

**National Citizens’ Coalition for Nursing Home Reform
Maryland Family Council Project
Preliminary Report of Survey Results**

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National Citizens' Coalition for Nursing Home Reform Maryland Family Council Project

Report of Survey Results

Introduction

Family interest, concern, and involvement in nursing homes can be an important component of assuring quality of care for residents. One vehicle for this participation and involvement can be effective and active family councils in nursing homes. The 1987 Nursing Home Reform Act¹ guarantees the families of nursing home residents a number of important rights to help them improve a loved one's nursing home experience and facility-wide services and conditions. One of these rights is the right to form and hold regular and, when desired, private meetings of an organized group called the family council. Federal regulations² require that facilities certified for Medicare and Medicaid must provide a meeting space, cooperate with the council's activities, and respond to the family group concerns. Nursing facilities also must appoint a staff liaison to the family council, and staff and administrators have access to council meetings - at the group's invitation.

In January 2000, the National Citizens' Coalition for Nursing Home Reform (NCCNHR) received support from the State of Maryland Department of Health and Mental Hygiene, Office of Health Care Quality to carry out a project promoting the establishment and effectiveness of family councils in Maryland nursing homes. Building on information gathered in a previous nationwide survey,³ in February 2000, NCCNHR conducted a survey of family members, ombudsmen, and nursing home facility personnel in Maryland to gather information about their particular experience working with family councils. The findings of the two surveys are similar in many respects. The survey identified many obstacles to family council development as well as many successes and positive contributions made by family councils (see "Family Council Successes," page 15).

Survey Responses

The Maryland survey was mailed to all nursing homes (257) identified by the Maryland Office of Health Care Quality, all local ombudsmen (19), and a small number of family members (37) of nursing home residents with whom NCCNHR has had previous contact or who were identified by recipients of the survey. A total of 313 surveys were mailed, and 167 responses were received. Follow-up mailings were made to both ombudsmen and facility administrators, to encourage maximal participation. Fourteen or 74% of 19 local Maryland ombudsman programs responded to the survey. Nine ombudsmen responded to the initial, detailed survey, three ombudsmen responded to a shortened form, one page survey, and two ombudsmen responded to the survey with phone calls. One hundred and thirty facilities or 51% of 257 total Maryland facilities responded. Twenty-three family members, or 62% of the family members

¹ Public Law 100-203, Social Security Act, 42 USC, Sec. 1396r, Sec. 1395i-3

² 42 CFR sec. 483.15 (c)

³ "Family Education & Outreach Final Report," National Citizens' Coalition for Nursing Home Reform, December 1997.

who received the survey, from nine different facilities also responded.⁴ The president of one family council shared the survey with other members of her council, and several (10) responded giving in-depth information about one particular family council. Also, respondents did not always answer every question or checked multiple boxes on some questions, so the total number of responses to individual questions varies.

The facilities that responded to the survey had the following characteristics:

Location	Suburban	Rural	Urban
# of Facilities	61	40	27

Structure	For-profit	Not-for-profit	Government-operated
# of Facilities	66	55	5

Payment	Medicare and Medicaid	Medicare only	Medicaid only	Neither Medicare or Medicaid
# of Facilities	113	5	9	1

Limitations of the Study

One limitation of the survey is the small number of family members of nursing home residents surveyed and the disproportionate number of family member respondents from one facility. Although this is a small sampling of families, the information family members provided is relevant and important. The disproportionate number of respondents from one facility affects the results because those respondents had experience with just one ombudsman and one facility. The ombudsman who worked with this particular family council was very supportive of their efforts and dedicated to the concept of family councils in nursing homes. NCCNHR will gather and report on further information from family members of nursing home residents throughout the project period.

A second limitation of the survey is that less than half of the ombudsman respondents filled out the long survey providing detailed information about their work with family councils. Though the information provided is useful, descriptive and a good basis for continuing study, it may not provide a completely accurate picture of ombudsman activity with regard to family councils.

The results of the survey will serve as a foundation for continuing to gather and report on information in areas such as successful family council activities, obstacles to family councils, ombudsman best practices in working with family councils, and the role that ombudsman programs and the survey agency play in supporting, hampering, or discouraging family council development.

Prevalence and Conduct of Family Councils in Maryland Nursing Homes

Though each family council is unique in its structure and the way it functions, advocacy groups with experience in promoting family councils report that a council's ability to operate independently of facility control is important in enabling it to advocate effectively for

⁴ Although this is a small sampling of families, the information provided is valuable. The large number of respondents from one facility is important to note when considering some of the results contained in this report. NCCNHR will gather and report on further information from family members of nursing home residents throughout the project period.

improvements in quality of care. Survey respondents reported various reasons why some family groups in nursing homes lack this independence. In some cases, family members are reluctant to take on responsibility for leadership. In other cases, the nursing home attempts to manage or control the council or discourage council autonomy. Related to the topic of family leadership and family council independence, the following survey findings, which show that the majority of family groups in Maryland facilities are facility-directed, are important to note.

Forty-two percent (55) of the facility respondents reported having a facility-directed family group in place, with 34% (44) reporting that there is no family council or family group at their facility. Fourteen percent (18) of the facility respondents reported that the family members of residents at their facility have organized a family-directed family council. Six percent (8) of the facility respondents reported that they have both a family-directed family council and a facility-directed family group.⁵ Another six percent (8) reported that they had other types of family groups or communication in place.

The survey attempted to determine the extent to which facility personnel believe the family councils or groups that are in existence are effective contributors to the nursing home community. Facility respondents were asked to assess the effectiveness and activity of the family council or group at their facility if one exists.

- 41 indicated that the council meets regularly, but does not attract many family members
- 12 indicated that the council/group meets regularly and many family members attend
- 14 indicated that the council is active and contributes importantly to the overall quality of facility life
- 15 indicated that the council meets regularly, but does not contribute significantly to the quality of facility life

These findings suggest that, from the perspective of facility personnel, family councils and groups are difficult to establish and that the groups that are in place struggle to attract family members and to be effective contributors to the nursing home community. An overall assessment of family council/group effectiveness and activity was not requested from ombudsmen and family members, however, these groups of respondents did supply information on obstacles to family councils and family council successes (see below).

Because one of the focuses of the family council project is to help existing councils be more effective, the survey attempted to determine which councils presently in existence could use assistance from the family council project. Sixteen facility respondents indicated that the council/group at their facility could use some extra help in organizing and maintaining its activities. Four respondents indicated that their facility's council/group is successful and could be used as a role model for other facilities. Nine facility respondents indicated they were not able to assess the family council/group at their facility at this time. Some felt that they could not currently assess the family council because it has only recently been established, or it is currently inactive. One facility respondent noted that the family council at her facility "is growing, and we continue to try new ideas for continued growth."

The survey also requested information on the frequency of meetings for family councils or groups in existence. Facility respondents reported the following frequency of meetings:

⁵ This unusual circumstance will be explored further in future reports as the project progresses.

Family Council/Group Meeting Frequency

Frequency of Meetings	Number of responses
Once every two weeks	1
At least once a month	25
At least once every two months	10
Quarterly or less	36
Once every six months	1
Meets infrequently	2

The information gathered on meeting frequency is significant because frequency of meetings can have a significant impact on group success. In order for family councils to have continuity and cohesion, and to be effective tools for open communication and advocacy, meetings must be held regularly. For many successful family councils, “regularly” means at least once a month. Frequent meetings enable the council to communicate continually with the facility, act on concerns and projects, and begin to feel progress toward goals. As the information displayed above indicates, more than half of the existing family councils and groups at Maryland nursing homes now hold meetings on a quarterly basis or less frequently.

Participation of Family Members in Family Councils and the Nursing Home Community

Another important factor in the viability of a family council is the extent to which residents’ family members are involved in their loved ones’ lives and care. Some facilities reported that all of the residents at their facility have regular contact with family members. An additional 84 facilities reported that at least 60% of the residents at their facility have ongoing contact with family members. However, other facilities (11) reported that more than 60% of the residents at their facility have little or no contact with family. Eighty-six facility respondents reported that less than 10% of the residents at their facility have no family members whatsoever, however five facilities reported that more than 20% of their residents have no family. These percentages are important to consider when assessing the level of family member participation in a council.

The reported percentage of participation in family councils or groups by family members at facilities varied, with some facilities reporting that arranged meetings drew no family participation and others reporting participation rates as high as 50 percent. Most facility respondents reported participation rates of 15 percent or less, some between 15 to 30 percent, and just two facilities reporting participation rates between 30 and 50 percent.

Low participation rates can be an obstacle to the capability, functioning, and influence of family councils. However, considering the notable percentages of little or no family involvement in the nursing home, family council participation rates of 10 to 15 percent are at least a solid foundation for improving communication between families and the facility and promoting greater participation.

Family Council Participants

Ombudsmen and family members surveyed were asked to provide information about the make-up of family councils and some of the factors that may influence individual family member participation in a council. Responses to these questions varied widely. Despite the generally

varied responses, ombudsman and families responded consistently in a couple of areas. The majority of respondents identified that family members aged 40 and over were most likely to get involved in a family council and under age 40 were least likely to get involved. Also, a substantial majority of respondents indicated that families of residents with care paid for by Medicaid or paid for privately were more likely to get involved in a family council than a family member of a resident with care paid for by Medicare. Residents with care paid for by Medicare traditionally have short-term stays in nursing homes, giving family members less time to become interested and involved in a family council. Most ombudsmen and family respondents also consistently indicated that the families that are most likely to get involved in a family council are those who have encountered problems with a nursing home or who have suffered neglect or abuse of a loved one.

All respondents identified that living in close proximity to the nursing home is an important factor enabling family council involvement. Some facility respondents indicated that the family members of all the residents at their facility live within commuting distance of the nursing home. However, many facility respondents estimated that as much as 25% of the residents at their facility do not have family members in close proximity, and others estimated higher percentages up to 71%.

One family member commented, "It would be very hard to develop a general profile. A family member perceiving a 'crisis' is most likely to get involved."

Diversity in Family Councils

Many times when a community group joins together for a common purpose, diversity is an important issue to consider. Different skills, opinions, ways of communicating, cultural backgrounds, languages, and racial identities all present challenges and opportunities in group formation. When these differences are recognized and individual differences are accepted and supported, they can foster group strength and vitality.

In response to the survey question to ombudsmen and family members about whether the resident populations in Maryland nursing homes were ethnically or racially diverse, 12 of the 23 family respondents from 5 different facilities said that the facility resident population was ethnically or racially diverse. Of the twelve family member respondents who indicated that resident populations were ethnically or racially diverse, six family members from four different facilities responded that the family council was proportionally ethnically and racially diverse. Several family members disagreed with the basis of this question because they indicated that they do not think diversity affects family council participation because all the families have the same concerns and participate or don't participate regardless of ethnic or racial differences.

Six of the ombudsman respondents indicated that in the facilities where they work, the resident populations were ethnically and/or racially diverse, but said that they did not think that all ethnic and racial groups participate proportionally in family councils. One ombudsman identified language barriers for some Hispanic and Asian families as a barrier to participation.

Family Council Outreach, Education, Recruitment, Promotion

One of the primary challenges in family council development, maintenance, and effectiveness is initiating and maintaining family member participation. Family councils gain vitality if the family members of many residents participate and contribute their points of view. However, as residents leave the facility for various reasons causing the membership and

leadership of the council to frequently be in flux, maintaining family member participation is not an easy task.

Acknowledging these difficulties, the survey asked family and ombudsman respondents to share information about the strategies they use to contact family members to encourage family council formation and involvement. Several ombudsmen reported that they most frequently contact family members by attending and speaking at facility-run functions (6); or by encouraging family members who call with complaints to organize a family council at their loved one's facility (6). Ombudsmen also reported that they try to encourage family council formation and participation through personal invitations (3); posting notices at nursing homes (2); including a notice in facility mailings to family members (3); conducting educational programs in the community (2); and through training ombudsman volunteers to encourage and support family councils (1). The ombudsmen who completed this part of the survey indicated that they felt that the most effective methods of outreach are to attend and speak at a facility-run family meeting; encourage family members who file complaints to organize a family council; and to personally encourage family members to attend meetings.

Several ombudsmen (5) indicated that they distribute educational materials and/or make speeches or provide workshops about family council formation at nursing homes. One has made speeches on this topic at local/state AARP meetings, and another ombudsman has done similar work at senior centers. Another ombudsman has promoted family councils at the Commission on Aging, while another promotes the idea within the ombudsman program in her presentations to ombudsman volunteers. Of the ombudsmen who completed this part of the survey, two indicated that they considered nursing homes to be the most effective places for outreach, with senior centers or ombudsman program meetings being second, and local/ state AARP meetings third.

The family members surveyed were also asked to provide information about their outreach and recruitment activities. Family member respondents reported that they most frequently posted notices at the nursing home (21) or personally invited family members to attend meetings either by phone or face-to-face (19) to promote their meetings. Family respondents also reported that they put notices in the nursing home's newsletter (10); mailed letters to a mailing list of families (4); used a membership committee or membership chairperson to promote the family council (3); and publicized the group in local newspapers, periodicals, television or radio (2). One family member indicated that council members posted notices on cars outside of the nursing home (1). One family council uses "wing contacts" to promote participation wing-by-wing in a large facility. Another family council produced a brochure for family council members to hand out and requested that the facility include it in the admission packet. Reportedly, the facility did not act upon the family council's request. Finally, a family council asked the ombudsman to recommend their group to other family members who contact her. She did this and several families that she advised of the existence of the family council then contacted the family council chairperson.

Family members shared the following suggestions for other ways family council participation can be increased:

- Conduct a statewide outreach campaign promoting family councils
- Enable family council members to participate in facility meetings about policy and procedures
- Use facility copy machines for duplication of family council materials and fliers
- Send out regular updates to family members

- Sponsor activities such as a tea, a cookout, a flea market
- Sponsor an open forum for airing concerns
- Have a council member “on duty” in the lobby once a month, preferably on a Sunday, to welcome families and hand out brochures or announcements explaining the council
- Make public announcements on radio and television about meetings
- Provide name tags for meeting participants
- Begin and end meetings on time
- Include discussion of concerns in meetings

Ombudsmen offered the following ideas for reaching family members and promoting the establishment of family councils:

- Identify a specific task or idea that all families and residents would be concerned about and discuss it at the first meeting
- Use a phone tree for special situations
- “Walk the halls” at varied times with handouts about family councils
- Supply family council information to family members who are outspoken, but who are also constructive in criticism, and encourage them to contact other families

Two of the challenges in family council recruitment and outreach can be the transitory nature of a resident’s stay in a nursing home and the emotional exhaustion that can accompany the experience. The survey attempted to determine what had caused family member respondents who had been, but are no longer involved with a family council, to cease their participation. Several family members who are no longer involved in a council indicated that either their own loved one or the leader of the council’s loved one died or left the facility. Another family member reported that some members of his family council stopped participating because they were exhausted by the effort of overseeing their loved one’s care. One family member reported that the facility had discouraged the family-led family council when the leader’s loved one died and she was no longer at the facility.

Facility respondents provided information about their own efforts to promote the establishment and maintenance of a family council. Facility efforts were tallied as follows:

Facility Actions Supporting Family Council Development

Facility Action	Number of Respondents
Provided space for the group to meet	71
Allowed family members to post notices to publicize meetings	33
Allowed family members to put information about meetings in a facility newsletter	31
Included information about the family council in admission packets	30
Made a mailing list of family members available to the family council to communicate with other family members	20
Some other action	19

Examples of other actions taken by facilities to facilitate the formation of family councils are: provide refreshments, lunch or dinner; secure speakers; make department heads available for meetings; mail letters/minutes/invitations for the council; staff put information about the family council in the newsletter; try events such as “Teatime with the Team” to spark interest; invite family members to speak and pick presentation topics; and conduct surveys to determine interests and convenient meeting times. Also, a social worker followed up on suggestions or concerns identified by the family council and reported back to the council. Several of these actions, such as providing space for the group to meet, and designating a staff person to provide assistance and respond to written requests that result from group meetings, are consistent with the federal requirements pertaining to family councils in nursing homes.

Financial Support for Family Councils

Two family members indicated that their family council had received some financial support from the nursing home for their activities. One other family member reported that her family council receives dues from members for this purpose. None of the local Maryland ombudsman programs reported having received financial support for family council education and outreach. However, since the survey was done, one local program has employed a staff person part-time to work exclusively with family and resident councils.

Support for Family Councils from the Ombudsman Program

Because family members may be overwhelmed by their loved one’s admission to a nursing home, and may not be knowledgeable about the laws and regulations applying to nursing homes, ombudsmen can be an important support for family council formation and an important outside contact for existing family councils. Acknowledging this important role, the Older Americans Act, as amended in 1978, outlined in the duties of local ombudsmen that they should “support the development of resident and family councils.” This project survey attempted to gather specific information from ombudsmen and family members on what family council support family members receive from the ombudsman program. Eleven of the 14 ombudsman respondents reported that their programs have been involved in assisting family members in forming or maintaining family councils. Six ombudsmen reported that “lack of staff” prevents them from pursuing more family council work and one reported that lack of financial resources acts as a barrier. Two ombudsmen cited lack of response from families as the primary obstacle to their efforts to promote the establishment and effectiveness of family councils in nursing homes.

Sixteen of the 23 family member respondents from six different nursing homes said that they had received assistance from the ombudsman program for their family council activities, four indicated that they had not. The ombudsman support documented in this survey was provided by two ombudsmen and one ombudsman volunteer in five of the six nursing homes. This distinction is important to note because the activities of these individuals may or may not represent the activities of ombudsmen across the state. Of the family members who reported receiving assistance from the ombudsman program, all reported that they made the first contact with the ombudsman program.

The support offered by ombudsmen was varied. Family member respondents reported that ombudsmen attended meetings for support, gave guidance and advice, answered questions, helped the council to get answers to questions from facility management, and gave the council information on federal and state laws and regulations.

The family members who did receive support from the ombudsman program indicated that the support had been crucial in getting a family council established and helping it to be effective. Family members suggested several important actions an ombudsman can take to support and foster family council development. (See Attachment A, page 23) One family member commented, “We could not have done it without our ombudsman. We lacked the information and knowledge about our rights and nursing home regulations.” As Attachment A indicates, one of the most important roles an ombudsman can play is to empower families by providing education about laws applying to nursing homes and specifically to family councils.

Another family member respondent commented on her frustration with the ombudsmen assigned to her loved one’s facility: “Two volunteer ombudsmen attended a facility-controlled family meeting and neither one voiced publicly any concern when the facility director referred to the meeting as the family council. Neither would, although asked by families, announce that another family-controlled family council existed.” Several ombudsman (6) respondents indicated that they had not distributed materials to family councils informing them of the federal regulations pertaining to family councils. Two other ombudsman respondents indicated that they had done this.

Several ombudsmen agreed that ombudsman support can be important in family council formation and effectiveness. Ombudsmen identified several best practices for supporting and fostering family council development as well. (See Attachment A, page 23)

Support for Family Councils from Facility Personnel

Other potentially important elements in the success of family councils are support from the facilities and openness of the facility to the suggestions and contributions of family members. Therefore, the survey attempted to gather information on the influence of facility support on family councils and what kinds of support can contribute to a successful family council.

About half (10) of the family members from seven different facilities indicated they had received support and assistance with family council activities from facility personnel. One respondent reported that the facility had been supportive initially, and then the support had waned. Two family respondents noted that the facility had opposed their efforts. One of these respondents reported that “they (the facility) discouraged it and said it had been tried before and failed.”

Family members who reported that the facility had provided assistance reported the following kinds of assistance: assigned a staff member to act as a liaison (6); informed the family council of their rights (4); provided the family council with educational materials (2) and technical support (2); and helped with arranging speakers (1). Two respondents said that facility staff had planned and run the meetings. One respondent said that a facility staff person had planned and run the first meeting only. Another respondent said that the facility had arranged for key staff people within the facility to meet with the council to discuss concerns.

Many facility respondents indicated frustration that their efforts to promote family council development at their facility have been unsuccessful or only marginally successful, and drew little response from family members. Both ombudsmen and family members provided suggestions about important actions facilities can take to encourage family councils (See Attachment B, page 24). Family member respondents, especially, provided some very valuable insight into what kind of facility practices can support and foster family council development. The first message that was repeated again and again by family member respondents was “Be open” and “Listen”. The second important point made by family member respondents was the importance of seeing some facility action or receiving a facility response to their efforts. The

third common point was for facilities to show their support and encouragement for the council. Many family members acknowledged the need for dialogue and interaction with the facility and encouraged staff and administrators to attend family council meetings when they are invited in order to give and accept constructive criticism and suggestions.

One facility respondent wrote, “I took a very proactive approach and began talking with families, sending out surveys, and finding out what they wanted out of a family council. The response I got was simple – they wanted resolution when they brought up problems and companionship and support from one another.” One family member respondent encourages facilities to “Be available to answer and hear concerns of the council and act on them in a positive manner. Be interested in our meetings and willing to work together to resolve issues that may arise. Do not act as though we are working against them but working with them even if it means that sometimes we have to bring their attention to shortcomings.”

Many facility respondents indicated that efforts to establish a family council had failed because meetings turned into complaint sessions. However, survey information received from other facilities, family members, and ombudsmen illustrated that family councils that start off with disjointed presentations of individual concerns can be encouraged to meet privately and to identify common concerns and concrete suggestions for problem solution to present to the facility. When the facility makes a sincere effort to address the common concerns, the “complaint session” can turn into a valuable opportunity for relationship-building between families and the facility and a valuable tool for improving the quality of life and care for residents in the facility.

Support for Family Councils from the Survey Agency

Several respondents indicated that support from the survey agency for the rights of family councils in nursing homes can be important for the success of family councils. If facilities know that the survey agency seriously considers the issues identified by family councils and actions taken by the facility in response to these issues, then facilities may, in turn, take family council recommendations seriously and act upon them. Family councils will become more widely used by family members if they see that their involvement leads to positive changes. Family councils can identify issues and prompt improvements in a non-regulatory way provided that they have regulatory support. Family council involvement can be a useful non-regulatory supplement to support the continual implementation of quality standards in nursing homes.

From the point of view of family member respondents, the most important actions the survey agency can take to support family council development are to a) apply pressure to the facility management to provide support to family members and act on family council recommendations, b) provide training on information needed in complaint filing, c) advertise the role of the survey agency, and d) include a family council member in the facility’s exit survey. One family member indicated she found it very useful when a surveyor convened members of the family council during the annual survey. Another suggested that surveyors be trained in how to work with family councils.

Obstacles to Family Council Development

Many family council successes and best practices were identified in the responses to the survey. However, the responses make clear that there are numerous obstacles to family council development in Maryland nursing homes. In this part of the survey, ombudsmen and family members were asked to indicate obstacles to family council development based on their personal

experience and to indicate the reasons that family members give for not participating in family councils.

Ombudsmen indicated that, *in their personal experience, the greatest obstacles to family involvement in family councils* are:

Obstacles to Family Council Development - Identified by Ombudsmen

Obstacle	Number of Ombudsman Responses
Family members lack time	6
Family members lack interest	4
Family members fear retaliation	3
Facilities have other functions or groups that compete with the council	2
Family members have difficulty getting names of other family members	2
Family members lack information and education	2
Resistance from nursing home personnel	1

Two ombudsmen identified “the amount of time it takes [for family members] to really be involved” as an important obstacle to family council participation. Another ombudsman, who previously worked as a social worker in a nursing home, commented, “As a previous leader of a family council meeting, it was always difficult to get families to return and be proactive, instead of limiting themselves to criticism and anticipating immediate results.” Related to ombudsman work with family councils, one ombudsman indicated that “lack of education and support from the state on how to proceed” was a barrier to family council work by ombudsmen.

Ombudsman respondents indicated that, from their experience, the most common *reasons family members give for not becoming or staying involved in a family council* are:

Family Reasons for Not Being Involved in Family Councils - Reported by Ombudsmen

Family Reason for Non-Involvement	Number of Ombudsman Responses
They feel it won't do any good	6
Lack of time	6
Fear of retaliation	2
Personal illness	2
Distance from the nursing home	2

Other reasons for lack of participation by family members that ombudsmen reported were the following: “Resident dies or resident ‘has no problem’ and family doesn’t want to create one (i.e. retaliation),” “Frustration – nothing accomplished in the past,” and “Families are overwhelmed, burned out.”

Family members indicated that, *in their own experience, the greatest obstacles to obtaining and maintaining family council involvement* are:

Obstacles to Family Council Development - Identified by Family Members

Obstacle	Number of Family Member Responses
Family members fear retaliation	15
Family members lack interest	15
Family members lack of information or education	12
Difficulty getting the names of family members	11
Resistance from nursing home personnel	10
Family members lack sufficient time	6
Competing facility activities such as family support groups or other facility-run family meetings	2
Family members lack support from the ombudsman program	1
Family members lack support from the survey agency	1
Family members lack financial resources	1

Some family members were more specific in their answers. One said that the facility allowed the forming of a family council, but didn't want to hear about any problems. Another reported that family members lack interest because the family council is facility-controlled. He commented that "Family members lack interest because it's run by the facility and is the facility's soapbox." Two family members identified that feelings of hopelessness prevent some family members from becoming involved. Another family member identified the difficulty finding meeting times that are acceptable for all the members as an obstacle to family council participation. One family member commented "Currently we are not experiencing resistance. However, during the tenure of an earlier administrator, we were granted space for meeting but she made it apparent that she felt that views expressed by the family council were not representative of those of family members in general and that, in effect, we were a group of malcontents."

Family respondents indicated that, in their experience, the most frequent *reasons family members give for not becoming or staying involved in a family council* are:

Family Reasons for Not Being Involved in Family Councils - Reported by Family Members

Family Reason for Non-Involvement	Number of Family Member Responses
Fear of retaliation	17
They feel it won't do any good	15
Lack of time	12
Lack of information or education	6
Distance from the nursing home	5
Personal illness	2

It is important to note that both categories of respondents reported that a reason family members frequently give for not becoming or staying involved in a family council is the feeling that "it won't do any good." This obstacle to family council participation can be addressed through meaningful action taken by the facility to address family council concerns and good communication between the family council and facility about the impact of the family council on facility life. Also, in cases where the facility refuses to recognize a family council or refuses to

listen to and act upon group concerns identified by the council, support from outside agencies such as the ombudsman program and survey agency to compel the facility to work with the family council can be important in ensuring that family councils are effective.

Keeping in mind that the number of family member responses in this preliminary study are small, there appears to be a difference between the way families and ombudsmen view obstacles to family council development. While only 5 ombudsman responses identified “fear of retaliation” as a significant obstacle or a reason that family members commonly give for lack of involvement, “fear of retaliation” was ranked first in both categories of family member responses as an obstacle to family participation in family councils. This is an important finding, and one which is consistent with the findings of NCCNHR’s previous survey⁶ in which “more than three-quarters of the participants ... named ‘fear of retaliation’ as a deterrent to family involvement.” Retaliation can take the form of something hard to document such as staff intentionally taking longer to answer calls for help or to act upon requests, or actions as blatant as limiting a family members visitation with the resident or attempting to discharge the resident. This issue will be explored more fully during the remaining project period.

Facility Practices

In order to take action to facilitate positive and constructive family council development, it is important to collect information about what specific practices act as obstacles to family councils. According to ombudsman respondents, *practices by facility personnel that create the greatest obstacles* to family council development are that some facility personnel:

- See the family council as adversarial and members as ‘troublemakers’
- Refuse to send out letters to families regarding the council
- Do not provide addresses of family members
- Pit families against each other
- ‘Dictate’ times and days for meetings
- Position a staff member at the family council meetings without an invitation by the council
- Refuse to allow publicity by the council
- Provide meeting rooms that have no privacy
- Become discouraged by low turnout for meetings at the beginning

Family member respondents also provided feedback about their experience with *practices by facility personnel that create the greatest obstacles* to family council development and effectiveness. Family members report that some facility personnel:

- Insist that a staff member monitor meetings (indicated by family councils from two different facilities)
- Do not provide space with privacy for the family council to meet
- Give the “cold shoulder” to council members
- Create an adversarial relationship between staff and the family council

⁶ “Family Education & Outreach Final Report,” National Citizens’ Coalition for Nursing Home Reform, December 1997. Identified barriers to family councils included fear of retaliation among family members, interference or lack of support from facilities, lack of support from ombudsman and regulatory agencies, the transitory nature of resident stays at nursing homes, and lack of family involvement.

- Refuse to recognize the family council
- Organize a competing facility-controlled family group
- Try to intimidate family members
- Avoid the truth about facility operations and personnel misconduct
- Provide no action on concerns
- Do not share information
- Require in-house refreshments and then charge for them
- Do not cooperate on publicizing meetings or the existence of a family council

Ten of 23 family respondents from 5 different facilities said that they had encountered resistance to the creation of family-run family councils from facility personnel. Two family members reported that posters advertising council meetings were repeatedly taken down at the administrator's direction. Another family member commented that, "Management tried to make the family council out to be the bad guy with staff by refusing to make improvements unless we gave them specific examples of staffing problems and then when we did they told the staff the family council was after them." Another family member commented that what her family council had experienced was "not necessarily resistance, but more lack of response to issues raised." Finally, another family member reported that, at a facility with a pre-existing family-led family council, the "director wrote a letter to each family stating that he would lead the council. It would meet at 3 p.m. on a certain day each month."

It is important to note that some of these practices, such as insisting that a staff member monitor family council meetings, failing to provide private space for family council meetings, and refusing to recognize the family council are violations of federal regulations applying to nursing homes.

Ombudsman Practices

The survey sent to ombudsmen and family members also provided space for respondents to comment on what obstacles may result from practices by those more peripherally involved in the facility such as ombudsmen and the survey agency. Ombudsman and family respondents were first asked to comment on any practices by ombudsmen that create obstacles to family council development. Ombudsman respondents cited the following as *practices by ombudsmen that create obstacles* to family council development:

- Lack of material or creativity to help spur council formation and productive family council functioning
- Ombudsmen taking leadership of the council
- Ombudsmen creating an adversarial relationship between the family council and facility staff
- Unwillingness to be involved
- Lack of time to properly address the issue due to part-time staffing and inadequate funding
- Ombudsmen becoming a scapegoat for the family council

One family member cited ombudsman violations of trust and confidence as a practice by ombudsman that may create an obstacle to family council development. Another family member

mentioned ombudsmen not distinguishing between family forums and family councils for family members as a practice by ombudsmen that creates an obstacle.

Survey Agency Practices

Ombudsman and family respondents were also asked to comment on practices by the survey agency that create the greatest obstacles to family council development. According to ombudsmen, practices by the survey agency that create the greatest obstacles to family council development are 1) unwillingness to ‘read between the lines’ when advised of facility interference with family council formation/activities, and 2) perceiving council members as complainers who lack credibility or reliability.

One family member related that the survey agency failed to back up the family council’s right to post signs in the nursing home.⁷

Overcoming Obstacles

There are concrete steps that family members and others can take to address and overcome some of the obstacles that impede family council development. Both ombudsman and family respondents provided useful suggestions of strategies and tools they have used in their family council work. Generally, ombudsmen emphasized the importance of communication, leadership, organization, constructive discussions and action in their suggestions. Family members emphasized the importance of privacy, self-sufficiency, and recognition of progress. Both ombudsmen and family member respondents emphasized the essential need for communication and perseverance in family council activities. (See Attachment C, page 25).

Family Council Successes

Despite the challenges in establishing family councils and working effectively as a family council, family member, ombudsman, and facility respondents alike indicated numerous family council accomplishments. The successes reported which had direct impact on the quality of care and life for residents are especially noteworthy.

Family council successes mentioned by family members were:

- A family council’s expressed concern about mouth care resulted in an in-service on mouth care for staff
- A meeting with personnel improved staffing assignments and stopped staff rotation
- A family council did its own survey about family member concerns, issued a report, met with management and regional corporate representatives about concerns and have seen some improvements
- A family council persuaded the administrator to require staff to put date/time on resident disposable briefs when changed
- The facility agreed to provide towelettes and direct staff to wipe residents’ hands at meal time

⁷ Additionally, in this section two other family members expressed specific dissatisfaction with the state survey agency operations. One family member commented that “Surveyors are not forceful enough with the homes,” and “The regulations in Maryland are written to put the burden of proof on the consumer instead of on the nursing homes.” Another family council member commented, “The surveys by the state are ineffective because they do not want to shut the nursing homes down.”

- One council got grievance/commendation forms at each station and drinks at each bedside
- Family councils sponsored staff appreciation and educational programs
- Facility steps were painted with a white strip to assure better night vision
- The director was persuaded to install a sensor light at a back door of the facility used for after hours exit by family members
- One council worked out billing/delivery issues with pharmacy representative for nursing home
- A family council got a family council notice board, and notice of the family council in admission packets

Family council successes reported by ombudsmen were:

- A family council conducted a survey that led to dialogue and credibility with surveyors
- One council spurred needed staff changes and care improved temporarily
- Another family council prompted a change in Administrator and Director of Nursing who were not fulfilling responsibilities - the new administrator is listening to the family council
- One council held the administrator accountable with a notebook list of concerns, date addressed, plans by the facility to rectify/resolve the issue, and date of completion - the council reviews the list monthly for continuation
- A family council conducted a staff appreciation event

Family council successes mentioned by facility respondents were:

- Family council advocacy resulted in better services to residents such as food (more of their preferences), care (more individualized to residents such as bathing, activities at specific times of the day)
- Family council meetings opened communication lines with family and staff and offered some support to the families
- Family council meetings provide an opportunity to meet in an open forum and discuss issues honestly
- Family council efforts improved education and communication between families and facility
- A family council developed a program to provide support to families during a resident's dying process
- Educational programming is routinely scheduled to meet the caregiving needs and personal interests of the group
- A family council sponsored an annual Christmas party for staff's children
- A family council sponsored two fundraising events which enabled the purchase of a special wheelchair for a particular resident and additional materials for resident activities
- A family council initiated an Employee of the Month recognition project

Though many families and facilities are struggling with the establishment and maintenance of family councils, there are inspiring examples of vibrant and effective councils in Maryland. One facility reported, “The family council has realized many successes since its formation in 1995. We are blessed to have a large group of dedicated and highly-motivated members involved in the council.”

Staff Member Involvement with Family Councils

Another important influence in the success or failure of efforts to establish family councils can be the extent of staff involvement and support and what kind of role the staff person plays in the council. Of the facilities that reported the existence of a family council or group at their facility, 76 indicated that a staff person is assigned to work with the family council. Two facility respondents reported that no staff person is assigned. When asked to describe the role of the staff person in the family council, the majority (68) of respondents indicated that the staff person “organizes, publicizes, formulates the agenda for, and runs meetings”, six indicated that the staff person attends at the invitation of family members, five indicated that the staff person “attends all meetings as an observer/resource person, but families publicize and run meetings,” and six indicated that the staff person plays some other role. Examples of the other roles staff persons play in family council are: At one facility, the staff person publicizes the meeting for family members and then gathers information that the family members request. At another facility, the staff member attends meetings at the invitation of family members and publicizes the meetings at the family members’ request. Family members at that facility form the agendas and run the meetings.

As mentioned above, work done by advocacy groups to date with family councils has shown that council independence is important in advocating for improvements in the quality of care for residents. Therefore, the above results, which indicate a high degree of staff control and responsibility for the family groups or councils are important to note. The lack of family leadership and lack of family council independence may contribute to the difficulty in establishing and maintaining family councils in Maryland. Also, based on survey responses received from families involved in family-directed family councils, it appears that family councils that have family leadership tend to result in actions that more directly impact on quality of care and life for the residents.

Leadership in Family Councils

In order for family councils to be more autonomous, strong family leadership is necessary. Most ombudsman, family member, and facility respondents identified effective leadership as a critical ingredient in the success of a family council. Questions of leadership can be perplexing, however, when it comes to family councils. The crisis-laden, emotionally exhausting nature of being a family member of a nursing home resident may discourage those who might otherwise assume a leadership position from participating. Because of these challenges, a focus on developing leadership is essential for those seeking to promote the establishment of family councils. The survey requested information from ombudsman and family member respondents about what strategies respondents have used to promote leadership in family councils and what leadership structures have been the most effective. Ombudsmen supplied the following feedback on strategies they have used to promote leadership:

- Act as a resource person

- Provide encouragement and allow the leadership to evolve
- Suggest good organization of concerns, prepared agendas, and family members taking responsibility

Several ombudsmen reported most frequently observing traditional leadership structures and co-chair structures for family councils. According to these respondents both of these structures work effectively for existing family councils. Other ombudsmen recommended a model where a single facilitator coordinates the group at the beginning, evolving eventually into a team-led, co-facilitator model. Others have observed that some family councils use an informal, round table discussion format.

Only twelve facility respondents (of 81 who reported having a family council or family group) indicated that the family council at their facility elects officers. The overwhelming majority of facilities indicated that the family group at their facility does not elect officers (69). Among facilities where officers are not elected, facility respondents indicated that the staff provides leadership. Many facility respondents indicated that family members are not interested in assuming responsibility for leadership. One ombudsman observed that she often sees facility staff act as the leader for family groups. In her opinion, families attend, but are not willing to take a leadership role. Another facility has arranged for a “non-biased” couple from the community to lead a family group. One facility respondent commented that the use of a leadership committee helps to minimize the impact of regular family turnover due to resident deaths and discharges.

Most family member respondents (8) indicated that their family councils use and find effective a traditional model of leadership. Three family member respondents reported that their family council uses a co-chair model, four reported using a leadership committee and two use an open informal discussion format. One family member reported that her family council set up by-laws so that officers serve for one year regardless of whether their loved one continues to reside at the facility or not. She reports that this provides some continuity for the council.

Another family member reported that “We have attempted to get volunteers to take leadership roles in different areas (e.g. outreach, social activities). . . The idea of committees is not appealing to members since there are not many regular members (about 12). After the last meeting I discussed with a few members the possibility of taking the lead in one of the areas, putting together some ideas and presenting them to the group. They were more receptive to this approach than forming committees.” Another family member described her council’s experience using a leadership committee saying, “The committee presents recommendations to the administrator and meets with them to discuss, then reports back to the full council.”

Linking Family Councils Between Facilities

One strategy used in programs that promote family councils in other states is to provide opportunities for connections between family councils from different facilities for support, information, and exchange of ideas. Most Maryland ombudsman respondents indicated that they had not focused on linking family councils from different facilities for support and networking. One ombudsman made a list of family council leaders available to the County Commission on Aging for a networking session. Another ombudsman notifies family council leaders about legislative meetings affecting nursing homes. One ombudsman reported that a family council representative requested that the ombudsman arrange quarterly meetings for family council representatives across the county for support. Another ombudsman indicated that she thought

families would respond positively to the idea of networking with other family members because they are eager for support.

One family member commented, “I strongly encourage the development of a Maryland Family Council Website. With so many people having access to the internet, this would be a valuable tool for sharing information and innovative ideas....There is relatively little information currently on the web regarding family councils. It would be helpful to learn of ideas and methods used by others that have been tried and proven effective.” Other family member respondents reported that they had had some limited contact with family councils at other facilities, but not in any structured way. Other family member respondents commented on the importance of exchanging of information between family councils saying that it would be useful to “coordinate a central method of relaying to councils what works and doesn’t work with other councils.”

Negotiating Techniques for Family Councils

Both facility personnel and family members play potentially powerful roles that can significantly impact on the lives of the residents. Facilities and family members may approach issues in the facility from different points of view and may have different ideas about what should be done about group concerns identified by family councils. When differences of opinion exist, a family council may need to advocate for action to be taken on group concerns and subsequently monitor and evaluate progress made in addressing concerns.

The survey solicited recommendations from ombudsmen and family members concerning family council negotiation techniques that have proven successful in bringing about improvements for the residents. Negotiation techniques suggested by ombudsman respondents were:

- Maintain open communication and understand the facts
- Use a cooperative approach since all have the same goal – quality of life and care for the residents
- Discourage conflict which may only hinder future attempts to negotiate
- Offer solutions when making complaints (its easy to come up with problems, the solutions are more difficult)
- Present concerns in a straightforward manner without an accusatory, confrontational style
- Submit written reports of concerns and schedule follow-up meetings with facility personnel
- Be part of the solution – assist in submitting ideas to the facility

Several ombudsmen suggested that, in their experience, the least adversarial negotiation methods have been the most successful. One ombudsman indicated that a cooperative method is good at first, but if it fails, family councils should pursue further recourse with outside agencies (ombudsman, survey agency, legislators).

One important step in family council advocacy is communicating concerns and recommendations clearly to the facility. When this is done, federal regulations require that “the facility must listen to the views and act upon the grievances and recommendations of families concerning proposed policy and operational decisions affecting resident care and life in the facility.” All of the family member respondents reported that their family council has presented

the facility with recommendations made by the family council. Eighteen of the 23 family member respondents said that the facility had responded to or acted upon the recommendations of the family council. The responses and actions by the facilities included exchanging letters and making personal contact, responding in writing and attending meetings when invited, and communicating family council concerns to the staff. Three family members said the facility had not responded to or acted upon their family council's recommendations.

As identified in the "Overcoming Obstacles" section, both ombudsman and family respondents stressed the need for perseverance in family council advocacy. This perseverance includes monitoring and evaluating progress made in addressing family council concerns. Some of the family member respondents who reported an initial facility response cautioned that improvements were subsequently lost or that implementation of agreed upon remedies was slow and irregular. One respondent complained that promises from facility personnel are not honored and that family council efforts and negotiations have brought about few positive results. Another family member indicated that the facility personnel had responded to her family council with sincerity and willingness to cooperate.

One family member commented: "We have had some success in negotiating with the administrator and the DON. We have had no success in negotiating with corporate representatives of the company that owns the facility." Another family member reported that "We are stressing the need for family members to be specific about their concerns. Documentation is very important. We recently developed a "report card" to target problems." Another family member pointed out that "Sometimes, as new personnel come on board, the same problems must be revisited."

If attempts to communicate concerns to and negotiate with facility personnel fail, one way for family councils to add some authority to their recommendations is to work in partnership with ombudsmen by providing them with copies of the recommendations that they make to the facility. Most ombudsman respondents (9) reported that they do not currently receive copies of the recommendations that family councils make to the facility. Two ombudsmen reported that they do receive copies of family council recommendations.

Twelve family member respondents from three different facilities indicated that their family councils provide copies of the recommendations they make to the ombudsman or survey agency. Six family members indicated that their family councils do not do this. One family member noted that the desire of the family council is to keep problems in the facility.

When ombudsmen do receive copies of recommendations, they can work with the family council to advocate for improvements to be made at the facility and pay attention to family council areas of concern during their visits to residents. Also, in one case, an ombudsman called the facility to prompt them to respond to communication from the family council.

Methods suggested by family members to negotiate with facility personnel are:

- Submit written recommendations
- Have facility representatives come to meetings
- Meet with higher-up officials in the company
- Follow up on recommendations with phone calls
- Have the CEO of the corporation attend meetings
- Develop a report card to document concerns
- Carefully document concerns and communicate clearly
- Be informed about the issue before negotiating
- Be direct and to the point in presenting concerns

- Call and involve the ombudsman
- Stay “cool”

Family members reported that they have achieved the most success when they:

- Call the ombudsman who elicits a facility response
- Use meetings and letters
- Have a constant presence at the facility
- Communicate continually and constantly remind the facility of the issues
- Forward written correspondence to the survey agency
- Have face-to-face meetings with facility personnel
- Present specific concerns in writing to the administrator

One family member commented, “They [the nursing home] made changes when given hard facts and demands for our rights. They responded to recommendations when they saw we were sincere and not being pesky and were willing to cooperate.”

Preliminary Conclusions

The survey results indicate that there is some work being done by ombudsmen, facilities and family members in Maryland with the intent of bringing family members of nursing home residents together to influence the quality of care of their loved ones. Family council participation is one way that family members can help to identify the needs of residents and problems within the facility that need resolution. Family councils can also work to help assure that needed services will be given and needed changes will be made. However, with only 81 or 32% of 257 facilities reporting having any type of family group in place and only 18 facilities or 7% of all Maryland facilities reporting a family-directed family council, these initial results clearly indicate that a lot of work is left to be done to encourage the establishment of empowered, constructive family-directed family councils in Maryland.

The survey results make clear that there are numerous challenges and obstacles to family council development in Maryland, including lack of family involvement, facility resistance, and lack of information and empowerment for family members. The responses received, including 41 facility respondents who reported that the family council of their facility meets regularly but does not attract many family members, show that a primary challenge in family council development is motivating family members to be involved. According to ombudsman and family respondents, an effective approach to addressing this challenge is the personal contact that ombudsmen and family members make with family members to educate and empower them to advocate for their loved one and contribute to the success of the nursing home community. Also, family members reported the importance of facility personnel listening to their concerns and demonstrating that family involvement and information is valued and acted upon.

A second common theme identified by both ombudsmen and facilities was the importance of having constructive, informed meeting discussions. It is important for family members to be knowledgeable about quality care in nursing homes and to be able to clearly articulate their concerns and specific recommendations. The survey results show that committed family members can be positive forces in nursing homes if this kind of communication takes place. The lists of family council successes provided by families, ombudsmen, and facilities demonstrate that families can indeed be effective advocates and influential participants in the

nursing home community. However, the responses also convey that the effort takes perseverance, clear communication, and the support of outside agencies if the facility is unresponsive. Several families expressed strong interest in opportunities to meet with and share information about their successes with family councils from other facilities.

An important area for further study is the obstacle to family council development presented by fear of retaliation among family members. Facilities can address this fear by demonstrating that they consider families to be valuable contributors to the nursing home community and are willing to respond to identified group concerns and recommendations from families in a positive way. Ombudsmen and the survey agency can also help to address these issues by supporting the rights of family councils in nursing homes should it be necessary for them to seek the support of outside agencies.

As one family member commented, “The potential influence of family councils has been untapped and overlooked. Family councils could be a tremendous influence on effectuating change at the nursing home level as well as adding their voice in the political process.” If those family councils that have formed or are trying to form are supported and their input valued and acted upon, their work will set a powerful example for other families. As another family member commented, “We have had progress – this is a difficult road, but it is possible to effect changes.”

As the project continues, we will gather further information on the topics addressed in this report (see Attachment D, page 26, Questions for Further Study), and will include findings in periodic progress reports and the final project report.