

Family Education & Outreach
Final Report

A PROJECT OF THE
NATIONAL CITIZENS' COALITION
FOR NURSING HOME REFORM

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Introduction

*If we're really going to provide for quality of life for older adults,
we need to provide for quality of life for families --
and not turn over 60 years of a relationship because somebody is in a nursing home.¹*



*We blame the agencies for lack of enforcement,
the nursing homes for greed and incompetence, but leave out the family and friends.
It's time we included them as key actors in the drama of the so-called golden years.²*

Through the years, family voices have helped to steer the national grass-roots movement to enhance the care and environment in nursing homes. By working with and listening to families, advocates have secured new standards that reflect the needs and respect the rights and dignity of residents. Unfortunately, many of these important standards have yet to be fully achieved. As the long-term care system evolves, advocates continue to work for policy improvements and systemic changes to address existing and emerging problems. Meanwhile, they seek more timely solutions that will truly improve the “real-life,” day-to-day experiences of residents, their care givers, their families, and their communities.

That was the ethos that inspired the National Citizens’ Coalition for Nursing Home Reform’s now-seminal and ever relevant study, *A Consumer Perspective on Quality Care: The Residents’ Point of View*. The two-year undertaking, funded by the American Association of Retired Persons, the Robert Wood Johnson Foundation, the Retirement Research Foundation, and the Health Care Financing Administration, compiled interviews with 455 nursing home residents of 105 facilities in 15 cities. Eliciting timeless directives in the continuing quest for compassionate, good-quality long term care, the 1985 study found that residents valued kind treatment from attentive staff. They sought independence and choice -- especially in food and activities. And they coveted basic comforts: pleasant rooms; compatible roommates; and homelike, palatable meal services, including “a good hot cup of coffee in the morning.”

In unveiling the landmark study, NCCNHR hosted a three-day symposium in Clearwater Beach, Fla. Joining the researchers, professionals and policy analysts were 17 nursing home residents, who courageously departed from Denver, Boston, and other distant cities to grapple with an issue at once deeply personal and nationally prominent: improving nursing home quality.

Identifying National Trends

With the same sense of excitement and purpose, 13 years later, NCCNHR embarked on its Family Education & Outreach Project in November 1997. Receiving support from AARP, we

¹Seattle family member

²Texas advocate

sought to document national trends in family involvement in nursing homes. Although we indicate “families,” our project recognizes and encompasses the important involvement of close friends in nursing home residents’ lives.

Specifically, our goals for this preliminary inquiry were to identify:

- venues and materials that advocates, ombudsmen and families successfully use to involve families and raise their awareness
- family characteristics that appear to prompt or discourage family involvement
- major obstacles to family involvement
- creative strategies that have helped to overcome hurdles to family involvement

Information Gathering

In all, we sent 101 informational surveys to the advocacy network. Each long-term care ombudsman in the 50 states, including Puerto Rico and the District of Columbia, received a survey. These 52 state ombudsmen were asked to forward the surveys to regional ombudsmen in their programs who are actively involved with families of long-term care residents. Another 49 surveys were mailed to long-term care citizen advocacy groups, a national network of both fledgling and firmly established grass-roots organizations.

The survey prompted an enthusiastic response, with 106 completed questionnaires returned to NCCNHR by the requested deadline of December 1, 1997, or shortly thereafter. The majority of responses (82, or 77 percent) came from regional ombudsmen and the remaining 24 surveys (or 23 percent) were returned by representatives of citizen advocacy groups. We continued to receive and analyze surveys after the extended deadline. Although we did not record these responses in our tallied results, we carefully reviewed and incorporated the ideas and experiences in our inquiry.

A site visit was made to Minnesota, home of the country’s one-of-a-kind mandatory funding mechanisms for family and resident council education. Our findings also draw on two dozen extended phone interviews with family members and citizen advocates across the country, selected partly for their extensive replies to our survey. In addition, we sought out union and corporate spokespeople. Specifically, we interviewed families and corporate officials from Extendicare Health Facilities. The Milwaukee-based company is among the most innovative and cooperative corporations when it comes to embracing and promoting family councils. Five years ago it launched the National Association of Extendicare Health Facilities Family Councils and has continued to support the growth of independent and effective family involvement.

NCCNHR is extremely grateful to everyone who contributed their valuable time, ideas, experiences and high spirits to this project. Like the findings in NCCNHR’s 1985 quality-of-care study, this preliminary project is “dedicated to the conviction that through partnership,

discussion, and cooperative efforts of residents, providers, the government and the public many... [hopeful] visions can be realized.”

Our current findings are a springboard to a broader project under development that will produce a working guide of “best practices” and approaches for reaching and involving family members in constructive advocacy in their day-to-day encounters with nursing facility staff. With a growing number of families facing the challenge of entering and coping with the long-term care system, we believe that a resource of this kind will provide a vital service to families and advocates in communities nationwide seeking to achieve meaningful gains for long-term care residents and their direct care givers.

Family Councils

*I think I feel somewhat empowered because our family council does make a difference. Whether we make enough of a difference hinges on my own expectations.*³

The 1987 Nursing Home Reform Act guarantees the families of nursing home residents a number of important rights to enhance a loved one's nursing home 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:⁴

- *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.*

Benefits of Family Councils

The benefits of an active, well-run family council are numerous and diverse. Many respondents underscored how councils give families a "united voice" to address issues as a "united effort" -- with greater credibility and assurance. Recalls an advocate and former family member:

³Connecticut family member

⁴42 CFR sec.483.15(c); Public Law 100-203, Social Security Act

When I wrote letters, I was going out on a limb and was all by myself. But in the ensuing months, I became involved with a few families who knew what was going on. I saw that as we banded together through the family council and people made their requests and concerns known, the facility then had to be much more responsive about addressing those problems. (Arkansas)

That cohesive voice also facilitates long-term care ombudsman efforts to resolve problems, as one local ombudsman describes:

It makes our job easier to have a supportive and intact family council who is willing to advocate for themselves and to advocate for all of the residents and not just their own loved one. You can get five different people from a facility calling on the same issue. But if you had a family council you could give support to that one group and it would be so much easier. (Michigan)

Family councils also challenge facilities to perform better. At the same time, they encourage providers to view outspoken family members with renewed respect and credibility, according to other advocates:

Family councils can be a positive [advocacy force] that's going to help the administration recognize a problem before it gets too large. (Wisconsin)

When [family councils] work, they really work well. They can be very effective tools. The ideal combination is when you have an administrator willing to work with them, and committed people who can see beyond their own ego gratification. We had some real problems with a facility, and worked closely with the ombudsman and organized a family council there. The facility made attempts to get rid of it with misinformation. But they got a new administrator who was wonderful, and instead of looking at the council as an adversary, the facility embraced it and they worked together -- on a theft and loss program, and on regularly ambulating residents. That really turned the place around. (California)

Guideposts

Family councils, advocacy groups, and ombudsman programs across the country have found models in the outstanding handbooks and other resources on organizing and sustaining family councils published by the Advocacy Center for Long Term Care in Minnesota.

The Center's manual, *Family Councils in Action*, identifies two main goals for family councils:

- *To protect and improve the quality of life in the home and within the long-term care system as a whole*

- *To give families a voice in decisions that affect them and their residents*

Councils, according to the manual, should define their own, unique purpose or purposes, which may include a number of wide-ranging options:

- *Support for families*
- *Education and information*
- *Action on concerns and complaints*
- *Communication within the home*
- *Services and activities for residents*
- *Legislative Action*

Defining Features

While certain basic and essential characteristics distinguish family councils from family support groups and nursing home auxiliaries, no two family councils are the same. “They’ve been all over the map in my experience,” says one longtime Kansas advocate.

The characteristics and activities of a family council reflect many factors, including the particular issue, or urgency of that issue, at hand. For example, when survey officials in one Southern state reportedly prompted facilities to abruptly stop using physical restraints, it caused fear and confusion among families concerned about their loved ones’ safety. Responding to the controversy, one family council conducted a seminar to help families understand both the facility’s and the survey agency’s roles and responsibilities.

Other factors that set family councils apart include:

- the circumstances that have brought the council together
- the facility’s degree of involvement, either positive or negative, and
- the goals and operating style of the council’s leadership

One state ombudsman stresses that there is no foolproof, cookie-cutter approach to forming an effective council. Instead, the impetus must come from within each particular group’s concerns and vision:

In today's society, with all the opportunities and things to do and spend your time on, including doing good works, people are going to choose to spend their time in a nursing home because it meets some need of theirs: It's important to them for some reason. That's why I rebel against any kind of one model. My belief is that the best practice is: Figure out the issues of the day in that particular nursing home and organize around them. And, let the group define what's important to it. (Minnesota)

An ombudsman offers a case in point from one nursing facility, where families opted for a support group, rather than an advocacy-oriented family council.

We have found that families have a lot of issues with placement and information about what to expect. They have a lot of their own grief issues. So the group is starting out to be a support group for families more than an advocacy group, and that's OK because that's what these families want. They want a support group to [discuss] the guilt they're feeling and how often they see their relatives. That's the purpose of this group at this point in time. I'm hoping they will turn to some advocacy issues in a positive way, and I think they will. But they need to have the ability to deal with some of the other issues. (Illinois)

Advocacy

Taking an advocacy approach does not, however, mean being “confrontational,” stresses one advocate whose group encourages family councils to be “credible and reasonable.” But while discouraging “raising red flags,” her group stresses that forthrightness and persistence are in fact powerful components of any council:

In some ways, the more effective [family councils] are the ones that don't back down on complaints, but also are doing a lot of positive things and maintaining a business manner with management. (New York)

A member of a new, thriving family council echoes the need for a serious, focused approach:

Our attitude is that any business takes a start-up period. We're a little business and we have to run like a little business, and we have to have people who persevere rather than get discouraged. We're making inroads: We have a forum; we have strong representation; our materials are out there and seen. We have a good corps membership, direct communication with the administrators and managers, and there is some improvement in response to individual concerns. But there are a lot of problems that we have not successfully approached. But we persevere. We pay attention to detail. We do not treat the council like a club. We're totally self-determining and self-organized. We instruct our members to be more pro-active. We really have to keep chipping away. (Connecticut)

Challenges

Family councils hold enormous potential for engaging in constructive advocacy and sharing vital information with other families, toward improving the quality of life and care in a facility. Yet advocates around the country point to ample, varied challenges hindering the development of truly authentic and effective family councils.

While many advocates and ombudsmen noted that nursing facilities often express an interest in starting a family council, facility resistance appears widespread. A regional ombudsman remembers the obstacles one group of families faced in trying to form a council:

The facility seemed to do everything to make it difficult. They placed them in a crafts room where they couldn't get more than 10 people inside, or in the dining room where it was so noisy because of the ice machine. They would tell the families that they were sending notices [about family council meetings] in monthly billings and would not. They told them they would let new family members know that there was a family council, and when council members would meet them they said no one ever mentioned it. The council decided it would like to help clean up the outside of the building and wash the windows so residents could see. They decided to get some ash cans for cigarette butts and fill the flower pots. Before they could get there on Saturday, the administrator found out and he had it all done. The administrator also sent his mother-in-law to the meeting because no one from the facility was supposed to be there unless invited. One of the family members recognized her. After taking care of the business part of the meeting they said they would take a break and anyone without family needed to leave. She sat there, and said she didn't really have any [family] but that she used to go to church with some residents. She was told the meeting was really for family members and real close friends of the residents who support them and share in their care. She got very upset that she was asked to leave. (Oklahoma)

When one advocate discovered that staff at one facility insisted on attending the family council meeting, she advised the council to hold its meetings in the conference room of a nearby hotel:

They published an announcement in the newspaper. So many people came out that there was no room to sit down. If you have the meeting outside of the nursing home, not only do families come but people in the area come. So it's more community-oriented, and people come from other nursing homes. That's good because they can compare notes, and they're very verbal when they're out of the nursing home. (Florida)

One family council leader remembers the challenges her group faced at the onset:

There was resentment initially, passive resistance, and blocking of any kind of cooperation on joint projects -- like a pamphlet for newcomers with specific information on our particular nursing home and contact names. The pamphlet would be in both our names, so it would appear we were cooperating and not adversaries. To this day it has not happened. The bottom line is we're fighting with them about our values. They still think we're in their face. (Connecticut)

One ombudsman says she has learned to be wary of facilities that seek to distort the purpose of the family council and turn it into a social gathering:

Some family councils aren't true family councils, but the facility says it has a family council when it's actually a family night. The facility invites the family and they have cookies and punch and they bring a speaker. Then, they ask if there's a problem. They call it a family council. I call it a family night. A family council is one where the family is the force behind what's going on. (Michigan)

Even with its strong state laws mandating support for family council education, Minnesota providers also exhibit passive resistance to empowered family councils, according to one ombudsman:

We have a requirement that facilities must document that they've made some kind of an effort annually to start a family council. The simplest way for an administrator to do that is to have an annual contact with the council education program and give them some names of people to work with, and then they can say: "I did this." And it either happened or it didn't. The other way facilities meet that requirement is to have one or two family nights a year. They'll put on some kind of an educational program and they'll have some social time, and in the course of that they'll say: "By the way, do you want to have a family council? If so, sign up." And you get one or two names. (Minnesota)

One advocate recalls how one nursing home's staunch resistance to its family council sparked new state legislation more than a decade ago:

There was a Santa Clara support group and the facility would not let them meet in the facility. They wouldn't let them post minutes. They were nothing but contrary. As a result, we sponsored legislation saying that when two or more relatives or friends organize a council, the facility has to let them meet, provide a place, etc. It took a while but passed two years before [the 1987 Nursing Home Reform Act.] It took five years to educate families. There were all kinds of attempts over the years to intimidate and subvert and alienate family councils. One of the messages I've tried to get forward when I do trainings for providers is to say that one of the first things I would do as a provider is work with the family councils. (California)

Discouraging “Gripping”

Many advocates and ombudsmen underlined the drawbacks using family councils as “gripe sessions” -- meetings where families come each week to describe their individual problems but never advance discussions to examine core or “systemic” issues or solutions. A former family member and advocate says:

Families tend not to appreciate informative meetings unless they can tell their specific horror stories. If grandma’s diapers are used by another resident, they don’t see the issue as one of legislation, that the nursing home should provide diapers to everybody. They see the issue as: Someone is stealing what I bought. Some people can’t get beyond that single issue. They can’t get to the systems problems. Councils have to get over that; they have to listen to individual problems for a certain length of time. And then it must dawn on them that they’ve been over this before, and they must ask: “What are we going to do about it?” Most of us want results too fast. I used to tell Mom, “Hang in there. I’m going to straighten it out.” (Louisiana)

Concerted efforts to discourage “venting” and steer families toward constructive action have bolstered the strength of one fledgling council:

What’s helpful has been the composite of family council members who have given their intelligence and compassion. Those who have come [with] stronger grievances and wanted to yell didn’t come any longer because we made it clear that we didn’t want that. (Connecticut)

In contrast, some family councils are reluctant to raise any kind of personal or facility-wide problems. According to one advocate, ending the silence entails some creative prodding.

There are [family council] meetings where the families sit there. They won’t communicate. That’s where you really have to use your ingenuity. I found the best and fastest way is by just saying, “I don’t work for the administration. I work for the residents. Who do you work for?” When you can get them to say that, then you can ask, “OK. What are the problems in your resident’s home?” In some ways, you almost have to shame it out of them. But then they talk about what’s going and you have somewhere to go and something to work with. (Minnesota)

Organizing and Recruiting for Family Councils

Experience demonstrates that many family councils form when problems escalate to an intolerable level that spurs families into action. But as advocates contend, intense beginnings can build a strong and enduring council:

It's harder to keep a family council involved and active when things are basically OK. There's a lot more interest and activities from family members in facilities where there are a lot of problems. When things get better, that involvement usually drops off. But human beings have this crisis mentality. We gear up and respond to crises. That's easy to understand. (Kansas)

The worst crisis situations can lead to one of the most effective councils. At one home, one of the worst problems was that the facility treated everybody terribly. They had a group of families get organized and a local politician got involved. One part of the group only wanted to have the administrator fired. Another part of the group wanted the home to start being nice to people. Everybody was furious. The families asked us to come talk and a staff person here said she would not work with any one part of the group and that they would never get anywhere if they were not united. They were told to work it out and come together. After several months, they all got working together and now they're an effective council. (New York)

Yet, says the same advocate, families confronted with “immediate and emotional” problems often, and understandably, find difficulty grasping the value of family councils:

Often it's hard to get people who want a loved one fed or taken to the bathroom to realize they must see the problem in terms of a long-term strategy, and monitor and keep track of the care and have persuasive, straightforward conversations up the line. Families who think the care is so terrible they can't stand it are not the best people to talk to about family councils. But that might not be true if you had a council in place. (New York)

But crisis or not, recruiting families for council participation presents a range of challenges for advocates, given that most families face myriad deterrents, including hectic lifestyles, home and work obligations, and, as one ombudsman notes, emotional burnout:

I think family councils are practically impossible to get going. You're lucky if you get six family members in home that has 100 residents. Frankly, families come and see three or four people and say: “What's the point?” Three-quarters of the people on the family council are children because the spouse is too heartbroken. They're discouraged and stressed and just want to pat the hand of their loved one and feed them. That's all they're capable of doing. They don't have the energy to get into any kind of advocacy issues. They would rather come there three times a day and feed their loved one because of insufficient staffing rather than go to a meeting and fight that issue. (Minnesota)

Profound distress and raging emotions explain why each family council must be approached individually, with a clear sense of its particular needs and goals. Too much structure, say some advocates, can destroy the momentum for family involvement. Says another local ombudsman:

Where families have come together as a result of major complaints and problems the last thing they want to hear is that you have to lay down a model -- a strict process that they're going to follow and that they have to do this, that, and the other thing. (Minnesota)

Once organized, the turnover of families presents another set of challenges that makes sustaining family councils difficult:

The problem with family councils, and it's endemic, is the fact that residents die and families change. And a lot of families say they've had it and want to get away after the resident dies. There's a big turnover, so that's where they wax and wane. You may have a family council that started and was very effective and for couple of years it was dormant. Maybe the social worker runs it and then it becomes activated again. It's usually triggered by a problem or an active family council that gets together and wants to get started again. (California)

Leadership

Ongoing, unaddressed and escalating problems with a loved one's care can prove exhausting, all-consuming and even maddening to a concerned family member. Forming and maintaining an effective council thus requires judicious direction and thoughtful organization. If not, says one California advocate, family councils "can provide a forum for some strange people who come out of the woodwork. So they have to be used carefully and properly." Indeed, like all kinds of collective action and efforts, well-run and steadfast family councils depend on good leadership.

The Advocacy Center's *Family Councils in Action* stresses that leadership can take many different forms, but advocates and ombudsmen agree on several key characteristics and patterns that build strong leadership. Absent that internal leadership, advocates and others say councils risk floundering and losing their independence to the nursing facility staff's direction and control.

While many family councils draw leaders from the ranks of active community members, good leadership cannot be narrowly defined, according to one advocate:

When I think of the human beings who have been family council pioneers, their individual profiles, personalities, backgrounds, and current activities in life are so different that it's not easily identified. In fact, some of the most effective family council leaders have been exceptionally quiet people, almost shy, but people with phenomenal human relations skills who you just want to do something for when they ask because they're so nice, but not in a clawing way, just truly decent people who have a volunteer spirit. I think it would be fair to say that, whether they're terribly sophisticated people or extremely unworldly, they have a spirit of volunteerism. They're people who command respect. (Minnesota)

Another advocate also stresses how effective leadership stems from a variety of skills and approaches:

The ongoing effect of a family council absolutely depends on the leadership. We've tried to identify two such people, someone who can work effectively with the administration and another who is the fire behind getting it going. The two [skills] do not always go together. (California)

Lack of good leadership partly explains the volatile nature of councils, notes one local ombudsman:

Lack of leadership is a serious problem. You can have dynamic leadership but then someone dies and the leadership leaves with them or the nursing home says the leader doesn't have anybody [living in the facility anymore] and therefore should not run the council. So you may not have a family council where one month ago you had an effective council. All of a sudden it's not there, and it's really a different situation. (Wisconsin)

In fact, one advocate says family members whose relatives have passed away should not be persuaded to abandon their leadership role in a family council:

After a resident dies, I often encourage people committed to the idea of a family council to give one more year. If it goes on too long, it's counterproductive. But to encourage people to stay in active leadership positions is a good idea. (New York)

While advocates and ombudsmen generally agreed that family involvement was more likely among individuals age 60 and older, one local ombudsman thought younger people were more oriented toward effective council leadership:

I've seen better organization and input from younger family members, maybe the grandchild rather than the resident's children. I don't know why. It's not necessarily more time or energy, but the culture of not complaining still holds in those who are age 60 with parents in their 80s. (Michigan)

But whatever generation, form, or style good leadership reflects, it must inspire a strong sense of group-wide commitment and participation, stresses one Connecticut family member, explaining how she helped put the pieces in place for the formation of an effective family council:

About three or four of us formed a steering committee. We had a meeting with the regional ombudsman, who was a big resource. Then I decided to take a step back and see what the grassroots would do. I was happy to see there were others who started running with it. As an artist, I like to see things get created. But I don't have to invent the wheel. I had the intuition that if it was going to mean anything, it had to come from the others, not just me. (Connecticut)

Good staff involvement can enhance good leadership, but often the staff person designated as the liaison to the family council is ill-prepared for the role, according to one advocate:

We're going to need more educated staff who can participate and understand their roles. And they have to learn to take criticism that may not be directed at them personally, and learn not to take it personally. Very often the activities person is chosen to organize the family council, and the problem is that person is the least knowledgeable of the dynamics of that kind of group. The social worker seems the obvious choice, and yet most of our nursing homes have social worker designees, rather than [a Master of Social Work degree], so they too can be high school graduates with no training whatsoever. If you get a bonafide social worker, I would think that would work. But it would have to be someone pretty secure who wouldn't get defensive. (Louisiana)

But even effective staff- and family-based leadership alone cannot sustain a family council through its evolution. Creative thinking and flexibility also are key, as one advocate explains:

In one family council, the family members have come through a rough period of dealing with an awful lot of problems and they're tired. A lot of people have stopped coming and it's dwindled down to two people. The president of the resident council comes to the family council meetings and I suggested asking his opinion. He said a couple of years ago the family and resident councils worked together and organized a Spring Fling. He said everyone loved it and that it raised a lot of money. I looked at the family council and said: "You have your challenge." The event gave everybody an opportunity to sit back, relax a little bit, learn more about the residents and find out what's going on from the residents' perspective and do something that will help everybody out. (Minnesota)

Resident and Family Councils: Drawing Lines, Forming Ties

There are no rules on the appropriate level of interaction between family and resident councils. However, most advocates and ombudsmen support open lines of communication and regular collaboration between the two groups so families do not lose sight of residents' perspectives.

Says one advocate whose work focuses on resident councils:

It's counterproductive if resident and family councils develop their own agendas and find themselves working at cross purposes because they're working on different issues that the administrator could then use to cancel each other out. It always makes sense to gather forces to agree on what the priorities are. The residents are on the floors and they know the issues. It's a two-way street. Resident councils can be educating family members about the issues of concern to those members of the group, and vice versa. We need to encourage inviting residents to family council meetings. That's very empowering. Residents find a lot of support in the knowledge that there is an active group of families

who are raising issues and concerns. (New York)

Lack of communication between the two councils has caused situations where families complained about the food, while some members of the resident council thought it was wonderful. In another situation, the family council began doing fund-raisers historically done by the resident council. Avoiding such missteps entails building an “allied relationship,” notes one advocate:

The family council should be able to say [to the resident council]: “We’re on your side too.” Go to the resident council and ask, “What needs to happen for this to be a better place to live than the first day I walked through the door?” Have those residents define those projects, ideas, and things that need to be purchased. The staff are coming from a different point of view. The administrator has his or her eye on people coming in the front door -- the visibility, having a good look, making sure there’s wallpaper in every entryway. But the residents are going to look at the nuts-and-bolts things. And in the exercise of doing that, you have a person from each council getting to know each other so the right and left hand know what each other is doing. (Minnesota)

When a group of oriented, competent residents at one nursing home proposed that they join with families to form an integrated group, one local ombudsman took the idea seriously and helped them to form a Quality Care Council. The format stemmed from the residents’ frustration that there were so few residents able to participate actively and effectively in the council, and the families’ discouragement over the administration’s failure to address their complaints. To date, the result remains unconventional but successful:

It works like a traditional council; there is no distinction between residents and families. They all sit around the table and bring up the issues. Two residents and two family members have taken on the leadership. A volunteer advocate keeps the council on track by handling various logistics. One family member acts like the secretary and submits all the complaints to the administrator on a form they developed. The other family member makes sure new families are invited when she sees them in the halls a week before the meeting, though they have a poster that encourages families to come. One of the residents also makes sure new residents who are competent know about the meetings. (Minnesota)

Area-Wide Councils

The advocacy community appears mixed on the value of another variation on family councils: area-wide councils. Some, like one regional ombudsman, commend them as a tool to draw in people for informational meetings and generate advocacy interest and support through the sharing of stories and ideas:

In one town with seven nursing homes and 34 assisted living facilities, the family councils all get together for meetings twice a year. They put up flyers and invite the entire public. The turnout is usually good. They arrange a special speaker, such as a legislator, attorney, or ombudsman supervisor, and they get the newspaper to do a story. The administrators and directors of nursing usually attend. So if we need to discuss an area of concern, we wait until end of meeting and them to be excused while we complete the meeting. (Oklahoma)

At the same time, area-wide groups or meetings pose logistical, funding and programming challenges. Explains one advocate:

People barely have enough time to do family council efforts at their facility when they are trying to spend enough time with their loved one. So, what seems to be valid is to be as localized as possible with family councils so that we can get at facility-specific issues. At the same time, it's necessary to keep a common thread among all of those councils so that when there are sea changes on the larger system level -- whether it's managed care or wholesale downsizing of nursing homes or massive changes in whether people will be eligible for a medical assistance subsidy for their level of care -- there is a forum through which people can act collectively. (Minnesota)

New Obstacles, Opportunities

The trend in nursing home care toward shorter-term rehabilitation presents its own set of hurdles. Though some say they families of short-term residents can provide an important perspective on a facility, one advocate observes:

Families of short-term residents just want to get out and not get involved. There's no long-term commitment. They're not interested in getting involved and don't think of their family members as residents; they're patients. As the makeup [of the nursing home population] changes, so do the stakes people have and what they're willing to put in a family council. (California)

The increasing emergence of cultural diversity in nursing homes also requires new strategies and approaches for promoting family councils. According to one advocate, family council participation from disparate groups requires building leadership that reflects ethnic and racial differences:

You cannot have participation from a minority [group] in the nursing home unless you pull them into the leadership. But it's hard to do. At one home, one third of the residents is Latino, another Chinese and another Black. That's real tough. Some family council leaders created three groups at one time, but now we're supporting one council that includes members from all three groups. (New York)

Finally, while family councils are not impossible to organize in board and care settings,

they do present even greater organizing and recruitment challenges. Says one advocate, explaining how board and care and adult family homes in his area typically have a larger population of deinstitutionalized people with mental illness:

If family councils are not very developed in many nursing homes, they are certainly not [established] in adult homes and board and care. The stigma of mental illness is very powerful. It fractures families, [adding] to all the other things that can conspire to make people afraid to advocate for a loved one, such as fear of retaliation. (New York)

Nonetheless, family involvement recently emerged at one adult family home after his advocacy group sponsored its first annual adult home resident council conference. A family member happened to read some of the conference materials and became excited about consumer- and resident-advocacy efforts.

Slowly they're beginning a fledgling family council. One of the things that they've already accomplished is getting the dining room repainted. In sitting with the administrator, they presented general concerns about the home's increasing shabbiness. Much to everyone's surprise, the administration was very open and agreed to repaint the dining room. (New York)

Key Points: Family Councils

1. The 1987 Nursing Home Reform Law guarantees families the right to form and hold regular meetings of a family council.
2. Families and advocates say the benefits of family councils are varied, including: giving families a "united voice"; streamlining ombudsman work; and affording families renewed respect and credibility.
3. Each family council is unique, reflecting many factors, including: the circumstances that led to the group's formation; the facility's degree and quality of involvement; and the goals and operating style of the council's leadership.
4. Facility resistance to active, empowered family councils is widespread, according to families and advocates.
5. Families and advocates discourage using family council meetings as "gripe sessions," instead encouraging constructive action and organizing.
6. Effective family councils demand strong, consistent leadership.
7. Regular communication between family and resident councils is crucial.
8. Increasing cultural diversity in nursing facilities among residents, families, and staff presents new challenges for overcoming barriers to building strong, effective family councils.

Case Example: Minnesota's Family Council Education Program

*Certainly, our philosophy is wonderful --
that you've got to have the people who are involved in that nursing home,
the families and the residents, get interested in seeing things change.*⁵

A Minnesota state law unique to the nation affords families and residents the right to be educated and informed about family and resident councils and other important issues enabling consumers to effectively maneuver and seek to improve the long-term care system. Moreover, the landmark 1985 law secures a continuous funding stream to fulfill that mandate. The funding comes from a licensing surcharge on nursing home beds, narrowly earmarked for a “statewide, independent, nonprofit, consumer-sponsored agency” to educate family and resident councils in nursing and board and care homes across the state.

Since the inception of its Resident and Family Advisory Council Education law (the “RFACE” law), Minnesota has awarded the grant to the Advocacy Center for Long Term Care in Bloomington, Minn. One of the country’s first resident-based advocacy groups, the Center is the impetus behind the unparalleled state law, which executive director Iris Freeman owes to a blend of “quirky fate” and good organizational strategy.

The Advocacy Center (formerly the Minnesota Alliance for Health Care Consumers) emerged from a group of 50 nursing home residents from six Twin City facilities who joined together in 1972 to establish resident councils and to improve residents’ quality of life. In 1977 the Center launched its Advocacy Program and within a year completed sufficient casework to identify the importance of addressing the special needs of residents’ families.

The Advocacy Center hired a “family advocate” and formed an auxiliary group, the Friends and Relatives of Nursing Home Residents, whose brief but significant history paved the way for the creation of the Advocacy Center’s statewide family council education services. With the help of VISTA volunteers participating in a NCCNHR federal grant, the Advocacy Center’s council development work thrived. But, the state’s budget crisis and the curtailing of private grants and philanthropic support jeopardized family and resident council development in the early 80’s, sparking a pivotal search for new funding that led to the RFACE law.

“Because our organization began with resident pioneers and because the community organizing part of our mission was so central, we didn’t ever want to be in a position where resident and family organizing would be secondary,” Freeman says.

⁵Meredith Hart, first director of Minnesota’s statewide Resident and Family Council Education Program

Freeman credits simple arithmetic with providing the answer to the Advocacy Center's fiscal predicament. At the time, Minnesota had about 45,000 nursing home beds. Securing \$1 per bed for a designated fund would raise \$45,000 -- roughly enough to enable the Advocacy Center to hire two staff people to focus on resident and family education. Freeman vividly recalls formulating the funding mechanism for the RFACE law at a restaurant she visited while in California to lead a training for ombudsmen. "It was really from that moment, in that particular Indian restaurant, in Oakland, Calif., that it occurred to me that the answer to the dilemma was a dollar a head," she says, adding how it proved "the easiest piece of statutory drafting that I'd ever had the opportunity to do." Freeman explains:

We already had a law that guaranteed that residents have some rights. We had a law that guarantees them some say in their lives, but there really wasn't any connection between that and the tools to do it. And this would give residents and families the tools to do the things that they already had the right to do. So it wasn't a law to create any new rights, new entitlement, or new benefits; it was simply an educational law.

Legislative Obstacles

While the solution eventually proved a win-win situation, it did not transpire without some wrinkles, including opposition from the nursing home industry. For its part, the trade group representing the for-profit sector did not oppose the initiative but rather the loss of Medicaid dollars that the bed surcharge would impose. Advocates, however, won providers' cooperation by successfully proposing that the state make the surcharge, and the licensing fee as a whole, a pass-through in the Medicaid program.

The nonprofit trade association, however, refused to support the provision absent an amendment to evaluate the council education program in two years and sunset the law if the program proved unsuccessful. Advocates agreed, confident that the program would easily prove its merits.

Meanwhile, "pure luck" helped to quell some of the sharp division separating the state's House and Senate during that year's legislative session. The good fortune arose when the Human Services Department unexpectedly issued an across-the-board increase in Medicaid nursing home rates. Because state health officials had not requested an increase in licensing fees, the additional money in the budget designated for licensing -- \$1.73 per bed -- was directed toward the surcharge. That the state would have an opportunity to provide beneficiaries a new, budget-neutral service enabled advocates to convince the House to hold a hearing on the bill.

Still, by the last day of the legislative session, the House had yet to approve the council education provision until receiving an endorsement from a conservative member of the state Board on Aging who viewed the notion of educated resident and family councils as a means to counter the role of regulations. While advocates had never considered that the bill had anti-regulatory aspects, they were nonetheless grateful for its multi-faceted appeal. Says Freeman:

More conservative people saw it as an alternative to regulations but more progressive people saw it as a way of organizing and empowering people. It was authentically a situation which we could call a “win-win.” It wasn’t just a begrudging compromise to get something we wanted by yielding; it was something where getting what they wanted didn’t hurt. And one of those days comes around every 15, 20 years.

‘Unchartered Territory’

When the law passed in 1985, families and residents won the right “to be educated and informed about”:

- *care in the nursing home or board and care home;*
- *resident rights and responsibilities;*
- *resident and family council organization and maintenance;*
- *laws and rules that apply to homes and residents;*
- *human relations; and*
- *resident and family self-help methods to increase quality of care and quality of life in a nursing home or board and care home.*

The law provided the Advocacy Center with the funding necessary to expand its resident and family council-education efforts beyond the Twin Cities’ metro area. Freeman says her agency was embarking on a ground-breaking venture:

Just the notion that any organization should have a program that is exclusively for the purpose of helping residents and families learn how to resolve conflicts productively at their own home was very, very unchartered territory.

Also untried was the opportunity to employ regional educators, who went “on the road,” setting up meetings and organizing area-wide council meetings all across the state. “That,” says Meredith Hart, who directed the Advocacy Center’s council education program for more than 10 years before retiring in 1996, “is what really put us on the map.” She adds:

My job was keeping everybody informed and together. That’s the most wonderful thing that we were able to do -- pass on information by traveling as much as we could to each nursing home. We were sort of like a seed that would come, and we’d talk to people about what was happening in other areas. So they got excited about trying it in their areas. And

it took off from there.

Onward and Upward

Today the program employs professional Consumer Council Educators in five regions of the state. They provide consultations, manuals and other resources, and assistance with starting a council or making an existing one more effective. The program numbers five council educators -- three full-time positions, one half-time position, and one three-quarter time position -- working under the direction of Mary Rehwaldt.

Throughout the state, educators regularly organize area-wide family council meetings that feature special topics, such as a meeting last spring titled, *Starting Over: Getting Families to "Buy" the Family Council Concept*. Each June, the Advocacy Center holds a workshop for family council leaders and their staff advisors or liaisons. Last spring's event was titled, *Go Ahead! Take A Risk to Assure Quality: Good Care is Worth a Dare*. Building on its 1997 initiative of giving classes for resident council advisors, educators will present two classes this spring for family council advisors.

According to Rehwaldt, about half of Minnesota's 450 nursing homes have family councils. She says the program's current goals include enabling councils to operate more independently of the staff liaison and encouraging family councils to seek out council educators as consultants when enthusiasm wanes or the council faces serious care problems or communication barriers with a facility.

Educators regularly follow up with family council projects and routinely send councils informational surveys to learn when the group meets, the name of its advisor, and main concerns. "Then we offer several options, like presentations or videos to custom-build all of the relationships and meet the council's needs at the moment," Rehwaldt says. When paying a visit to a family council, Rehwaldt stresses that educators always seek an invitation from the family council president. If the council's staff advisor asks an educator to attend a meeting, educators remind the advisor that he or she must first obtain the family council's permission. At homes where there is not a council in place, educators meet with potential advisors.

Under the state's health licensing laws, facilities must routinely make a good-faith effort to organize resident and family councils. The 1987 mandate emerged after several Minnesota nursing homes owned by Beverly Enterprises, the country's largest nursing home chain, experienced serious problems and lawmakers sought to establish stronger consumer protections.

That same year, advocates successfully sought to raise the licensing surcharge for family and resident council development to \$2.75. It did not go up again until 1995, when advocates were able to raise the surcharge to \$5. The state's commissioner of health collects the money and deposits it in the state treasury, in an account called the nursing home advisory council fund. The money is appropriated to the state board on aging, which disperses the funds and annually

evaluates the programs and issues a report to the state legislature.

Passage of the law in 1985 drew grassroots interest from advocates in New York, Massachusetts and, more recently, Ohio, Wisconsin and Texas. Still, no state has adopted Minnesota's family and resident council education model. Freeman laments the absence of analogous efforts, saying: "It's good public policy for public money to be there for this service."

At the same time, she admits that the downsizing of the nursing home industry and the growth of unlicensed beds signal a diminished revenue stream for council education -- and the need to examine alternative funding sources. "In terms of the ombudsman program and resident and family council development in Minnesota, we've gone about as far as we can go with public funding," she concedes.

Ombudsman Link

Minnesota state long-term care ombudsman Sharon Zoesch says she's grateful for the support that family council educators provide to ombudsmen, whose typically heavy workloads are dominated by complaint handling.

Our ombudsmen have really appreciated the fact that there is somebody devoting all of their time and attention and energy to getting the councils developed and to providing the educational materials. It's wonderful to find that, when you have a large number of complaints from a single facility where there are clearly systemic issues, that a council is there, or you are able to call in an educator who has the expertise to get a well-informed, concerned group of family members together.

Family council educators meet with ombudsmen quarterly for training on issues and to discuss policies and education. In 1997, council educators and regional ombudsmen jointly planned and facilitated a series of eight statewide long-term care forums delving into financing, staffing, quality and other issues. Some of the forums drew more than 100 attendees, including families, volunteers and elected officials. "We have a long ways to go in terms of building an informed citizenry who will think beyond the nursing home in their town where their relative lives," Zoesch said. "I don't think we've gotten anywhere near the kind of success that is possible or that we're shooting for. But it was a first step."

Describing the link between ombudsmen and council educators, Zoesch says: "The ombudsman is the crisis-intervention piece and the council educator is the long-term quality assurance piece." Current efforts are underway to more clearly identify each group's strengths, recognize their common mission and achieve greater collaboration and communication, adds Zoesch:

We have clearly come to an agreement that neither program has the resources to fulfill all of its mandates and responsibilities and to provide coverage statewide. So we need to do a better job in identifying how we're going to target those resources together.

Recent Resurgence

Council educators recently have identified a renewed interest in family councils. Struggling to name a reason for the trend, they are reluctant to link it with a rise in care problems, owing it more to stepped-up education and outreach. At the same, they credit families with displaying greater initiative and interest in consumer advocacy. Families, says council education director Rehwaldt, “are becoming a little more savvy and obviously understand in a new way why [a family council] pays off.”

A council educator in central Minnesota suggests that some industry trends may be forcing families to pursue the benefits of a family council and other outside resources. For example, many facilities no longer use social workers to guide residents and families through the complex and overwhelming admissions process. Facilities, she said, “are admitting that person and they’re saying ‘bye-bye’ to them, so families are seeking support more often.”

Still, even in a state that boasts the only publicly funded program devoted to building the ranks of informed, organized and empowered residents and families, “the trickiness of getting people together for the common good is even trickier,” Freeman says. That is because Minnesota faces many of the same challenges to supporting and sustaining effective family and resident councils that are common in other areas of the country. These obstacles include:

- the trend toward short-term residents whose families have diminished interest in the facility
- increasingly debilitated residents whose physical and mental impairments challenge the existence of self-governing resident councils
- society’s growing cultural diversity and its impact on collective action.

Thus Freeman does not discount providers’ claims that achieving family involvement is more difficult than ever. “The reply is: ‘It sure is. And that’s why we’re doing more and more outreach and specialized resources,’” she says, adding: “Our hope is that we can say, ‘We know it’s harder, and we know how to do it. So call us on us.’”

Key Points: Minnesota’s Family Council Education Program

1. Minnesota is the only state in the nation that guarantees families and residents the right to be educated and informed about family and resident councils. The 1985 state law mandates a licensing surcharge on nursing home beds that provides the funding, which is earmarked for a “statewide, independent, nonprofit, consumer-sponsored agency.”
2. State-wide council educators from the Advocacy Center for Long Term Care provide consultation, resources and assistance with forming and sustaining councils across Minnesota. About half of the state’s 450 nursing homes have active family councils.
3. Council educators and long-term care ombudsmen in Minnesota say they enjoy a

symbiotic partnership, with council educators' efforts to build strong family councils lending valuable support to ombudsmen's heavy complaint-handling workload.

Information & Outreach: Educating. Encouraging. Raising Expectations.

*If corporations are going to be more responsive,
then families and residents must behave like a consumer who knows what's going on.*⁶

Advocates, families, and ombudsmen agree that consumers commonly lack the information they need to ensure a satisfying nursing home experience for themselves and the people close to them. In even greater absence is information specifically geared toward family involvement in a loved one's nursing home care. Participation in the affairs of a child's school through the local Parent Teacher Association (PTA) is a familiar, routine activity and investment for most parents. Yet many families of long-term care residents do not know about family councils or fail to feel the same sense of civic and familial duty in taking an involved, constructive role in monitoring their own relative's well-being and the delivery of appropriate care and services for each resident in the nursing facility.

That nursing homes, like public schools, depend heavily on public tax dollars should incite more families to become involved and assume a sense of ownership about their community nursing homes. But many families are not adequately informed about the financing and delivery of nursing home care and its reliance on public Medicaid and Medicare dollars. Others may feel intimidated by a nursing home's medical orientation or unprepared to challenge a large, national corporation.

More than half (69 percent) of our survey respondents reported that families fail to get involved in a loved one's care due to "lack of information." Another common reason cited by a significant number of respondents (54 percent) was "lack of knowledge." A recent national poll of health-care executives confirmed these findings. While it found that the health-care system is becoming more consumer-oriented, it reported that "long-term care organizations are the least likely to have innovative patient education efforts."⁷

Yet, many advocates, ombudsmen and families across the country are working hard to shorten the learning curve for families of long-term care residents:

- Nearly all of the respondents to our informational survey (91 percent) reported having conducted community education programs to reach or involve family members in long-term care advocacy.
- More than half (61 percent) reported that they had organized, or helped to organize, a

⁶Local Illinois ombudsman

⁷*Modern Healthcare*, January 26, 1998, p. 32

family council or a citizen advocacy group.

- Significant numbers of recipients also had used newspaper articles (62 percent) and television and radio appearances (49 percent) to involve families and raise their awareness.

Distribution of Materials

Nursing homes and other long-term care facilities emerged as the most widely used venue for distributing information, such as providing brochures and other educational materials and making speeches or conducting workshops. Respondents also made use of senior centers; their own agencies, programs and organizations; hospital discharge staff; assisted living facilities; board and care homes; houses of worship, and local AARP meetings.

But of the survey's 18 possible venues, nursing homes ranked as notably worthwhile sites/organizations for conducting outreach, with 77 percent of respondents rating them "most effective." Nearly half (48 percent) named senior centers as the "most effective" sites for outreach, while 42 percent selected hospital discharge staff as "most effective."

In contrast, advocates appear struggling to find ways to make doctors' offices valuable sites for conducting family outreach. Specifically, 27 percent chose doctor's office as the "least effective" category, followed by: county medical societies (14 percent), libraries (13 percent), and houses of worship (also 13 percent).

Several respondents underscored the merits of more vigorous outreach toward women's groups. Recommends one advocate:

In November 1996, AARP convened a symposium of leaders of national women's groups on "Long Term Care as a Women's Issue." There was great interest among these presidents and directors of leading women's organizations in becoming involved in the issue -- many had direct family experience themselves -- but they cited: 1) competing concerns from other issues 2) lack of resources, and 3) lack of information about the issue. There is a clear need to get women's groups to work with advocates at the local, state and national level. Women care about the issue. We must provide information and organizing assistance to make their voices active. (Washington, D.C.)

Lack of Information

Lack of information, especially about family and resident rights, can worsen a family member's fears about a resident's well-being and heighten the anxiety that typically strikes families confronted with a nursing home experience. Remembers one family member whose initial lack of information caused much anguish:

My sister was in three different nursing homes and on three different occasions I was told we must take her out of the home. It caused a great deal of distress. The first time I

thought they could do that. So, for six months, I feared and trembled that at anytime they could lower the boom and say: "Get out." I couldn't find another facility so the administrator let it ride. Later, I became informed. I was told to leave again, but I knew better. (Arkansas)

For this family member, the more she became involved, the more assured she grew -- and the better she was able to advocate for her sister and other residents. Aligning with other family members, she helped to start a state-wide advocacy group whose meetings continue to include a strong educational component, with invited experts and state officials who share information:

Most of us have learned through our meetings. Next month the subject will be on complaints and how the state handles them. We tape the meetings and get the tape out to members. We get the information we need and we study it. If we avail ourselves of available resources, we will be learning. And that's how I've learned. (Arkansas)

Timing is Key

Just as important as what kind of information families receive is *when* they receive the materials. Typically, a long-term care situation catches a family by surprise and it scrambles for support and guidance. When families do receive information, it is often overwhelming in the context of all that is happening so quickly and all the complex financial and other information they are receiving. Or, the information is neither meaningful nor geared to help families make thoughtful decisions. Explains one state survey official:

The problem starts at admission time. Basically, it's a crunch-time situation. Somebody breaks their hip. They're in the hospital and they've got two days. In some cases the person is discharged tomorrow morning. These folks don't have a clue as to what's available. They know the word "nursing home," so they panic. They don't know anything about assisted living, adult family homes or high-tech home care. When they're in the system and they would like to change things they feel disempowered and don't know how to leverage the system. They know they're dissatisfied but they don't know what to do about it. The feeling is that this is the best they're going to do. (New York)

One local ombudsman says she has devised a solution to assist families who find themselves suddenly drowning in information or too distraught to digest that information during the early stages of a nursing home episode. What she lacks is the resources in her program to carry out her idea, she says, explaining how she has had to prioritize outreach activities to maximize her program's impact on families:

Ideally, we would like to be able to meet with family members after a resident has been at

the facility for 30 days or so. The purpose would be to introduce the ombudsman program, [discuss] care issues, and answer any questions they may have. Due to time constraints, we have not been able to work on this. With the little amount of time we have, we try to organize family councils. But we have decided that we have to educate those who are not yet in nursing homes so when they go in they will be more informed residents and families, and go in knowing they can ask questions and act like consumers. (Illinois)

Asked for suggestions on expanding outreach, one local ombudsman in Arizona replied: “Give us more staff,” describing how 1.5 paid ombudsmen in his program oversee the well-being of residents and their families in 96 nursing homes and more than 800 other long-term care facilities.

Overcoming Families’ Reluctance to Get Involved & Organized

Typically, families are unfamiliar with effective consumer behavior in the nursing home setting; they need an informed advocate to instruct them about their rights and direct them toward the path that leads to effective family involvement, say ombudsmen:

Families need bolstering. They need written information and verbal encouragement from the ombudsman program, which can say: “Listen, you have this right.” It has to be reenforced that the point is not to bring the facility down, but to make the facility better. You don’t necessarily need to hold their hand the whole way, but they need an initial boost, and for someone to say: “This is what you can do, and you have a right to do it.” (Michigan)

Most of the time when families receive information they are empowered and do try to resolve problems. They just need to know their rights and know they have a support system to turn to. (Oklahoma)

Yet, for numerous reasons, most families initially are reluctant to take a more active role in a loved one’s care. As a result, many advocates suggest drawing families’ attention and interest with information that does not cause them concern about how they will be viewed by the facility’s administration. Explains one advocate:

If you’re going to advertise a workshop in a facility, you can’t say “patient rights” or theft and loss because families hesitate to come. They don’t want to create the perception that they’re complainers or agitators. Having non-threatening workshops on such things as estate planning for long term care or how to avoid estate claims brings people in and together. Once you can get them together, the rest is easier. (California)

What is difficult is getting families comfortable with the idea of building a solid, effective family council, according to one local ombudsman, who believes educating and informing families is key to sparking a more advocacy-oriented family council:

Sometimes families just need an outside ear to pump them up and remind them of the regulations and to talk about residents' rights. Sometimes they just need to be armed with information. Families don't understand the power they have. So education to me is the best role that ombudsmen can play in the family council. (Missouri)

To organize family councils, advocates, families and ombudsmen rely heavily on the array of materials by the Advocacy Center for Long Term Care in Minnesota, namely the manual titled, *Family Councils in Action*. Comprehensive and easy to use, the materials have won praise across the nation.

One advocacy group recently created and began sending out a brief description of family councils with all its mailings. A practical handout, the piece outlines in one page what a family council is, what it is not, and the rights of families and the nursing home. The piece was adapted from the large, complicated book the state publishes on the topic. In fact, the group's resourcefulness prompted state officials to revise its unwieldy resource, says one advocate:

The state's information on family councils was so overwhelming. When we did the one-page description, I called the people at the state because they wanted input. I said they could make it simpler, and say everything up front. At our last meeting, we learned that the state now has a final copy of a new family council book and that it is very skinny compared to the other one. (Arkansas)

Once organized, family councils themselves can effectively increase the quality and flow of information in a nursing home. For example, a council in Connecticut persuaded the facility's administrator to send all families in the facility a quarterly informational update on the home that formerly had been sent exclusively to the family council.

Moreover, the need for reliable, understandable information does not end with families. Frequently, facility staff require education about the importance of family involvement, and need ideas and techniques to inform and involve families. Said one advocate:

You have families who are very, very capable to run their own council but have not been convinced, so it takes time and effort to educate both the family and the staff advisor -- and not to mention the administrator and the director of nursing and everyone who's part of the administration. Families need to have independent thought coming out of their council and the advisor encourages it. We have to educate all the advisors, and convince the families that they need to take the reins. (Minnesota)

Consumer Expectations

Many lament that consumers' low expectations about nursing homes fuel the continuance of poor-quality care and services. Complacency around the widespread problem of theft and loss helps to illuminate one of the problems that low expectations perpetuate, says one advocate:

I've been with family groups and everybody is amazed about all the things that have been stolen or lost. But they didn't bother reporting it because the home treats their mother well and the food is good and they're not beating residents. So it's OK to steal?! We used to have a campaign to try to raise expectations and to show how ludicrous it was to pay \$4,000 a month to let staff steal residents' things. (California)

Still, family expectations -- while still cause for concern -- are on the ascent in Minnesota, observes one advocate. The trend could attest to this state's distinct and historic commitment to informing and educating residents and families:

People's expectations have risen in the past 20 years. They're less willing to wait to the outright scandal and much more willing to engage in the day-to-day argumentation about what it takes to get it right. People are more willing to assert a claim and are willing to ask for help. There are still miles to go. But it certainly does feel to me that there is a greater level of expectation that people will have information about their care and information about how to influence decisions that are reached in a plan of care. (Minnesota)

More skeptical, an ombudsman in the same state agrees that, indeed, there are "miles to go" to raise consumers' standards on long term care. The problem, she says, reflects society's attitudes about older people and the rights and needs of the frail, vulnerable elderly:

We still have a current nursing home population of both residents and relatives that has incredibly low expectations about nursing homes and settles far too easily for far too little. I would make that statement despite all of the consumer education that has gone on. Sometimes I think it's just ageism, and that it's never going to be overcome. But I think we tolerate things in nursing homes that no one would tolerate in a child-care center or in schools. And we accept it because these are "old people." (Minnesota)

Media

Powerful media coverage has proven a staple tool throughout the history of the nursing home reform movement. In recent years, a number of newspapers across the country have published hard-hitting series on nursing homes, including the *Detroit Free Press*, the *Quad-City Times* in Iowa, the *Milwaukee Journal Sentinel*, and, most recently, the *Philadelphia Inquirer*. 20/20 and other television news-magazine programs also have probed poor care, neglect and abuse in nursing homes. In some cases, such media coverage has spurred policy makers into action. Also to their credit, editors and reporters increasingly recognize the value of providing readers and viewers with important information about consumer resources and contacts.

But, while stunning news reports can frighten and outrage the public, they often fail to spark meaningful community action and participation. Nevertheless many respondents to our survey underscored the value of good media relations. They noted that news coverage -- which includes the names and phone numbers of support services -- can generate enormous inquiries

from concerned individuals relieved to learn about outside resources. “The telephone and the press are your best friends. Use them,” advises one advocate:

Important articles should always include a name and phone number for readers to call for more information. Many people clip articles and file them for future reference. I had a call recently from a lady who had saved an article from 1983. I received over 200 phone calls and letters due to the 1995 Consumer Reports article. Telephone contact must be available seven days a week [because] people will call but many are reluctant to speak up at meetings. (Florida)

Maintaining good press relations includes working with editors and reporters to find the human-interest angle in stories about involved family members standing up for theirs and residents’ rights, holding nursing home providers accountable in their communities, and improving the lives and environments of residents by supporting consumer-oriented legislation. Says one ombudsman:

It would very helpful to have media involvement in informing families and the public about the existence of family groups -- the types of topics and activities these groups can and do get involved in. The greatest barrier I run into is ignorance. I do not think the general public is aware of these items. (Utah)

Key Points: Information and Outreach

- 1.** Overwhelmingly, family members and advocates say that “lack of information” discourages family involvement.
- 2.** Nursing homes and other long-term care settings are the most widely used venues for distributing informational materials to families.
- 3.** Advocates and family members believe that consumers’ low expectations about nursing homes perpetuate problems with inadequate care and services.
- 4.** Media coverage that includes the names and phone numbers of useful resources and services is key to informing families, advocates and families say.

Building Family Participation and Leadership

They're the "doers" in the community.

They're the folks who were in the PTAs and attending the school board meetings and volunteering for scout activities or the sport leagues. Now, in this end of their lives, they're volunteering and giving up their time to doing good things in long term care.⁸

A crisis or shocking occurrence of neglect or abuse in a nursing home can quickly jump-start organized family involvement. But advocates who want to lay a foundation for consistent, effective engagement know that family participation does not develop overnight. Instead, building families' confidence and commitment to positive changes in the nursing home requires sustained contact and support. Securing ample time and resources to conduct family-outreach activities is just one of many hurdles to overcome. Another is grasping the notion that family involvement has been, and remains, a force that reflects unique individuals with their own personal challenges and comfort levels. Explains one advocate:

There isn't an entity that we can call "family advocacy." When we began in the early 70's to try to bring families together as advocates for residents, we ran into a number of roadblocks. Of the group that was brought together, most wanted to be there for mutual support, to hear one another's stories, to feel that they weren't isolated as family members who were having trouble with their loved one. There was another equally strong half who wanted to burn down the capitol. That was one dichotomy. The other was there were people who very much wanted to be involved but had to come to meetings in the afternoon because they could not be out after dark. And there were those who couldn't come until after the kids were in bed. So it was not only a time-of-day difference; it was in some ways a style difference. (Minnesota)

Trends and Traits of Family Involvement

With mixed success, our survey sought to tease out the characteristics and circumstances common among involved, proactive family members. Not surprisingly, proximity to a relative in a nursing home drew the most responses under the category "most likely to get involved," with 67 percent of respondents selecting it. The next most frequently cited characteristic indicative of family involvement was "retired" (59 percent), followed by "encountered problems in a LTC facility" (58 percent).

Nearly half of the respondents said people "age 60+" were most likely to become involved. And, overall, respondents told us that family participation increases with age. For example, 51 percent said people "under age 40" were the "least likely to get involved," with "unemployed" receiving the next highest number of responses in this category, followed by the characteristic "enjoyed positive nursing home or LTC experience."

⁸Minnesota ombudsman

Challenging popular opinion, a local ombudsman observes that younger families demonstrate greater consumer savvy and thus are inclined to play a more active role:

Younger people know they can do something about problems -- it's the idea that, I know somebody out there that can help me, that this isn't right, and I don't have to stand for it. (Michigan)

Survey questions about family members' educational backgrounds appeared to perplex -- and exasperate -- some respondents. "Education does seem to correlate with involvement but I'm not sure where the cutoff is. Too little education means less likely; but at some point, more education does not mean more likely involvement," an advocate in New York says. "I don't believe educational level has any impact on involvement," a local ombudsman in Missouri writes, criticizing the survey's limited focus. "You don't have a category for religious background, family values, or moral ethical standards. These are more important than any of the factors you list."

Also confounding, according to some respondents, were inquiries about race and ethnicity. Nearly half of the survey respondents selected "white" as the characteristic "most likely" to predict family involvement. But as one respondent in California rightfully noted, the correlation simply reflects the narrow racial makeup of the nursing home population.

According to one advocate, race and ethnicity are less powerful indicators than whether a family member either 1) has adapted to American culture 2) can communicate and identify with the person doing the outreach and 3) has learned about advocacy services or resources through his or her own cultural community:

Whites, African Americans and Hispanics and other minorities are the least likely to get involved if there is a language barrier; and they are the most likely to get involved if there is substantial presence in the organization of the same group. Ethnic minorities are most responsive if the outreach is in their own language and by a person of the same group, whether or not language is a barrier. Good networking within the language/cultural community matters too. Minorities are more likely to respond if the church or another respected service provider confirms that we can help or that our staff is personally known to the reference. (New York)

One respondent in Washington, D.C., noted that people working in the field of long-term care are most likely to get involved in advocacy efforts. That minorities are under represented in the aging field thus raises additional obstacles. "Often," points out a local ombudsman in Alabama, "this translates into many minorities not having the knowledge base or required information to access services relative to their well-being."

Barriers

Not surprisingly, key among the barriers to family involvement is “lack of time,” with families juggling multiple responsibilities at work and at home. Says one advocate in Washington state: “Most family members feel they do what they can for their resident. They have very little extra time or interest for others.” And -- though an ombudsman in Indiana reported that people who are “handicapped” are most likely to get involved -- many family members themselves have a physical illness or a disability that may hinder their ability to become actively involved.

Emotional fatigue similarly discourages family involvement, according to the survey. Frequently, says a local ombudsman in Oklahoma, “Families are under so much stress that they can’t stand any further involvement.” Some are “torn by other family responsibilities,” explains an advocate in Washington, D.C., noting how a once-active family member’s involvement lapsed when her husband developed cancer: “She was not able to be as strong an advocate for her mother and other residents when she was caring for her husband full-time.”

Another local ombudsman paints this stark scenario:

Most families have a resident who is incompetent, and it’s not like they go to the facility that often. It’s an unpleasant thing to go there. Mom doesn’t know who they are, or that they’ve been there. It’s a relief when Mom dies and the family can be done with the unpleasant experience. It’s a terrible experience to endure and families want to stay away as much as possible. When the resident dies, they thank God it’s over. (Minnesota)

An advocate in Illinois named “pervasive apathy and denial” as a widespread deterrent. But others countered that such apathy reflects lack of support and an all-consuming negative focus. One local ombudsman says families’ apathy stems from receiving scant attention from facilities’ staff and administrators. Feeling hopeless, families think: “What’s the use?” she says, explaining:

The family councils that aren’t working are the ones with members who are so totally worn out. They can’t burn out because they can’t let Momma down. So they come to the family council meetings and have coffee and a cookie. They’re worn to a frazzle and they just want to be talked to. (Texas)

Indeed, for many families, what appears to be apathy is in fact resignation, says another local ombudsman:

It’s almost like families have reached the end of their strength. They feel there’s only so much more they can do. Therefore, they have to [place a loved one somewhere], and they project their [own] lack of time and energy onto the institutions and accept it. (Minnesota)

Indeed, just like residents, “family members have to be whole, healed and nurtured and

loved,” echoes one family member, explaining:

The family member feels cheated when, despite their best wishes, they have to place a resident in a nursing home with dread and reluctance. Then when they see how bad things are they become full of rage and sorrow because the system failed them. Families have to begin to have hope in their own life. They have to be healed; then he or she can be an invaluable resource. Families and family councils are going to be apathetic and burned out if everything they focus on is problem-related. But if they get involved in a project that is uplifting -- facilitating an art program, leading a chorus on the floor, starting a garden club -- families can raise questions and be recognized as a life force in the facility. Once you're recognized as a life force, the facility can hear your concerns. In that context, you can still raise questions and say the same thing to staff in a non-attacking way. But if all you're doing is complaining, they will tune you off and the family gets burned out. (New York)

Leadership

Effective leadership also ranked high among respondents, who cited it as a crucial component to effective, organized involvement among families. Too often, says an advocate in Washington state, families lack experience “confronting authority” and “feel unnecessarily intimidated by medical situations and devalue their own experiences and knowledge of what is ‘good care.’” Good leadership is key to overcoming the “you can’t fight city hall mentality,” says a local ombudsman in Wisconsin, stressing the need for offering training to families and circulating family-advocacy success stories.

Many said it is often easy to pick out the natural leader in a group. An advocate in Arkansas describes one such force: “He is a gentleman, and he has a gift for being very open about the problems, but at the same time diplomatic. He is friendly to people in authority, but he does not back down. He’s very reasonable in what he insists they do.” Still, many family members do need coaching and bolstering. Says one advocate:

People are afraid to become leaders. And I don’t blame them. Once you become a leader all sorts of things happen, like taking pot shots. When you make a fuss about something you become known as a troublemaker and that’s hard to take. (Minnesota)

Another advocate stresses that leaders among family members are emboldened, not born:

Leaders are often lacking, and you cannot make a leader just appear. Some family members have never been politically active or involved with an organization working to produce change. You need to show examples of how to produce change. Citizens should not be afraid of that, but sometimes they are. (Washington state)

Beyond Family Involvement

Advocates say they strive to instill the idea that speaking up for one’s own family member and

trying to resolve individual problems can have a collective and resounding impact in a nursing home. Says one advocate:

We encourage families to be involved. We say you may feel as though this is not something you want to do, but it's something you need to do. We say it helps everyone for families to be involved. (Kansas)

One advocate says families tend to focus on personal crises while residents are in a facility and later turn their attention to broader advocacy issues once a loved one has passed away:

Family members of current LTC residents focus on specific problems such as the theft of grandma's slippers... After the death of the relative, families are able to work on systems problems. (Louisiana)

But getting people to take an interest if they have never personally endured a family nursing home experience remains a major -- and unique -- challenge for the advocacy movement, notes one ombudsman:

Whether it's a political official, or a community leader, once they have a relative in a nursing home, people "get it." They understand; they know the issue. But until that point in time, you have to get over that barrier of denial. Everybody will be compassionate and get involved in a disaster, like the floods that occurred here or in a famine in Africa or China. You just have to flash some images and it touches everybody. But you just don't get that same kind of response to nursing homes. (Minnesota)

Key Points: Family Participation

- 1.** Characteristics associated with family participation include: living in close proximity to a nursing home resident; being over age 60 or retired; and having encountered problems in a nursing home.
- 2.** Emotional stress and physical illness and disability hinder family participation, according to advocates and participants.
- 3.** What often appears to be apathy on the part of families is, in fact, emotional burnout, resignation, and a response to lack of crucial support and information, according to advocates and families.
- 4.** Effective leadership is key to inciting family participation, say advocates and families, stressing that people with leadership skills also need encouragement and guidance.

Confronting Fear of Retaliation: How Families Cope with Industry Resistance

There are things they can do to make it uncomfortable for you. I helped with my sister's care a lot, and when the home couldn't give her a whirlpool I did the whirlpool. After I complained about something one day, they told me I could no longer go in the whirlpool room. So they know how to get you where it hurts.⁹

Concerns about families' and residents' fear of retaliation came to the fore in 1996 when the Health Care Financing Administration hosted a national series of "Listening Sessions" probing the new federal enforcement system. Although the issue of retaliation was familiar to advocates, the forums underscored how this sweeping phenomenon is detrimental to establishing a consumer voice in the nursing home system.

More than three-quarters of the respondents to our survey (77 percent) named "fear of retaliation" as a deterrent to family involvement. Says one local ombudsman in Illinois: "I only checked [fear of retaliation] because this is what stops families and residents -- everything else is secondary."

While two respondents say they think families "use" fear of retaliation as an excuse to avoid involvement, the vast majority of participants view it as a truly serious, widespread problem. Fear of retaliation is among the most common excuses that family members give for not becoming involved, respondents report. Families, says a local ombudsman in Missouri, "fear rocking the boat. They believe staff will take it out on their loved one, and they also believe nothing will be accomplished." An advocate in Minnesota says families who fear neglect and abuse are the most likely to get involved because they also fear retaliation and want to join a group.

Group action, however, carries its own consequences, as one ombudsman explains:

In any situation where we've had a group that's come together to solve major, systemic problems, one of the facility's responses out of sheer defensiveness is the "divide and conquer" approach -- which is to get only those few who are the outspoken leaders labeled as the complainers. All the rest are the silent participants. They are there giving moral support and affirmation and have filed their own individual complaints with the ombudsman program but won't speak up in an open meeting, and so they are pitted against the others. It gives the administration that edge, even though the silent participants have filed complaints and are very unhappy. (Minnesota)

⁹Arkansas advocate

Subtle and Blatant

Retaliation manifests in various forms. Whether families fear retaliation that is either real or imagined is ultimately insignificant. In either case, families' fears greatly determine whether, and how, they become involved in trying to improve a loved one's care. A local ombudsman describes how one family member's fears prevent him from taking a stronger stand:

He spends time with his wife and tries to deal with the care problems himself. The facility doesn't take good care of her and yet he doesn't want to upset anything or get anybody in trouble. When families say that, I think it means they're afraid of retaliation and think that maybe their loved one's medication won't be brought on time, or a resident won't get enough food or won't get a bath. (Missouri)

Often retaliation emerges in subtle ways but carries a devastating effect, according to one ombudsman:

If an aide knows a resident has complained the care does suffer, even if it's not an overt response. It could be ignoring the resident -- not saying good morning, for example. And when the aide is the only person you see during an eight-hour shift that's pretty retaliatory. (Michigan)

One family member says her family council is working to help families move beyond their fear of retaliation, even though she has experienced retaliation firsthand:

We're doing what we can, but fear of retaliation is subliminal. No one admits it, but when you have the administrator and management saying that some families won't speak up because of fear of retaliation, it gives me the impression that maybe it does exist. I have had [family council] signs taken down and family members' things disappear. I hand-made personal archival calendars with a series of 12 antique photos. One hung on my aunt's wall and one hung on my mother's wall. They loved them but one day they were gone from the walls. These are perverse acts and it happens a lot. (Connecticut)

Retaliation by Discharge

Federal nursing home standards narrowly limit the circumstances under which facilities can discharge residents against their will. But one local ombudsman says facilities are abusing the law to evict residents whose families have spoken out on their behalf:

The guidelines say a nursing home can only discharge a resident when they can't meet the medical needs of a patient. And what I see nursing homes doing more and more of is using that provision when they've got a complaining family. I'm fighting those right now, but to me that's retaliation. (Alabama)

An advocate echoes how inappropriate discharge has emerged as a common form of retaliation:

How retaliation occurs depends on the situation. It's usually the administration retaliating, as when a person is transferred to acute care and the administration refuses to let the resident back in the facility instead of holding the bed like they're supposed to. I know cases where the administrator said he didn't care how much the fine was. (California)

Subtle, Blatant and Seriously Troubling

Often, retaliation manifests in overt harassment or subtle abuse. Explain two ombudsmen:

We have also seen the blatant situation where a family council president was shadowed and staff trailed him whenever he was in the facility. Staff were instructed: "Don't speak to him without a witness." I think it has been subtle, in terms of impact on the individual resident, and in some cases it's been very blatant and open and hostile toward the family members. (Minnesota)

A woman moved her father out of a home, and in the new home staff noticed him shying away from the staff when he knocked over his drink. When staff came to clean it up, he said, "Don't hit me. I'm sorry; I won't do it again." The woman wants to call in a complaint but is worried about her father's former roommate and afraid of the consequences. (Kansas)

No matter what form it takes, retaliation clearly raises the stakes for families inclined to speak out. It presents families and advocates with hard decisions, knowing that loved ones may bear the brunt of well-meaning actions:

Some family members are so frightened that my advice to them is, "No. You can't run the risk. Your advocacy may have to come later." I hate to do that. (South Carolina)

When my mother was a resident in a nursing home and she was very vulnerable because of a stroke, I said, "You make up your mind. You can sit here like a mouse, or I can make waves and you may suffer for it." She chose that I make waves. (Louisiana)

Strategies

Many advocates are struggling to find ways to help families avoid retaliation and ease their fears about getting involved, speaking up, and trying to make a difference for their residents and others in the facility. One advocate says avoiding retaliation requires a careful balancing act:

In our work we're trying to teach people how to rattle cages in a way that's respectful because if you take the low road you're asking for it. You must find anything and everything you can to say what's good in a facility. That's your biggest insurance package against retaliation because you're not seen as the bully and the bluff even though you have 100 pieces of documentation. It's really just a balancing act and it's all packaging. That helps disarm that feeling of vindictiveness. People can take bad news, and if it's packaged in the right way staff will still come out saying: "These people want to work with me and make it better." (Minnesota)

Strong leadership among families is another way to help families overcome fears of retaliation. Says a local ombudsman:

In one family council the people who became the most involved were community leaders who had family members in the nursing homes. Had they not been community leaders -- in terms of their education, their rapport with the community in general and their own feeling of responsibility for what was going on -- I don't know that they would have been as active as they were. And had they not been spearheading and guiding, I don't know if a lot of the other people would have come on board because of their fear of retaliation. (Minnesota)

Another way to bolster families' resilience is to acknowledge their fears, emphasize their victories, and stress the adage that there is strength in numbers. One advocate offers this advice for working with residents and families alike:

[Allaying fear of retaliation] occurs over the long haul, working with a group of residents over a period of time and showing them that when they did indeed complain as group or as an individual they succeeded. We build on that. I'm continually telling people that indeed they are more likely to get better care if they complain and that if they work together with other residents they're going to be more protected. It's important that, if someone is afraid, whether the fear is real or not, you have to respect that absolutely. (New York)

Along with support and encouragement, advocates say honesty is crucial when it comes to addressing families' fears of retaliation. One local ombudsman explains:

I can't guarantee that retaliation won't take place. I can say that if they don't complain I know nothing will change. So, while there's the possibility of retaliation, there is also the possibility of change. I don't want to give them roses and candy, and say nothing bad will happen because I can't guarantee that, and no one can. (Michigan)

Key Points: Fear of Retaliation

1. Fear of retaliation is believed to be seriously widespread among families.
2. Retaliation manifests both in subtle and blatant ways, according to advocates and families, who say that fear of retaliation -- whether real or imagined -- significantly discourages family involvement.
3. To ease families' anxieties, advocates and families recommend validating fears, while reminding families that family councils and other collective efforts can provide valuable reassurance and important protection against retaliation.

Family Connections: Creating A Community with Staff and Management

*Once families know that the staff is on their side,
people will do their damndest to get their families into that nursing home.¹⁰*



*In a normal home, you've got a bunch of people -- parents, kids, and extended family who care
for each other. That's our idea of a home: a group of people living together.*

A nursing home is a group of people living together, but the residents are not the owners.

There's no ownership in that home. In the worst places, residents are called "guests."

The people who provide the care are visitors; they live someplace else.

And the big shot with the suit running the show might answer to a guy living in another state.¹¹

To the family member who feels alone, uncertain and powerless, an authentic, well-run family council provides many benefits. Not the least of them is meaningful connections with other families contending with similar dilemmas, despair and frustrations related to a loved one's long-term care needs. Often, the affinity that develops between families becomes the foundation that fuels and sustains organized efforts to bring about needed changes in the nursing home. Yet the nursing home community offers other valuable sources of collective action and a common vision beyond family councils.

Front Lines, Common Grounds

Certified nursing assistants (CNAs), the so-called "front-line" workers in nursing homes, provide 90 percent of the direct caregiving and emotional support to nursing home residents. Given the link between good working conditions and good quality-care, CNAs and families are obvious partners. Indeed, CNAs sometimes form strong ties with family members. However, as one labor representative explained, these bonds can be rare and tenuous due to widespread short staffing and low wages. These and other conditions leave CNAs caught in the middle between corporate directives and families' demands. As nursing assistants struggle to carry out their duties under near impossible circumstances, supervisors are instructing workers "to be more patient" with families who raise concerns about inadequate care and services.

The high rate of turnover resulting from understaffing and low wages further undermines the potential for positive connections between families and nursing assistants. Says one union organizer: "A tricky problem is turnover. A family member is a family member until the loved one dies. With workers, you don't have a stable group." In addition, many families do not realize that CNAs make minimum wage or lack health insurance. Struggling with equally stressful and frustrating situations, families and nursing assistants are likely to miss their common ground,

¹⁰N.Y. family member

¹¹N.Y. advocate

says this union organizer:

We need to get more of a dialogue going between workers and advocates and family members. There are workers who understand families as allies, and there are families who understand workers as allies. But there are families who feel that the workers don't work, and there are workers who think that families just complain too much.

Solidarity

Labor unions have begun reaching out to families through organizing, contract and legislative campaigns. Two years ago the United Food and Commercial Workers Union sought the support of families in Alabama during union efforts to secure a contract provision that would create “patient-care committees.” At stake was the right of CNAs to meet regularly with management and address and make recommendations about resident care. While the committees do not involve families directly, “the workers communicate with the family members and encourage them to see the union as a place to bring problems,” says one labor representative.

During another recent labor campaign, workers and families assembled in front of a Houston nursing home and jointly petitioned for improved care. Company managers wrote to families, discouraging them from aligning with the union. The union also distributed a survey to workers, seeking their views on quality care and adequate staffing. The company claimed that the survey violated patient confidentiality rights and sought an injunction. But a district court judge sided with the workers, citing their First Amendment rights and federal labor standards that allow workers to discuss issues relevant to working conditions.

Fear of retaliation, which emerged prevalent in our inquiry, also appears to hinder family and worker alliances. Says one union representative:

My first big shocker was fear of retaliation. Everybody knew about it. I was used to hearing about it from workers who know they could get fired if they talk to a union organizer. But it was amazingly universal among families. Rare is the family member who hasn't expected it. A lot of families fear that there has been either real or perceived retaliation, meaning they often have to increase their vigilance. It's indicative of how much families realize that the best interests of family members may not be the goal of the facility. (Washington, D.C.)

The Service Employees International Union helped to dissipate some fear of retaliation when it aired week-long radio announcements in several media markets publicizing a free hotline for families and advocates. The announcements, which targeted two major nursing home chains, prompted hundreds of calls. Callers who agreed to give their names and addresses also received a newsletter. One union representative said the hotline, which is currently dormant, offered a necessary, confidential forum for families to vent their frustration, voice their perspective and receive information on area resources and specific issues, such as prescription drug costs:

One of the things that made the hotline so successful is that families could be anonymous. As their comfort level grew, they could become more public and take the first step toward getting active. (Washington, D.C.)

Clearly, the notion of aligning with organized labor can heighten families' fears of retaliation. Thus, educating families about CNAs' personal plight and how their working conditions directly affect resident care is key. Says one labor representative:

Families may not like unions, but if the workers are out front and involved in the campaign they may not fear the union. I suspect there are family members who think unions should have no place, so the people we're talking to are a relatively self-selected group. (Washington, D.C.)

Yet unions, and their resources and organizing skills, also can provide needed leadership to concerned but reluctant families. A case in point occurred at a facility in Pittsburgh, Penn., where administrators barred two women from visiting their loved ones, claiming that the CNAs said they were "in the way." In fact, 87 CNAs signed a petition stating that they happily welcomed having the families in the facility. Says one union representative:

All of the family members knew about the situation but they didn't band together until the union got involved and helped to motivate, encourage and organize them. (Washington, D.C.)

Corporate Partners

According to a recent industry trade report, nursing facilities committed to "continually improving quality care" increasingly are reaching out to communicate with families. A fax poll sent to affiliates of the American Health Care Association and the American Association of Homes and Services for the Aging examined how facilities solicit feedback from families.¹² The top three responses were:

- Family councils (85 percent),
- Interpersonal discussions (78 percent), and
- Newsletters/mailings (72 percent)

The poll reveals hopeful information about nursing homes and their views toward family councils, although our inquiry uncovered many examples of facilities seeking to discourage or distort family councils and their efforts to resolve problems and improve the environment.

Yet one corporate official at Beverly Enterprises, the country's largest nursing home chain, says the company is making a concerted effort to view families as "partners" and members of the care team, rather than entities "to deal with." She also notes how Beverly Enterprises is

¹²*McKnight's Long Term Care News*, February 1998, p. 14

striving to be more proactive about addressing grievances, in part by promoting family councils and encouraging families to “tell us up front” about problems with a relative’s care and services. “One should hear the train before it runs over you,” she says.

Extendicare Health Services¹³

Among the country’s major nursing home companies, Extendicare (formerly Unicare) Health Services is notable for its willingness to support families who are dealing with problems in a facility. In 1993, the company established the National Association of Extendicare Family Councils with a goal to establish a family council in each of its facilities. To date, more than one-third of the company’s some 230 facilities in 16 states have active family councils.

The Association of Extendicare Family Councils’ board of directors includes: eight family representatives reflecting the company’s regional diversity; one facility administrator serving as the board secretary; and two company officials, Extendicare executive director Ronald Retzke and Al Malz, the company’s executive director of ethical standards. Regional directors nominate board members who are active members of family councils and demonstrate enthusiasm, a willingness to work in “partnership” with facilities, and the ability to travel to Milwaukee for the board’s annual meeting. The board acts as an advisory body to Extendicare family councils and the corporate office. Stressing that the board is designed to operate with maximum autonomy, an Extendicare spokesperson notes that board members conduct two conference calls a year absent the participation of company officials.

In its efforts to build a national network of family councils, the Association issues its own resource packet on starting a family council, which draws from the materials produced by the Minnesota consumer group, the Advocacy Center for Long-Term Care. To recognize and support staff, the Association also sponsors the “Red T” thank-you program. Family council members sign and prominently post cards emblazoned with large red T’s that include the name of the staff member and why he or she is being honored.

The Association also publishes a newsletter three times a year that covers current nursing home policy and advocacy issues and includes activity reports from family council members. Retzke and several family representatives attended NCCNHR’s 1997 Annual Meeting, and a recent issue of the newsletter reported on highlights of last fall’s event, including a plenary on the risk of malnutrition in nursing homes and a workshop on the dangers of bedrails. Extendicare circulates the newsletter to regional directors, facility administrators, and some 400 members of Extendicare family councils. Additional copies are sent to facilities for further distribution to family members.

‘Not rocket science’

¹³**Based on telephone interviews with the following board members of the National Association of Extendicare Family Councils: Carl Bohn, Donald Wright, Eleanor Staves, and Al Malz.**

Traditionally, nursing homes have tended to keep families at arms' length, according to Extencicare's Al Malz, describing the company's ongoing efforts to change that mindset and encourage family involvement. The company's impetus for promoting family councils is plain, Malz says:

Mostly, it had to do with the desire to make it clearly known that the home office supports the concept of family involvement, and that family councils are an excellent way of doing it. It's not rocket science to figure out that a chain of facilities should support family councils.

A brochure from the National Association of Extencicare Family Councils offers an extended, wide-ranging list of options for family councils that encourages various activities, including being "involved in volunteer programming, arranging for speakers, family support groups, staff recognition, entertainment committee, etc."

However, Extencicare appears committed to upholding the councils' core purpose: advocacy. Its booklet, *Family Questions: The First 30 Days*, published with input from residents, family members, family councils and staff, offers a true-to-form description of a family council and its goals:

A family council in a nursing center is, in effect, a consumer advocate group, comprised of relatives and friends of the center's residents. A typical council meets monthly at the center, is run by the relatives and friends of the residents, and focuses its energies on several established goals and objectives. Usually a staff member of the nursing center serves in an advisory capacity to the council, but is not actually a member of the council. A family council has two main goals: to protect and improve the quality of life in the center 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 mission statement of the National Association of Extencicare Family Councils outlines the following important goals for the Association:

- *To promote the development of the self-governing and independent Family councils in Extencicare Health Facilities.*
- *To provide a forum among the Family councils for the exchange and dissemination of ideas.*
- *To assist the Family councils in the development of support programs for new and prospective families of nursing home patients.*
- *To promote the development of volunteer programs and involvement of the community.*

- *To disseminate to families information on long-term care issues.*
- *To coordinate the advocacy activities of family members on behalf of the elderly.*
- *To provide a forum for exchanging ideas on improving the quality of life of nursing facility residents and consumer satisfaction in general.*

A Cooperative, Energetic Influence

Active family council members affirm the company's integrity and its commitment to authentic family councils. Explains one family member:

When we first started and [Extendicare] was going to try and back up the family council, my initial impression was: Uh-oh. It's going to be dictatorial, and they're going to tell us, as family council members, what's what. I would say that has absolutely not been the case. They have been very cooperative and allowed us to express ourselves and not put any of their opinions in a forceful way to the families. They have been energetic in trying to develop that open attitude and provide information and help. (Minnesota)

Extendicare's philosophy has effectively enhanced relations between the family council and the staff and administrators, he says, adding: "We have a good relationship and they have accepted the family council. We have tried to make it clear that this is not a 'jump-down-your-neck' kind of thing. This is: 'How can we do it better together?'"

Echoes another family member:

Since Extendicare encourages the concept of family councils, we have found that the administration is listening and also taking an active part in the betterment of the facility. Literally, we have not had a problem as far as working with and through the administration. We just point out that it's for the betterment of the employees and the residents. I think Extendicare has been extremely positive about family councils. It is those other institutions that may not have the corporate backing that may need some work. (Wisconsin)

But corporate cooperation is not a cure-all for the typical struggles of the family council, including lukewarm attendance. Members of family councils in Extendicare facilities, however, say they are more concerned about maintaining continuity and providing a resource that people can seek out when they do have a problem.

Fear of retaliation is another common hurdle that Extendicare's family councils have not evaded. The fear is real, says one family member, "no matter how much you tell them the [family council] is backing them and that we're right there."

Extendicare’s support of family councils has not, however, denied each group its own distinct focus, spirit and challenges. Every facility “has its own unique problems” and every family council, though linked by common threads, weaves a separate identity and raison d’être, says one family member:

Some family councils tend to be more social. Other family councils tend to be more advocates; others tend to be a combination. Others tend to be just a sounding board and also a type of support group. Depending on the facility, where it is located, the type of people visiting or coming in to the family council, they’re all different, but they all seem to have some commonalities. (Ohio)

Key Points: Creating a Community with Staff and Management

1. Families and direct-care staff are natural allies, but heavy staff turnover and other factors hinder efforts to build meaningful bonds.
2. Direct-care staff often become caught between families’ frustrations with inadequate care and management decisions that subject staff to severe staffing shortages and other impossible working conditions.
3. Increasingly, labor groups are reaching out to families and seeking to engage them in union efforts to improve both the quality of care and the working environment in long-term care facilities.
4. Extendicare Health Services has established a national association with the goal to form a family council in each of its 230 facilities across the country.

Family Education & Outreach: “Best Practices”

Families need more “how-tos” -- examples of success across the country, and examples that are about taking charge because these are your rights and this is the law. Some families have never been involved with an organization working to produce change. Citizens should not be afraid of that, but sometimes they are.¹⁴

Family Councils

- I develop family councils almost exclusively in the form of a “first meeting” at the facility. Usually the administration has sent out a notice and I have a good crowd. We learn about the operations of a proactive family council, elect a chairperson, plan the next meeting and role play on how to approach other family members about attending. (Texas)
- Each family council member wears a badge on each visit that says, “Ask me about [the] Family Council.” It was thought up by volunteers and it has worked great. One volunteer ombudsman wears the badge when she’s visiting homes where she’s not a part of the family council and invites people who ask her about the badge to her family council. (Oklahoma)
- Some family councils are getting their mission statements framed and hanging them by the elevator. That way they know what it’s all about, and new family members coming in get an idea of what it’s all about. (Minnesota)
- We have a little card that families can give to other families, letting them know about the family council meetings. It’s a passive way for families who aren’t outgoing to be able to hand someone something, so at least they feel they made that one effort. And that person can keep and read the card and maybe come to the meeting. It’s a whole lot better than having to get on the phone. (Texas)
- We ran our first annual adult home resident council conference last year. We got a lot of feedback about the conference and it empowered people who started moving on different fronts. A family member at an adult home saw a conference package and became excited about consumer advocacy and resident advocacy efforts, and slowly they’re beginning a fledgling family council. One of the things that they’ve already accomplished is getting the dining room repainted. In sitting with the administrator, they presented general concerns about the home’s increasing shabbiness. Much to everyone’s surprise, the administration was very open and agreed to repaint the dining room. (New York)

¹⁴Citizen advocate, Washington state

- Unique in the country, an innovative Minnesota state law initiated by a statewide advocacy group places a small surcharge on licensing fees for nursing and board and care homes to fund resident and family council education. Since 1985, the program has grown to include four regional offices across the state to assist in organizing and developing family and resident councils. Five council educators and one director provide consultations, printed materials and speakers. Except for printed materials, the services are provided free of charge.
- One family council calls itself “Families and Friends.” That allows people whose resident died but are still interested to stay in the group. There’s a little more continuity then, because if the president’s family member dies and the president quits suddenly, the group is without a leader for a while. Inserting friends widens the horizon and increases the time people are willing to devote. (Louisiana)
- In one family council, the family members have come through a rough period of dealing with an awful lot of problems and they’re tired. A lot of people have stopped coming and it’s dwindled down to two people. The president of the resident council comes to the family council meetings and I suggested asking his opinion about what the group should do. He said a couple of years ago the family and resident councils worked together and organized a Spring Fling. He said everyone loved it and that it raised a lot of money. I looked at the family council and said: “You have your challenge.” The event gave everybody an opportunity to sit back, relax a little bit, learn more about the residents and find out what’s going on from the residents’ perspective and do something that will help everybody out. (Minnesota)
- Our family council has planned a series of programs called “Prospectus on Caring” from the point of view of everyone -- the nursing home’s chefs, laundry staff, etc. We have gotten the certified nursing assistants (CNAs) to some of our meetings. One of our goals is to give CNA’s the sense that they are important, and to have input from the people who take care of residents. (Connecticut)
- In one town with seven nursing homes and 34 assisted living facilities, the family councils all get together for meetings twice a year. They put up flyers and invite the entire public. The turnout is usually good. They arrange a special speaker, such as a legislator, attorney, or ombudsman supervisor, and they get the newspaper to do a story. The administrators and directors of nursing usually attend. So if we need to discuss an area of concern, we wait until end of meeting and ask them to be excused while we complete the meeting. (Oklahoma)

- This year we had funding for a full-time person to organize family councils. Getting people excited about family councils has worked in some places, but we're having trouble getting changes made and keeping people focused through a long-haul struggle. Even with a staff person designated for working with family councils, recruiting and supporting people is challenging. We can't organize family councils in 170 nursing homes with one staff person. (New York)
- What's most effective for family councils is finding a good working model and asking the president and secretary of that family council if they will come and talk to a new or struggling family council because they've "been there and done that" and it really does help. It's someone who has walked in their shoes. That's the most significant when it comes to changing a family council around. (Texas)

Leadership

- The ongoing effect of a family council absolutely depends on the leadership. What we've tried to do is identify two leaders -- someone who can work effectively with the administration and another who is the fire behind getting it going. The two sets of skills and characteristics do not always go together. (California)
- After a resident dies, I often encourage people committed to the idea of a family council to give one more year. If it goes on too long, it's counterproductive. But to encourage people to stay in active leadership positions a year afterward is a good idea. (New York)
- I realized that every time that I raised concerns in whatever venue it did seem to help the resident, if only by drawing attention. It also set an example for other residents and other relatives and friends who would gain some courage and gain some ideas on how to approach problems. (Minnesota)
- I try to get to new family council officers elected every six months so that no one person is having to do everything all the time. It gives that person a break. One gentleman said he didn't mind doing the work to get everything done but that he can't speak in front of people. I talked to a school teacher who was a natural but didn't have time to do the footwork. So, as a team it worked. (Oklahoma)
- One facility was without a family council at one facility for three years. Everyone is willing to help, so I'm going to set up a rotating leadership position on a month-to-month basis. I've got enough family members to cover the whole year with everyone's help, but no one that will take it on for good. (Minnesota)

- I had the intuition that if the family council was going to mean anything, it had to come from the others, too, not just me. I passed around a sign-up sheet to see who was interested in forming a family council. About three or four of us formed a steering committee and had a meeting with the regional ombudsman, who was a big resource. Then I decided to take a step back and see what the grassroots would do. I was happy to see there were others who started running with it. (Connecticut)
- It takes at least three people to provide leadership to a family council. Sometimes it's a question of convincing people that it's not so hard or mysterious to lead a council. Sometimes you have to get the group to jointly commit, so no one feels burdened. But sometimes you get such a strong leader that you don't get followers. (New York)
- One family council had a strong leader -- a lady who used to work for a bank and was pretty savvy. She called the corporation and said: "We have an administrator who never leaves the office; we complain and he never does anything." She threatened to call the media and someone from the home office was up there right away because she meant business, and they eventually got a new administrator. She used to be an army nurse, and she knew how to do things. She met with families and asked what the problems were. They told her everything and she helped to bring about some changes. (Washington)
- I tried a new concept, the "Quality Care Council," consisting of family members and oriented residents. It's the residents who started the idea and suggested teaming up with family members. It works like a traditional council; there is no distinction between residents and families. They all sit around the table and bring up the issues. Two residents and two family members have taken on the leadership. A volunteer advocate keeps the council on track by handling various logistics. One family member acts like the secretary and submits all the complaints to the administrator on a form they developed. The other family member makes sure new families are invited when she sees them in the halls a week before the meeting, though they have a poster that encourages families to come. One of the residents also makes sure new residents who are competent know about the meetings. (Minnesota)

Information & Outreach

- With the approval of the state and our advocacy group's board, I wrote a one-page description of family councils. The state has a big book on family councils that is too overwhelming, but it could all be simplified and put on one page and that's what we did. We use it as a handout on how to form a family council, what a family council is and what it is not, and the rights of families and the rights of the nursing facility. (Arkansas)
- Our advocacy group has persuaded the local women's club to purchase copies of *Nursing Homes: Getting Good Care There* on our behalf so that we could distribute them to libraries, doctor's offices, community centers, etc. (South Carolina)

- The telephone and the press are your best friends. Important articles should always include a name and phone number for readers to call for more information. Many people clip articles and file them for future reference. I had a call recently from a lady who had saved an article from 1983. I received over 200 phone calls and letters due to the 1995 *Consumer Reports* article. Telephone contact must be available seven days a week. People will call but many are reluctant to speak up at meetings. (Florida)
- For years, our advocacy group's name and phone number has been published in the local newspaper every Sunday. (Missouri)
- If you're going to advertise a workshop in a facility, you can't say "patient rights" because families hesitate to come. They don't want to create the perception that they're complainers or agitators. Having non-threatening workshops on such things as "estate planning for long term care" or how to avoid estate claims brings people in and together. Once you can get them together, the rest is easier. (California)
- We work through the local Ethnic Support Council to provide information on facilities where second languages are spoken. Many minority groups don't use long-term care because of the language and cultural barriers. (Washington state)
- Advocates should target the League of Women Voters in their community. These women work at the city, county and state level and often take on projects that are valuable tools to certain segments of the community. They also receive a lot of press for their work. (Illinois)
- In 1996, AARP convened a symposium of leaders of national women's groups on "Long Term Care as a Women's Issue." There was great interest among these presidents and directors of leading women's organizations in becoming involved in the issue -- many had direct family experience themselves -- but they cited: 1) competing concerns from other issues 2) lack of resources, and 3) lack of information about the issue. There is a clear need to get women's groups to work with advocates at the local, state and national level. Women care about the issue. We must provide information and organizing assistance to make their voices active. (Washington, D.C.)
- I think families and family councils are going to be apathetic and burned out if everything they focus on is problem-related. But if they get involved in a project that is uplifting -- facilitating an art program, leading a chorus on the floor, starting a garden club -- families can raise questions and be recognized as a life force in the facility. Once you're recognized as a life force, the facility can hear your concerns. But if all you're doing is complaining, they will tune you out and the family gets burned out. (New York)

- Most important is continuing to keep the issue in the news -- and not only the abuses, but the general level of care and how we're treating elderly people. The negative publicity has helped raise awareness and galvanize people to a certain extent. It has galvanized legislators and policymakers. Wisconsin passed some nursing home legislation this past year and that would not have happened without a series of articles in the *Milwaukee Journal*. Even lawmakers on the federal level have started to jump on the bandwagon. They are people who we contacted in the past and had little reply. But these articles spurred some action. (Wisconsin)
- What appeals to people is not so much programs about theft and loss but whether they are going to be eligible for Medicaid or can keep their home. People want practical information and their immediate needs are invariably financial because facilities are costing them \$4,000 to \$5,000 a month. (California)

Fear of Retaliation

- Don't discount a family member's fear of retaliation because it's real to them. Understand that the family member is vulnerable and that residents can be very vulnerable. Talk about what other things you can do and what other ways you can protect the resident. Ask them to think about what will happen if they don't make a report or complain. Talk about strength in numbers and uniting with other family members and residents because, if the complaint comes from several families and residents, it's harder to single anyone out. (Kansas)
- [Easing the fear of retaliation] occurs over the long haul, working with groups of residents over a period of time and showing them that when they did indeed complain as group or as an individual they succeeded. We build on that. I'm continually telling people that indeed they are more likely to get better care if they complain and that, if they work together with other residents, they're going to be more protected. It's important that, if someone is afraid, whether the fear is real or not, you have to respect that absolutely. (New York)
- I can't guarantee that retaliation won't take place. I can say that if they don't complain I know nothing will change. So, while there's the possibility of retaliation, there is also the possibility of change. I don't want to give them roses and candy, and say nothing bad will happen because I can't guarantee that and no one can. (Michigan)

Consumer Resources for Families: A Preliminary Listing

Advocacy Center for Long-Term Care

Bloomington, Minn.

- *Attracting Short-Term Residents and Their Families to Resident and Family Councils.* (1997).
- *Discussion Topics To Stimulate Participation in Family Council Meetings.*
- *The Effective Council Advisor: A manual for advisors of resident and family councils in nursing and boarding care homes.* (1997).
- *Family Council Purpose.* (1997).
- *Failsafe Your Family Council.* (1997).
- *Family Councils in Action: A manual for organizing and developing family councils in nursing and boarding care homes.* (1994).
- *Framing a Bill of Rights and Responsibilities for Residents' Families.* (1997).
- *Increasing Council Participation.* (1997).
- *Making the Most of Cultural Diversity.* (1997).
- *Minnesota's Nursing Home Residents' Bill of Rights.* (1997, January).
- *Promoting Your Family Council.* (1997).
- *Recruiting Members for Your Family Council*
- *Team Building in Resident and Family Councils.* (1997).
- *What Do Family Councils Do?*
- *From the Family's Perspective: A training video to help staff understand the family's perspective and expectations while a loved one lives in a nursing home.* (1998).

Friends and Relatives of Institutionalized Aged (FRIA)

New York, N.Y.

- *Family and Friends Councils: Start-Up Packet.*
- *FRIA Bulletins: Family Councils.*
- *FRIA Bulletins: Food: A Family Guide to Effective Participation.*
- *FRIA Bulletins: Mobility: A Family Guide to Effective Participation.*
- *FRIA Bulletins: Pressure Sores: A Family Guide to Effective Participation.*

- *FRIA Bulletins: Recognizing Over-medication: A Family Guide to Effective Participation.*
- *What Families, Friends Need to Know & Do About Nursing Homes.* (Spring 1996)¹⁵
- *Nursing Homes: Getting Good Care There* (1996).

California Advocates for Nursing Home Reform (CANHR)
San Francisco, Calif.

- *Getting Involved in the Care Plan: A Guide for Family Members/Legal Representatives of Nursing Home Residents.*¹⁶
- *Organizing Family Councils in Long Term Care Facilities.*

American Association of Retired Persons (AARP)

- *Nursing Home Life: A Guide for Residents and Families*

Extendicare Health Facilities, Inc.
Milwaukee, Wisc.

- *Family Questions: The First 30 Days* (1994).

National Citizens' Coalition for Nursing Home Reform (NCCNHR)

¹⁵Also available in Russian, Chinese, Korean and Spanish

¹⁶Publication (or parts) also available in Spanish and Chinese.

Resource Contacts

The experiences and insights of individuals and programs across the country offer a wealth of information on reaching and involving families. To date, the Family Education & Outreach Project has identified the following individuals for their skill, commitment and fluency in this area. All have agreed to receive inquiries on building and sustaining family involvement.

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Hill Care Center, Westport, Conn.

Robert Snow, Citizen Advocates for
Nursing Home Residents, Butler, Wis.

Willa Stanford, Southeast Missouri Area
Agency on Aging, Cape Girardeau, Mo.

Anna States, Area Agency on Aging, Enid,
Okla.

Eleanor Staves, National Association of
Extendicare Family Councils, Kenosha, Wis.

Marylou Stone, Ark-Tex Council of Governments, Sulpher Springs, Tex.

Sandy Strand, Kansas Advocates for Better Care, Lawrence, Kan.

Kevin Strickland, Columbia-Montour Area Agency on Aging, Bloomsburg, Penn.

Fran Sutcliffe, Nursing Home Hotline Patrol, St. Petersburg, Fla.

Ila Swan, Vacaville, Calif.

Gregory D. Tanner, Lumber River Council of Governments, Lumberton, N.C.

Beverly Tenoria, Southwestern Area Agency on Aging, Las Cruces, N.M.

Jeff Thompson, Department of Aging Services, Muscle Shoals, Ala.

Karen Trela, Advocacy Center for Long Term Care, Duluth, Minn.

Jean Trimble, Board on Aging and Long Term Care, Milwaukee, Wis.

Betty Tyler, East Alabama Regional Planning and Development Commission, Anniston, Ala.

Catherine Unsino, New York, N.Y.

Jean Vantiger, Calcasieu Council on Aging, Lake Charles, La.

Norma Venegas, Office of Elderly Affairs, San Juan, Puerto Rico

Gordon Verrill, Lewis-Mason-Thurston Area Agency on Aging, Olympia, Wash.

Chris Wade, Area II Ombudsman,

Plymouth, Ind.

Wayne County Area Agency on Aging, Honesdale, Penn.

Cathy Weightman-Moore, Catholic Charities, Diocese of Rockford, Rockford, Ill.

Janet Wells, Washingtonians for Improvement of Long Term Care, Washington, D.C.

Nancy G. Whitty, Alternatives for the Older Adult, Rock Island, Ill.

Sharon C. Wilder, Triangle J Council of Governments, Research Triangle Park, N.C.

Betty Williams, American Association of Retired Persons, Dallas, Texas

Marie Wisdom, Advocates for Nursing Home Reform, Austin, Texas

Kristin Woellmer, Area Agency on Aging, Towanda, Penn.

Donald Wright, National Association of Extending Family Councils, St. Louis Park, Minn.

Eleanor Wright, Southern Alabama Regional Council on Aging, Dothan, Ala.

Sandy Zarick, Northumberland County Area Agency on Aging, Coal Township, Penn.

Sharon Zoesch, Office of Ombudsman for Older Minnesotans, St. Paul, Minn.

Susan Zwerling, Orleans Parish Ombudsman Program, New Orleans, La.

RECOMMENDATIONS TO DEVELOP A NATIONWIDE INFORMATION & ADVOCACY INITIATIVE FOR FAMILY INVOLVEMENT

The Family Education and Outreach Project work has revealed that citizen-advocacy organizations, ombudsman programs and family groups need considerable support, encouragement and ideas in their ongoing work to enlist and sustain active, informed, energetic family members. NCCNHR proposes the following set of recommended activities that need not be exclusive of each other. Taken together, these activities present an appropriate framework for a nationwide campaign.

Networking and Promotion

1. Initiate a series of meetings with long-term care industry leaders to explore the results of this project, and to encourage the industry to promote and motivate independent family councils utilizing useful material identified and ideas generated by this project. Enlist the industry in efforts to address the issue of family and resident fears of retaliation.
2. Plan, organize and maintain a series of teleconferences with a network of advocates and family members most experienced in family organizing to generate new ideas and participate actively in a potential national campaign.
3. Plan and conduct meetings with officials and staff of the Health Care Financing Administration (HCFA) to discuss project findings and generate HCFA support for family education and involvement projects.
4. Plan a series of meetings with leading women's groups and religious organizations to discuss ideas for their support and promotion of family involvement.
5. Identify and share information about potential funding sources to support various family education and outreach projects.
6. Approach a public relations firm to design a logo or theme for use in materials designed to motivate active family involvement.
7. Explore the potential for a donated advertisement and/or advertising campaign publicizing family council involvement for use by citizen groups, ombudsman programs, and others.

Products

8. Develop a joint project with industry associations and/or specific corporations to prepare a pamphlet to distribute to all family members, encouraging active family participation in monitoring care delivery and advising the facility on resident needs.
9. Develop a newsletter for family members of residents of long-term care facilities.
Negotiate nationwide distribution with industry leaders and/or specific corporations.
10. Create a training video for organizing effective family councils, based on a round table discussion of several effective organizers. This could be a two-part video, with one part portraying an effective council at work. The video could be offered to family members, citizen groups, ombudsman programs, facilities and corporations.
11. Incorporating ideas and insights gleaned from this project, develop a training guide for recruiting and forming effective family councils in long-term care facilities. *(This work would be planned and coordinated carefully with existing materials, and thus may entail only updating or upgrading current resources in concert with experienced programs.)*
12. Develop a set of brief, understandable fact sheets or pamphlets covering special issues of concern to family members, including but not limited to:
 - Resident assessment and care plans
 - Effective monitoring of care delivery
 - Resolving problems effectively
 - Knowing what to expect from an ombudsman program
 - Understanding the survey (inspection) system
 - Promoting the rights of residents
 - Understanding the day-to-day operation of a nursing home
 - Cost of care and other financial considerations
 - Staffing issues and concerns
 - Effective communication with long-term care facility staff
 - Loss and theft prevention in a long-term care facility
 - Potential harm of physical and chemical restraints
 - Family member disagreements about a loved one's care
 - Key points in an Admissions Process and Care Contract
 - Issues to consider when choosing a long-term care facility
 - Principles of operating a family council

(Some prototypes already exist but warrant updating, editing, or expansion. Grouped together, these fact sheets could evolve into a concise and user-friendly “workbook” for family members.

Promote dissemination of these materials through citizen groups, ombudsman programs and industry associations and/or specific corporations. Design of materials should allow inclusion of local/state resource contact information.

13. Generate educational materials, such as the fact sheets, for Internet distribution.
14. Organize and conduct an intensive study session on Family Council development for NCCNHR's annual meeting, November 1998.

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RESIDENT PERSONAL EXPERIENCES AND RESIDENT COUNCIL ACTIVITIES

There is a real bonus in knowledge to glean from the few recorded experiences of individuals who have actually lived in a long-term care facility. Additionally, the historical successes and problems associated with resident council activities bring valuable information, since many of the issues are the same as for organizing family members.

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ORGANIZING GROUPS: RESOURCE INFORMATION

There are times when organized family groups decide to broaden their scope of activities to become a citizen advocacy organization, often dealing with more than one community facility. There are many educational materials which can be helpful at this stage.

Organizing Citizen Advocacy Groups:

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15) *Talk is Cheap: A Dialogue About Communication*. Rick Carter and Iris C. Freeman, American Health Care Association Journal, September, (year unknown) 35-37.*

16) *Community Presence as a Key to Quality Life in Nursing Homes*. Jane Lockwood Barney, Presented at the 100th Annual Meeting of the American Public Health Association, 1972.

17) *Quality Care Advocate*. Newsletter of the National Citizens' Coalition for Nursing Home Reform, 1424 16th Street, N.W., Suite 202, Washington, D.C., 20036. 202-332-2275. \$45 for six issues per year.

Background Resource Material Helpful for Understanding the Nursing Home System:

1) *Real People, Real Problems: An Evaluation of the Long-Term Care Ombudsman Programs of the Older Americans Act*. Committee to Evaluate the State LTC Program, Institute of Medicine. National Academy of Sciences. National Academy Press, Washington, D.C. 1995.* Report provides important information for families and advocates to help them understand the ombudsman program: its requirements, its strengths, its struggles and challenges, and its needs.

2) *Who Really Cares?* Alice Mattison, R.N., Carlton Press, Inc., New York, N.Y. 1993. A long-term rehabilitative nurse, became concerned about her own grandmother's care in a nursing home, convinced she died of neglect. Stories are often told from residents point of view. Described as an expose of the inhumanity of nursing homes. **

3) *Making Gray Gold: Narratives of Nursing Home Care*. Timothy Diamond, The University of Chicago Press, Chicago and London, 1992. This ethnography, written by a professor of sociology, offers valuable insights into the day-to-day life of residents and their caregivers in nursing home facilities.**

4) *The End of Time: Life and Work in a Nursing Home*. Joel S. Savishinsky. Bergin & Garvey, New York. An account of nursing home life based on six years of anthropological research in geriatric facilities in New York. 1991.

5) *Death Without Dignity*. Steven Long, Introduction by Elma Holder, Texas Monthly Press, 1989.*

6) *Uneasy Endings: Daily Life in an American Nursing Home*. Renee Rose Shield. Cornell University Press, Ithaca and London. 1988.**

7) *Tender Loving Care*. Mary Adelaide Mendleson. Alfred A. Knopf, New York. 1974.*

8) *It's Okay, Mom: The Nursing Home from a Sociological Perspective*. J. Retsinas. The Tiresias Press, Inc., New York. 1986.

9) *Improving the Quality of Care in Nursing Homes*. Institute of Medicine, Committee on Nursing Home Regulation, National Academy Press, Washington, D.C. 1986.*

10) *Too Old, Too Sick, Too Bad: Nursing Homes in America*. Frank Moss and Val Halamandaris. Aspen Systems Corporation, Germantown, Maryland. 1977.*

11) *Old Age: The Last Segregation*. Claire Townsend. Ralph Nader's Study Group Report on Nursing Homes, Bantam Books, New York, 1971. For copy of this out-of-print book, check library or order a copy from the National Citizens' Coalition for Nursing Home Reform, Ste 202, Washington, D.C. 20036. 202-332-2275. \$15 includes postage.*

12) *Students as Advocates for Nursing Home Residents*. Elma Griesel (Holder), Synergist, 4-8, Winter 1978.*

13) *Special Problems in Long-Term Care*. Hearing before the Subcommittee on Long-Term Care of the Select Committee on Aging, U.S. House of Representatives, October 17, 1979.

14) *Unloving Care*. Bruce V. Vladeck. Twentieth Century Fund, 1980.* Primary study of nursing home system.

15) *Nursing Home Care in the United States: Failure in Public Policy*. Introductory Report. Followed by a series of reports. United States Senate, Special Committee on Aging, Subcommittee on Long-Term Care. December, 1974.

* Denotes item is available in the library of the National Citizens' Coalition for Nursing Home Reform, May 1998.

Family Education & Outreach

October 20, 1997

5:45pm to 7:45pm

Dinner Discussion with Family Members
& Advocates for Families

Long-Term Objective:

To inform and empower family members of LTC facilities so that they can advocate constructively and effectively to assure quality care and life for their loved ones.

Evening's Objectives:

1. To begin a dialogue with family members and advocates -- individuals identified by our member groups as having personal experience and expertise.
2. To identify common substantive concerns that families want addressed by long term care providers and by government regulators.
3. To identify effective community education and outreach techniques to reach (a) those soon to enter long term care facilities and (b) families of current residents.
4. To identify issues and problems faced in organizing family groups -- e.g., family councils.

INTRODUCTIONS

Elma Holder welcomed the participants and described the Family Education and Outreach project funded by the American Association of Retired Persons. The participants then introduced themselves and briefly shared their experience working with families who are actively advocating for long term care residents.

“We all do different kinds of advocacy work,” Holder said, “but all of us around the table believe very strongly that the best thing we can do is get the family at the bedside, or even before they’re at the bedside, empowered with enough information to become effective, informed advocates for the people -- the residents -- who live in the facility.”

Joanna Deighton: Became interested in the issues when mother was in a nursing home, and the only thing she “could depend on was neglect and mistreatment.” She would find medication on the floor, the room unclean, etc. Ten years ago the situation led her to form OK INCH, Oklahomans for the Improvement of Nursing Care Homes, which now has some 300 members. Not all are family members, but there are quite a few family members on the board who would be happy to be interviewed for this project.

Judy Murphy: Came to this issue through being “a family member going through the needless suffering” of abuse in a nursing home. “That’s what brings us to this point many times; you don’t want to see it happen to someone else.” Now she is executive director of an advocacy group she

started, APE -- Association for Protection of the Elderly, a S.C.-based “network of independent advocates throughout the United States.” The advocates are trying to help each other from state to state with information resources. “We depend on NCCNHR for our help in resources; we can’t duplicate that but we can add to it and hope to compliment it as independent advocates.”

Betty Williams: Health representative in AARP’s Dallas office. Comes with professional interests and personal ones, being a long-distance caregiver for elderly relatives.

Janet Wells: Mother entered a nursing home in 1993, and shortly afterward became intrigued when she saw a reference in a magazine to the National Citizens’ Coalition for Nursing Home Reform. She eventually came to work for NCCNHR for seven years. During that time she joined with others to form a local advocacy group, WINH -- Washingtonians for Improvement of Nursing Homes. On staff at AARP for the past five years.

Martha Mohler: On staff at the National Committee to Preserve Social Security and Medicare. Concerns stem from having a mother and a father-in-law in nursing homes, and hearing from National Committee members who call to share their personal experiences with nursing homes. At her mother’s nursing home, she discovered that the network of families was “the most important support group.” It was a “secret network.” She became familiar with the problem of trying to deal with and identify problems, running into “lack of interest on the part of the management.” Encountered staffing shortages, poor management, loss and theft, and mental abuse.

Hilke Faber: Health representative for AARP’s west region in Seattle. Formerly involved in the issues as an ombudsman and as founder and program coordinator for the Resident Councils of Washington. “As we begin to see increasing debility of residents, the family, more and more, is going to be playing a key role in advocacy in long term care facilities.”

Mary Edwards: Psychotherapist and consultant to nursing homes. Came across problems in that capacity. As psychotherapist has worked with families, and is trying to provide more support groups and training to get families to be advocates.

Sue Harang: Former director of nursing in a nursing home. When she asked management for additional support to uncover some abuse, she was told that there would always be abuse and neglect in nursing homes. She left that facility and eventually her nursing career. She has been working on nursing home litigation with her husband since 1985. She recently had to move her great aunt to another nursing home, where she just learned that her great aunt’s leg was fractured. The orthopedist at the hospital said the leg had been fractured for almost a month. “That’s my present experience as an ‘informed consumer.’”

Judith Mangum: Has a mother in a nursing home, and is herself a resident of a nursing home in Bowling Green, Ky. Also been a chaplain in a nursing home. The first time she was in a nursing home she saw a women who had a stroke being pinned against the wall, and there was no one

there to help her. Her worst experience in a nursing home occurred when she was strapped to the bed by a nurse and an orderly, and they lit a pipe and put it up to her face. "They laughed about it, and it was my word against theirs. So we need some advocacy out there."

Sarah Burger: Worked in nursing homes for six years in D.C. That experience led to writing a book for residents and their families 20 years ago titled "Living in a Nursing Home," and to her work at NCCNHR. Also part of WINH.

Jane Garnett: Ombudsman in Pueblo County, Colo. Over the past three years has worked closely with a family council that first had to fight to exist. Successfully worked with the family council to address problems around the facility's access to information from the health department about surveys. The family council has grown and seen the results of their work and is very excited. Have developed a proposal to bring the Eden Alternative to the facility. Been threatened by staff, administrators and asked to remove relatives from the facility. "They have been through everything that you can imagine." What really made them come together is the facility's prediction that they would not succeed. Said she's seeing more and more families accused of being "dysfunctional," and would "like to see more support for families from the facilities -- emotional, psychological support."

Ilene Henshaw: Father in a Maryland nursing home where he's getting good care, but moved from another home in the state where it "was a horrendous experience." All the incidents were reported verbally, but nothing was ever done. After she moved her father, she contacted another family member from the first home whose name she saw in a newspaper article. She had thought she was alone, but it turned out nearly 100 people had been meeting all along, though the ombudsman never told her about the group. Has become involved in organizing the group -- Advocates for the Enhancement of Long Term Care, for families with residents still there, for those who have moved relatives out, or with loved ones who have passed away. Had a lot of media events. The state is "absolutely useless in helping us. The surveys come back deficiency-free. We're just beginning to get people to listen."

Lou O'Reilly: Had a mother in a nursing home and saw the need to advocate, and vowed to continue to speak out for people who need help. Founder of TANHR -- Texas Advocates for Nursing Home Residents. Motivated and instructed by leaders of CANHR -- Calif. Advocates for Nursing Home Reform. Currently sponsoring training sessions for volunteers in nursing homes. Speak to and help organize family councils, help them know the rights and regs. Have some very strong, active councils. Have five TANHR chapters across the state.

Mary Gorale: Founder and president Florida Advocates for Nursing Home Improvement. Became involved when she was working for AT&T and transferred to Florida. She traveled around the state assisting pensioners with their benefits. Found people having problems in nursing homes. One pensioner lost everything she owned in a matter of months, and felt so badly that she vowed she was going to learn how to help her pensioners. AT&T allowed her to investigate what happened to the woman, and that further encouraged her to get involved.

Recently she advocated for a neighbor with cancer who moved to a nursing home. The facility ran out of her friend's pain medication. She contacted the abuse registry and got very good results. Had the inspectors in the facility three times in three months. "She died last Sunday, in peace. She was warm; she was dry. And she was relaxed because she put her trust in me. And I was so glad I knew what to do." Also been working with family councils in the state.

Diane Menio: Executive director of the recently renamed CARIE -- Center for Advocacy for the Rights and Interests of the Elderly. Organization serves inner-city homes and don't have many families or active family councils, so trying to build that up. By and large facilities organize families. Recalled how helpful it was a few years ago to organize families to testify against the expansion of a nursing home chain with a poor track record. Personally, grandmother had several nursing home admissions. Remembers how her mother and grandmother both were afraid to make complaints. Had to advocate for her grandmother when the home summarily diagnosed her grandmother with dementia, which in fact turned out to be a bladder infection. The incident raised her awareness about families, their reluctance to speak out, etc. Also made her more aware of families who are isolated from sound information, support, and resources. "In our work we find that families are sometimes the best advocates for not only their own family members but other residents."

Patricia Powers: Former consumer advocate in Iowa and Utah. In Iowa, formed citizen monitoring teams, with a social worker, nurse and community activist inspecting every nursing home and boarding home in the area. In Utah, put out a guide evaluating every home in the state so family members could have some choices, based on personal inspections by consumer advocates. Now has an aunt in a Chicago-area nursing home that's part of a continuing care community. Seems to have a lot of resources, but there have been problems between patients -- people wandering, getting into other people's beds. "There doesn't seem to be common interest among family members," with relatives disagreeing on how to go about advocating for a relative. "I think that it's very hard for people without our experience to have a real sense of even what you can demand."

Ila Swan: California advocate and a victim. Mother in a nursing home.

SUBSTANTIVE CONCERNS, KEY ISSUES TO TAKE TO PROVIDERS AND GOVERNMENT REGULATORS

- **Roommates are Mismatched.** "You're in a small room, taken out of a big house, the hospital or another facility, and it's a shock when you get a roommate that you don't mesh with. Every day, from the time you get up to the time you go to bed, you're stuck." (Judith Magnum)
- **Personal Items Are Lost or Ruined in the Laundry.** "Obviously, a resident on \$40 a month does not have the money to go out and purchase new clothes every month." (Judith Magnum)

- **Facilities Fail to Facilitate Communications Between Residents & Distant Relatives** (Judith Magnum)
- **Families Fear Retaliation Against Those who Organize or Actively Participate in Family Councils or Even Speak Out.** “Some family members are so frightened that my advice to them is, ‘No. You can’t run the risk. Your advocacy may have to come later.’ I hate to do that.” (Judy Murphy) But, if facilities see that families are organized, they will back off. (Lou O’Reilly)
- **The Government is Turning a Blind Eye.** Officials don’t acknowledge complaint letters, give deficiency-free ratings, etc. The ombudsman’s office apologizes for the administration and say they can’t do anything unless families submit their names. (Ilene Henshaw)
- **Families Do Not Want to Get Involved with Groups or Make Waves.** They prefer to solve it themselves by dealing with the nurses, “making deals and passing money under the table.” (Ilene Henshaw)
- **Families Hire Private-Duty Nurses.** The home takes no responsibility for these nurses. They are not supervised, and some are abusive. And when people come into the facility, it looks as if the home is well-staffed. (Ilene Henshaw)
- **Nursing Home Residents are Becoming More Transient, with more Frequent Discharges.** This will create new challenges for organizing families, who may be even more reluctant to make waves knowing that a relative will only be in the facility for a short time period. (Diane Menio)
- **Facilities are too Eager to Deal with the Person who has Power of Attorney.** They forget about the need to communicate with other family members and the resident -- and often don’t bother informing the resident of his or her right to rescind that power. “There’s a big need for mediation among family members.” (Diane Menio)
- **Families Need to Advocate for Mental Health Services,** especially in light of new Medicare Part B changes that will make mental health providers even more reluctant to provide services in nursing homes. But nursing homes are supposed to provide mental health care within the fee they’re getting. “Sixty percent of all nursing home residents are depressed.” (Mary Edwards)

STRATEGIES FOR COMMUNITY EDUCATION AND OUTREACH

- If a facility knows that a family member is unable to make a long day trip to visit a family member in an out-of-town facility and lacks the funds to stay overnight, staff should

make every attempt to contact family members and coordinate communication. (Judith Magnum)

- Help families select a home, before the problems begin -- eliminate the “bad homes” from the equation. Should also check out the criteria used by companies that claim to “rate” nursing homes. Families really don’t know what to look for. “We’re always swayed by clean, nicely decorated, landscaped facilities, and that’s probably the last thing you should look for.” (Ilene Henshaw)
- Empower families to know their rights about starting a family council and to know what a “real” family council is -- not one where the home controls the agenda and tries to usurp the power of the council. Families that don’t know better can think that the facility is being responsive when in fact it’s not. (Ilene Henshaw)
- One family council convinced the home to put a letter of introduction to the family council into the admission packet. But it took some arm-twisting. (Jane Garnett)
- To compile a list of families in the facility, get a microcassette recorder and walk by each room and dictate the name of the resident. Then use the phone book to match the resident with the family. You can pick up 50% of the family members that way. You can pick up the other half simply by passing by the rooms and introducing yourself to visiting family members. Tape recorders also come in handy when documenting unanswered call bells and other problems. (Ila Swan)
- Families need to know to be a part of the care-planning process, from the admissions process on. Families don’t understand that the care plan is their agreement with the home. (Ilene Henshaw)
- Families need to know how to document problems and make a complaint. (Ilene Henshaw)

Jane Garnett agreed: “The family proposed having a written complaint in triplicate. The DON gets the first copy, the second copy to come back to the family council with some kind of a plan of correction, and the third copy the family keep. Once you create a paper trail, you get results. The same as you do if people walk around with a notebook. The notebook was very effective in terms of retaliation. Staff knew their names would be written down, the times would be written down, and the witness to what was going on.”

Added Ila Swan: “State licensing and certification always believe the nursing homes because they have it documented. If you have documentation, too, you can ask why they believe them over you.”

Mary Edwards: “You have to fight fire with fire and document as much as you can.”

- Family councils should appoint a Grievances Committee that can take issues to the administrator. (Lou O'Reilly)
- Get all the families in the council involved in doing something. Otherwise they come a few a times but then drop out. (Joanna Deighton)
- Provide trainings over the telephone, via a toll-free number. Tell families to get tape recorders, cameras, and yellow legal pads and let staff know that they are documenting. "As long as the people gather forces, there's more power and a lot of numbers than one big blob of money." (Mary Gorale)
- Advise families to report directly to Robert Streimer (HCFA Director of the Disabled & Elderly Health Program) and to Michael McMullan (HCFA Director of Beneficiary Services). Martha Mohler: "I don't think we should fool around with state governments if they're not responsive."

INFORMATION SURVEY: FAMILY EDUCATION AND OUTREACH
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APPENDIX 2

RESULTS

METHODS USED TO FIND/EDUCATE FAMILY MEMBERS

➤	Organized/helped organize family council or advocacy group:	64
➤	Conducted educational programs in the community:	96
➤	Newspaper articles:	66
➤	Television/radio appearances:	52
➤	Other:	33

“Other” methods used to find and educate family members

- Handouts and individual mailings (#7)
- Educational programs for employees of private/public agencies and corporations (#21)
- Ombudsman visitors have informed family members about the ombudsman program. Residents also are able to inform family members about the ombudsman program. Church ministries have become concerned about LTC issues and presentations have been made at several. (#23)
- Established pilot project in 1990 that allows the community to petition our department of public health when a new group/individual seeks to buy a LTC facility. Present testimony at hearing on research and past history. (#25)
- Our group name and my phone number published every Sunday in local newspaper for years now. Also: Person-to-person conversations or meetings with caregivers who are having unpleasant experiences and helping them to find their solutions. (#26)
- “My office” (#41)
- Tables at health fairs in shopping malls (#44)
- Operating family councils & phone calls from families (#54)
- Educational pamphlets (#57)
- Attending family council meetings with LTCOP information (#65)
- Publish nursing home booklet and residents’ rights brochure (#66)
- Telephone contact (#69)
- Helped facilitate support group (#70)
- Taking information regarding ombudsman program to various organizations (#74)
- Training at universities and police agencies by ombudsman staff (#76)
- Published pamphlet on ombudsman prevention of loss and theft; produced video for nursing assistants (#79)
- Forums on legislation (#85)
- Telephone hotline (#88)
- Presenter at local women’s conference and at local bar association (#104)

- Send newsletter and/or helpful articles to persons on mailing list, and distribute welcome packets with information to new residents (#105)

Outreach methods that have been most successful

- Organized/helped organize family council or advocacy group: 33
- Conducted educational programs in community: 65
- Newspaper articles: 40
- Television/radio appearances: 21
- Other: 18

“Other” outreach methods that have been most successful

- Volunteer Visitor Program and Technical Assistance Program, serving as overall community resource (#11)
- Educational programs for employees of private/public agencies and corporations (#21)
- Educational inservice at family council meetings (#49)
- Resident councils, resident/family meetings, and inservices with nursing home staff (#50)
- Taking information regarding ombudsman program to various organizations (#74)
- Published pamphlet on ombudsman prevention of loss and theft; produced video for nursing assistants (#79)
- Send newsletter and/or helpful articles to persons on mailing list, and distribute welcome packets with information to new residents (#105)

WHERE MATERIALS DISTRIBUTED OR PRESENTATIONS MADE ABOUT ORGANIZATION/PROGRAM

Doctor’s Office

Brochures: 32 Ed’l Materials: 9 Speeches/Workshop: 3

County Medical Society

Brochures: 8 Ed’l Materials: 5 Speeches/Workshop: 6

Hospital Discharge

Brochures: 59 Ed’l Materials: 39 Speeches/Workshop: 30

AARP Meetings

Brochures: 30 Ed’l Materials: 29 Speeches/Workshop: 42

Senior Centers

Brochures: 73 Ed’l Materials: 57 Speeches/Workshop: 69

Houses of Worship

Brochures: 33 Ed’l Materials: 24 Speeches/Workshop: 35

Adult Day Care

Brochures: 28 Ed'l Materials: 20 Speeches/Workshop: 15

Silver Haired Legislature

Brochures: 10 Ed'l Materials: 11 Speeches/Workshop: 9

Other Senior Groups

Brochures: 24 Ed'l Materials: 17 Speeches/Workshop: 25

Women's Groups

Brochures: 25 Ed'l Materials: 24 Speeches/Workshop: 32

Professional Associations

Brochures: 27 Ed'l Materials: 25 Speeches/Workshop: 32

Union Retiree Groups

Brochures: 16 Ed'l Materials: 12 Speeches/Workshop: 23

Nursing Homes

Brochures: 86 Ed'l Materials: 75 Speeches/Workshop: 81

Assisted Living

Brochures: 51 Ed'l Materials: 40 Speeches/Workshop: 41

Board & Care

Brochures: 43 Ed'l Materials: 31 Speeches/Workshop: 29

Libraries

Brochures: 24 Ed'l Materials: 20 Speeches/Workshop: 2

Your Agency/Organization

Brochures: 60 Ed'l Materials: 52 Speeches/Workshop: 58

Other

Brochures: 42 Ed'l Materials: 34 Speeches/Workshop: 40

Most Effective/Least Effective Outreach Sites/Organizations

Doctor's Offices

Most Effective: 0 Least Effective: 29

County Medical Society

Most Effective: 1 Least Effective: 15

Hospital Discharge Planners

	Most Effective: 44	Least Effective: 12
AARP Meetings	Most Effective: 21	Least Effective: 13
Senior Centers	Most Effective: 51	Least Effective: 11
Houses of Worship	Most Effective: 24	Least Effective: 14
Adult Day Care	Most Effective: 13	Least Effective: 9
Silver-Haired Legislature	Most Effective: 11	Least Effective: 6
Other Senior Groups	Most Effective: 22	Least Effective: 3
Women's Groups	Most Effective: 12	Least Effective: 9
Professional Associations	Most Effective: 24	Least Effective: 3
Union Retiree Groups	Most Effective: 6	Least Effective: 5
Nursing Homes	Most Effective: 82	Least Effective: 3
Assisted Living	Most Effective: 31	Least Effective: 4
Board & Care	Most Effective: 22	Least Effective: 4
Libraries	Most Effective: 9	Least Effective: 14
Your Agency/Organizational Meetings		

Most Effective: 48

Least Effective: 1

Other

Most Effective: 26

Least Effective: 3

“Other” Senior Groups

senior apartments/housing; city senior council; foster grandparents; Illinois Coalition on Aging; ATT & Bell Telephone Pioneers; caregiver groups; Area Agency on Aging Advisory Council; Metro Detroit Aging Coalition; county aging units; Shine Programs; 55 Alive; Brooklyn-wide Intra-Agency Council; United Senior Citizens, RSVP; National Association of Retired Federal Employees; Florida. Council on Aging; Coalition of Wisconsin Aging Groups; Widowed Persons Support Group; Older Women’s League; Kansas Coalition on Aging

Professional Associations

National Association of Social Workers; National Association of Activities Professionals; Illinois Bar Association; Illinois Health Care Association; nursing home administrators association; trial lawyers associations; American Nurses Association; administrators roundtable; police and sheriff; Chamber of Commerce; parish nurses; ministers; American Bar Association; Women’s Business Exchange; American Dietetic Association; provider council; DuPage County Association. Of Senior Service Providers; Missouri Board of Nursing Home Administrators; Missouri Board of Nursing; lawyers; American Association of University Women; information referral providers; Kansas Medical Directors Association; Kansas Nurses Association; Kansas AAHSA affiliate; Kansas AHCA affiliate; personal care home Providers; geriatric care managers; library advisory Boards; senior providers; Florida Medical Association; pharmacists association; Florida Health Care Association

“Other”

University gerontology classes; Rotary; Kiwanis; Lions; Optimists; “active union members”; credit union; service organizations; LPNs; CNAs; Alzheimer’s support groups; university fairs; area festivals; state attorney general office’s “Community Awareness Day”; “16-county-wide educational blitz”; Chicago Police Department senior meetings; retirement centers; EXPO 50 Plus; Elderfest; human services organizations; media; legislators; Area Board for Aging Ethics Committee; health expos; state employees; community college and university-level classes in physical therapy, social work, etc.; legislative forums; educational sessions on Alzheimer’s; health fairs; home health agencies; ALTRUSA (service group); colleges; hospice; YWCA; homemakers; Midwest Bioethics Center; hospital-sponsored presentations; estate planning attorneys; legal services programs; ombudsman programs; the World Wide Web; Parkinson’s Disease support groups; corporations; newsletters; CNA training for certificate; nutrition sites; community mental health & mental health ombudsmen; independent living retirement apartments; neighborhood associations; Community Volunteers in Action

Comments

- Our presentations and resources have been very helpful to groups from other states who have not been able to focus on family education the way we have. (#6)
- Wouldn't really rate any as being effective in the past two years. (#43)
- We really haven't done an organized outreach. (#53)
- Have not evaluated. (#54)
- We do not intentionally do outreach for the purpose of involving families. Our outreach is either to recruit volunteers or to inform the community at large. (#81)
- Most people hear about CANHR from social workers/discharge planners and from the media. (#85).

GREATEST OBSTACLES TO REACHING/MAINTAINING FAMILY INVOLVEMENT

➤ Getting names:	36
➤ Facility resistance:	38
➤ Families lack information:	63
➤ Families lack interest:	54
➤ Families lack financial resources:	10
➤ Families fear retaliation:	82
➤ Families lack time:	72
➤ Other:	13

“Other” obstacles

- Families not in proximity. (#2, #13)
- Lack of financial resources in my program to cover needed materials and my time to work in this area. (#7)
- I only checked one [fear of retaliation] because this is what stops families and residents -- everything else is secondary. (#14)
- In my 7 years as sub-state ombudsman, it appears that people are not interested in topics of this nature until the day it affects them directly. I would appreciate the sharing of successful endeavors to reach family members. (#15)
- Most want a quick solution and are not interested in a real commitment. (#26)
- They are frequently under so much stress they can't stand further involvement. (#28)
- Our Medicaid Waiver Case Managers do not always have the time to spend on ombudsman activities as much as they would like. (#40)
- Availability -- we often play phone tag. (#58)
- Family members work; family councils meet in evening. (#66)
- Lack of staff time. (#68)
- Timing of visits when family members are available. (#70)

- Lack of staff time. (#78)
- Interest dwindles when family council solves major issue they came together for. (#90)

Comments

- The nursing home administration is very effective in keeping us away from family council meetings/keeping names private. (#5)
- Some facilities are still reluctant to share the names of prospective families (for the FC). We point out OBRA's guidelines to surveyors which say that facilities should provide access to prospective members. (#6)
- I am only allowed 10-14 hours/week as ombudsman.(#7)
- If we had the names, families would not be lacking. Public information is not a sufficient way to reach families. (#13)
- Some family members are not aware of the regulation which requires the facility to provide a meeting place for family council meetings.(#22)
- Community/family show little interest in issues until facing their own crisis. (#31)
- Family members are mostly interested in their own. (#69)
- Family members often are working but they also are torn by other family responsibilities. An active and outspoken family council member recruited for our board became inactive when her husband developed cancer. She was not able to be as strong an advocate for her mother and other residents when she was caring for her husband full time. (#79)
- Apathy! Apathy! Apathy! (#83)
- Frequently family members call us with concerns but hesitate to involve us because they fear rocking the boat. They believe staff will take it out on their loved one, and they also believe nothing will be accomplished.(#86)
- Lack of leadership. Too many groups will meet in facilities and let staff run meeting. Need a strong leader, not intimidated to meet independently outside of facility if necessary. Facility in Seattle had many problems; leader was ex-business exec. Called corporation and said if conditions didn't improve would call TV and newspapers. Change occurred. Got new administrator and many changes. (#89)
- Another obstacle is when the council has resolved the major issue they have come together for interest dwindles. (#90)
- Eighty-five to 90 percent of long term care residents in Louisiana are Medicaid recipients.

Generally, their culture is based on receiving rather than participating. In New Orleans, only 20 percent of the population pay property tax; so city services are free to 80 percent. They do not understand that through education by and financial support of our organization, they become empowered. They expect and appreciate the services without obligation. Louisiana's Medicaid program has paid for very little except nursing homes; so the Medicaid recipient's family is not interested in learning about private-pay alternatives. (#91)

- Families need to know about Florida Advocates for NH Improvement and FANHI needs to know who these families are. (#96)
- [re family members "lack info and education"] If they understood the potential benefit to their loved one, they would be more receptive to a family council. (#97)
- Most family members who report typically demonstrate a desire to be involved. Retaliation is a common fear, however, the terms of confidentiality seem to be comforting and create greater participation. (#101)

MOST COMMON REASONS FOR NOT BECOMING MORE INVOLVED IN LOVED ONES' CARE

- Lack of time: 79
- Lack of appropriate meeting place: 5
- Lack of financial resources: 11
- Lack of knowledge or information 57
- Fear of retaliation 71
- Other: 19

“Other” reasons for not becoming involved

- Lack of interest (#5)
- Burnt out from caregiving before LTC and now want to pass all caregiving on to LTC facility staff (#7)
- Complacency (#8)
- Disinterest (#20)
- Are real reluctant to become involved in any local, state, or federal and political entity dictating Medicaid policies (#26)
- The “designated decision maker” for the resident doesn't brook any involvement from other members of family (or other non-family) (#28)
- Geographic distance (#42)
- “My relative has been there for years, and nothing has changed.” (#60)
- Geographic distance (#61)
- Lack of interest (#67)
- Guilt (#68)
- Lack of physical and emotional energy (#70)

- [Lack of appropriate meeting place] includes finding a “neutral” and accessible meeting place in a large, racially divided city (#79)
- Family members defer to staff (#84)
- Lack of a feeling of their power; no experience in confronting authority or grassroots savvy (#89)
- Lack of access. Resident resides in a different state. Involvement is by telephone calls to facility (#101)
- Lack of appropriate meeting times due to work schedules (#102)
- Dysfunctional family relationships (#103)

Comments

- Family education should begin with the hospital discharge planner... once decision has been made to do nursing home placement. (#1)
- Offering classes to advisors helps facility staff with publicity ideas, tips for getting started, suggestions for maintaining interest, and support for themselves and their role. (#6)
- Pre-Admission screeners need to be educated and passing information and brochures along to those they screen and the families. (#7)
- Greater emphasis should be placed on family participation at the time of admission to LTC facility. (#8)
- Community health fairs and other workshops (#17)
- Family potlucks before the meetings. Entertainment or guest speakers. (#20)
- Be available when they’re ready to talk. (#21)
- Some family members are employed and cannot attend family council meetings or care plan meetings. It would be helpful if corporations would provide educational workshops for employees at their work sites. (#22)
- Presentations to various non-profit community groups who advocate for benefits. (#25)
- Private-pay families seem to fare better than those on Medicaid -- who, for whatever reason, really fear the system, the nursing home owners, and state regulators. Residents’ Rights (if there are any left) should be stressed and education on the Medicaid system explained. (#26)
- Pass laws that carry stiff penalties for threats and retaliation by facilities. (#27)
- Be sure your name is available. They’ll find you if you have a problem. (#28)

- I would like to see a program developed in our area that combines all facility residents' family and friends. This program would not only educate people on subjects such as public benefits, LTC insurance, federal and state regulation, and survey process, etc. But this program would also be in place to support this population while dealing with this for LTC information/counseling. This type of program would require professional support from a lawyer, ombudsman, and social worker/counselor. (#35)
- Have family councils develop newsletters written by them and not the facility. Also family councils discuss issues privately and not with the nursing home staff members present. (#36)
- I was a member of a committee who put together a consumer checklist to assist family members in determining if a facility or program provides adequate and appropriate dementia-specific care. (#37)
- We need someone who could strictly devote their time to this job full time if we had sufficient funding. (#40)
- Newsletter hand-delivered to residents in nursing homes, board & care (#44)
- Web site which will be up and running within a month. (#48)
- A dinner or fish fry will produce the largest groups in my area. (#50)
- Each family member/resident should be given name and phone number of ombudsman upon entrance into facility and a description of what an ombudsman does/is. (#52)
- I feel more positive PR in newspapers and on TV would help. Would like to see our program do a regular newspaper column monthly. (#53)
- Development of a community coalition (#62)
- Nursing homes to offer support groups for new residents' families; offer support groups for spouses of resident (#66)
- Program staff spend all their time trying to keep up with complaint investigations. (#68)
- Educating staff in the importance of family involvement and in techniques for family education -- also counseling for unique family characteristics. (#70)
- Meet with administrators and help educate the total staff on the job and responsibilities of the ombudsman program and the services we have to offer.(#75)

- Our area has hard time with families wanting to continue a family council. Facilities I have dealt with are willing to assist in any way, but families lose interest after a couple of meetings. (#77)
- Ombudsman brochures required to be in admittance packet. (#81)
- County-wide advocacy meetings (#82)
- We can only persist in supplying information to people on how to find a good nursing home and what they must do if they have problems. (#83)
- Ideally, we would like to be able to meet with family members after resident had been at facility for 30 days or so. Purpose would be to introduce ombudsman and program, care issues, questions they have, etc. Due to time constraints, we have not been able to work on this. Currently, I have a volunteer who keeps our educational materials and brochures updated and adds new materials as she finds them. She also schedules some public information speaking engagements. (#84)
- Having non-threatening workshops on such things as “estate planning for long term care” or how to avoid estate claims brings people in and together -- once you can get them together, the rest is easier. (#85)
- Statewide, county-by-county outreach initiative to begin Jan. 1, 1998. Family council newsletters would be good idea. (#87)
- Many people feel unnecessarily intimidated by medical situations, setting, staff, doctors, etc., and feel that medical facilities always know what is best and thus devalue their own experiences and knowledge of what is “good care.” (#89)
- I have made suggestions to councils to try to reach new admissions in the facility. If the council will put a letter in the admissions packet, and ask if the facility will send a follow-up to family during the first months. (#90)
- Families might not have to be so well educated if nursing home staff had better knowledge of Resident Rights and the Standards for Payment. In my nursing home, I persuaded the home to make photo copies of **MEDICARE AND MEDICAID REQUIREMENTS FOR LONG TERM CARE FACILITIES...** to give to each staff person after a discussion about the document. Members of the Resident Council also received copies. Each time at Care Plan Conference, for instance, that I have to mention a right or a regulation, I write to the care plan clerk and cite the Federal as well as the State statute and the page in the Standards for Payment. I copy the letter to the administrator and the social worker. If the family member asks, he also gets a copy. It’s slow and time

consuming. For more than a year, three of our members have participated in a DHH Task Force on LTC Policy. We have attempted to make the system more user-friendly by recommending and organizing a single point of entry, a better assessment tool, and a tracking system of applicant's choices to establish the need for more or different services, and a case management system to link applicants who wish to age in place with private/public services that will help them. Until last month, those of us who worked on the task force were not allowed to discuss our work, but last month DHH Secretary Jindal announced our progress at a press conference; so families will know that our organization has been involved. (#91)

- One family council has a meeting quarterly for the entire area (town with 7 nursing homes and 34 assisted living) and through newspaper articles and notices at other facilities invites all interested persons. At these meetings we usually have a special speaker such as a legislator, attorney, ombudsman supervisor, etc. Administrators and DONs usually attend. If need to discuss area of concern, we wait until end of meeting and ask them to be excused while we complete the meeting. (#95)
- Florida Advocates for NH Improvement sends out PSA reports throughout Florida. We have a toll-free number. (#96)
- Need to overcome the "can't fight City Hall mentality." Leadership is key -- specific training for leaders would be useful. A collection of success stories would be helpful as well. (#97)
- Most family members feel they do what they can for their resident. They have very little extra time or interest for others. (#99)
- Legislation should demand that all administrators comply with the ombudsman program. It can work to their advantage -- why do the administrators feel so threatened? (#100)
- Families could be better reached by way of a monthly Family Council Newsletter. The newsletter would serve to inform families of upcoming events, source for recruiting new family members and include an educational section to discuss topics of interest. One of the best ways of reaching families is during the admissions process of a loved one. The facility could consider giving the family member a welcome package. Information about the family council, ombudsman program and upcoming in-service training could be placed in the package. Because there is continual turnover in agency offices serving the elderly, and other programs offering services that may affect the elderly, we find that there are continually people lacking knowledge of the LTCOP. A one-page explanation of the Ombudsman Program services geared to elderly service agencies (such as the Alzheimer's Assoc.) would assist their staff in referring and reaching families about our services. Admission directors and social service directors should be more informative and knowledgeable of the LTCOP. They should be sure upon admission that the resident and

care giver understand what the facility provides and fully explain their contract. Have seminars in the hospitals for patients who are being transferred to LTC facilities. (#101)

- At point of resident admission, nursing home should notify family of availability of ombudsman orientation. Complaint handling process needs to be presented by facilities separate from all the paperwork done on first day of admission. (#102)
- Family Caregiver Program with the AAA is a good way of reaching out to caregivers in the community. (#106)

GENERAL PROFILE OF ACTIVELY INVOLVED FAMILY MEMBERS

Age 60+

Most Likely: 52 Likely: 36 Least Likely: 5

Age 40-60

Most Likely: 42 Likely: 43 Least Likely: 12

Under 40

Most Likely: 11 Likely: 14 Least Likely: 54

White

Most Likely: 52 Likely: 19 Least Likely: 1

African American

Most Likely: 12 Likely: 34 Least Likely: 11

Hispanic

Most Likely: 5 Likely: 12 Least Likely: 20

Asian/Pacific Islander

Most Likely: 4 Likely: 11 Least Likely: 18

Other Minority

Most Likely: 4 Likely: 8 Least Likely: 13

Unemployed

Most Likely: 11 Likely: 25 Least Likely: 35

Employed

Most Likely: 24 Likely: 44 Least Likely: 15

Retired

	Most Likely: 62	Likely: 31	Least Likely: 1
<u>More than 1 family member involved</u>	Most Likely: 41	Likely: 35	Least Likely: 10
<u>Single</u>	Most Likely: 24	Likely: 28	Least Likely: 15
<u>Lives in Proximity</u>	Most Likely: 71	Likely: 21	Least Likely: 0
<u>Positive LTC Experience</u>	Most Likely: 32	Likely: 24	Least Likely: 23
<u>Encountered Problems</u>	Most Likely: 61	Likely: 29	Least Likely: 10
<u>Suffered Neglect/Abuse</u>	Most Likely: 53	Likely: 17	Least Likely: 12
<u>Completed High School</u>	Most Likely: 23	Likely: 28	Least Likely: 3
<u>Completed College</u>	Most Likely: 36	Likely: 28	Least Likely: 3
<u>Completed Graduate School</u>	Most Likely: 26	Likely: 29	Least Likely: 7
<u>Other</u>	Most Likely: 10	Likely: 2	Least Likely: 2

“Other” characteristics suggesting family involvement

- **Most Likely:** Afraid of neglect and abuse and want to get involved as a group because of fear of retaliation. (#6)
- **Most Likely:** The more familiar with resources families have been the more likely they are to look for assistance. They are more able to recognize neglect and abuse. (#7)
- **Most Likely:** Understand consumer complaints/advocacy. (#9)
- **Likely:** Visitors (friends) from resident’s home, church family. (#10)
- **Most Likely:** Handicapped (#60)
- **Most Likely:** Professionals who work in the field, both advocates and nursing home workers. (#79)

- **Most Likely:** Well-educated, many life experiences, politically knowledgeable, self confident. (#89)
- Family members of current residents are **more likely** to use the organization's services for crisis intervention but not to join and work in the organization until after relatives are deceased. I think family members of current LTC residents focus on specific problems such as the theft of grandma's slips and fail to see why the organizational focus is all theft. After the death of the relative, families are able to work on systems problems. (#91)

EXPERIENCES/RECOMMENDATIONS FOR EXPANDING OUTREACH/EDUCATION TO CERTAIN CATEGORIES/GROUPS OF FAMILY MEMBERS

- Most family members feel guilty about placing their loved ones in a nursing home. Community education to dispel some of the myths -- negatives -- would be beneficial to minorities. As a rule, in particular, African Americans have great difficulty in placing parents, grandparents, etc., in a nursing home. Organizations... that can assist in educating those families are local churches, senior centers, civic and social clubs, etc. (#2)
- ... the American Association of University Women would be a good group to target. (#4)
- We need to do a whole lot of publicity to minority groups. On the other hand, in Minnesota, there are not a lot of people of color in the nursing homes. (#6)
- It would be very helpful to have mailings for each church, encouraging them to copy and send to any organizations that might use the information. High school classes in health education, health professions, home ec and family courses, and college courses in social work, health-related professions, psychology professions, and counseling professions would all benefit from information regarding residents' legal rights because they are our future caregivers. (#7)
- Groups: Church Women, Service Organizations; People need to understand the difference between demanding good care (complaining) and fear of resistance or retaliation for doing so. (#8)
- League of Women Voters, Federated Women's Clubs, Church Women United, Junior League, Business and Professional Women's groups should be involved. However, women's groups in some communities have disbanded. It is most important to have legislation to allow ombudsmen more access to families when residents enter a facility. This needs to tie in laws. (#13)
- I feel it would be very helpful to have media involvement in informing families and the public about the existence of family groups -- the types of topics and activities these groups can and do get involved in -- that there is an Ombudsman to act as an advocate for each resident, etc. The greatest barrier I run into is ignorance. I do not think the general public is *aware* of these items. We have had great results from a recent campaign on

- Elder Abuse. Maybe more extended family members would participate -- if they were aware of the opportunity. (#17)
- Nutrition site outreach workers need to know all resources. For women's groups, try to speak at county and local level of Farm Demonstration Clubs. Start at early age and present at 4-H and Home Ec classes in high school, and adult education class in Vocational Tech. (#19)
 - Minorities are under represented, professionally, in the field of aging. Often, this translates into many minorities not having the knowledge base or required information to access services relative to their well-being. Aging minorities need information relative to their health, economic security, emotional stability and other aspects. Workshops which address the aforementioned issues should be scheduled at least three or four times annually at selected sites to provide minorities with information which will be helpful to them. Efforts should be made to include minorities as facilitators. (#22)
 - My husband and I helped set up our local Alzheimer's Assoc., and worked there organizing 18 support groups in the 22-county area. We had two things going for us there: social workers and PSAs. My advice to NCCNHR would be to delete the word reform from our name -- it enrages the industry, and secondly develop a PSA to be aired nationally equating abuse of the elderly to that of child abuse -- rape -- battered wives, etc. Only when we become really MADD can we do a credible job on outreach! Distribute Federal Residents Rights Law. (#26)
 - A good thing is to go to a woman's group (Junior Services League, AAUW) and give them a job to do, or a project. They are good for sporadic help. (Have them review involuntary transfer cases and tabulate or tabulate political contributions or [take a] few members for trip to capitol.) It is hard to get general populace involved. We have only one person besides board members who is actively involved who has not had someone abused and neglected. Same with legislators; you have to take them into the facilities at night and weekends and show them the horrors. (#27)
 - 1) Kiwanis, Hospital Assoc; Mental Health; Program directors of AAA funded programs; I came to this ombuds job with 14 years of experience directing OAA programs and I keep those contacts aware of our residents' needs. 2) Also at times the AAA advisory council 3) Minority church groups (#28)
 - We work through the local Ethnic Support Council to provide information on facilities where second languages are spoken, or we do the calling to find facilities willing to obtain this help. Many minority groups don't use long-term care because of the language and cultural barriers. Some are starting to think about establishing their own adult family homes. We have provided training, information, and dates, etc. (#29)
 - People don't get involved because of frustration that nothing will happen.... The real

problem is in enforcement--or lack of. SB 190 here in Texas supported by AARP state legislature committee is a total consumer protection disaster. (#30)

- Minority issues do not seem to arise at this time. This area is still very rural and this ruralness is what affects outreach greatest. In addressing either women's issues or minority issues access through community churches seems most effective. (#31)
- Give us more staff. We have 1.5 paid ombudsmen for Maricopa County, which has 21,000 licensed beds, 96 nursing homes, 800+ other LTC facilities. Size of the state of Mass., with population of 2.6 million. Fast growing; many older retirees. People whose families live in other states. 40+ ombudsmen volunteers. Phoenix, Meja, Tempe, Scottsdale, Sun City and many other towns. (#32)
- Need more funding. (#33)
- As a member of our public policy committee for the local Alzheimer's Association we recently held two public policy forums for caregivers, professionals, and the community. A segment of the agenda was entitled "Resources Available." I presented a short presentation at each forum defining the ombudsman program, the importance of advocacy, and the rights of the LTC consumer. Inquiries for information and counseling have increased as have the new cases (complaints). The two trainings encompassed 7 counties. (#37)
- Concentrate on young adults through civic groups -- also brochures should be used with corporate entities to expand outreach into the workforce. (#39)
- I don't believe I can see a pattern or general profile. Involved families come from varied backgrounds, race, etc. (#42)
- It seems that those with more education are too busy pursuing self interests to become involved. (#47)
- Information included in all admission packets; access to family members; address/phone upon admission for an informational call. (#56)
- Malls, outreach on health days; getting into schools and Sunday schools at a young age so youth are not afraid of elderly. (#60)
- Educational materials such as residents rights in other languages. (#62)
- Nursing homes to provide guest speakers about topics families are interested in: financial planning, power of attorney, guardianship; support groups such as Alzheimer's (#66).
- I don't believe educational level has any impact on involvement. You don't have a

category for religious background, family values, or moral ethical standards. These are more important than any of the factors you list. (#70)

- In November 1996, AARP convened a symposium of leaders of national women's groups on "Long Term Care as a Women's Issue." There was great interest among these presidents and directors of leading women's organizations in becoming involved in the issue -- many had direct family experience themselves -- but they cited: 1) competing concerns from other issues 2) lack of resources, and 3) lack of information about the issue. There is a clear need to get women's groups to work with advocates at the local, state and national level. Women care about the issue. We must provide information and organizing assistance to make their voices active. (#79)
- Key is to contact pertinent individuals rather than targeting community groups. (#81)
- There needs to be a positive working example showing where a Family Council made a positive impact within the nursing home. In Alabama the Best Practice concept could be expanded to include family councils. This working example could then be incorporated into educational opportunities. (#82)
- The League of Women Voters should be targeted in each community. These women often take on projects/and or surveys which are valuable tools to certain segments of the community. They also receive a lot of press for their work. They also work at the city, county and state level. Perhaps put on ombudsman programs for city, county, state employees -- good way to reach large numbers of people. Information on grants or funding may be searched and applied for by program. This in turn helps educate families and secures possible new funding resources for program. (#84)
- Since 80+% of people in nursing homes are white, participants are more likely to be white. Making certain that consumer publications are available in other languages helps. Still, for low-income African Americans, nursing home reform isn't the most pressing issue. For people with limited English-speaking skills, they, too, seldom get involved. Otherwise, majority of participants are women and many are minorities. (#85)
- Develop a newsletter for family council members. Send our newsletter to more women's organizations and minority organizations. (#87)
- Whites, African Americans, Hispanics and other minorities are most likely to get involved if they are most Americanized. They are the least likely to get involved if there is a language barrier; and they are most likely to get involved if there is substantial presence in the organization of the same group. Ethnic minorities are most responsive if the outreach is in their own language and by a person of the same group, whether or not language is a barrier. Good networking within the language/cultural community matters too. They are least likely to respond if our outreach is alone. They are more likely if the

church, or another respected service provider confirms that we can help or that our staff is personally known to the reference. (#88)

- Education does seem to correlate with involvement but I'm not sure where the cutoff is. Too little education means less likely; but at some point more education does not mean more likely involvement. (#88)
- We have never attempted to target any special group or minority. After all, nursing home residents and their family *are a minority*. Probably Citizens for Quality Nursing Home Care should change its name to Citizens for Quality LTC, as we are interested in alternatives to nursing homes. Our philosophy has always been that every adult in the community should be as interested in the quality of its LTC as it is in its schools and churches. Members speak at support groups sponsored by the Alzheimer's Association of the No-AIDS Task Force, etc. Although groups associated with a specific disease prefer to support legislation or regulations that pertain only to their group, they will sign on in support of the legislation. The AARP is very helpful in supporting legislation. Most of the time, the local people don't really understand the issues, but their numbers make a difference. Tulane and Loyola Universities have a Public Law Center that accepts topics for legislation or regulation from our organization. The law students do research and write the proposed legislation and/or regulation. They and their professors help us march the bills through the legislature or DHH. The Public Law Center helped us put much of OBRA '87 into state law, helped equalize private-pay rights with Medicaid rights, and have almost convinced DHH to regulate nursing home staffing ratios per shift instead of per 24-hour periods. Residents and their families benefit from these actions without necessarily realizing it. We are currently working with a coalition of agencies to create some board and care homes for low-income elderly. The city is working to rid the community of blighted housing by forcing owners to renovate or to sell to those who will. We are encouraging the city to provide small business loans to those buyers who will create small board and care homes. Families are not necessarily involved in this process, but they will benefit from having alternatives to nursing homes. The group is led by family members of former nursing home residents. (#91)
- We respond to those who are actually having a serious problem in/with nursing homes. The churches need to get more involved. They need to ask questions, check to see if they are fed... Church groups make visits but do not investigate further... (#96)
- ... not LTC facility "resistance" but "disinterest" (#98)
- I speak to any group that requests a presentation. (#98)
- We are 80 to 100 miles from any large city. It would be helpful to have news media, hospitals and doctor's offices become more involved in helping people select their choices in nursing homes -- but if there are only two (fair) nursing homes in the area --

and the administrators know that paying a fine will make their problem disappear, any amount of involvement from the outside would be useless. (#100)

- There is a need to expand outreach efforts to minority groups such as Black Americans. My recommendations for expanding outreach and education to this group are as follows: Increase outreach in black churches (facility speakers, family council speakers, etc.); black newspapers could serve to educate families; black radio and tv stations; create appropriate, affordable transportation; increase awareness in the form of brochures, PSAs, etc. (#101)
- Women's groups: seminar on How to be an Informed Consumer of LTC Services; Redefining Complaints as Your Right to Participate in Your Care; Families of Recently Placed Nursing Home Residents: seminar on Everything You've Always Wanted to Know about Nursing Home Placement for Your Loved One (or you mean they didn't tell you about that?) (#102)
- Family Caregiver program offered via the AAA and hospital support groups have been very effective in reaching the community. (#106)

RESOURCES USED

Nursing Homes: Getting Good Care There

Yes: 79 Not Used: 10 Not Familiar With: 8

Avoiding Physical Restraints

Yes: 73 Not Used: 14 Not Familiar With: 7

Avoiding Drugs Used as Chemical Restraints

Yes: 64 Not Used: 18 Not Familiar With: 9

Using Resident Assessment & Care Planning

Yes: 53 Not Used: 19 Not Familiar With: 17

Where Do I Go From Here?

Yes: 32 Not Used: 26 Not Familiar With: 31

Nursing Home Life (AARP)

Yes: 47 Not Used: 22 Not Familiar With: 20

Medicare & Medicaid: Guide (HCFA)

Yes: 77 Not Used: 12 Not Familiar With: 3

Other Materials Used/Helpful

- The Role of the Ombudsman--We Can Help; Obstacles to Implementation of Residents Rights in Nursing Homes; How to Make a Complaint; Reasons Why Nursing Home Residents Do Not Exercise their Rights; Residents Responsibilities; Incident Prevention; The Family-Centered Approach to Resident Care (#1)
- AARP information very helpful but difficult to get large quantities with no resources; video Look at Me; and What to Look for in a Nursing Home (HCFA) (#7)
- We need more material on caregiving and how families can assist appropriately in nursing home care. (#9)
- Code of Maryland Regulations; Maryland.'s Reference Manual; Maryland Nursing Home Contracts; Nursing Homes: What You Need to Know. The following are dated but were used extensively: Nursing Home Reform Law: The Basics; Nursing Home Law (Training Module); Psychotropic Drugs: Meeting OBRA Requirements; also literature from "Untie the Elderly." (#10)
- As We Are Now, May Sarton's book (#11)
- Individualized Dementia Care: Creative, Compassionate Approaches, by Joanne Rader et al. -- "the best resource for an ombudsman" (#13)
- Texas Advocates for Nursing Home Residents (TANHR) brochures; NCCNHR brochures; Grief and bereavement guides (#21)
- Ensuring an Abuse-Free Environment (video); What About Me? (AARP); A Matter of Rights; Know Your Rights: Nursing Home Residents (AHCA); A Guide for Caregivers of Alzheimer's Patients, Dr. Richard Powers, University of Alabama, Birmingham (#22)
- 1995 20/20 exposé; Untold Suffering, Ila Swan; Patients, Pain & Politics (Have had several community meetings on this topic; used members of "Toastmasters" to review book) (#27)
- Consumer Reports, Aug., Sept., Oct. 1995 articles on nursing facilities; videos: Look at Me and others (#28)
- Legal Status; Choosing a Nursing Home and Making it Work for You (#35)
- Family Councils in Action, Minn. Advocacy Center (#37)
- "We use the federal bill of rights a great deal... in very large print." (#38)
- Guide on Medicare (AARP); Choosing a Nursing Home (Dept. Of Health); Senior Citizens Handbook (young lawyers) (#39)
- The Legal Rights of Indiana Nursing Home Residents, Senior Law Project; Legal Reference for Older Hoosiers, Indiana Bar Association; The Eden Alternative, William Thomas (#42)
- In-Home care materials by local council on aging; Choices: Making a Good Move to a Retirement Community, Heather Young and Rheba de Tarryay; Maryland AG Office's Nursing Homes: What you Need To Know and The Guardianship Handbook; Inside Guide to Nursing Homes, Robert Bua ("first 100 pages") (#43)
- Family Councils in Action, Minnesota Advocacy Center (#44)
- The Legal Rights of Indiana NH Residents (#46)
- Guide to Retirement Living (#48)
- Dealing with Dementia; Alzheimer's Disease: Activity-Focused Care; Overcoming Barriers to Mental Health Care; Care of Alzheimer Patients: A Manual for Nursing Home

- Staff (#49)
- Psychotropic Drugs, Keltner et al.; Psychological Foundations of Psychiatric Care, Kelmar et al.; Research & Studies at the University of Alabama; Reference books on gerontology from University of California (#50)
 - Look at Me, video; Know Your Rights, video (#52)
 - Eden Alternative books (#60)
 - Maryland publication: Nursing Homes: What You Need to Know (#61)
 - When Love Gets Tough, Doug/Manning; Living in a Nursing Home, Sarah Greene Burger; I Chose to Live in a Nursing Home, Sollenberger (#67)
 - Teach families to use nursing home inspection reports; attend care plannings when they receive notice of meetings (#69)
 - Alzheimer's publications; activities material; parent care; validation therapy (#70)
 - The Legal Rights of Indiana NH Residents (#77)
 - Advocacy group developed its own theft and loss pamphlet, geared to helping local residents navigate local laws and legal resources. (#79)
 - Partnership Beyond Restraints, videos and handouts (#84)
 - Video, No Easy Answer--Moving Beyond the Guilt; video series, Everybody Wins! (#86)
 - KABC publications: Consumer Guide to Kansas Nursing Homes; Choosing a Nursing Home; New publications on assisted living to be released Dec. '97; publications from Kansas Dept. on Aging: A Caregiver's Guide on Alzheimer's; Legal Guide; Explore Your Options; Kansas Insurance Dept.: LTC Insurance: Shopper's Guide (#87)
 - Nursing Home Community Coalition book; Choice in Dying; Statewide Senior Action Coalition (on hospital discharge); Medicare Rights Center, DFTA's on housing; Minnesota Advocacy Center's family council materials (#88)
 - Minn. Advocacy Center's family council books (#90)
 - Organization's own Guide to Choosing a Nursing Home in Louisiana; Minn. Advocacy Center's "Choosing a Nursing Home and Making It Work for You"; "Making Gray Gold," Timothy Diamond (#91)
 - AARP: Fact Sheet on Dealing with Problems in Nursing Homes; NCCNHR fact sheets; materials from state (#92)
 - Minnesota Advocacy Center's Family Councils in Action (#93)
 - Videos: Look at Me; A Matter of Choice; Right Choice, Handle with Care: An Insider's Guide to Selecting a Nursing Home, Lynn Smith; Florida Health Care reference manual, Life Styles; A Guide to Choosing a NH in Florida," Agency for Health Care Administration; The Elder Update, newsletter by the Department of Elder Affairs; Use of Restraints in Nursing Homes: A guide for Residents and Families, by Colo. Ombudsman Program and NCCNHR; About Restraints, from NCCNHR (#101)
 - Residents rights brochure from Pa. Dept of aging are the most helpful. (#102)
 - Everyone Wins!, video discussion series on restraint reduction; Incident Report, video discussion and in-service on preventing and identifying resident abuse; Know Your Rights as a Nursing Home Resident & Know Your Rights as a Personal Care Home Resident, video and booklets developed by the Penn. Dept. Of Aging (#104)
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AVAILABILITY FOR PHONE INTERVIEWS

Yes: 81

No: 17

CITIZEN ADVOCACY GROUP OR OMBUDSMAN PROGRAM

Citizen Group: 24

Ombuds Program: 82

Is Citizen Advocacy Group a Member Group

Yes: 20

No: 5

How Long Group/Ombuds Program in Existence

0-5 years: 10

6-10 years: 23

11-20 years: 47

21+ years: 15

RECEIVED FINANCIAL SUPPORT FOR FAMILY EDUCATION/OUTREACH

Yes: 26

No: 60

Financial Support Received

- Area Agency on Aging (#1)
 - AARP (#5)
 - Surcharge on licensing fee of every nursing home bed; Minn. United Way; Department of Correction (#6)
 - Two-year grant from Retirement Research Association (#9)
 - Donations from families receiving assistance; civics clubs; churches (#11)
 - Get some for community education (#18)
 - Small donations from community and concerned citizens (#21)
 - Community services block grant funds through Commonwealth of Mass. (#25)
 - Part (5%) of contributions for this (#27)
 - Nothing separate from OAA (#28)
 - Health care foundation grant to develop and print “Enjoying Your Visits to the Nursing Home” (#29)
 - Monies allocated to Elder Abuse Prevention used for family education, outreach and caregiver support. These program issues managed through ombudsman program. (#31)
 - State LTC Office (#41)
 - Grant to increase newsletter distribution and create video for community education (#44)
 - Grants to provide outreach through seminars (#49)
 - Foundation, government (#57)
 - Donations solicited while providing community education (#64)
 - United Way; donations; memorials, raffles (#67)
 - National Committee to Preserve Social Security and Medicare underwrite publication of theft and loss pamphlet. Families USA provided general support grant. (#79)
 - Private funding (#83)
 - Grants to do family council organizing (#85)
 - Minority outreach grants; family council organizing grant; grants underwriting developing and producing publications (#88)
 - Elder rights money for annual conference for community education on elder abuse/elder advocacy. (#93)
-

CURRENT/FORMER/NEVER BEEN A FAMILY MEMBER OF LTC RESIDENT

Current: 17 Former: 55 Never: 24

If current/former family member, type of facility

Nursing Home: 65 Assisted Living: 4 Board & Care: 6

Ever had close friend in LTC facility Yes: 21 No: 9

Become involved in monitoring care Yes: 18 No: 8

Type of facility

Nursing Home: 19 Assisted Living: 0 Board & Care: 0

Time involved in friend's care

Ongoing; 10 years (#19); 8 years (#20); 4 years (#23); 9 months (#24); 5 years (#49); 2 years (#50); 2 years (#60); 10+ years (#69); 11 months (#86); 1 year (#95); 3.5 months (#96); 3 months (#98); 1 year (#103)

ADDITIONAL COMMENTS

It is important to get information out to family members; most of the time when they receive information they are empowered and do try to resolve problems. They just need to know their rights and know they have a support system to turn to. (#19)

In order to have a strong and effective Ombudsman Program which will reach a large number of people, more funds need to be appropriated to the program. Funds would enable ombudsmen to attend trainings as well as purchase resources which they can use when conducting in-service trainings for the community and the staff at the board and care facilities, including nursing homes, assisted living facilities, and boarding homes. Workshops should be conducted without charge to caregivers and assist them with becoming familiar with the services provided by the Ombudsman program. (#22)

Public meetings (of the Nebraska Advocates) are held five times a year and are educational and informative. We urge people who attend to share their concerns and experiences. The Ombudsmen are our speakers a couple times a year. We have two for the whole state. Our greatest achievement has been through legislation. WE were the driving force that put the State Ombudsman bill into law. The latest was a board member was put on the committee which put the Volunteer Ombudsman program in place for the Eastern Nebraska Agency on Aging. This community has a Human Services Organization made up of staff and interested people from the various agencies. Each month a speaker from one of the agencies gives information about their activities, etc. Attendance varies from 50-75. Our organization has been invited to speak twice as well as to recommend speakers on the problems in aging. (#24)

Too many senior groups do not wish to discuss or even think about nursing homes... From the beginning of my advocacy, the focus has been on abuse and neglect of nursing home residents. My greatest tool has been the Quality Care Advocate. No one can argue with the stories on abuse you print. Mailing copies of such articles has been (to key individuals) a source of real concern...Generally speaking, my members are very intelligent, articulate, well-informed, and caring people; and that is a problem when nursing home staff, owners, and even regulators may not be... I was responsible party for my mother (4 years) and father (20 months) and mother-in-law (10 years) from 1976 to 1985 in four different facilities in search of "utopia." They were all private pay (very costly). I now deal only with Medicaid patients -- after lots of research and experience. (#26)

None of the [outreach sites/organizations] have been very effective. There is pervasive apathy and denial. Radio, TV and newspapers have been best. (#27)

The family councils with best attendance are the ones where food is served after normal working hours. (#29)

We don't have enough staff to do as much outreach as we should. (#32)

Evaluating effectiveness on outreach sites is difficult and at best an estimation on my part. (#38)

The ombudsman program is a wonderful program. But we are inundated with so many calls each day that we don't have the time to do outreach. We need to prioritize our time already. More funds should be earmarked in the Older Americans Act for the ombudsman program. We have many successes each day, and we feel we are effective -- despite our limited staff. Best response documented was to our press release about a toll-free number. (#43)

I would like to increase the number of organizations contacted. However, with a 7-county, 150+ facilities area, time is limited. (#58)

I have had many wards under court appointed guardianship. I never had a problem with quality care. My reputation as an outspoken advocate took care of that going in. This is a good example of why family and friends should speak up. The telephone and the press are your best friends. Use them!... [From question #1] Important articles always included name and phone number. Many people clipped articles for future use. Had a call recently from a lady who had saved article from 1983..... Over 200 phone calls and letters due to Consumer Reports magazine article. Good press relations vital. Telephone contact must be easy and available 7 days a week. People will call, as and learn more by phone. Many are reluctant to speak up at meetings. (#69)

How do we measure effectiveness? The only least effective site has been churches, where we get little response when asking for volunteers, but, even there, the response to informational meetings is excellent... Blue collar workers in some cases appear to have a keener sense of family values, respect issues and less tolerant of abuse/neglect and quality of care issues. (#84)

Family councils not controlled by the facility tend to be successful.... Nursing home staff tend not to attend meetings unless they are held during working hours for which they are paid. Families tend not to appreciate informative meetings unless they can tell their specific horror stories.... I personally visited or hired someone to visit my mother every day for 15 years. For ten of those years, she spent each Sunday and holiday in our home. Family members tend to look after each other's residents. While a friend went to Australia, I visited her mother each day, paid her bills, etc. She would have done the same for me. (#91)

I develop family councils almost exclusively in the form of a "first meeting" at the facility. Usually the administrations have sent out a notice and I have a good crowd. We learn about proactive family council, plan the next meeting (when the chairperson is elected), and role play how to approach other family members these persons will meet between then and now to attend that next meeting. The numbers of involved family members attending family council drops somewhat after the first few meetings... especially if an objective/even-tempered chairperson is not available. A successful council thrives if the members truly believe that the facility *belongs* to the residents and that the facility only exists to *serve* the persons that live there. When the council assumes some responsible "ownership" of the goings on at the home that's when they are successful. Otherwise, the council becomes a gripe session. Administrators or some other staff person always attends, takes notes, lectures, and family members attend because they are duty bound.. And don't want to miss anything. (#93)

Each family council member wears a badge on each visit that says, "Ask me about Family Council." Fliers are put in with monthly billings from facility. Newsletters from facility announce meeting time and place.... also worked in a nursing facility as LPN and aide. Then became DON for 3 years. (#95)

Tried a new concept, The Quality Care Council, consisting of family members and oriented residents. This experiment results from so few oriented residents in a nursing home who attend resident councils. (#98)

How do you succeed when an administrator threatens the activity director of the nursing home with her job if she makes out a list of family members with phone numbers to enable the ombudsman to ask if they are interested in forming a family council to assist their loved ones in that nursing home? (#100)

Office of Senior Services must rely on the Pa. Dept. Of Aging for funding which is woefully pitiful amounts compared to the state's expectations for the program and the program's importance to consumers of LTC services... It is so important to let consumers of long term care services know of their rights. If a person can be empowered to be an active part of the care plan process, then facility staff are less likely to treat them like a "task" instead of respecting them as a person... The Ombudsman program in Penn. Has a higher priority on investigating and mediating complaints than on education of consumers and their families. Although in theory Both roles are equally important, funding by the state does not match the state's expectations for the program...

The Catch-22 comes into play because without family and consumer education, more Ombudsman complaints are referred. If residents and families could be reached for education and empowerment, complaints could be dealt with within the facilities, as it is designed to be, as per regulation... Facilities, whether nursing homes or personal care homes, are NOT blameless. Much more effort on their part could be expended to educate families on the complaint/grievance process. It should be done as a follow-up to the mass confusion and paper-signing marathon that makes up the bulk of activities on the first day of admission. Facilities need to present this effort in a positive vein to families so it is seen as a desire on the facilities' part to encourage open lines of communication for better quality, Individualized care of its residents. (#102)

INFORMATION SURVEY: FAMILY EDUCATION AND OUTREACH

APPENDIX 3

Summary of Findings

All totaled, in mid-November 1997, the National Citizens' Coalition for Nursing Home Reform (NCCNHR) sent 101 informational surveys probing family education and outreach in long term care. Survey recipients comprised each of the 50 state long-term care ombudsmen, including the ombudsmen for Puerto Rico and the District of Columbia. The state ombudsmen were asked to forward the surveys to their regional ombudsmen known to be most directly and actively involved with families of long-term care residents. Another 49 surveys were mailed to NCCNHR's national network of citizen advocacy groups, covering a range of both newly formed and well-established grass-roots organizations.

The survey prompted an enthusiastic response, with 106 completed questionnaires returned to NCCNHR by the requested deadline of December 1, 1997, or shortly thereafter. The majority of responses (82, or 77 percent) came from regional ombudsmen and the remaining 24 surveys (or 23 percent) were returned by representatives of citizen advocacy groups.

Locating and Educating Families

Nearly all of the respondents (96, or 91 percent) reported having conducted community education programs to reach or involve family members in long-term care advocacy. More than half (64, or 61 percent) reported that they had organized, or helped to organize, a family council or a citizen advocacy group. Significant numbers of recipients also had used newspaper articles (66, or 62 percent) and television and radio appearances (52, or 49 percent). A preliminary review of the responses suggests that providing families seamless access to advocacy support and resources is vital. This includes both establishing and widely publicizing a toll-free hotline. Said one long-time citizen advocate: "Telephone contact must be easy and available seven days a week... People will call [but] many are reluctant to speak up at meetings."

Distribution of Materials

Nursing homes emerged as the most widely used venue for three forms of outreach: placing brochures, distributing educational materials, and making speeches and conducting workshops. With respect to brochures, 86 respondents said they had used nursing homes, 73 listed senior centers, and 60 reported using their own agency and organization. Respondents also reported supplying brochures to hospital discharge staff (59), assisted living facilities (51), board and care homes (43), houses of worship (33), and AARP meetings (30).

Seventy-five respondents reported distributing educational materials at nursing homes, followed by senior centers (57), and their own agency or organization (52). Eighty-one respondents reported giving speeches or workshops at nursing homes. Other prominent venues for speeches and workshops that appeared were senior centers (69 respondents), the respondent's

own agency or organization (58), and AARP meetings (42).

Of the survey's 18 possible venues, nursing homes ranked as notably worthwhile sites/organizations for conducting outreach, with 82 respondents rating them "most effective." Fifty-one respondents named senior centers as the "most effective" sites for outreach, while forty-four respondents selected hospital discharge staff as "most effective."

In contrast, doctor's offices were most frequently cited as the "least effective" venue for family outreach. Specifically, 29 respondents chose doctor's office as the "least effective" category, followed by county medical societies (15), libraries (14) and houses of worship (also 14).

Obstacles to Family Involvement

Of eight possible obstacles, respondents named "fear of retaliation" as the leading deterrent to family involvement and advocacy. Said one of the 82 respondents who selected it as an obstacle: "I only checked [fear of retaliation] because this is what stops families and residents -- everything else is secondary." Receiving the next highest number of responses was "lack of time" (72) and "lack of information" (63).

Respondents also offered "apathy" as an obstacle to family involvement, along with insufficient program resources, especially on the part of the ombudsmen. "We are inundated with so many calls each day that we don't have time to do outreach," said one. Another lamented that the ombudsman program in her state provides greater funding for complaint investigations than family education, creating a "Catch-22" situation. Said she: "Without family and consumer education, more ombudsman complaints are referred. If residents and families could be reached for education and empowerment, complaints could be dealt with within the facilities." Asked for suggestions on expanding outreach, one ombudsman replied bluntly: "Give us more staff," relaying how 1.5 paid ombudsmen in his program oversee the well-being of residents and their families in 96 nursing homes and more than 800 other long term care facilities.

Emotional fatigue also discourages involvement, according to the survey. Some families, said one respondent, "are burnt out from caregiving... and now want to pass all caregiving on to LTC facility staff." And, "frequently," said another respondent, "families are under so much stress that they can't stand any further involvement." Some are "torn by other family responsibilities," explained one respondent, noting how a once-active family member became inactive when her husband developed cancer. "She was not able to be as strong an advocate for her mother and other residents when she was caring for her husband full-time," the respondent wrote.

Common Reasons for Avoiding Involvement

Asked to name the most common reasons families give for not becoming involved in monitoring the quality of a loved one's care, respondents answered "lack of time" most frequently (79 respondents). Again, "fear of retaliation" (71 respondents) emerged prominent. Families, said one ombudsman, "fear rocking the boat. They believe staff will take it out on their loved one, and they also believe nothing will be accomplished." Another common reason cited by a significant number of respondents (57) was "lack of knowledge." Wrote one respondent: "The greatest barrier I run into is ignorance." Another survey participant stressed the potency of good outreach

and education: “Most of the time when [families] receive information they are empowered and do try to resolve problems. They just need to know their rights and know they have a support system to turn to.”

Key to overcoming obstacles and excuses for non-involvement is providing perks, according to some respondents. This includes enticing participation with fish fries, family pot luck dinners, entertainment and guest speakers. “The family councils with the best attendance are the ones where food is served after normal working hours,” explained one respondent. Another suggested hosting events that focus on financial planning and other “non-threatening” issues prior to arranging more advocacy-oriented initiatives. That, she said, “brings people in and together -- once you can get them together the rest is easier.”

Effective leadership also ranked high among respondents, who cited it as a basic staple to effective, organized involvement among families. Too often, said one respondent, families lack experience “confronting authority.” Others “feel unnecessarily intimidated by medical situations... and devalue their own experiences and knowledge of what is ‘good care.’” Good leadership is key to overcoming the “you can’t fight city hall mentality,” said another respondent, stressing the need for offering specific training and amassing success stories.

Family Member Profiles and Characteristics

Being in the vicinity of a relative in a long-term care facility proved to be the most positive indicator of family participation, according to the survey. The greatest number of respondents (71) selected “lives in facility proximity” as a factor under the category of “most likely” to become actively involved. The next most frequently cited characteristic indicative of family involvement was “retired” (62), followed by “encountered problems in a LTC facility” (61), “age 60+” (52), and “white” (52). The latter, according to one respondent, simply reflects the narrow makeup of the nursing home population. “Since 80+ percent of people in nursing homes are white, participants are more likely to be white.... for low-income African Americans, nursing home reform isn’t the most pressing issue.” Another respondent said that race and ethnicity are less powerful indicators than whether a family member either 1) has adapted to American culture or 2) can communicate and identify with the person doing the outreach.

“Whites, African Americans and Hispanics and other minorities are most likely to get involved if they are the most Americanized. They are the least likely to get involved if there is a language barrier; and they are the most likely to get involved if there is substantial presence in the organization of the same [ethnic or racial] group,” she wrote. “Ethnic minorities are most responsive if the outreach is in their own language and by a person of the same group, whether or not language is a barrier.”

One respondent noted that people working in the field of long-term care are most likely to get involved in advocacy efforts. However, underrepresentation of minorities in the field of aging raises additional obstacles, according to one respondent: “Often this translates into many minorities not having the knowledge base or required information to access services relative to their well-being.”

Family participation seems to increase with age, according to the survey. The characteristic in the category “least likely” to get involved receiving the highest number of responses was “under age 40” (54), followed by “unemployed” (35) and “enjoyed positive

nursing home or LTC experience” (23).

The survey’s questions about the educational backgrounds of family members appeared to perplex -- and exasperate -- some respondents. “Education does seem to correlate with involvement but I’m not sure where the cutoff is. Too little education means less likely; but at some point, more education does not mean more likely involvement.” Another wrote: “I don’t believe educational level has any impact on involvement. You don’t have a category for religious background, family values, or moral ethical standards. These are more important than any of the factors you list.”

A number of respondents underlined the importance of reaching out to women’s groups. One respondent reported that a 1996 symposium AARP convened revealed strong interest in long-term care advocacy among the leaders of national women’s organizations -- but a weak grasp of the issue. “Women care about the issue,” she wrote. “We must provide information and organizing assistance to make their voices heard.” One respondent recommended that advocates target the League of Women Voters in their community, noting that these women often take on valuable projects, receive ample press, and work at the local, county and state level. Another respondent suggesting approaching a women’s group, like the American Association of University Women, for support on a specific project or task.

Resources

The survey probed respondents’ use and familiarity with a sampling of NCCNHR and other resources. Seventy-nine of the respondents reported having used NCCNHR’s consumer manual, *Nursing Homes: Getting Good Care There*. More than half of the respondents also had used NCCNHR’s companion consumer booklets, *Avoiding Physical Restraint Use* (73) and *Avoiding Drugs Used as Chemical Restraints* (64). Forty-seven respondents had used AARP’s *Nursing Home Life: A Guide for Residents and Families*. Many offered that they heavily relied on the manual *Family Councils in Action* and other materials produced by the Bloomington, Minn.-based Advocacy Center for Long Term Care. Videos also proved valuable resources, including *Look at Me*, produced by the U.S. Department of Veterans Affairs, and *Everybody Wins!: A Family Guide to Restraint-Free Care*, a video series produced jointly by the Kendal Corporation, the American Health Care Association, and the American Association of Homes and Services for the Aging.

Funding for Family Outreach

Many respondents were uncertain when asked whether their program had received special funding for family education and outreach activities. Twenty-six reported receiving funding, while 62 replied they had not received money for such purposes. Of those who had secured some funding, replies ranged from Minnesota’s unique licensing surcharge for resident and family council development to the United Way to grants from private foundations. Others noted funding from their area agency on aging, Older Americans Act monies intended for Elder Abuse Prevention, donations, and support from national nonprofit organizations.