

**Conference Call:**  
**“Family Councils: Focus on Rights and Advocacy”**  
**Thursday, July 31, 2008 – 3pm & 7pm (ET)**

## CONFERENCE CALL NOTES

### **Welcome and Introduction – Jessica Brill, NCCNHR Project Coordinator**

- NCCNHR: The National Consumer Voice for Quality Long-Term Care is excited to be hosting this conference call titled Family Councils: Focus on Rights and Advocacy!
- NCCNHR (formerly the National Citizens’ Coalition for Nursing Home Reform) is a nonprofit membership organization founded in 1975 by Elma L. Holder to protect the rights, safety, and dignity of America’s long-term care residents, and NCCNHR has vast experience with family councils.
- This call is part of the project *Family Councils for Quality Long-Term Care: Support, Strengthen and Empower*. Through this project, NCCNHR is working with Virginia family councils, as well as councils across the country. This is a unique opportunity to strengthen and network family councils. In addition to conference calls such as this, councils across the country have access to a webpage, listserv and mailings with information and resources related to family council advocacy. On this call, we have family council members and a few Citizen Advocacy Group representatives. This call is not open to ombudsmen, though they can play an important role in family council support.

NCCNHR appreciates the Frances Lane Memorial Family Council Fund of the Edward H. Lane Foundation for making possible such opportunities.

- All of the materials related to this project are available on NCCNHR’s website: [www.nccnhr.org](http://www.nccnhr.org). Click on Frances Lane Memorial Foundation on the homepage.

### **Speaker Introduction – Jessica Brill**

- Robyn Grant is the former Indiana state ombudsman. She currently works with United Senior Action, an Advocacy Organization in Indiana. Robyn is a consultant with NCCNHR and NORC, the National Ombudsman Resource Center, and she is a member of the NCCNHR board.

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- Donna Smith is a member of the Presbyterian Homes family council in Evanston, IL, where her father resides. She has been a member since the council's inception slightly less than one year ago.
- Susan Bardes is the Chairman of the Family Council at Wellington Manor Rehabilitation and Nursing Facility in Indianapolis, Indiana, where her mother resides. Susan and her sister, along with others, started the council in 2005.
- Bob Bronaugh is Co-President of the Manor Care Chevy Chase Family Council in MD, and has been a nursing home advocate for ten years, since his Family Council was founded in 1998. Bob is also a longtime NCCNHR member.
- Representatives from two fantastic groups are also on the call:
  - FRIA - the voice and resource for eldercare with dignity in New York
  - The ElderCare Rights Alliance in Minnesota, which has been involved in advocacy and education to Promote and Protect the Rights of Elders and Adults with Disabilities since 1972.

### **OBRA Background – Jessica Brill**

- The Nursing Home Reform Law of 1987, also known as OBRA, provides family councils with a specific opportunity, as they are guaranteed rights under that law. You will learn more about these rights in a moment. NCCNHR pulled together the coalition that got the NH Reform Law passed.
- We know that there are limitations with the law, but there is a lot in the law that has changed the way nursing home care is given, such as staff training and protecting residents' rights. We are also proud of the requirement for family council rights, as set forth in the law. OBRA created, for the first time, a mechanism for families and residents to meet with one another in the nursing home setting!

### **The Rights of Family Councils – Robyn Grant, Long Term Care Policy Director at United Senior Action, IN; Consultant, the National Long Term Care Ombudsman Resource Center (NORC)**

- Family councils are win/win for everyone.
- Rights of Family Councils are set by the federal nursing home regulations. In the packet is a copy of what the rights are of family councils. These rights apply to all nursing homes that receive Medicare/Medicaid funding.

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- Five major rights:
  1. Must be allowed to form family councils and be allowed to meet in the facility, without interference.
  2. Families are allowed to meet privately.
  3. Nursing home staff can only attend family council meetings at the invitation of families.
  4. Facilities must assign one staff member to work with and support the family council.
  5. Facility must listen to the views expressed by the council and act on any concerns/complaint brought to them by the council.
  
- Family councils can work around barriers that facilities may throw up. Illinois and Maryland are two states that have developed state laws to protect and promote family councils.

### **Family Council Panel Presentation**

#### **Donna Smith, Member, Family Council, Presbyterian Homes, Evanston, IL**

- Started out as a family support group but found that they were spending a lot of time advocating for their families members. They involved the local Ombudsman who has been very helpful.
  
- Do not have assigned roles. They are working on developing structure and becoming more of a presence in the facility. They are reaching out to folks in the community.
  
- Key areas:
  1. Organizational structure
    - a. Work like a team and support each other like family
    - b. When residents pass away we lose members
    - c. Time issues
    - d. Share ideas
    - e. Key success was getting help for a resident who does not have any family. It benefited not only this resident but our love ones too.
    - f. Communication has improved
  2. Emotionally
    - a. This is a different way of doing things for us
    - b. Personally empowering

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## **Susan Bardes, Chairman, Family Council, Wellington Manor Rehabilitation and Nursing Facility, Indianapolis, IN**

- Susan was approached by the facility and encouraged to start a family council. Their group has elected officers with assignments.
- The administrator responds to concerns in writing before the next meeting.
- There is a \$10 fee to belong to the group. They have used the funds to support the residents. They also have groups that come in to speak to the council.
- The administrator supports the group and is good to work with. She is the first administrator in a string of administrators who helped the council.
- Successes:
  - Resurfaced driveway in front of the facility.
  - Employees are required to wear nametags at all times
  - Consistent assignment of CNA's
  - Improved communication between staff and residents
  - Improved laundry transportation to laundry room
  - Residents are not left sleeping in their wheelchairs
  - Younger female residents are only bathed by female staff
  - Improved consistency on care plans
  - Changed food service

## **Bob Bronaugh, Co-President, Manor Care Chevy Chase Family Council, MD**

- Established in 1998. The administrator at the time had been an administrator at the facility for 29 years. The first act of the family council was to send a 12 page letter to the Regional Director of the company. She was let go for someone who was "younger and cheaper". This new administrator had several poor surveys. The company sent in the corporate trouble shooter. It took her 13 months to clean up the facility. She also hired a great administrator who just recently left. The facility also lost the Regional Director after Manor Care was bought out.
- Are working right now to deal with the Carlyle Group and the new administration.

### **QUESTIONS:**

**Q:** How much information is required when a family council makes a complaint to the facility? Do they have to give names and information?

**A:** No you do not have to give this information. But do give them as much information (times and shifts) as possible without the names.

**A:** Our family council has some boundary issues. We just have to identify the problem.

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We do not have to solve the problem, that is the facility's job.

- Q:** What do you do if the administrator does not allow you to meet in private?
- A:** If you are not getting anywhere with the administrator move on to the Ombudsman program and the regional director.
- Q:** What do you do when you submit a concern over and over and get no help in resolving concerns?
- A:** If the council has submitted a concern repeatedly and nothing has happened, you could contact local ombudsman, who can work with family council and the administration to address the issue. This can get the facilities' attention.
- A:** The council can file a complaint with the licensing agency about the concerns that are not being corrected, and about the fact that the administration is not responding.
- A:** The family council can go above the administrator. If the nursing home is part of a chain, there is usually a regional corporate representative – find out who they are, and send a letter, and CC the administrator.
- Q:** How much support should councils expect to receive from the home? For example, how do you grow a council and remind people of meetings when the council doesn't have a budget to send out reminder cards?
- A:** Have a telephone tree among council members to remind other members of meetings.
- A:** Email reminders
- A:** If the council doesn't have a budget, the money can be raised if the council establishes a family council bank account. The council can charge voluntary dues (i.e. \$25 a year) and use that money to contact members.
- A:** The Administrator at one home pays for all newsletters and announcements or reminders because the family council doesn't have access to any addresses. This council sends a newsletter at least once a month.
- A:** The council can put fliers in billing statement.
- A:** The council can ask administration to pay for fliers to go out – the council can tell them that there are a number of facilities that do that for their council. For larger facilities, maybe the family council can kick in some money to help subsidize the cost.
- Q:** How does enforcement compare with state Medicare and Medicaid enforcement?
- A:** Enforcement of family council rights are part and parcel of the Medicaid and Medicare regulations. They are part of what surveyors and inspectors look at when they go in to facilities.
- Q:** Is there any open mechanism for a family council to share issues and solutions in a public forum?
- A:** Yes, NCCNHR has just started a family council discussion group/listserv for family

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councils across the country to dialogue with one another, share successes and obstacles, and network. Contact NCCNHR for more information or visit [www.nccnhr.org](http://www.nccnhr.org).

**Q:** What if the ombudsman is unresponsive, along with the administration?

**A:** File a complaint with licensing agency.

**A:** Work your way up the corporate ladder.

**A:** Determine if there is an ombudsman supervisor or coordinator, or state ombudsman and talk to them about your concerns and the lack of responsiveness. Contact information is on the NCCNHR website.

**Q:** Is there any kind of client CNA or nurse ratio?

**A:** A few states have a minimum staffing standard. NCCNHR has been pushing that at the federal level for many years now. NCCNHR website can help you determine if your state has a minimum staffing standard.

**Q:** Facility response to family council concerns lasts only briefly.

**A:** Ombudsman involvement can help a lot.

**A:** Can file a complaint with the licensing agency.

**A:** One council invited the state senator to come over to the nursing home, and visit with residents in their rooms.

### **Wrap-up and Announcements – Jessica Brill**

- We hope that this call has been useful and informative for you! NCCNHR wants to know more about the issues and barriers that your family councils face, and concerns that you have. This will help us to plan upcoming conference calls and events. So please call or email me at NCCNHR to share your thoughts: 202.332.2275, ext. 225 or [jbrill@nccnhr.org](mailto:jbrill@nccnhr.org).
- Two upcoming opportunities related to NCCNHR:
  - Residents' Rights Week is designated by NCCNHR and is celebrated the first full week in October each year to honor residents living in all long-term care facilities. It's a time for celebration and recognition offering an opportunity for every facility to focus on and celebrate awareness of dignity, respect and the value of each individual resident. This year, Residents' Rights week will take place October 5-11, and the theme is Recipe for Home: defining and creating home in long-term care facilities. Visit our website where there will soon be information on ways to celebrate Residents' Rights week with your loved ones!
  - The NCCNHR Annual Conference is being held in Indianapolis this year, October 15-17. The theme is Making It Happen: *Advocacy into Action* ~

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*Action into Care.* Please contact us at NCCNHR for more information, especially about our meeting for families, as well as help with registration, rates, and scholarships!

- We encourage you to join NCCNHR, who coordinated this call today. By joining NCCNHR, you will be helping to improve advocacy and our work on behalf of long-term care residents. So join today, by calling NCCNHR, or going to our website!
- NCCNHR's website has a great deal of resources regarding family councils and advocacy. Visit the Family Council Center, and the page dedicated to this project – where you can learn about upcoming opportunities for networking, support, and strengthening of your family council!
- Two new resources:
  - A DVD available from NCCNHR titled *Strength In Numbers: The Importance of Nursing Home Family Councils*. The DVD contains a companion booklet - a Program Leader's Guide with discussion guidance, additional resources, fact sheets, and other information. The cost is \$25.00 per DVD or 4 DVDs for \$100.00. There is a flier and order form included in your materials, as well as NCCNHR publications list.
  - A resource from FRIA – a Family Council Manual and Toolkit titled *A Guide for Creating and Sustaining Effective Family Councils in Nursing Homes*. This is a basic, how-to manual for family councils, and it includes a CD-Rom Tool Kit, containing sample materials and templates. The manual is \$30.00 - to order a copy, please email FRIA at [http://fria@fria.org](mailto:fria@fria.org) or call 212.732.5667.
- Thank you to our speakers and to our call participants for joining us, and for all the terrific information and questions!

## **Family Councils for Quality Long Term Care: *Support, Strengthen and Empower***

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