

National Citizens' Coalition for

NURSING HOME REFORM

1424 16th Street, NW, Suite 202

Washington, DC 20036-2211

Diane Menio, *President*

Elma Holder, *Founder*

Donna R. Lenhoff, Esq., *Executive Director*

Phone: 202-332-2275

Fax: 202-332-2949

Maryland Family Council Project Final Report, Phase I– October 2001

In January 2000, the National Citizens' Coalition for Nursing Home Reform undertook an 18-month project to promote the formation and effectiveness of family councils in nursing homes in Maryland with funds provided by the Maryland Office of Health Care Quality (OHCQ). NCCNHR began the project by conducting a survey (see Attachment A). Using the information gathered in the survey and building on NCCNHR's experience working with family members of nursing home residents and family councils, NCCNHR provided training to family members at 33 facilities, sponsored 7 workshops in partnership with local Maryland long-term care ombudsman programs, provided training to facility staff, ombudsmen, surveyors, and created workshop materials (see Attachment B) throughout the 18-month Phase I of the project. This report will:

- describe achievement of project objectives, and
- report the results of a July 2001 survey regarding project services,
- submit a compilation of project materials.

I. Summary

The results of this survey show that the services of the NCCNHR Family Council Project are having a positive impact on the formation and effectiveness of family councils in Maryland nursing homes. Examples of this impact can be seen in the increase in percentage of family-led family councils and reports from ombudsmen, family members and facility staff of a number of newly formed family councils. Most encouraging are the examples of family council successes given by survey respondents. Each of these examples represents a tangible improvement in the lives of some of Maryland's nursing home residents.

Respondent feedback with regard to particular project services was positive from all three groups of respondents. The results seem to indicate that the services are most useful to family members and less useful to facility staff. These results are expected since many of the project services are tailored for family members. NCCNHR is planning a workshop designed specifically for facility social workers and others on supporting family council development and effectiveness in January 2002. Other positive information gathered from the survey were suggestions from respondents about additional project services that would be helpful to them. Many of the suggestions (such as a video, continued workshops and training, lists of speakers, etc.) are already part of plans for project services for the coming year.

As expected, while some barriers have been addressed, other obstacles to family council development and effectiveness still remain. Project staff have, however, purposefully included suggestions for overcoming obstacles for family members as a part of training content and

materials. We look forward to continuing to work with family members, ombudsmen and facility staff to overcome these obstacles and make further progress on family council development.

II. Survey Results About Project Impact

To evaluate the effectiveness of project activities and services from January 2000 through June 2001, NCCNHR conducted a second survey in July 2001. The July 2001 survey (see Attachment C) was mailed to all Maryland nursing homes, all Maryland local long term care ombudsman programs, and a mailing list of 114 family members of Maryland nursing home residents that NCCNHR has compiled. A follow-up reminder was mailed to all recipients 3 weeks after mailing out the survey. Sixty-two Maryland facilities, 16 Maryland ombudsmen, and 14 family members responded.

Limitations of the Study

The validity of the survey results were somewhat limited by the level of responses received (24% of facilities, 84% of ombudsmen, 12% of family members). Although the information received is useful in evaluating project activities, especially in areas where the feedback is very consistent, the results may not give a complete picture of the impact of Phase I of the project. By comparison, 51% of facilities, 74% of ombudsmen, and 62% of family members surveyed responded to the survey conducted in Spring 2000.

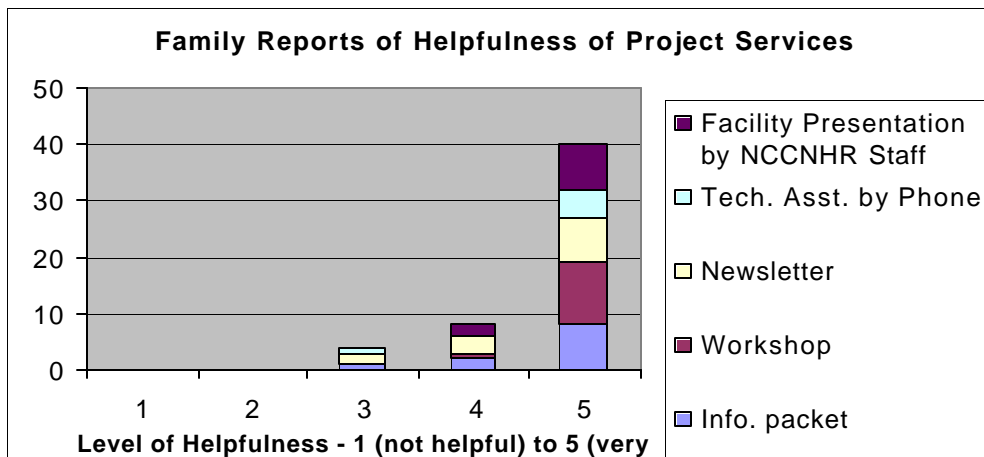
A. Family Responses

Contact with the Project

All of the family member respondents reported that they had received information from or attended a presentation by a staff member of the family council project and found the information to be helpful in starting or strengthening a family council at their loved one's facility.

Relevance and Effectiveness of Project Services

In order to reach the largest number of people in the most effective ways possible, the NCCNHR Family Council Project offered a variety of services to family members in Maryland. These services included presentations to groups of family members at individual facilities, a quarterly newsletter, county-level workshops in counties around the state of Maryland, the provision of a packet of information on family council development, and technical assistance by phone to family members trying to establish or strengthen family councils. Family responses



regarding the helpfulness of particular project services are summarized in the chart below:

These responses indicate that family member respondents find the project services very useful. Additionally, family members offered the following suggestions regarding future project services:

- Continue workshops for networking
- Sponsor joint meetings with other family councils
- Offer information on how to spark interest in family councils
- Distribute a card with Maryland contact numbers for family members (ombudsmen, OHCQ)
- Offer information in workshops on how to get more people involved in leadership roles
- Make more presentations at family council meetings
- Share information about the activities of family councils in other facilities in presentations
- Provide a training video on family councils
- Support the formation of a Maryland state group of family councils
- Formulate a list of potential speakers for family councils in Maryland
- Include information in presentations and newsletters regarding workshops or seminars on subjects related to issues affecting the elderly to provide more emotional support for family members

Family Council/Group Characteristics

Family members provided the following information with regard to the nature of the family grouping at their loved one's facility:

Kind of Direction	Number of Responses
Family-directed family council	6
Facility-directed family group	3
Both	2
No Group	2

These results are important to note because they give insight into the level of independence the family council or group has at the facility. They also indicate the level of responsibility that family members are taking for leading the council or group. The issue of family leadership can be a complex one with factors such as family member interest/commitment and facility openness to family council independence affecting the outcome.

Family Group/Council Initiation

Seven (7) family members indicated that the council/group at their loved one's facility has been formed since this project started in January 2000. Five (5) family members indicated that the family council at their loved one's facility was formed previously.

These responses demonstrate the initiation of a number of new family councils at nursing homes in Maryland in the last 18 months. To determine how these groups were initiated, we asked family members to identify where the impetus for starting the group originated. Responses were as follows:

Source of Initiation	Number of Responses
Family member started	1
Staff initiated, then families took over	3
Staff initiated and continues to run	2

One respondent indicated that a family member and the ombudsman worked together to start the family council.

Strengthening of Existing Councils

One goal of Phase I of the project was to help councils that may have been in place prior to the beginning of the project to become more effective. We asked family members to indicate whether the level activity and effectiveness any pre-existing councils/groups had changed in since January 2000. Family members indicated the following:

Level of Activity/Effectiveness	Number of Responses
Council/group has become more active/effective	3
Council/group has become less active/effective	0
Council/group's level of activity/effectiveness same	2

Frequency of Meetings

Ten family member respondents indicated that the council/group meets once a month. One respondent indicated that the council at her loved one's facility meets twice a month.

Promoting Participation

Another goal of Phase I of the project was to educate family members about how to promote the participation of other family members in family councils. To evaluate the effectiveness of this education, we requested information about the level of attendance at family council meetings since the beginning of the project. Family respondents indicated that between 8 and 30 people currently attend the family council meetings.

Family members provided the following responses about the strategies they use to promote participation in or strengthen their family councils:

Promotion Strategy	Number of Responses
Post meeting notices	12
Elect or appoint family council leaders	5
Include family council info. in the facility newsletter	9
Formulate by-laws	3
Remind families about meetings by telephone	6
Include family council information in admission packets	5
Put recommendations to the facility in writing	9

Other strategies family members have used to promote family council participation are:

- Emailing the agenda and minutes to members with email
- Conducting “membership drives”
- Doing monthly mailings to family members
- Solving problems at meetings and record the solution in minutes
- Writing to corporate representatives out of state

Extent of Improvements Made as the Result of Family Council Involvement

Because one measure of whether our project is a success is whether it has an impact of the quality of care and quality of life for nursing home residents, we are interested in knowing if family councils are making a “difference” for their loved ones in nursing homes. Family council successes cited by family members included:

- Assisted a council member in resolving a financial issue
- Invited facility administrator to meetings where family members can voice concerns in particular areas
- Prompted the facility to provide incontinence briefs on a regular basis
- Produced a newsletter which is distributed to family members and staff
- Sponsored a new year’s party and creation of a memorial garden for residents
- Prompted a facility to put in additional walkways for residents and family members
- Invited department heads speak at meetings
- Council stimulated improvements in certain departments
- Prompted the facility to install long distance telephone service and cable
- Conducted a fundraiser for updated equipment
- Stimulated improvements in food and on making sure that CNAs wear name badges

Family Council Leadership

Because family leadership is important in giving family councils the independence they need to advocate within the facility, we asked respondents to supply information about whether their family council elects officers. Seven (7) family members indicated that their family council does elect officers. Four (4) respondents indicated that their family council does not. Of the family councils that do not elect officers, two (2) indicated that staff members lead the group. Two (2) others indicated that while the council does not formally elect officers, family volunteers lead the group.

Obstacles to Family Council Formation and/or Effectiveness

Family members indicated the following obstacles they have encountered in working with the family council at their loved one’s facility:

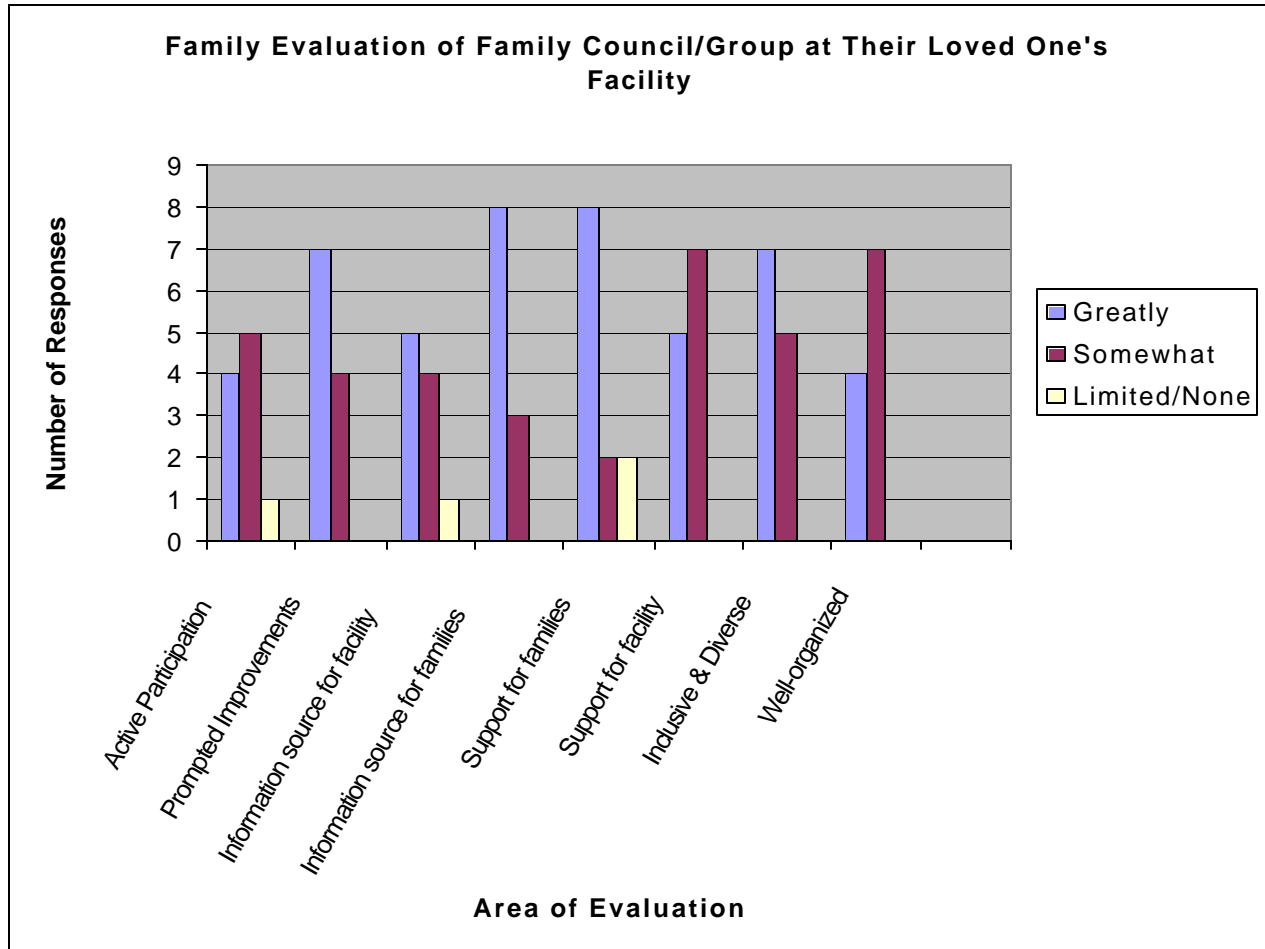
- Lack of participation -- family members “too busy” to get involved
- Difficulty updating membership and electing officers
- Difficulty assuring facility management that we can work together
- Lack of interest by family members

- Changing rooms given to family council to meet, removing newsletter and brochure, turning staff against the family council, facility accusing the council of being bad

Three family respondents commented that the facility has been very supportive of their efforts to establish and strengthen their family council.

Family Council Assessment

We also asked family respondents to assess the family council at their loved one’s facility in a number of areas. Responses are compiled in the chart below:



Additional comments included:

“I am proud to be in a facility that has a family council in place and cooperates fully with family members. I think belonging to this group is a help to the residents.”

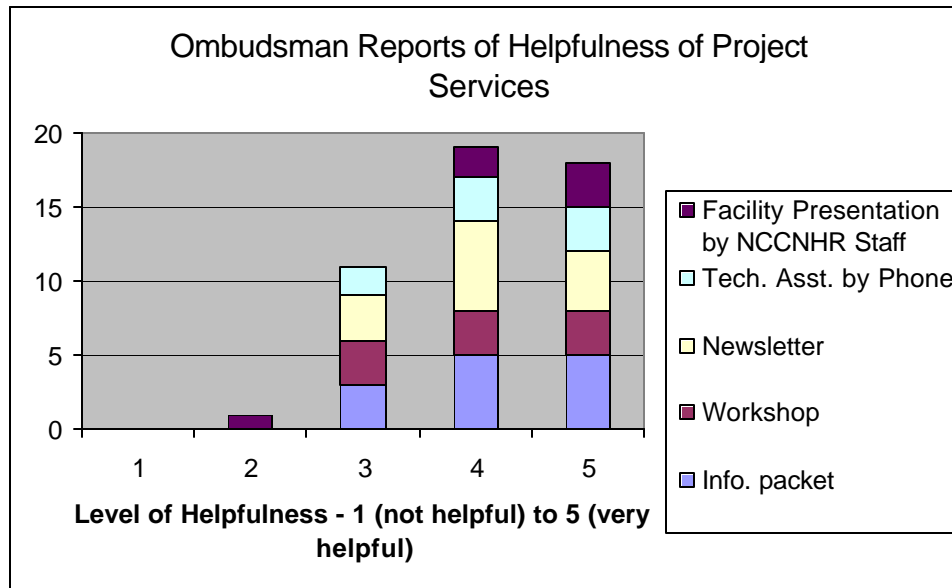
“Several of us formed a council at my mother’s facility and had regular meetings. Family members like the support of the large group with mutual problem solving.....”

B. Ombudsman Responses

All of the ombudsmen who responded (16) had received information from or attended a presentation by a staff member of the family council project. Fourteen of the 16 indicated that the information was helpful to them in starting or strengthening family councils in their area.

Relevance and Effectiveness of Project Services

A summary of ombudsman responses regarding the helpfulness of particular project services are compiled in the chart below:



Seven (7) ombudsmen responded that they distribute the “Family Matters” newsletter (see Attachment D) to family members they come into contact with, four (4) ombudsmen responded that they display it at their office, three (3) responded that they read it, but do not distribute it. Other ombudsmen reported that they:

- make copies for the facilities in their area
- give the newsletter to facilities for their family council meetings
- display them at the facilities in their area

Ombudsmen offered the following suggestions regarding other services that would be helpful to them in their work with family councils:

- a family council conference in Baltimore City
- publicity stressing family participation to get the message out to families pre-admission
- training for staff and administrators about how family councils can help
- a video to help teach families about their role in facilities
- advice on how to work effectively as the ombudsman with the family council

Family Council/Group Leadership

Altogether, ombudsmen reported 17 *family-led* family councils and 24 *facility-led* family groups at facilities in their areas. Ombudsmen respondents indicated that 6 family-led family councils and 6 facility-led family groups have been formed in their areas since January 2000.

Encouraging Formation of Family Councils

A 1997 NCCNHR study regarding family involvement in nursing homes and the survey completed by the NCCNHR Maryland Family Council Project in May 2000 indicated that ombudsman support of family council development and effectiveness can be a critical factor in family council success. Ombudsmen in Maryland reported that they have facilitated the formation of family councils in their area in the following ways:

Promotion Activity	Number of Responses
Helped advertise the existence of family councils	6
Helped a family council get a response from the facility	2
Attend family council meetings	8
Encouraged family members to start family councils	7
Helped initiate family councils and then families have taken leadership	3
Referred families to the family council project	6

Other ombudsmen reported that they have:

- spoken with staff about the importance of family councils
- provided technical support to a family council with flyers and brochures
- co-sponsored a family council workshop with NCCNHR

Family Council Successes

Some family council successes listed by ombudsmen included:

- increased communication between families and facilities
- survey developed by the family council and mailed to all families for input on areas of concern. Data was analyzed by the council and a formal letter of recommendation was sent to the administrator. Some positive outcomes have been realized such as increased attention to mouth care.
- family councils sponsor presentations.

A couple of ombudsmen mentioned that facilities in their counties have recently restarted family groups and are trying hard to be supportive.

Obstacles to Family Council Development and/or Effectiveness

Ombudsmen reported the following obstacles to development or effectiveness encountered by family councils in the last 18 months:

- stubborn administrators
- lack of willingness to lead among family members

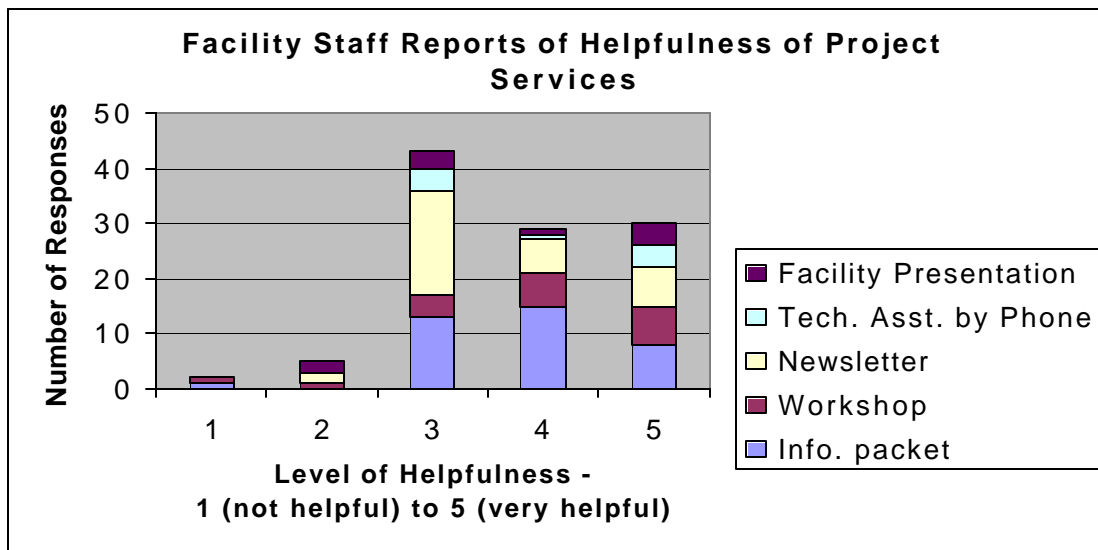
- decreases in interest after improvements are made at the facility
- dependence on staff
- lack of knowledge and support of prior and current leaders
- poor attendance
- lack of family leadership -- families hesitant to “take over” and be family led

C. Facility Responses

Forty-two (42) facility staff indicated that they had received information from or attended a presentation by NCCNHR. Seventeen (17) facility staff responded that a family member from their facility had received information from or attended a presentation by NCCNHR. Eleven (11) facility staff indicated that neither they nor a family member from their facilities had received information of any kind from NCCNHR with regard to family councils. (Note: NCCNHR mailed informaton to and advertized workshops and services with all Maryland facilities continually throughout the project period.)

Relevance/Effectiveness of Project Services

Twenty-nine (29) facility staff reported that the information they have received from the project was helpful in starting or strengthening a family council and nine (9) reported that it was not. A compilation of facility staff responses evaluating specific project services is below:



Family Council/Group Characteristics

Facility staff provided the following information regarding the direction of family councils/groups at their facilities:

Council/Group Direction	Number of Responses
Family-directed family council	19 (30%)
Facility-directed family group	27 (44%)
Both	3 (4.8%)
No Group	11 (18%)

Three respondents indicated their facility holds some other kind of gathering for family members.

By way of comparison, in response to the May 2000 survey 14% of facility respondents reported the presence of a family-directed family council at their facilities, 42% reported having a facility-directed family council, and 6% reported having both. Although the response level to the second survey was lower, the increase in percentages of family-directed family councils from May 2000 to July 2001 may be the result of the promotion and education efforts of Phase I of the project.

Facility Staff Role in Family Council/Group Formation and Functioning

Twenty-five (25) facility staff indicated that the council/group at their facility has formed since the beginning of the family council project in January 2000. Twenty-one (21) indicated that the council/group was in existence before that time.

To help assess our efforts to build support for the formation of family councils among facility staff, we requested information from facility staff about what actions they have taken to facilitate the formation of a family council at their facilities. Responses from facility staff were the following:

Facility Action	Number of Responses	Percentages from 5/00 Survey
Provided space for the group to meet	45 (73%)	55%
Allowed family members to post notices to publicize meetings	29 (47%)	25%
Allowed family members to put information about meetings in a facility newsletter	20 (32%)	24%
Included information about the family council in admission packets	17 (27%)	23%
Made a mailing list of family members available to the family council to communicate with other family members	13 (21%)	15%
Some other action	8 (13%)	15%

Again, because the response level was lower for the July 2001 survey, it is hard to draw conclusions, however, the higher percentages of facilities taking specific actions to support family council development may be the result of Phase I outreach and education to facility staff through presentations and mailings.

Some facility staff have taken the additional step of initiating a family council at their facility. Information about staff members' roles in the initiation of family councils is summarized in the following chart:

Facility Staff Role in Initiation	Number of Responses
Suggested idea to a family member, who started it	2
Initiated council/group, then families took leadership	15
Initiated council/group and continue to run	9
Other	3

Facility staff also supplied the following information about the role they continue to play in the functioning of the council/group:

Facility Staff Role	Number of Responses	Results from 5/00 Survey
Organize, publicized, form agenda, run meetings	31 (50%)	52%
Attend all meetings, but family runs	8 (13%)	4%
Attend at invitation of family members	13 (21%)	5%
Other	5 (8%)	5%

These results seem to indicate that many family councils may still lack independence to control the functioning and content of their family councils. Unfortunately, these results indicate little improvement in the level of control and responsibility that family members have for family council functioning. These results do indicate, however, an increase in the number of facility staff who are asking family members their preferences with regard to facility staff attendance at family council meetings.

Level of Activity/Effectiveness	Number of Responses
Council/group has become more active/effective	11
Council/group has become less active/effective	0
Council/group's level of activity/effectiveness has stayed about the same	18

Of the active councils described by facility staff respondents, 19 of the councils meet once a month, 10 meet every two months, and 17 meet quarterly or less. Facility staff also estimated that between 3 and 40 people usually attend family council meetings, with approximately 10 people attending on average.

Family Council/Group Leadership

Twelve (12) facility respondents indicated that the family council at their facility elects officers. Thirty-four (34) indicated that the council does not. Facility staff reported that the family groups/councils that do not elect officers are led by staff or by a family "chairperson" who volunteers but is not formally elected.

Family Council/Group Successes

Facility staff cited the following successes of the family council/group at their facility:

- They are truly concerned for the welfare of our staff and residents and offer many good suggestions related to quality of life
- unit-specific discussion groups
- staff recruitment/retention brainstorming session
- family council has stressed the need for improvement in customer service
- increased staff on weekends resulted from their concerns
- decrease in use of temporary staff as the result of council's preferences
- increase in security on weekends
- improved communication between facility staff and families puts both groups at ease
- offer input concerning improvement/enhancement of facility operation
- providing education on issues such as pain management and restraints
- menu changes
- have instituted a "Good Samaritan Award" which is given by the family council to an employee who goes above and beyond

The successes of family councils reported by facilities in response to the July 2001 survey were encouraging. The majority of successes reported are substantive improvements that have a direct impact on improving the quality of care and quality of life for residents.

Family Council Difficulties/Obstacles

Facility staff cited the following difficulties they have encountered in working with the family council at their facility:

- getting the group to become a family-led council
- recruitment of new members
- sometimes one family member monopolizes meeting discussion
- two leaders have lost their loved ones, leaving the leadership role to one person currently
- lack of participation/interest by families
- regular changes in executive board due to resident deaths
- coordinating a date and time convenient to all interested parties
- the council never seems to have an agenda
- it has become a gripe session rather than proactive
- there are very few family members who live near the community

The obstacles reported in response to the current survey are similar to those reported in the May 2000 survey. These obstacles will likely continue to present a challenge in the development of family councils, however, the NCCNHR project is promoting strategies that family councils can use to establish and maintain family leadership, spark interest and promote participation, and running meetings and advocating effectively.

Family Council/Group Assessment

Facility staff also evaluated the family council/group at their facility in a number of areas.

The responses are summarized in the chart below:

