a resident for any item or service for which payment is made under this subchapter or subchapter XVIII of this chapter.

(7) Limitation on charges in case of Medicaid-eligible individuals

(A) In general

A nursing facility may not impose charges, for certain Medicaid-eligible individuals for nursing facility services covered by the State under its plan under this subchapter, that exceed the payment amounts established by the State for such services under this subchapter.

(B) "Certain Medicaid-eligible individual" defined

In subparagraph (A), the term "certain Medicaid-eligible individual" means an individual who is entitled to medical assistance for nursing facility services in the facility under this subchapter but with respect to whom such benefits are not being paid because, in determining the amount of the individual's income to be applied monthly to payment for the costs of such services, the amount of such income exceeds the payment amounts established by the State for such services under this subchapter.

(8) Posting of survey results

A nursing facility must post in a place readily accessible to residents, and family members and legal representatives of residents, the results of the most recent survey of the facility conducted under subsection (g) of this section.

APPENDIX B
ASSESSMENT AND CARE PLANS
THE KEY TO GOOD CARE

ASSESSMENT and CARE PLANNING: THE KEY TO GOOD CARE

Consumer Information Sheet

Each and every person in a nursing home has a right to good care under the 1987 Federal Nursing Home Reform Law. The law, which is part of the Social Security Act, says that a nursing home must help each resident “attain or maintain” his or her highest level of well being - physically, mentally, and emotionally. To give good care, staff must *assess* and *plan care* to support each resident’s life-long patterns, current interests, strengths, and needs. Care planning conferences are a valuable forum for residents and families to voice concerns, ask questions, give suggestions, learn nursing home strategies, and give staff information (such as resident background and daily routine). This requirement in the law is vital to making sure residents get good care.

Resident Assessment

Assessments gather information about the health and physical condition of a resident and how well a resident can take care of themselves. This includes assessing when help may be needed in activities of daily living (ADLs) or “functional abilities” such as walking, eating, dressing, bathing, seeing, hearing, communicating, understanding, and remembering. Assessments also should examine a residents’ habits, activities, and relationships in order to help him or her live more comfortably and feel at home in the facility.

The assessment helps staff to be aware of strengths of the resident and also determine the reason for difficulties a resident is having. An example of where a good assessment helps: A resident begins to have poor balance. This could be the result of medications, sitting too much, weak muscles, poorly fitting shoes, or a urinary or ear infection. Staff must find out the cause of a problem in order to give good treatment. Figuring out the cause is much easier with a good assessment.

Assessments must be done within 14 days of the resident’s admission to a nursing home (or 7 days for Medicare residents) and at least once a year after that. Reviews are held every three months and when a resident’s condition changes.

Plan of Care

After the assessment is completed, the information is analyzed and a care plan is developed to address all the needs and concerns of the resident. The initial care plan must be completed within seven days after the assessment. The care plan is a strategy for how the staff will help a resident every day. This care plan says what each staff person will do and when it will happen (for example, a nursing assistant will help Mrs. Jones walk to each meal to build her strength). Care plans must be reviewed regularly to make sure they work and must be revised as needed. For care plans to work, residents must feel they meet their needs and must be comfortable with them.

Care Planning Conference

The care plan is developed by an interdisciplinary team -- nurse, nurse aide, activities and dietary staff, and social worker, **with critical input from the resident and/or family members.** All participants discuss the resident’s care at a Care Plan Conference to make certain that all medical and non-medical issues, including meals, activities, therapies, personal schedule, medical and nursing care, and emotional needs are agreed upon and addressed. Resident and family member concerns should be listened to by staff and addressed in the care plan. A good Care Plan Conference takes time. It should not be rushed, and could take at least one hour. Every 90 days after development of the initial plan, or whenever there is a big change in a resident’s physical or mental health, a Care Plan Conference is held to determine how things are going and if changes need to be made.

Good Care Plans Should

- Be specific to that resident;
- Be followed as an important guideline for providing good care for the resident;
- Be written so that everyone can understand it and know what to do;
- Reflect the resident's concerns and support his or her well-being;
- Use a team approach involving a wide variety of staff and outside referrals as needed;
- Assign tasks to specific staff members;
- Be re-evaluated and revised routinely.

Steps for Residents and Family Participation in Care Planning

Residents and family members have the right to be involved in the care plan conference in order to make choices about care, services, daily schedule, and life in the nursing home. Even if a resident has dementia, involve them in care planning as much as possible. Be aware that they may understand and communicate at some level and help the staff to find ways to communicate and work with them. They can express when they hurt or suffer if they are actively listened to. Participating in care plan conferences is a way to be heard, raise questions, and come to a clear agreement with the facility about how the resident will be cared for.

Before the meeting:

- Ask staff to hold the meeting at a convenient time for you and/or your family member;
- Ask for a copy of the current care plan (if one already exists) so that you can examine each aspect thoughtfully;
- Know about or ask the doctor or staff about your or your loved one's condition, care, and treatment;
- Plan your list of questions, needs, problems, and goals, and;
- Think of examples and reasons to support changes you recommend in the care plan.

During the meeting:

- Make sure the resident is involved and listened to carefully.
- Discuss options for treatment and for meeting your needs and preferences;

- Ask questions if you need terms or procedures explained to you;
- Be sure you understand and agree with the care plan and feel it meets your needs;
- Ask for a copy of the care plan;
- Find out who to talk to if changes in the care plan are needed, and;
- Find out who to talk to if there are problems with the care being provided.

After the meeting:

- Monitor whether the care plan is being followed;
- Inform the resident's doctor about the care plan if s/he was not directly involved;
- Talk with nurse aides, staff or the doctor about the care plan, and;
- Request another meeting if the plan is not being followed.
- See NCCNHR's "Resolving Problems in Nursing Homes" for additional information.

If you are interested in learning more, the National Citizens' Coalition for Nursing Home Reform (NCCNHR) has several publications that may be of interest. Call 202-332-2275 for a publication list or visit the website at www.nursinghomeaction.org

- **Nursing Homes: Getting Good Care There**
- **Avoiding Physical Restraint Use - consumer booklet**
- **Avoiding Drugs Used as Chemical Restraints - consumer booklet**
- **Using Resident Assessment and Care Planning: An Advocacy Tool for Residents and their Advocates**

APPENDIX C
FREEDOM FROM RESTRAINTS

**CONTEXT FOR FREEDOM FROM PHYSICAL OR CHEMICAL
RESTRAINTS USED FOR DISCIPLINE OR
CONVENIENCE¹⁶**

Issue	Context for Advocacy
Resident view of physical restraints (Strumpf & Evans, 1988)	Research shows that restrained residents suffer greatly: “I feel like a prisoner.” “Why are they punishing me?” “I feel as if my chest is being crushed.” “I can’t get to the toilet and I wet my bed.”
Physical harm from physical restraint use (Burger, 1993)	Be proactive with residents, families, and staff about the harm (risk) that may occur. Restraints can negatively affect every system of the body causing decreased appetite (malnutrition), dehydration, pneumonia, urinary tract infections, constipation, incontinence, decreased bone strength, decreased muscle strength, contracted muscles, bruising/cuts/redness of skin, pressure sores, fall-related injuries, death by asphyxiation.
Emotional harm from physical restraint use (Burger, 1993)	A restrained resident feels isolated and dehumanized suffering: mental distress including agitation, calling out, depression; withdrawal from others and from surroundings; decreased participation in activities; inability to move around or to get to the bathroom; more problems with sleep; reduced contact with friends, family and doctors.
Less Staff to care for non-restrained residents (Charles Phillips, 1993)	If caregivers are to prevent these poor physical and psychological outcomes, it takes more staff to care for restrained residents than non-restrained. (e.g. turning, toileting, getting water and food, doing exercises to keep bones and muscles strong). Most facilities do not have the staff to provide these kinds of preventive services.
Frail, older residents, often with dementia are most often restrained. (Evans and Strumpf, 1989)	The reason for restraining is usually unsafe mobility, wandering, confusion and agitation. These issues can always be addressed by thorough assessment (using the RAP on physical restraints), individualized care planning to strengthen mobility, providing a safe place to wander, lowering beds and side rails, and knowing the details of a person’s life to provide activities and approaches to care familiar to each resident.
Bedrails can be a physical restraint (Hospital Bed Safety Workgroup)	Clinical research suggests that bed rails may not be benign safety devices. For example, evidence indicates that half-rails pose a risk of entrapment and full rails pose a risk of entrapment. Falls also occur when patients climb over the rails or footboards. ^{17, 18} Recognizing this risk, the U.S. Food and Drug Administration (FDA) and CMS have acted to reduce the likelihood of injuries related to bed rails. The FDA MedWatch Reporting Program receives reports of entrapment hazards. In 1995 the FDA issued a Safety Alert entitled, “ <i>Entrapment Hazards with Hospital Bed Side Rails.</i> ” In 1997, the FDA authored an article, based on the reported hospital bed adverse events which identified potential risk factors and entrapment locations about the hospital bed. The FDA continues to receive reports of patient deaths and injury that provide documentation of patient entrapment.

¹⁶ The Ombudsman’s Guide to the Nursing Home Reform Amendments of OBRA ’87. S. G. Burger, National Long-Term Care Ombudsman Resource Center, NCCNHR. 2005.

¹⁷ Parker, K., Miles, SH. (1997). Deaths caused by bed rails. Journal of the American Geriatrics Society 45:797-802.

¹⁸ Feinsod, F.M., Moore, M., Levenson, S. (1997). Eliminating full-length bed rails from long term care facilities. Nursing Home Medicine 5:257-263.

Issue	Context for Advocacy
Psychoactive drugs	There are four classes of psychoactive drugs: Antipsychotics (to treat hallucinations, delusions), sedative/hypnotics (to treat sleep disturbances); Anxiolytic (antianxiety drugs); and antidepressants (to treat depression). These drugs can improve the quality of life for residents who need them; however, all drugs pose both risks and benefits.
What are chemical restraints? (Burger, 1993)	While CMS defines chemical restraints as drugs used for discipline or convenience, advocates can also think of them a “psychoactive drugs used to treat behavioral symptoms in place of good care.” Older people should take as few drugs as possible, because the more drugs they take the greater the possibility of suffering a poor outcome. Psychoactive drugs can have serious and life threatening side effects.
Like physical restraints, chemical restraints may lead to poor outcomes. (Burger, 1993)	Psychoactive drugs may cause falls, fractured hips, inability to urinate, development of pressure sores, infections, dry mouth, repetitious movements of the lips, tongue, head, fingers, and toes, blurred vision, constipation, rigidity like Parkinson’s, increased agitation rather than decreased. The person may think, talk or move more slowly and lose the ability to care for himself. He may sleep through meals.
Behavioral Symptoms are expressions of an unmet need (Burger, 1993)	People, who are unable to use words due to a medical condition such as dementia, express themselves through actions. These symptoms include wandering, agitation, screaming, spitting, swearing and many others that are expressions of distress. From the resident’s perspective, he is expressing an unmet need. For families, friends and caregivers, the challenge is to discover the unmet need and deliver the care to meet it. (e.g. constant movement or moaning might signal untreated pain, lashing out at caregivers many mean the resident is frightened of the way care is given, trying to leave a facility may mean the resident is trying to meet her children after school-a lifelong habit from the past, repeatedly getting up out of a chair may be a need for water or to go to the bathroom.)
Labels mask the unmet need and increase the use of chemical restraints (Burger, 1993)	Sometimes caregivers use the term “behavior problem” to describe a resident’s actions. Even the 2002 CMS RAP on behaviors uses that term. By labeling someone as a “behavior problem,” the cause of the distress is masked. It blames the resident for the symptoms of a disease process. If the symptom such as hitting a caregiver who frightens a resident is treated with a chemical restraint, the cause of the symptom , or unmet need, is masked. A change in caregivers or training and supervision of the caregiver is the appropriate approach.
In depth assessment and individualized care reduce chemical restraint use, including antidepressants. (Burger, 1993 and Burger et al, 2001)	The MDS identifies symptoms and the RAPs on physical and chemical restraints provide the process for systematically ruling out causes of behaviors. Another adjunct to identifying unmet needs is the Appendix in “Nursing Home Getting Good Care There,” entitled, “What I Want You To Know About My Mother.” One of the Pioneering facilities uses that on admission with every resident because it provides the details of a person’s life. For example, a resident with Parkinson’s and an unsteady gait and some dementia, escaped from the facility every morning. His lifelong routine was to arise early, eat a good breakfast, and head outside for a day of work. The nurse asked the doctor for a drug order for agitation. After the drug was given, the family became alarmed at the droopy appearance of this active man. The facility had provided nothing for him to do, until the family provided this lifelong information. The outside maintenance man was trained as a nurse aide and the two worked together each morning. No drug was needed.

Issue	Context for Advocacy
	Another resident under similar circumstances might have reacted to the situation with a major depression. An antidepressant would have been a chemical restraint, because more appropriate care could be provided.
Staffing and chemical restraint use (OIG 2001)	This report concludes that 85% of the psychoactive medication use in their sample (excluding antidepressants) is appropriate and not a chemical restraint. NCCNHR reviewed two of the homes mentioned and related it to self reported staffing. The facility in Idaho with 27% drug use among the residents with behavioral symptoms (with everything from schizophrenia to dementia) had high staffing of 4.04 hours per resident per day (hprd) and used in depth assessment and individualized care. The facility in Maryland that had a 65% drug use in this population had low staffing of 3.38 hprd and was not described as using in depth assessment or individualized care.
Pain identification and treatment: an unmet need (Brown University, 2001)	Research has shown that of those who had persistent or excruciating pain on consecutive assessments, 41% still had pain on the second assessment. Pain is not treated. This statistic is a very understated number because until recently those with dementia were not included. It was assumed that their symptoms were a result of the dementia. Not so, pain is real for those with dementia. Facilities are reporting a decrease in psychotropic drug use, when pain is identified and treated.
Pioneering approaches to care reduce the need for antidepressants (Crestview Nursing Home, 2003)	Facilities that use pioneering approaches to care and have stable staff report a decrease over time in antidepressants. These drugs, like all drugs, are useful for treating serious mental illness. A depression caused by basic unmet needs such as not being taken to the bathroom or being told “you have a diaper on” or having nothing to do should not be treated with an antidepressant. The philosophy and approach to care must change. Remember polypharmacy is a dangerous for frail, older, and often demented individuals.

APPENDIX D: RESOURCES

**RESOURCES ON RESIDENTS' RIGHTS AND
QUALITY OF LIFE¹⁹**

¹⁹ From *An Ombudsman's Guide to the Nursing Home Reform Amendments of OBRA '87*, revised 2005.

Books and Reports

An Ombudsman's Guide to The Nursing Home Reform Amendments of OBRA '87. Revised 2005. Burger, S. The National Long-Term Care Ombudsman Resource Center of the National Citizens' Coalition for Nursing Home Reform, 1828 L St., NW, Suite 801, Washington, DC 20036. www.ltombudsman.org

Nursing Homes: Getting Good Care There. Burger, S., Hunt, S., Frank, B. and Fraser, V. Impact Press, 2nd Edition, 2001. Includes chapter on residents' rights and quality of life. Also includes a piece by Carter Catlett Williams on "What You Should Know About My Mother." Some nursing homes use this on admission to gather information about each resident.

Person Centered Care: A Model for Nursing Homes, Rantz, Marilyn and Flesner, Marcia American Nurses Association, Washington, D.C. order at www.nursingworld.org or call 800-637-0323. (A Story of Professional Commitment: A Study of an Exemplar Long-Term Care Facility) (First book on a Pioneer Network home and how it operates).

Getting Started: A Pioneering Approach to Long Term Care Culture Change. Misiorski, Sue, RN Springer Publishing, 2004. (A how to for Pioneer Network Practices with teaching modules).

Bathing without a Battle: Personal Care of Individuals with Dementia. Barrick, A; Rader, J; Hoeffler, B; and Sloane, P., Springer Series in Geriatric Nursing, 2002. (See Videos/CD ROM below)

Everyday Ethics: Resolving Dilemmas in Nursing Home Life, Rosalie A. Kane and Arthur L. Caplan, Editors. Springer Publishing, 1990.

He's 20, and at 93, She's His Oldest Friend, New York Times, N.R. Kleinfeld, May 14, 2003.

Quality of Life Measures for Nursing Home Residents, Kane, R.L.; Kling, K.C.; Bershadsky, B; Kane, R.L.; Giles, K.; Degenholz, H.B.; Liu, Jiexin; and Cutler, L.J. The Journal of Gerontology: Medical Sciences, Vol 58A, No. 3, 240-248, 2003.

Long Term Care and a Good Quality of life: Bringing them Closer Together, Kane, R.L., The Gerontologist, Vol 41, No. 3, 293-304, 2001.

Quality of Life in Nursing Homes From a Consumer Research Perspective, Gwen C. Uman, RN, PhD, Vital Research, Los Angeles, CA, Paper presented in July, 1996.

Evaluation of the LTC Survey Process, HCFA (now CMS), Chapter Five, "Quality of Life: Results from Resident Interviews and Observations." Contact Karen Schoeneman, Project Officer, Centers for Medicare & Medicaid Services, 7500 Security Boulevard, Baltimore MD at 410-786-6855 or kschoeneman@hhs.cms.gov. This study was done by ABT Associates in 1994 and became the basis for the new survey procedures in quality of life.

Resident Council Handbook. A step by step guide to forming resident councils. Ideal for residents, facility staff, and ombudsmen. Created by and for residents. Contact Resident Councils of Washington @ www.residentcouncil.org

Videos and Game

Bathing without a Battle: Personal Care of Individuals with Dementia. A training video and CD ROM of Barrick, A; Rader, J; Hoeffler, B; and Sloane, P., Springer Series in Geriatric Nursing, 2002. Purchase at: www.bathingwithoutabattle.unc.edu for \$30.

Making It Home: Residents' Rights In Board And Care And Assisted Living. A 15 minute video with a self-instructional Study Guide. Colorado State Long-Term Care Ombudsman Program. The Legal Center, 455 Sherman Street, Suite 130, Denver, CO 80203. (800)288-1376.

Nursing Home Care Plans: Getting Good Care. A 16 minute video, leader's guide, and handouts on individualized care planning and resident participation. 1999, 2000. AARP, 601 E Street, NW, Washington, DC 20040. www.aarp.org

Residents Have the Answers: Improving the Quality of Life in Long-Term Care. A 33 minute video, a complete training and resource guide and PC computer diskette with questionnaire templates that can be customized for different facilities. Available from Terra Nova Films, Inc., (777)881-8491 or Lisa Zabar at Independent production fund (800)727-2470.

Residents' Rights Bingo Game. A board game on the residents' rights in nursing facilities. Can be used in many ways for teaching or reviewing with residents, facility personnel, or ombudsmen. Developed by Virginia Fraser when she was CO State Long-Term Care Ombudsman. To obtain contact the Colorado State Long-Term Care Ombudsman Program. The Legal Center, 455 Sherman Street, Suite 130, Denver, CO 80203. (800)288-1376.

Strength in Numbers: The Importance of Nursing Home Family Councils. A 20-minute video and leaders guide provide an overview of techniques and strategies for effective family council development. National Citizens' Coalition for Nursing Home Reform, 1828 L Street, NW, Suite 801, Washington, DC 20036. (202)332-2275, www.nursinghomeaction.org

NCCNHR Publications

For more information, contact NCCNHR at 1828 L Street, NW, Suite 801, Washington, DC 20036, (202)332-2275 or www.nursinghomeaction.org

Residents' Rights Week packets include resources and ideas for year-round effective training. Easy to carry "kit" with room for state and facility specific information. Kit includes diskette with presentations, promotional items and training materials.

“24/7 Residents’ Rights Around the Clock”- Residents’ rights Week packet 2003

“Giving Voice to Quality: Affirming Residents’ Rights in Long Term Care”
Residents’ Rights Week packet 2002

“Opening the Door: A Residents’ Right to Visitation” Residents’ Rights Week
Packet 2001. Care Planning, 2005

Maryland Family Council Project, “Why Family-Led Family Councils Benefit Families,
Residents, and Facility Personnel.”

Consumer Fact Sheets related to residents’ rights and quality of life- two-page free fact
sheets:

Residents’ Rights

Access and Visitation

Restraint Use

Involuntary Transfer and Discharge