

Illinois Department on Aging
**Illinois Long-Term Care Ombudsman Program
Supplemental Training Curriculum**

**Supplemental Module # 13
Family Councils: the Key to a United Community Voice**

Pre-publication Edition I

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TABLE OF CONTENTS

- I. Introduction
- II. What is a Family Council?
- III. Legal Rights of a Family Council
- IV. The Legal Responsibility of the Ombudsman Program for the Support of Family Councils
- V. Barriers to Establishing a Family Council
- VI. The Ombudsman's Role in Establishing and Maintaining a Family Council
- VII. Summary

Handouts

- Family Council Informational Sheet
- The Rights of Family Councils in Nursing Homes
- What IS a Family Council?
- Getting Started
- Talking Points for Meeting with Administrators
- Keeping Families Interested
- Structure and Leadership
- Sample Purpose and Bylaws
- Sample Agenda
- Sample Activity Checklist
- Recruitment and Promotion
- Educational Topics for Family Council Meetings
- Resolving Problems and Concerns
- Staff Liaison
- Retaliation
- Combating Excuses: Why Don't Some Homes Have Family Councils?
- Pioneer Practices
- Pioneer Blue Sheet
- Pioneer Chart

Works Cited

Appendices

- A. Resources
- B. Family Council Laws and Regulations of California and Minnesota

PROCESS FOR USING THIS MODULE

The supplemental modules for ombudsmen have been created to accommodate different learning styles and are based on research about how most people learn. The premise on which this module is based is the idea that new information is learned best when there is an opportunity for discussion and to ask questions. This module incorporates individual reading, group discussion, questions on what is not clear to you and an evaluation of what you have learned.

This module is designed to be adaptable to various teaching methods and settings: training/ in-services for ombudsmen or presentations to families or facility staff. This module can be divided into as many training sessions as needed and a variety of methods can be used, including a lecture method.

For ombudsman training, after the discussion, you will be asked to work as a group to

- 1) Write a plan or outline of a plan on how you would approach the facility and families in initiating and/or sustaining an independent family council. Select a facility that does not have a family council, **or** a facility that has a family council that is not operating independent of the facility, **or** a facility that has an independent family council but is not fulfilling its advocacy or other role.
- 2) Implement the plan in cooperation with your supervisor.

PURPOSE OF THE MODULE

The purpose of this module is to:

- Inform the ombudsman on the importance of family councils;
- Identify how a family council should operate so that it remains independent;
- Inform ombudsmen and families how to speak with administrators about family councils;
- Provide materials for family councils to use;
- Provide suggestions for programs and advocacy issues for family councils;
- Identify the role of the ombudsman as one of empowering family councils; and
- Identify the role of the ombudsman as one of promoting and protecting family councils' right to self-determination.

SUPPLEMENTAL MODULE #13

FAMILY COUNCILS: THE KEY TO A UNITED COMMUNITY VOICE

By Erin Strotheide and Margaret Niederer

I. INTRODUCTION

A. THE IMPORTANCE OF A FAMILY COUNCIL

Residents of nursing homes are guaranteed the right to quality care and a quality of life. Family members are often the only advocates residents have to assure they receive the care to which they are entitled. Many times, families of residents do not understand that they are needed as much, or more, by their loved one after the resident enters a facility than before.

Countless family members feel helpless to change the poor care their loved ones receive. Visits can become so distressing that families stop visiting. Some ombudsmen estimate that about twenty percent of residents have no families, have families that live too far away, or have families unwilling to visit.

B. FAMILIES PLAY A SIGNIFICANT ROLE IN RESIDENTS' LIVES AND THE FACILITY AS A WHOLE

At the heart of family participation in a facility is the critical need for relationships. Both residents and families need to feel that the nursing home is a safe and comfortable environment in which relationships can evolve and be sustained. Carter Catlett Williams, a Pioneer in the long-term care industry, states, "relationships are not only the heart of long-term care, they are the heart of life. And life ought to continue, wherever we live."

Family councils can provide a "safe haven" for family members to meet with other individuals who have experienced or are experiencing the same situations, feelings, and difficulties. Families can gain strength from each other and be empowered to speak up on behalf of their loved ones.

Organized family councils can identify residents that receive no visitors and develop a system to visit and advocate for these frail and vulnerable residents who are most at risk of not having their care and personal needs met.

Relationships are not only the heart of long-term care, they are the heart of life. And life ought to continue, wherever we live.

Carter Catlett Williams

Family councils are becoming increasingly important because, as the nursing home population becomes more frail and disabled, the number of residents who can participate in the required resident councils decreases due to physical illness, dementia, or communication difficulties. Many resident councils no longer provide the collective voice for residents in facility decisions as was originally intended. Most often, the incapable resident's legal representatives do not know that they have the right to attend the resident council in place of an incapable resident or by a resident's invitation. Since

resident councils are most often held during the day, the legal representative is unable to attend. Resident councils should not be disbanded, but it is essential for families to take an active role in facility life, and a family council is a good alternative.

Perhaps the most important reason for the establishment of family councils is that the council gives families a united voice within the facility to address issues. The formation of local independent family councils in every part of the State should be the catalyst for

There is not a statewide coalition that has a significant statewide membership able to speak to the legislators and state officials on the underlying problems of nursing home residents.

There is no more important work for the ombudsman than to assist families to develop this voice.

families having a collective voice statewide. There is not a statewide coalition that has a significant statewide membership able to speak to the legislators and state officials on the underlying problems of nursing home residents. One group, TLC in LTC (Tender Loving Care in Long-Term Care in Illinois) has a website on the importance of family councils, www.tlcinltc.org.

Experts in the nursing home industry say that a family council is

- The best way for families to address issues in an united effort;
- The best prevention against abuse and neglect;
- The best vehicle for conveying to a facility the need for a change in culture;
- The best way to assist the activity director in obtaining assistance from the community in providing community activities and other activities;
- The best way to provide ongoing appreciation for staff;
- The best way to address systemic issues regarding changes in laws, regulations and policies that affect residents in facilities across the state and nation.

C. RAISING EXPECTATIONS ABOUT HOW NURSING HOMES SHOULD OPERATE

Every resident, family member, ombudsman, facility staff and administrator needs to know that nursing homes can be different! Nursing home residents, including those with dementia, should have, and can have, individualized care in a homelike environment that resembles the lives they lived before entering the facility.

Nursing homes were developed according to the medical model in the 1960's. Built like hospitals with long hallways, central nurses' stations, task-oriented staff routines, and sterile environments, nursing homes were intended to treat the diseases of the frail and elderly.

However, residents of nursing homes need far more than basic medical and nursing care. Residents need a place that meets social, religious, emotional, occupational, recreational, and cultural needs. Nursing home residents need a HOME where they can LIVE and enjoy life-long habits and interests.

A group of nursing home professional staff, called The Pioneers, envisioned something far beyond the traditional nursing institutions and identified new ways of operating a nursing home. These nursing home administrators proposed innovative strategies to reconstruct the long-term care system and make “deep system change”—culture change.

Family councils can be catalysts for this type of change in nursing home culture. Advocacy efforts of a family council, in cooperation with facility administration and staff, can develop creative approaches to care, activities, the facility’s authority structure, and the facility environment that truly transform life in the facility into one that is “life-affirming, satisfying, humane and meaningful” (*Values, Vision, Mission*). A family council can help assure individualized care that meets residents’ needs and affirms the value of our elders.

An Elder is a person who is still growing, still a learner, still with potential and whose life continues to have within it promise for, and connection to the future. An Elder is still in pursuit of happiness, joy and pleasure, and her or his birthright to these remains intact. Moreover, an Elder is a person who deserves respect and honor and whose work it is to synthesize wisdom from long life experience and formulate this into a legacy for future generations.

Barry Barkan, Pioneer, The Live Oak Living Center

II. WHAT IS A FAMILY COUNCIL?

A family council is an independent (self-led and self-determining) group of families and friends of residents that together protect and improve the quality of life for residents and provide families with a voice in decisions that affect their loved ones.

The name “family council” can be intimidating for some families, but a family council may select whatever name it chooses. It can be called Family Support Group, Friends of Residents, or Quality of Life Advocates, etc. What is imperative for a family council to function effectively is for it to operate independently. When staff do not attend meetings, families have the opportunity to voice concerns without fear. Family groups that are run by facility staff do not constitute a family council.

This does not imply that the family council does not work with the facility. Effective councils do work with facilities and maintain an open dialogue. Truly supportive facilities will be proactive in educating families about the potential benefits of independent family councils and in continuing recruitment efforts to get new families involved with an already established family council. It can be helpful for facility staff to identify families for an introductory meeting and provide guidance to a council until it can become independent and assume leadership. Facilities that attempted to establish family councils found that it took approximately six meetings before the families felt

ready to assume leadership (*Insights from Test Sites 1*). However, after the families have assumed leadership, it is essential that the council be completely independent and the facility not influence the council's direction.

A family council can benefit all parties involved. Families, residents and facilities must be informed of the potential benefits.

For families:

- Orientation, support, and information for the families of new residents.
- Ongoing mutual support—strength drawn from shared experiences.
- Individual family members can check on residents for other family members and report to them.
- Sense of community belonging that builds relationships, commitment, and connectedness to the life of a facility.
- Education and information related to the long-term care system—residents' rights, best nursing home practices, facility operations, policy, rules, and the health conditions, such as Alzheimer's Disease, affecting the residents.
- A means to express concerns and solve problems— a “united voice” to address issues as a “united effort.” A family council is a group in which the families can be the catalyst for positive actions to improve care. A council can support and protect residents who do not have concerned families or friends.
- Advocacy efforts to effect changes statewide.

Family Councils offer benefits to everyone when families, residents, facility staff, and the community focus on one goal—Quality Care for Residents!

For Residents:

- Family input into care decisions and facility changes.
- Increased sense of community within the facility, and connectedness with other residents, families, and staff.
- Family council sponsored activities and events to supplement the activity program.
- Support and protection for residents who do not have concerned families or friends.
- A connection to the community outside the facility.

For the Facility:

- Two -way communication between the facility and families—facility administration and staff are informed of concerns before they escalate to major problems. Families are informed of facility news, policy/procedure changes, and updates on the long -term care system as a whole.
- The council can be a sounding board for new ideas and facility changes.
- Family input to aid staff in problem solving and finding solutions.
- Support on mutual concerns and goals.
- Means to know families and residents better—their past experiences, and their likes and dislikes, etc.
- Help families and residents express meaningful appreciation for the staff.
- Sense that the facility is a mutually-supportive community and increased connectedness with residents and families.

III. THE LEGAL RIGHTS OF FAMILY COUNCILS

(See Appendix B for laws and regulations regarding family councils from other states)

A. *FEDERALLY CERTIFIED FACILITIES (MEDICARE AND MEDICAID):*

The 1987 Nursing Home Reform Act (OBRA) guarantees the rights of families, which includes close friends of residents, to form a family council and hold regular private meetings. Specifically, the federal law states the following:

- A resident's family has the right to meet with other families in the facility.
- The facility must provide a private meeting space.
- Anyone may attend the meetings at the group's invitation,
- The facility must provide a designated staff person responsible for providing assistance in developing and maintaining a family council or other family group. **(NOTE:** This does not necessarily mean attendance at council meetings. Facility staff and ombudsmen can attend upon invitation only.)
- The facility must respond to written requests from a family council or other family group meetings.
- When a family group exists, the facility must listen to the issues and act on any grievances and recommendations concerning facility policy and operational decisions affecting the care of residents (Adapted from 42 CFR sec.483.15(c)).

B. *PRIVATE-PAY ONLY FACILITIES*

State law and regulations do not specifically address family councils, but recent additions to the state regulations for facility activity departments specify family involvement as an activity category (Sec. 300.1410 (h) (8)). A family council is an important component of that family involvement. Facilities that only admit private-pay

residents are not required by state law to support family councils, but best nursing home practices would indicate that support of a family council would be a priority in order to more effectively meet consumers' needs.

IV. THE LEGAL RESPONSIBILITY OF THE OMBUDSMAN PROGRAM FOR THE SUPPORT OF FAMILY COUNCILS

A. THE FEDERAL LAW

The authorization for the ombudsman **to promote and support family councils** is in the federal Older Americans Act (Sec.712 (a) (3) and (5)), which authorizes the ombudsman program and specifies the duties of the program. The State Ombudsman office is to

- “promote the development of citizen organizations to participate in the program” (H) (ii), and
- **“provide technical support for the development of resident and family councils to protect the well being and rights of residents”** (H)(iii).

The regional ombudsman programs are to **“support the development of resident and family councils”** (B)(vi).

Besides the law specific to family councils, the federal law delineates the ombudsman program's responsibility to effect changes at the systems level. Ombudsmen can partner with organized and empowered family councils to give long-term care consumers a voice at the state level. Ombudsman programs have a duty to support systemic advocacy efforts of family councils.

The following portions of the act specifically requires advocacy for changes in laws, regulations and policies. The long-term care ombudsman program is required to

- “represent the interests of the residents before governmental agencies and seek administrative, legal and other remedies to protect the health, safety, welfare and rights of residents ((a) (3) (E) and (5) (B) (iv))
- “provide administrative and technical assistance to entities designated under paragraph (5) (which are the regional ombudsman programs) to assist the entities in participating the program” ((a) (3) (F));
- “analyze, comment on, and monitor the development and implementation of Federal, State, and local laws, regulations and other governmental polices and actions, that pertain to the health safety, welfare and rights of residents with respect to the adequacy of nursing homes and services in the State ((a) (3) (G) (I)),
- “recommend any changes in such laws, regulation, policies and actions as the Office determines to be appropriate” ((a) (3) (G) (ii) and (5) (B) (V) (I)
- facilitate public comment on laws, regulations, policies and actions” ((a) (3) (G) (iii) and (5) (B) (V) (III).

[Older Americans Act Sec.712]

The regional ombudsman programs are also mandated by law to “represent the interests of residents before government agencies and seek administrative, legal and other remedies to protect the health, safety, welfare and the rights of residents” (B (iv).

The regional programs are to “review, and if necessary, comment on any existing and proposed laws, regulations and other government policies and actions, that pertain to the rights and well-being of residents (B)(v)(I), and “facilitate the ability of the public to comment on the laws, regulations, policies and actions” (B)(v) (II).

B. THE STATE REQUIREMENTS

The Illinois Act on Aging mandates that the ombudsman program carry out all the mandates listed in the federal law. The state regulations mandate that the ombudsman program support the development of family councils:

The Office (Ombudsman Program) shall provide technical support for the development of resident and family councils to protect the well being and rights of residents.

[89 Illinois Administrative Code Ch,II, 270.110 (n)]

V. BARRIERS TO ESTABLISHING A FAMILY COUNCIL

- Families are afraid of retaliation. The families do not want to do anything to “rock the boat.” (See handout on page 32)
- Families do not know that they have the right to form a family council.
- Most do not know basic residents’ rights.
- Families are uninformed about what an independent family council can do. The families, collectively, do not recognize their influence to help the facility take better care of residents.
- Families may not have leadership skills and do not know how to form a functioning family council.
- The facilities do not assist the families in knowing that they can form a family council and the importance of a council.
- The families do not know about best nursing home practices, such as Pioneer Practices, or how a facility climate can change for the better through the adoption of some best practices.
- The families appear to have emotional burnout, and resignation. Families feel hopeless. (Research shows that this is because they lack support and information.)
- The families know nothing about the opportunity to advocate for changes at the state level to change laws, regulations and state policies to improve nursing home conditions.
- Administrators who attempt to “control everything” in a facility are afraid of independent family councils. They feel the need to control any type of family council. They are afraid that there will be so many problems that they will not be able to handle them.

What nursing home administrators fail to realize is that when family councils are independent, these councils can synthesize and consolidate problems. Family

councils taking complaints is a better way to address complaints than in a fragmented fashion.

Facilities that are experienced with independent family councils know that in the beginning there will be many complaints, but after about three or four months, the families will begin to change from only making complaints, to offering solutions that support staff and make the facility a better home for residents.

VI. THE OMBUDSMAN'S ROLE IN STARTING AND MAINTAINING A FAMILY COUNCIL

- Be informed. Gather resources.
- Talk to the administrator about best nursing home practices, such as Pioneer Network Practices, which include starting a family council. Identify any concerns about a family council and address those concerns. Ask for the administrator's support in contacting families.
- Visit when families are at the facility (evenings and weekends). Inform families of residents' rights and the importance of family councils.
- Talk to residents and/ or the resident council and ask them for names of family members that you could contact about starting a family council.
- Write a letter to families about starting a family council, set a time for the meeting and ask the facility to mail it to families (speak with the regional ombudsman prior to making these arrangements to prevent the ombudsman program from having to cover the cost).
- Identify one or two family members interested in starting a family council. Meet together (ombudsman and family members) with the administrator to gain his/her support for the effort.
- Address the barriers that the administrator may have. The attitude of the administrator is the key to starting a family council and ongoing participation. The attitude of the administrator, as the leader of the facility staff, is key in informing staff of the benefits of family councils for residents. If the administrator understands the importance of a family council, his leadership team will support the concept.
- Assist in providing materials, posters for the facility, etc. for the first meeting of families.
- Offer to present family council information at the first introductory meeting.

- Offer to periodically present information on residents' rights, especially to family members of new residents.
- Contact the council leadership by phone or other means at least every other month to determine level of family participation in the council.
- Meet periodically with council leadership to assess need for further resources, contacts for guest speakers and state agencies; advice on laws, regulations, and policy; help with individual concerns; etc.
- If the ombudsman program has not provided technical assistance to a family council, and the facility has made little or no effort to continually promote a family council, then family councils may eventually disband. There are always new families in facilities and families whose loved ones have left. It is important that families know that such a council exists when their loved one enters a facility.
- Encourage the facility to have a procedure for including family council information in the admissions packet and orientation routine. In this manner, the family will know that the facility believes that family councils are an important source for support to the facility.
- Inform all family members how to contact you about problems or concerns.
- Empower all family members to be their own advocates.
- Inform family councils of the ombudsman legislative plan. Ask councils what they will do to inform the general public and legislators of long-term care issues.

VII. SUMMARY

Too often, families and friends of nursing home residents feel hopeless and helpless to assure their loved ones receive the quality care to which they are entitled. Like many residents, family members fear retaliation and feel they have "been beaten" by the long-term care system. But families armed with knowledge of their rights, the rights of their loved ones, and the opportunities for system change through Pioneer Practices, can avoid feelings of helplessness and hopelessness and be empowered to take an active role in increasing the quality of their loved ones' care. Empowered families, joined together as an independent family council, can be a united voice for all residents, including those unable to speak for themselves.

Ombudsmen are often the key to the establishment and maintenance of a family council in a facility. Ombudsmen must inform family members of their right to meet in independent family councils, help families gain the support of facility administration and staff, provide resources and training for families to become their own advocates, and provide encouragement.

The following pages can be used as handouts for the ombudsman's use in informing the facilities and families about family councils.

Blue family council sheet

INGREDIENTS OF A SUCCESSFUL FAMILY COUNCIL*

1. Regular meetings held frequently enough to maintain interest and continuity. Most active councils meet monthly.
2. Meetings planned and led by members (family and friends).
3. Meetings of reasonable length that begin and end on time.
4. Sound organization, including purposes, bylaws, agendas, minutes, and officers elected by families and friends. In some councils planning or steering committee members share leadership duties.
5. A variety of activities, rather than a focus on just one or two efforts that may not appeal to everyone.
6. Involvement in activities that address the needs, concerns, and interests of families and residents.
7. Ongoing efforts to notify all families and friends about council meetings, events, and accomplishments, with special efforts to reach out to the families of new residents.
8. A supportive staff advisor who understands and promotes council independence and self-determination.
9. Financial independence from the nursing home.
10. Meetings conducted in such a way that members feel free to express their concerns without fear.
11. Realistic, effective efforts to resolve concerns. This often hinges on a council's decision to focus on the concerns of the group rather than on individual problems.
12. Opportunities for council members to gain needed information about the home and the long-term care system.
13. Commitment and involvement of staff and administration.
14. Open communication and mutual respect among the council, administrator, and staff. This means planning for regular opportunities for council members to inform staff and administration of their concerns and ideas, and for staff and administration to keep the council informed of nursing home news, changes, and issues.
15. Family council input into nursing home decisions [on policy, resident activities, etc.]
16. Appreciation, by council members and staff, of the accomplishments of the family council.
17. Recognition of members' individual efforts and contributions on behalf of the council.

* Advocacy Center for Long-Term Care, 1998

THE RIGHTS OF FAMILY COUNCILS IN NURSING HOMES

The 1987 Nursing Home Reform Act guarantees the families of residents a number of important rights to enhance a loved one's facility experience and improve facility-wide services and conditions. Key among these rights is the right to form and hold regular private meetings of an organized group called a family council.

Facilities certified for Medicare and Medicaid must provide a meeting space, cooperate with the council's activities, and respond to the group's concerns. Nursing facilities must appoint a staff advisor or liaison to the family council, but staff and administrators have access to council meetings only by invitation. While the federal law specifically references "families" of residents, close friends of residents can and should be encouraged to play an active role in family councils, too.

Specifically, the federal law includes the following requirements on family councils:

- *A resident's family has the right to meet in the facility with the families of other residents in the facility.*
- *The facility must provide a family group, if one exists, with private space.*
- *Staff or visitors may attend meetings at the group's invitation.*
- *The facility must provide a designated staff person responsible for providing assistance and responding to written requests that result from group meetings.*
- *When a family group exists, the facility must listen to the views and act upon the grievances and recommendations of residents and families concerning proposed policy and operational decisions affecting resident care and life in the facility.*

Guidelines:

- *"Voice grievances" is not limited to a formal, written grievance process but may include a resident's verbalized complaints to facility staff. "Prompt effort to resolve" include facility acknowledgment of complaint/grievances and actively working toward resolution of that complaint/grievance.*
- *If residents' responses indicate problems in voicing grievances and getting grievances resolved, determine how the facility deals with and makes prompt efforts to resolve resident complaints and grievances.*
- *The facility is required to listen to resident and family group recommendations and grievances. Acting upon these issues does not mean that the facility must accede to all group recommendations, but the facility must seriously consider the group's recommendations and must attempt to accommodate those recommendations, to the extent practicable, in developing and changing facility policies affecting resident care and life in the facility. The facility should communicate its decisions to the resident and/or family group and why the decision was made.*

WHAT *IS* A FAMILY COUNCIL?*

IT'S NOT A FAMILY NIGHT

In most nursing homes, family night is an event planned and led by staff for the families of residents. Usually family night is held quarterly or semi-annually. In some homes, it is completely social in nature; in others, a program of education or information is included.

IT'S NOT A SUPPORT GROUP

A support group for families that is led by facility staff helps families share and resolve emotional conflicts and negative feelings associated with having a loved one in a facility.

IT'S NOT AN AUXILIARY OR VOLUNTEER GROUP

An auxiliary or volunteer group usually supplements a home's services. Auxiliary members and volunteers frequently raise funds, provide resident care that does not require professional staff, or become involved in additional activities for residents.

A FAMILY COUNCIL IS:

A family council is a self-led, self-determining consumer group of relatives and friends of residents. It usually meets monthly and engages in a variety of activities.

Family councils may have activities similar to those mentioned above. For example, a council might sponsor a family support group or provide activities and events for residents. However, a council is **not limited to these activities** and is not led or directed by staff. Family councils give members the opportunity to express concerns, and to **work for meaningful change in the home**. Because a family council is self-determining and not limited to one type of activity, its focus can change as the needs and interests of its members change.

Family councils may be called by any name that is decided by its members. Some may call themselves a family group, a family support group, families in action, loved ones of residents, welcome and support committee, etc. Whatever the name, **the important aspects of a family council are its independence and the way in which it functions.**

Each of the above groups is important to a facility. Each has important functions. However, they are not interchangeable. Family night is not a family council. A support group is not a family council. An auxiliary or volunteer group is not a family council.

The first step in making your council active and effective is to understand the special role of a council and to ask yourself what kind of group you have.

* Advocacy Center for Long-Term Care, 1999

GETTING STARTED

PREPARATION

- Visit the families of facility residents and ask these family members to join you in starting a family council.
- As a group of families, approach the administrator about starting a family council. The support of the administrator and facility staff is important, but not essential, to a family council's success. (NOTE: Support does not imply attendance at councils meetings. Staff cannot attend meetings unless invited.)
- Contact your local Long Term Care Ombudsman for technical support, information, and resources.
- Set a time for the first meeting.
- Request the facility provide a meal or refreshments for the initial meeting. Some facilities may even provide a meal.
- Publicize the meeting by posting flyers, handing-out invitations, face-to-face contact with visiting family members, announcements in the facility newsletter and local newspapers, etc. Ask the facility to send a letter to all family members along with the billing.

FIRST MEETING

Prepare to present information on what a family council is, why it is important, and what it can do for residents, families, and the facility.

- Discuss the rights and benefits of a family council.
- Explain the importance of group independence.
- Invite your local ombudsman to attend and provide resources, or even present family council information.
- Invite your facility administrator and department heads for a brief part of this initial meeting in order for them to show their support of the effort.
NOTE: Make it clear that they are expected to leave for the remainder of the meeting to allow for private discussion among the families.
- Establish ground rules for sharing concerns. It will be important to allow time for individual concerns, but the council must go the next step and work with the administrator to improve identified problems.
- At a minimum, appoint a temporary chair, vice chair and secretary until the group is organized.
- Make arrangements for the next meeting.
- Offer drinks or refreshments. The facility can show its support by providing refreshments.

TALKING POINTS FOR MEETING WITH ADMINISTRATORS

- We are meeting with you in good faith to help in improving the residents' quality of life.
- We believe that a facility that works with a family council is a better facility than those that do not.
- We believe that support of a family council is a best practice for a facility.
- We want to support you and your staff in caring for our loved ones.
- We want you to support a family council.
- We believe that a family council can work with you to make the environment more homelike for residents.
- We believe that a family council can support staff and help you to retain staff.
- We believe that families talking about resident issues and complaints and thinking through the problem(s) may lead to solutions.
- We believe that family involvement is critical to the staff knowing the past interests of each resident.
- We would like to request that you have someone plan with us on how to contact the families.
- We would request that for the first meeting that the facility provides some refreshments.
- We would request that for the first few meetings that you provide someone to talk about some aspect of care.
- We would like to work with the social services director and activity director on community events.
- We would like the family council to promote more community involvement in the facility.
- We would like the family council to know more about best practices (Pioneer Practices) and that a facility can change into one in which all residents have individualized care and a quality of life.
- We would like to help the facility to support best nursing home practices, one practice selected by the facility and one practice selected by the residents.
- From this meeting, on, who will be our contact?
- How do you want to be kept informed about our activities?
- How do you want to be kept informed about the complaints and concerns we receive?
- Thank you. We appreciate your interest in our loved ones.

KEEPING FAMILIES INTERESTED AND EMPOWERED

- Council meetings should be scheduled regularly enough to hold families' interests.
- Develop and follow an agenda at each meeting.
- Start and stop on time. Respect the time commitments of others.
- Continue recruitment efforts--posters, face-to-face contact, council information included in admissions packet, etc. (See pages 26-27).
- The administrator and staff should actively inform all families about the family council, especially families new to the facility.
- Allow time to discuss family and resident concerns. Establish a system to address individual concerns, e.g. a committee or occasional set times during meetings to discuss individual concerns.
- Synthesize individual concerns and identify 1 or 2 facility-wide concerns for which the council develops strategies and action plans to improve conditions.
- As a group, take concerns to staff, establishing a strong, cooperative link between facility staff and family members.
- Plan special events and activities to supplement the facility activity program and to avoid focusing solely on individual concerns.
- Have educational/informational sessions about facility and long-term care issues.
- Establish some type of structure and leadership (See pages 20-21).
- Meet regularly with the local ombudsman for technical support and to identify valuable resources.
- Develop a system (e.g. phone tree, e-mail) to reach council members for support and problem resolution outside of the regularly scheduled meeting times.
- Keep a listing of all family names for reference; there may be, at times, a rapid turnover of families and former families can help new families re-establish or maintain a family council.
- To avoid family council meetings that primarily focus on individual concerns that may not be appropriate for the whole council to discuss, the council must educate and empower family members to be their own advocates.

STRUCTURE AND LEADERSHIP

Although the organizational structures of family councils vary greatly, there are some common features of most councils. Family councils are run by friends and relatives of the facility's residents, choose their own topics, have elected leadership, meet on a regular basis, and have some method of exchanging information with facility staff. Two structures are common:

1. **Town Meeting Model**—If the group of interested families and friends is small, the council usually invites all families to each meeting. Planning, decision-making, and other basic tasks are carried out at these meetings.
2. **Executive or Planning Committee**—If the group is large, a committee may be needed to plan and make decisions that would be too time consuming to deal with in meetings of the full council. The committee may meet monthly and plan bimonthly or quarterly events or projects to which all families are invited.

OFFICERS (AT A MINIMUM)

Encourage officers to remain part of the council even after their family member has passed away until a replacement can be found.

President/Chairperson—A temporary chair should be appointed at the first introductory meeting, until council members can hold an election. One advocate suggests “identify two people. One who can work effectively with the administration, and one who is the fire behind getting it going.”

Possible Duties: Preside over council meetings (If council establishes an executive committee, the president will also preside over the committee meeting.)
Keep the meeting on-task and maintain order
Maintain impartiality
Maintain communication with facility administration/staff

Vice President/Co-Chairperson—Performs the duties of the president when the president cannot attend a meeting. May also share some duties with the president.

Secretary— A temporary secretary should be appointed at the first introductory meeting, until council members can hold an election.

Possible Duties: Take notes during meetings
Prepare meeting minutes for distribution and posting
Organize council correspondence
Write thank-you notes to guest speakers, etc.

Alternate—Performs the duties of any officer when the officer cannot attend a council meeting.

STRUCTURE BY COMMITTEE

Committees allow council members to creatively share responsibilities. Committees may be appointed permanently or temporarily.

Potential Committees

Committees may be more appropriate for councils with large membership, rather than small councils. Committee meetings occur outside of regular council meetings.

- **Executive/Leadership Committee**—plan and conduct council meetings, secure guest speakers, meet with administrator/staff regularly, maintain meeting minutes and bylaws, etc.
- **Complaint Committee**—council members can bring individual resident concerns to the complaint committee for advice on resolution, or resolution by the committee.
- **Outreach/Communications Committee**—post and advertise council meetings, develop brochures and other resources to recruit new families, make personal phone calls to invite families to council meetings, etc.
- **Welcoming Committee**—focus on meeting family members of all new residents, have facilities contact welcoming committee members to visit with family members of new residents upon admission, greet new attendees during meetings, coordinate birthday celebrations/sympathy efforts, etc.
- **Special Events Committee**—plan and coordinate with the facility to conduct parties, celebrations, family council sponsored resident activities, special meals, etc.

SAMPLE PURPOSE AND BYLAWS

From Minnesota Veterans' Home Family Council*

I. NAME

The name of the organization shall be the Minnesota Veterans' Home Family Council.

II. PURPOSE

The purpose of the Minnesota Veterans' Home Family Council is to:

- 1. Comfort, inform and motivate friends and relatives of nursing home residents.**
- 2. Improve the quality of life, well-being and happiness of all residents of the nursing home.**
- 3. Provide input on nursing home decisions and act on shared concerns and problems.**
- 4. Promote positive attitudes toward aging and the role of the nursing homes in long term care.**

III. MEMBERSHIP AND ATTENDANCE

A friend or relative of a resident may become a member of the Minnesota Veterans' Home Family Council.

Residents of Minnesota Veterans' Home may not attend Minnesota Veterans' Home Family Council meetings, unless invited for special events.

Members of deceased residents are encouraged to continue their active membership.

IV. OFFICERS AND COMMITTEES

Officers of the organization shall be Chairman, Co-Chairman, Secretary and General Alternate.

The Chairman shall preside over all meetings. In the event of his/her absence, the Co-Chairman shall preside. In the event the Chairman and Co-Chairman's absence, the General Alternate shall preside.

The Secretary shall record the minutes of each meeting and maintain the minutes as a permanent record. In the absence of the Secretary, the General Alternate shall fulfill the duties of the Secretary.

The Executive Committee shall consist of Council officers.

Committees may be set up by the officers and may include Activities, Welcoming, Grievance, etc.

V. ELECTIONS

Elections shall be held every year in October.

A Nominating Chairman shall be selected by the Executive Committee, who in turn selects her/his committee to make a selection of candidates to present to the membership for election.

VI. MEETINGS

Meetings of the Minnesota Veterans' Home Family Council shall be held monthly, alternating between the fourth Tuesday of one month and the fourth Sunday of the next month.

Meetings of the Executive Committee shall be held as deemed necessary by the Executive Committee.

Meetings may be changed with a majority vote of the membership attending a meeting, should the need arise due to holidays, etc.

VII. AMENDMENTS

All proposed amendments shall be mailed to all council members prior to a meeting. Amendments may be made to these Bylaws at any regular or special meeting of the Council by a majority vote. Amendments go into effect immediately.

VIII. RULES OF ORDER

Each meeting will follow the agenda prepared by the Executive Committee.

Each person wishing to speak shall raise his/her hand and be recognized by the Chairperson.

* Advocacy Center for Long-Term Care. *Family Councils in Action*. Minnesota, 1994.

SAMPLE AGENDA

Council leadership (chairperson or committee) prepares the agendas. Agendas will help the council meetings stay on task, and together with posted minutes, allow all council members to follow the council's progress.

Pre-meeting activities can include refreshments and mingling. Be sure to start and end on time.

1. Welcoming of new family members

2. Guest speaker/educational presentation/film/news from administrator or department heads/update from resident council president *(Be sure this agenda item does not require the council to limit the time spent on the discussion of, or the planning of strategies to resolve concerns.)*

*Any staff or other non-family member or friend of a resident is
asked to leave for the remainder of the meeting*

3. Reading of last meeting's minutes

4. Old Business

- a. Reports from council committees that have met since last meeting
- b. Report of most recent family council sponsored project/ resident activity/ event
- c. Report on progress of concerns voiced at last meeting
 - Written reply from staff;
 - Results of a meeting with administrator/staff;
 - Other ways concerns were resolved; or
 - What still needs to be done to resolve the concerns

5. New Business

- a. Planning of next family council sponsored event/activity
- b. Concerns/complaints regarding the following areas: *(Though a family council should focus most of its efforts on facility-wide concerns, discussion of individual concerns continues to be important. Families have identified the peer support gained from sharing concerns as a vital function of a family council.)*
 - Nursing
 - Dietary
 - Housekeeping/Laundry/Maintenance
 - Activities
 - Social Services
 - Administration
- c. Suggestions for future meetings (guest speakers, education topics, etc.)

6. Final Announcements

7. Next Meeting Date

SAMPLE ACTIVITY CHECKLIST*

Activity: Speaker on Alzheimer's Disease

Date and Time: April 4, 1993 at 7:00 p.m.

Place: Conference room of the home

Tasks	Deadlines	Workers
Locate and invite speaker	March 1	Willie Lee Robinson
Reserve room with the home and arrange for coffee	March 1	George Jones
Put notice of the meeting in the home's newsletter	March 3	Jane Thomas
Invite the administrator	March 3	Willie Lee Robinson
Make and display posters	March 15	John Smith
Type, copy, and distribute the meeting agenda	March 15	Sandra Washington
Bring cookies to meeting and set up refreshments	April 4	Bill and Nancy Brown
See that chairs, tables, and equipment are available and set up at the meeting	April 4	George Jones
Chair the meeting and introduce speaker	April 4	Sandra Washington
Clean up after the meeting	April 4	George Jones, Bill and Nancy Brown
Write thank-you note to speaker	April 15	Jane Thomas
Coordinate the event	Throughout	Sandra Washington

* Advocacy Center for Long-Term Care. *Family Councils in Action*. Minnesota, 1994.

RECRUITMENT AND PROMOTION

Best practices for recruiting members for the family council

- Staff and administration know the purpose of a family council and support the concept. They actively inform all families of the family council meetings, especially families new to the facility.
- The council has a mission statement that family members know and accept.
- The council offers a variety of opportunities for family involvement in the improvement of quality in residents' lives.
- Opportunities exist for the family council to hear concerns from its members and for the group to offer solutions.
- Meetings include time for socializing.
- A concrete plan is in place to recruit new members.
- The council takes time to formally recognize its achievements and its members' contributions.

Practical advice to inform, publicize, and educate families and residents about the family council.

- Flyers, nametags—encourage all family council members to wear a nametag or handout flyers to families they see while they're visiting the facility.
- Family council bulletin board in the facility with current announcements.
- Post the family council meeting minutes in the facility.
- Personal phone calls to family members of new residents.
- Work with the administrator or admissions department to have family council information and the family council contact's name and phone number included in the admissions packet.
- The administrator and staff should also support the council by verbally informing all new families about the family council upon admission.
- Ask the facility to provide the family council with the names of new family members. *If the home is concerned about confidentiality, it can ask families to sign a waiver when their resident is admitted.*
- Appoint a welcoming committee—persons responsible for contacting family members of new residents.

- Meetings with resident council members. Ask them if their family members would be interested in attending a family council meeting.
- Mailings—ask the facility to include the newsletter with monthly billing information.
- Ask the activity department to include a section about the family council in the facility newsletter.
- The family council can develop its own newsletter.
- Post the names and telephone numbers of two or three family council members who are willing to receive calls at home from other families.
- Hold periodic orientation programs—When a resident first enters a facility, it is a traumatic time for both the resident and the family. The admissions process can be overwhelming and fraught with emotion. The family council can invite family members of all recently admitted residents to discuss their questions, concerns, experiences and feelings to help them cope with the difficulties of entering a facility.

EDUCATIONAL TOPICS FOR FAMILY COUNCIL MEETINGS

- Education about the facility and the duties of each department—One family council planned a series called “Prospectus on Caring.” In order to learn more about the staff. Cooks, laundry and housekeeping staff, Certified Nursing Assistants (CNA), etc. each explained their daily routines and duties.
- Regular review of residents’ rights would provide family members with essential knowledge and empower them to resolve issues by working with nursing home staff. If initial resolution steps are not successful, families could be informed about next steps such as contacting nursing home owners, legislators, etc.
- Many families need to be informed about individual Care Plans for residents. The care plan can be viewed as a contract for care with the facility. A resident’s care plan is the key to quality care that meets individual needs. Families have the right to be informed of and attend the care plan conferences if their loved one wishes.
- Information on disease processes is vital for families. The Alzheimer’s Association and similar groups can be invited to the council meetings to educate families
- Advocacy groups (long-term care ombudsmen, Alzheimer’s Association, etc.) would be available for presentations on various topics.
- Many families may be interested in the Department of Public Health and the survey process. Families need to know their role in the process.
- Pioneer Network practices are innovative models of care that nurture the human spirit while retaining staff in nursing homes. These Pioneer models of care move away from the traditional medical model that focused solely on the treatment of disease and begin to think of caring for the entire person. A family council familiar with the principles of the Pioneer Network could support staff and the administrator in implementing of these practices.
- The Medicare/Medicaid system often raises questions for families. The council can ask facility staff to explain the details of the Medicare-Medicaid system.
- The council can ask staff to share information from conferences they have recently attended such as the Pioneer Workshops, Alzheimer’s Conference, provider association meetings, etc. Families can then work with staff on implementing ideas from those conferences.

RESOLVING PROBLEMS AND CONCERNS

Monthly meetings, written replies, chain of command, corporate, brainstorm for solutions with staff

FIRST TIER STRATEGIES FOR RESOLVING A PROBLEM

1. Allow individuals to share their concerns during family council meetings
2. Distinguish between individual and group concerns. Assess if other family members have the same concern.
3. Have council members decide if it is an issue they would like the council to pursue.
4. Gather information about the nature of problem
 - a. Review federal and state regulations and facility policies related to that problem.
 - b. Have family members make observations and keep a log when they visit.
 - c. Talk to residents about the problem.
 - d. Speak with resources outside of the facility with expertise on the issue.
5. Have council members brainstorm for possible solutions.
6. Develop an action plan for resolving the concern. Establish time frames for taking action on each step.

SECOND TIER STRATEGIES FOR RESOLVING A PROBLEM

1. Present the concerns formally (the concern will come from the whole group, no individual names will be revealed without permission) to the appropriate facility staff—follow the chain of command as appropriate. State the problem in a friendly, but firm manner and present facts, not generalities. Share the council's ideas for possible solutions. Allow staff time to respond and resolve a stated concern. Avoid making unreasonable demands.
 - Establish monthly meetings between council leadership and the administrator; or
 - Develop a system for presenting concerns to the staff in writing, requesting a written response from staff.
2. Put it in writing who will do what by when?
 - a. Record tasks council members and staff have agreed to do in meeting minutes.
 - b. Take notes during meetings and phone conversations with staff.
 - c. Send follow-up letters outlining the agreed upon plan of action with time frames.

MONITOR THE PROGRESS

1. Stick to time-lines.
 - Has everyone done what he or she agreed to do?
2. FOLLOW UP!!
 - Make phone calls
 - Send letters
 - Schedule follow-up meetings

3. Report progress to your members.
 - Recognize steps that have been taken
 - Do not always focus on what has not been accomplished
 - Talk about what still needs to get done in terms of tasks that members need to assume
4. Establish a revised plan of action if the issue has not been resolved.
5. Show appreciation when things go well and are effectively resolved.

THIRD TIER STRATEGIES FOR RESOLVING A PROBLEM

Pursuing issues beyond the facility—if the facility either does not have the authority to resolve the concern, or has refused to take action,

1. Draft a letter and meet with the corporate office (if applicable) regarding the concern.
2. Draft a letter and meet with the governing board (if applicable) regarding the concern.
3. Contact your Regional Long-Term Care Ombudsman to determine what legislative issues the regional ombudsman and office of state ombudsman have as priorities. Provide information to your regional ombudsman about what laws, regulations and policies should be changed to insure care in the facility. Call the Illinois Department on Aging for the number of the regional ombudsman in your area, Senior HelpLine 1-800-252-8966
4. Call Department of Public Health when necessary. In cases of abuse and neglect, all staff in a nursing home are mandated reporters. (DPH Nursing Home Hotline 1-800-252-4343)

STAFF LIAISON*

The family council members decide if they will need the services of a staff person. By federal law, facilities must provide a staff liaison, but the council decides what role the staff member will play.

A staff liaison can be useful when the facility administration and staff approach the family council effort with support, enthusiasm, and an understanding of the need for independence.

A staff liaison that develops a good rapport and friendship with the council can

- provide enthusiasm and motivation,
- provide assistance and advice without violating the council's right to self-determination,
- explain facility policy and procedure,
- provide resources and contacts with outside agencies,
- creatively develop solutions to council concerns,
- inform other staff members of the purpose, benefits, and importance of a family council,
- help coordinate special events sponsored by the family council,
- inform the family council of the latest updates and changes within the facility,
- involve the family council in some facility decision-making,
- help inform families of new residents about the family council upon admission to the facility,
- help the council show appreciation to staff,
- help develop a system for the staff to know the residents and their families better,
- help council leadership gain knowledge on effective leadership strategies (how to run a meeting).

It is inappropriate for the staff liaison to make decisions for or speak on behalf of the council, or select meeting topics/projects/activities. These are the responsibilities of the family council.

A staff liaison may be instrumental in establishing the family council and “getting it off the ground,” but the families must eventually assume leadership and decision-making duties to gain independence. The staff liaison then takes a “back seat” support role in the family council effort, only attending meetings upon invitation. **“Staff-run councils are rarely effective.”**

* Advocacy Center for Long-Term Care. *Family Councils in Action*. Minnesota, 1994.

RETALIATION

The fear of being retaliated against for voicing grievances is a very real fear for residents of nursing homes and their families.

Though retaliation is not exclusive to the long-term care setting, it is understandable that nursing home residents, who rely on staff for help with many daily needs and activities, can feel extremely vulnerable.

Too often families tolerate poor care for fear that if they complain, the staff will "take it out on them" or their loved one. Families also fear that if they complain, the caretakers of their loved one will be fired. Most often families complain about system issues, such as lack of staff, not about a single staff person. In fact, the fear of retaliation is the number one reason cited by families for not expressing their concerns and for not being outspoken advocates for their loved ones. This retaliation can take different forms—subtle and overt. Retaliation can range from staff who suddenly treat a resident differently and are not as warm and friendly as before, to call lights being ignored, and even the recommendation of discharge.

Though the fear of retaliation can spawn an atmosphere of oppression, families must keep in mind that if things are going to change, and if care is going to improve, they must speak up and be a voice for their loved ones. One Michigan resident advocate explains, "I can't guarantee that retaliation won't take place. I can say that if they don't complain, nothing will change. So, while there's the possibility of retaliation, there is also the possibility of change" (NCCNHR 41).

Nursing home resident advocates recommend that the laws be changed to be more forceful in preventing retaliation and offering families recourse when retaliation does occur. Minnesota law is one example of a stronger law in which "any facility that retaliates against any person because of a report of suspected maltreatment is liable to that person for actual damages, punitive damages up to \$10,000, and attorney's fees" (Minnesota Statutes 626.557, Subd. 17). In contrast, Illinois only provides for a \$501 business offense fine.

Being empowered as an advocate starts by being informed about one's rights. All residents have the right to safety and good care that meets their individual needs. They also have the right to complain to anyone inside and outside of the facility and "be free of interference, coercion, discrimination, and reprisal from the facility in exercising his or her rights" (CFR 483.10 (a) (2)). All families have the right to meet as a group in a private place and voice their grievances.

Family councils can be an answer to the fear of retaliation families and residents feel. Family councils offer families anonymity. Council members can take concerns to the facility staff and administrator as a group. No one is singled out and ten voices will always be stronger than one.

COMBATING EXCUSES

WHY DON'T SOME HOMES HAVE FAMILY COUNCILS?*

Why don't some homes have family councils? Below are some of the more common reasons that ombudsmen will hear when talking to administrators:

“In our home families have access to staff at any time, so perhaps they don't feel they need a family council.”

Good communication between staff and families is important, but this statement assumes that family members always speak freely to staff, never fearing retaliation.

Consider these points:

- Sometimes staff is able to “explain away” problems to an individual family member. Explanations are not as easy if many families, talking together, discover they have similar problems.
- Families may be able to solve a problem for their resident. What happens to a resident with the identical problem, but has no relative to act as an advocate?
- Individuals are not encouraged to make recommendations regarding facility policy in the same way that family councils are. The right of families, through their councils, is found in the both federal and state law.

Communication, including bringing up concerns, is not a council's only purpose. Families may need support from each other, information on the long-term care system, or the opportunity to be involved in the facility's activities because it is their resident's home.

“We sent a questionnaire to families two years ago, and not one was interested in a family council.”

Asking by mail if families are interested in a council is like asking people for opinions of food they have never tasted. How can they know? Without explaining what a council is and what it can accomplish, one cannot expect families to respond positively.

“We already have an active auxiliary (volunteer) program.”

A family council is a unique group whose members have special needs and interests. The family council's primary function is not to perform services for the home. The goals of a family council are two-fold: to protect and improve the quality of life in the home and within the long-term care system as a whole, and to give families a voice in decisions that affect them and their residents. The auxiliary/volunteer program and the family council have separate, vital functions, but are not interchangeable.

“Our family council has disbanded. We were getting only two or three members to a meeting twice a year.”

Family councils disband for a reason. Look for the reason and try to solve the problem. Here, the key phrase may be “twice-a-year.” Councils need to meet frequently enough to make plans, carry out projects, maintain continuity, and give members a chance to know one another.

Another reason for declining participation may be that the needs of present family members have changed. Gathering dedicated family members together to look at established goals and to consider other goals may give the council a new direction.

“As the only social worker, I am too busy to concentrate on family council.”

Family councils cannot depend on the efforts of an already overworked staff advisor. Instead of doing the work, staff advisors need to help family members accept responsibility for the work by providing the support and training to make this possible. This practical solution will lead to a more effective, self-determining council.

The social worker should begin by enlisting the support of a few interested family members, assuring them of her continued involvement and support. Gradually, the social worker should pass the actual work of the council to these members, then limit her involvement to advising, which is the appropriate role for staff.

* Advocacy Center for Long-Term Care, 1999

PIONEER PRACTICES

Nursing homes were developed according to the medical model in the 1960's. Built like hospitals with long hallways, central nurses' stations, task-oriented staff routines, and sterile environments, nursing homes were intended to treat the diseases of the frail and elderly.

However, residents of nursing homes need far more than basic medical care. Residents need a place that meets social, religious, emotional, occupational, recreational, and cultural needs. **Nursing home residents need a HOME where they can LIVE.**

Every resident, family member, facility staff and administrator needs to know that **nursing homes can be different!** Nursing home residents, including those with dementia, should have, and can have, individualized care in a homelike environment that resembles the lives they lived before entering the facility.

A group of nursing home professional staff, called The Pioneers, envisioned something far beyond the traditional nursing institutions and identified new ways of operating a nursing home. These nursing home administrators proposed innovative strategies to reconstruct the long-term care system and make "deep system change"--culture change.

Culture change is a transformation of the whole nursing home atmosphere—the physical environment, staff routines, authority structure, and resident care—into an atmosphere that is "life-affirming, satisfying, humane and meaningful. Culture change has been shown to transform demoralized, dispirited staff into productive teams and dispirited, isolated elders into active members of engaged communities" (*Values, Vision, Mission—The Pioneer Network*. The Pioneer Network. 19 Sept. 2001 <www.pioneernetwork.org>).

Culture change begins with a revolutionized mindset. Facility administrators and staff, along with residents and families, must challenge their assumptions that long-term care cannot be changed. They must work together to achieve truly individualized care.

PIONEER PRINCIPLES

- Respond to spirit, as well as mind and body.
- Put person before task.
- All elders are entitled to self-determination.
- Community is the antidote to institutionalization.
- Do unto others as you would have them do unto you.
- Practice self-examination, searching for new creativity and opportunities for doing better.

ELEMENTS OF PIONEER PRACTICES

- **Residents get what they want**-- Staff follow each resident's schedule and preferences related to dining, bathing, sleeping, activities etc.
- Residents and staff are grouped into **small communities** within the larger facility.
- **Permanent staff assignments**-- Staff know residents well and are part of the facility community.
- **Direct care staff** are an integral part of the facility's decision-making team.
- **Homelike environment**-- Animals, plants, gardens, homelike decor, kitchenettes, no central nurses' stations.
- **Intergenerational programs**-- Families and children bring life to a facility and allow residents a chance to give care.
- **Family and Resident Councils**-- Facility staff listen and respond to the concerns of the councils. Councils are independent and staff only attend meetings when invited.
- **Activities**-- Opportunities for spontaneous and scheduled activities all day, every day. Family members, children, animals, and plants create an environment for spontaneous activity and relationship building.

Save for Pioneer blue sheet

Save for 2nd page of pioneer blue sheet

	Individualized Care	Regenerative Community	Resident-Directed Care	Eden Alternative
Resident Quality of Life	Restores choice and autonomy to residents with dementia	Empowers residents to initiate culture change	Restores the power of choice to residents.	Creates a living and diverse environment that sustains life
Defining Characteristics	Staff learns to speak the language of dementia No physical or chemical restraints	Emphasis on wellness instead of illness Interconnected community that incorporates residents of all abilities	Home-like environment—Neighborhoods Incorporates residents with different abilities	Smaller communities within the larger facility Home-like environment that incorporates plants, animals, children, and personal items
Staff	Permanently assigned interdisciplinary staff	Staff is part of interconnected community	Permanently assigned, cross-trained staff teams Staff follow residents' schedules	Interdisciplinary staff teams
Authority Structure			Inverted organization of authority—Decision making power is in the hands of residents and the direct care staff	Inverted organization of authority—Decision making power is in the hands of residents and the direct care staff
Activities	Creative and individualized activities to cope with behavioral symptoms	Daily meeting Comprehensive individualized activity program Spontaneous activities	Opportunity for daily service activities Spontaneous activities	Residents have opportunities to give and receive care De-emphasizes planned activities, emphasizes spontaneous activities

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Values, Vision, Mission—The Pioneer Network. The Pioneer Network. 19 Sept. 2001 <www.pioneernetwork.org>.

APPENDICES

APPENDIX A RESOURCES

Advocacy Center for Long-Term Care: An independent nonprofit consumer protection agency providing education, training, and support to resident and family councils since 1972.

Advocacy Center for Long-Term Care
2626 East 82nd Street, Suite 220
Bloomington, Minnesota 55425
Phone 952-854-7304

Family Council Network: The Family Councils' Project is a joint endeavor between Concerned Friends of Ontario Citizens in Care Facilities and the Self-Help Resource Centre of Greater Toronto. The goal of the 3-year project is to develop and implement a strategic plan to sustain Family Councils in Ontario.

Pamela Bailey
Family Councils' Project Resource Coordinator
c/o Self-Help Resource Centre
40 Orchard View Blvd. Suite 219
Toronto, ON M4R 1B9
Phone 416-487-4355/ 1-888-283-8806 (toll free)
www.familycouncils.net

Family Education and Outreach: Final Report: a project of the National Citizens' Coalition for Nursing Home Reform which was distributed in January 2000.

National Citizens' Coalition for Nursing Home Reform (NCCNHR)
1424 16th Street, N.W. Suite 202
Washington, DC 20036-2211
Phone 202-332-2275 fax 202-332-2949
www.nccnhr.org

Families: Partners in Care: a project of the Illinois Council on Long Term Care, an Illinois association of more than 400 providers, which has an active education outreach to its members on how facilities can better support families. This publication provides materials for facilities to encourage families to be more involved in developing family-centered activities and to support family involvement in the residents' lives.

Families: Partners in Care
Illinois Council on Long Term Care
3550 West Peterson Avenue—Suite 304
Chicago, Illinois 60659
Phone 773-478-6613 fax 773-478-08
www.nursinghome.org

Friends and Relatives of the Institutionalized Aged (FRIA)—a New York group of family councils.

11 John Street, Suite 601

New York, NY 10038-4009
Phone 212-732-5667
<http://fria.org>

National Long Term Care Ombudsman Program Resource Center can be contacted through NCCNHR.

National Citizens' Coalition for Nursing Home Reform (NCCNHR)
1424 16th Street, N.W. Suite 202
Washington, DC 20036-2211
Phone 202-332-2275 fax 202-332-2949
www.nccnhr.org

Tender Loving Care in Long-Term Care in Illinois (TLC in LTC)—an Illinois network of families and friends of nursing home residents whose mission it is to “achieve the quality of life for residents of nursing homes that we would want for ourselves.”

TLC in LTC in Illinois
620 North Walnut
Springfield, Illinois 62702
Phone 217-523-8419 / 1-800-842-8538
www.tlcinltc.org

**APPENDIX B
FAMILY COUNCIL LAWS AND REGULATIONS
OF CALIFORNIA AND MINNESOTA**

SECTION 1418.4 OF THE HEALTH AND SAFETY CODE OF CALIFORNIA

1418.4 (a) No licensed skilled nursing facility or intermediate care facility may prohibit the formation of a family council, and, when requested by a member of the resident's family or the resident's representative, the family council shall be allowed to meet in a common meeting room of the facility at least once a month during mutually agreed upon hours.

(b) Facility policies on family councils shall in no way limit the right of residents, family members, and family council members to meet independently with outside persons, including members of nonprofit or government organizations or with facility personnel during nonworking hours.

(c) "Family council" for the purpose of this section means a meeting of family members, friends, or representatives of two or more residents to confer in private without facility staff.

(d) Family councils shall also be provided adequate space on a prominent bulletin board or other posting area for the display of meeting notices, minutes, newsletters, or other information pertaining to the operation or interest of the family council.

(e) Staff or visitors may attend family council meetings, at the group's invitation.

(f) The facility shall provide a designated staff person who shall be responsible for providing assistance and responding to written requests that result from family council meetings.

(g) The facility shall consider the views and act upon the grievances and recommendations of a family council concerning proposed policy and operational decisions affecting resident care and life in the facility.

(h) The facility shall respond in writing to written requests or concerns of the family council, within 10 working days.

(i) When a family council exists, the facility shall include notice of the family council meetings in at least a quarterly mailing, and shall inform family members or representatives of new residents who are identified on the admissions agreement, during the admissions process, or in the resident's records, of the existence of the family council. The notice shall include the time, place, and date of meetings, and the person to contact regarding involvement in the family council.

(j) No facility shall willfully interfere with the formation, maintenance, or promotion of a family council. For the purposes of this subdivision, willful interference shall include, but not be limited to, discrimination or retaliation in any way against an individual as a result of his or her participation in a family council, or the willful scheduling of facility events in conflict with a previously scheduled family council meeting.

(k) (1) Violation of the provisions of this section shall constitute a violation of the residents' rights.

(2) Violation of the provisions of this section shall constitute a class "B" violation, as defined in Section 1424.

MINNESOTA STATUTES

CHAPTER 144 DEPARTMENT OF HEALTH

144.651 Patients and residents of health care facilities; bill of rights.

Subd. 27. **Advisory councils.** Residents and their families shall have the right to organize, maintain, and participate in resident advisory and family councils. Each facility shall provide assistance and space for meetings. Council meetings shall be afforded privacy, with staff or visitors attending only upon the council's invitation. A staff person shall be designated the responsibility of providing this assistance and responding to written requests which result from council meetings. Resident and family councils shall be encouraged to make recommendations regarding facility policies.

CHAPTER 144A NURSING HOMES AND HOME CARE

144A.10 Inspection; commissioner of health; fines.

Subd. 8b. **Resident advisory council.** Each nursing home or boarding care home shall establish a resident advisory council and a family council, unless fewer than three persons express an interest in participating. If one or both councils do not function, the nursing home or boarding care home shall document its attempts to establish the council or councils at least once each calendar year. This subdivision does not alter the rights of residents and families provided by section [144.651](#), subdivision 27. A nursing home or boarding care home that is issued a notice of noncompliance with a correction order for violation of this subdivision shall be assessed a civil fine of \$100 for each day of noncompliance.