

**Maryland Family Council Project
Final Project Evaluation
2000-2005**

I. Project Synopsis

From 2000-2005, the National Citizens' Coalition for Nursing Home Reform (NCCNHR) conducted a project in Maryland with the goal of developing and strengthening nursing home family councils in the state. NCCNHR, with funding from the Maryland Department of Health and Mental Hygiene, Office of Health Care Quality, made presentations at nursing homes; created written materials that were distributed to family members, family councils, ombudsmen, facility staff, and state-wide groups such as the Maryland Alzheimer's Association; produced and distributed a "how to" video on family council development titled "Strength in Numbers: The Importance of Nursing Home Family Councils"; held training conference calls; created a website with topical information specifically for Maryland family councils; created and distributed consumer fact sheets; and held a state-wide family council conference, among other activities.

This project began with a survey of family councils, ombudsmen, and facilities to find out what family councils needed to effectively develop and advocate for quality care for nursing home residents. With that information, NCCNHR set out to connect with family members, family councils, facility staff, ombudsmen, and other community members to begin the process of getting information and tools into the hands of consumers on family council development.

Each year the project built on prior years activities. As Maryland consumers became more savvy in their family council work, NCCNHR created materials and sponsored activities that met the on-going needs of family councils. Ultimately, bringing family council members together at the State-wide Family Council Conference in March 2005, was the pinnacle of the project and exemplified how a movement was just beginning to take shape.

As this project came to an end, we realized that there was truly a momentum in the community that was fostering family council development and sustenance. This was a bitter-sweet realization for project staff, knowing that NCCNHR would not be available on such a focused level to participate in the further growth of the Maryland family council movement.

II. Evaluation Process and Intent

As part of the 2004-2005 grant period NCCNHR conducted a project evaluation survey of family members, family council members, facilities, and ombudsmen with the intent of evaluating if the resources and tools that NCCNHR produced and distributed had an effect on family council development and effectiveness.

In April 2005 NCCNHR sent evaluation surveys to a mailing list of approximately 300 family members whom NCCNHR had been in touch with over the course of the project. This list included family council chairs and family members who attended workshops, presentations, or who had contacted NCCNHR project staff by phone or email for technical assistance.

All of the 239 nursing homes in Maryland also received a copy of the evaluation survey. These surveys were addressed to the administrator at each facility but they were advised to pass them on to those individuals most involved with the family members and/or the family council at the facility. In many cases this person is a social worker or activities director.

The 22 local ombudsman programs in the state also received copies of the survey and were asked to complete a condensed version.

The objective for conducting this survey was to answer the following questions:

- 1. Were the materials and resources developed through this project used by the target audience and were they helpful in developing and strengthening family councils?**
- 2. What do family councils in Maryland look like after 5 years of the Family Council Project and are they using the NCCNHR model?**
- 3. Has this project had any direct influence in family council development in Maryland?**

III. Survey Results and Findings

Of the approximately 300 surveys that were sent to Maryland family members sixty-nine or approximately 23% responded to the survey. Sixty-eight or 28% of the 239 surveys sent to Maryland nursing homes were completed and returned. And of the 22 surveys sent to Ombudsmen, 12 or 55% responded to the survey.

- 1. Were the materials and resources developed through this project used by the target audience and were they helpful in developing and strengthening family councils?**

The survey results indicate that some of the materials and resources developed for the project were more frequently used and more useful for all groups. The *Family MATTERS* newsletter stands out as the most important tool produced by the project. Not only did family members and ombudsmen find this an invaluable resource, but facility staff as well, relied on the newsletter and the majority found it helpful to extremely helpful in their work with family councils. It is important to note that the majority of family members found the newsletter considerably or extremely helpful. The video, “Strength in Numbers: The Importance of Nursing Home Family Councils” was also used and very helpful for all three groups surveyed.

The other resources that were most widely used and most helpful to family members and ombudsmen were presentations made at facilities, workshops outside facilities, the state-wide conference, and the project web page where people could download information. Ombudsmen in particular used and found most helpful the workshops NCCNHR staff conducted as part of county level programs and the state-wide ombudsman training NCCNHR offered in years four and five of the project.

Of note are the responses about the topical conference calls. This resource, primarily targeted at ombudsmen and family members, was only part of the last grant period, 2004-2005. Although only half of the ombudsmen who responded to the survey participated in the calls and only 40% of family members participated, the majority of each group found the calls to be helpful to extremely helpful. Anecdotally we know that these calls became more popular, especially with family member, over time. The numbers of family members participating in the call increased each call.

The resource that was used least and thus proved to be least helpful to all groups was the family council listserv. There are several reasons why this may have been the case. First, there were some technical difficulties associated with the technology. We think, for many people, the concept of a listserv is something they were not familiar with. In fact, many of the family members and family council chairs we worked with did not use email or other computer technology regularly or at all. Although project staff promoted the listserv at family council presentations and in the newsletter, it was a vehicle for communication and support that never took off for family members.

2. What do family councils in Maryland look like and are they using the NCCNHR model?

One of the most important questions relates to the independence of the family council. Family councils, by law, are run and organized by family members. Many family members and facility staff may say that the “family group”, organized and run by the facility, is a family council. One of the goals of the project was to promote and help develop family-directed family councils. A family-directed council, where family members meet without staff present, ensures that family members can speak freely without fear of reprisal from facility staff, reprisal against either themselves or against their loved one living in the facility. During the course of this project NCCNHR spent much of its time educating facility staff, family members, and ombudsmen about the distinction between a facility led “family group” and an independently organized and run family council. The results of the survey indicate that of those facilities and family members that responded, that if a family council is in place, the majority of the nursing homes do in fact have a family-directed family council.

The NCCNHR model for an effective family council includes several key components, such as: solid family leadership, either elected or volunteer; the use of an agenda during family council meetings; a member who takes minutes; staff that attend meetings at the family council’s invitation; and that family council efforts focus on advocacy related to resident care and quality of life. Generally, the survey findings indicate that the majority of

family councils are following the NCCNHR model and utilizing the components that enable a family council to be successful. Both facility surveys and family surveys indicate this. This is true, even where “family groups”, those groups organized and run by facility staff, operate.

One statistic that does stand out as troubling is related to the independence of the family council. By far, the majority of the family respondents indicated that staff attends family council meetings only occasionally, or come for part of the meeting, or not at all. This is ideally the relationship that staff should have to family council meetings. As stated earlier, when staff are not present at meetings, family members are able to speak freely without fear of reprisal or retaliation against themselves or their loved one living in the facility. Unfortunately this did not ring true for the facility evaluations. The majority of facilities, according to the survey, are attending the entire family council meeting. Although there are some facilities where staff attends for part of the meeting or only occasionally, none of the respondents indicated that the staff does not attend any of the meetings.

3. Has this project had any direct influence in family council development in Maryland?

In a study published earlier this year by Dr. Charlene Harrington, a leading researcher on nursing home care at the University of San Francisco found that the percentage of certified nursing facilities with family “groups” in Maryland increased from 42.5 percent in 1999 to 68.2% in 2003. (52% in 2000, 64% 2001, 69% 2002, 68% 2003) With 68.2% of facilities with family “groups,” Maryland has the highest percentage of facilities with family groups of any state in the nation. This increase can be directly attributed to the Family Council Project and the work that NCCNHR has done in Maryland.

Survey results validate this statistic as well. Of the family members that responded to the survey, the majority of family councils had become more active/effective in the last 5 years. Seven of the respondents said that family council activity had remained about the same (which NCCNHR sees as a success since family council stability is so tenuous), and only 5 reported that the family council had become less active in the last five years. Facility responses confirm this as well. The majority of the facilities report that the family council has been more active or activity/effectiveness level has remained the same over the last 5 years.

IV. Conclusions

Overall, the survey indicates and other research validates that the Family Council Project positively impacted how family councils in Maryland were developed, sustained, and organized. The focused effort of this project was critical to its success.

However, the project would not have been a success without the motivation and commitment of family members. NCCNHR was the conduit that equipped family members,

ombudsmen, and facility staff with the tools and resources – the family members did the real work of networking with other family members, publicizing meetings, creating agendas, taking minutes, and confronting and following up with facility staff about issues and concerns identified by the family council.

Obstacles to family council development and effectiveness are not in short supply. So, the perseverance that these family members have shown is truly admirable. The survey asked what obstacles the family council faced in developing and maintaining. Responses included: HIPAA, particularly related to the fact that facilities use HIPAA as an excuse for not allowing family members to share information or to allow family councils to advertise family council meetings; constant change in staff, particularly administrators and nursing directors; staff harassment of family members and residents of family members that participate in the family council; staff not responding to concerns; unwillingness of staff to send out meeting notices; family members stop participating once residents die or leave the nursing home; lack of participation by family members; and finally, a lack of leadership in the family council.

Despite these obstacles family members continue to be successful in advocating for quality of care for nursing home residents. When asked, often-times family members are unable to articulate success the family council may have had. Family council members can be so discouraged by the on-going obstacles that they cannot see what they have accomplished. The survey asked respondents to include successes that their family councils have had. It is encouraging to see that in fact, many councils have had a variety of successes, both internally with the council itself and with raising concerns and advocating for changes at the facility. Successes described by family members, facility staff, and ombudsmen include: getting the facility to purchase handicapped picnic tables; initiating a welcome group for new residents' families; family council members attend resident council meetings and advocate for residents at the following family council meeting; coordinate a resident handbook that is distributed at the time of admission; getting additional GNA training for staff; repairs and improvements completed in a timely manner; worked with the facility to improve room lights, call lights, noise levels and adequate toileting; helping family members understand the importance of complete and specific advanced directives; getting TV channels that residents liked when the nursing home switched from cable TV to satellite TV; getting the facility to purchase trays to keep meals hot; organizing family council recruitment Sundays; getting family participation in care plan conferences; instituting follow-up conference calls with the administrator after each family council meeting; and many more.

These successes are truly inspirational and speak to the potential that family members have when they ban together as a single family council voice and advocate for improvements at facilities. Although the project has ended, the written resources and video NCCNHR produced are available, not just to Maryland family members, ombudsmen, and facility staff, but are available to consumers nation-wide. The Maryland Family Council Project, and the tools, resources, and lessons we have learned from this project, are invaluable as we pursue other projects that equip family members of nursing home residents with what they need to advocate for quality care for their loved ones.