

**STATEMENT TO THE
SENATE SPECIAL COMMITTEE ON AGING
ON BEHALF OF
FRIENDS AND RELATIVES OF INSTITUTIONALIZED AGED (FRIA)
May 2007**

Friends and Relatives of Institutionalized Aged, (FRIA), thanks Senator Kohl and the Senate Special Committee on Aging for your leadership and concern in calling attention to the health and living conditions of the elderly residing in federally funded nursing homes. We express our deep appreciation for the opportunity provided to FRIA to add our voice to your hearings entitled, "The Nursing Home Reform Act Turns Twenty: What Has Been Accomplished, and What Challenges Remain?"

Since 1976, FRIA has been NYS's unique consumer resource for free information and assistance on long term care issues, with a special focus on nursing home care. FRIA has played a pivotal role in reforming the industry since its inception. In addition, FRIA provides direct services to seniors and their informal caregivers, working to improve individual problems with long term care as well as positively impact the state system generally. FRIA's services include:

- Free telephone bilingual Helpline service that assists over 1,500 callers each year on a wide array of long term care concerns,
- Organizing, assistance and support for over 60 NYS Family Councils attendant to nursing homes, representing over 20,000 nursing home residents,
- Caregiver Advocacy Center that provides information and interventions on resident rights, family rights, and care complaints, and,
- Community education and outreach that educates seniors and their families on NYS's long term care system, reaching over 1,000 community members in 2006 alone, not counting media appearances.

Over 1.6 million people are living in nursing homes in the U. S. today; in New York State where FRIA is based there are 657 nursing homes with 120,347 certified beds. Generally, people in these homes suffer from chronic disease, physical disabilities and mental disabilities and/ or dementia and depend on professional assistance for day-to-day care and continued survival. They may or may not have close family or friends nearby to oversee their care. They depend on the compassion and professionalism of the nursing home staff to make their end of life days more dignified, supportive and as pain free as possible. It is our important grassroots, individual consumer work with the New York residents and their families that informs our policy insights and brings us to submit these comments today.

As you know, demographic projections predict a doubling by 2030 of people over 65 years of age, with expectations of increasing numbers of over 85 year olds and of those

with dementia. Addressing the issues presented by the NHRA is critical not only for those older Americans alive today, but also, given the staggering aging baby boomer demographics, so we can resolve the issues before the problems take on unmanageable proportions. The Nursing Home Reform Act has had notable successes in reducing restraints, in some cases reducing overmedication of residents, and in recognizing family and friend council organizations. Yet, it continues to miss its mark in ensuring the broader mission of the Act- to ensure that residents receive quality care that will result in their maintaining or achieving the highest practicable physical, mental, and psychosocial well being- largely because the following, important elements of our federal legal framework are absent:

- 1- Minimum staffing levels are not established for nursing homes,
- 2- State agency oversight, through surveys, complaint investigations, and sanctions, are weak and agencies are not made appropriately accountable to CMS,
- 3- Financial transparency of federally supported nursing home operations, with enforceable random auditing, is non existent,
- 4- Nursing home closures are not adequately addressed.

1- Minimum staffing levels are not established for nursing homes

Current federal and NYS laws only call for “sufficient” staffing in each home, a vague standard and one honored more in the breach than in the practice. The absence of an enforceable, federal standard has resulted in inconsistent and low staff levels in homes throughout the country. The GAO, HCFA/CMS, and FRIA’s own Helpline callers, among others, consistently document that low levels of staffing directly result in poor resident outcomes: indignities, miseries, injuries, and deaths. CMS itself recommends minimum total (not including administrative) staffing levels that range from 2.75 to 3.9 hours per resident per day. Other experts, some of whom have testified before you in the hearings, recommend a higher level of hours per resident per day. It should be remembered that these are minimum standards, below which experts *expect* harm to residents will result. Evidence exists to indicate that no more than 10% of homes nationwide meet these minimum standards. In NYS, for example, a study was done by NYS Attorney General Elliot Spitzer, to determine the staffing levels in homes. This study found that 2% met this minimum standard. Moreover, in the last few years, the population living in nursing homes has become more frail and less competent. Thus, residents need even more staff time and attention than the population did when the experts developed these minimum standards.

Cases drawn from FRIA’s Helpline can illustrate how low staffing levels translate into real life crises for our nations’ elderly.

- A daughter is concerned because her 75 year-old father, who has both Alzheimer’s disease and depression, is having difficulty swallowing. He needs to be fed slowly but the nursing home is attempting to place him on a feeding tube against his wishes. She requested that the facility take time to feed him, she knows her father enjoys eating his meals and will suffer greatly if he were denied that pleasure. Also, the daughter recently discovered her father developed a pressure

sore but the doctor did not notify her of this development and her father is being left in a wheelchair all day, which exacerbates this condition.

- A women's sister had a fracture and suffered a stroke, she was sent to a nursing home to recuperate and receive rehabilitative therapy. Her sister was not toileted or changed in a timely manner, frequently left to sit in her excrement, and developed a pressure sore and a painful rash.
- A daughter complains that her mother is depressed because she is rarely taken out of her room for activities, even though she is otherwise mentally competent.
- A spouse is afraid because his wife has lost 15% of her body weight since she arrived at the home a month ago, and seems to be missing meals and he is afraid she is wasting away.

Because most homes operate on a profit margin basis, there is no incentive for them to staff up to these higher needs without federal government intervention. For that reason, legislative requirements are the only way to ensure that appropriate staffing will occur. And, although some states have addressed the issue with lesser state standards, the nursing home program is largely a federally funded program, driven by CMS standards and reporting. It is therefore incumbent upon the federal government to take a strong lead in this area.

For that reason, FRIA supports federal legislation, like that introduced previously by Rep. Henry Waxman, that would require *minimum* nurse staffing ratios totaling 4.1-4.85 hours per resident per day. In March, FRIA personally delivered to Congress over 500 petitions from New Yorkers calling for this minimum staffing level in homes. Extracts from their heartfelt petitions reflect the urgency and pleas for this simple but meaningful reform:

“Please remember all of us will be old at some time.”

“There are those people in facilities who have no one to help out if their care needs aren't met because of understaffing.”

“We are not just talking about the elderly. I speak for my 25 year old daughter.”

“It is an outrage that seniors who spent their lives taking care of us cannot achieve a standard of health care in nursing homes that secures adequate coverage for them!”

FRIA also supports the interim step urged in NCCNHR's testimony that Congress require CMS to collect accurate staffing data from the nursing homes and make this information available to the public. It is remarkable in this world of high tech data collection, that consumers and the government are forced to rely upon self-reported data about such a

crucial element of care and appropriate usage of federal money. Currently, staffing level data at homes are accepted by CMS with no independent verification of this information. Based on what families and residents tell us, we must seriously question whether the data provided by nursing homes to CMS is reliably accurate, and we fear that even the low levels currently reported are higher than what is provided to residents in actuality.

Establishing appropriate, minimum nursing staff levels in nursing homes is the single most important protective act we can take for the safety and well-being of our nation's elderly residents. Moreover, establishing staffing minimums will provide preventative protection for residents. It is a far better, more reliable model than continuing to solely rely on enforcement efforts of state agencies 'after the fact' of poor care, efforts we recognize are grossly inadequate. Care of the elderly requires personal attention. There is simply no short cut. Setting minimum staffing levels alone would give new meaning to the promise of the NHRA.

2- Lax government enforcement

It comes as no surprise to those who have loved ones living in nursing homes that the GAO's new report, "Nursing Home Quality and Safety Initiatives," found that homes are not sanctioned for non-compliance with federal standards, despite actual harm caused to seniors by their failures. Historically we have witnessed the GAO issue similarly glaring reports with no corresponding action from federal or state officials, evidencing a callous disregard for our frail seniors. In fact, there are numerous regulations governing quality of care that provide a basis for sustaining quality of care deficiencies as violations of law. Yet, according to the GAO, more than 300,000 elderly and disabled residents lived in chronically deficient nursing homes where they were "at risk of harm due to woefully deficient care." Other GAO reports have found that these figures actually understate the actual number and the seriousness of violations.

Part of the problem is that enforcement must be non negotiable and swiftly pursued when deficiencies are found- but it is not. We believe that the process by which survey findings are disputed by homes may provide an inappropriate opportunity for homes to 'reduce' both deficiency findings and fine imposition. We all recognize that, on occasion, a surveyor may make a mistake requiring appropriate supervisory discretion to modify the results. However, we have been led to believe that substantive changes are made to at least the state findings routinely, along with reduction of fines. This process undercuts the viability and credibility of surveyor work and misleads the public about the quality of care in nursing homes. In this regard, it should be remembered that the survey findings are key tools disclosed to consumers representing the government's professional assessment of the nursing home. By intentionally modifying the original survey results to minimize the findings, states are providing consumers with an erroneously 'better' picture of the home on which to rely. As such, consumers are deceived and potentially injured by this approach.

Surveyors in few states routinely speak to families and family councils to determine the consumer perspective about the quality of care and responsiveness of facilities. In New York State, it is a rare occurrence for surveyors to speak to residents or families, unless

these individuals are selected for conversation by the nursing home administration. More random conversations with consumers are necessary. And, such conversations must be private with the identity of the parties fully kept confidential. Off-site discussions are the best way to accomplish this result and most families we know would welcome the chance to provide helpful input.

FRIA believes that the government has the requisite knowledge and capacity to perform professional surveys appropriately. We would urge new training of surveyors to impress the need for thoroughness, inclusiveness of family, correct categorization of deficiencies, review of extant complaints against the nursing home, and proactive questions.

And, complaint investigations need to be beefed up, by detailing specific legislative process demands, and possibly monetary recourse for consumers who have been retaliated against because they raised complaints against a nursing home. During the past ten years, FRIA has answered over 14,000 telephone calls from residents and families raising nursing home complaints. Few substantiated complaints result in a statement of deficiencies. For example, in New York City only 22.9% were substantiated but only 4.7% received deficiencies in 2004. Similarly, in 2005 26.7% of complaints were substantiated but only 3.8% resulted in deficiencies. In some cases, the complainant was never interviewed by the state Department of Health. In others, the complainant was interviewed early on, but never given an opportunity to respond to the facility's arguments or explanations thereafter. Often, a complainant may have information demonstrating the falsity of a facility's account but is not given a chance to present it to the investigator. In most cases, DOH investigators seem to simply accept the facility's version of events and use it as the basis for not sustaining a complaint, not going beyond the four corners of the nursing home's documentation, even when conflicting documentation is presented by the consumer. And, there is no appeal mechanism for a consumer to challenge a finding, even if it involves allegations of serious, irrevocable harm.

In reconsidering the complaint process, it must be remembered that residents and families harbor tremendous fear of retaliation being directed against their vulnerable loved one or themselves, if they complain about a nursing home or staff member. It is easy for a retaliating nursing home to 'ignore' the resident of a complaining family member, or to restrict the family visits, on a wide variety of fabricated grounds. Given the enormous courage it takes to file such a complaint, it is truly disheartening and disempowering for a resident or family when its complaint is not sustained following an inadequate investigation.

3- Financial transparency

The lack of financial transparency results in significant opportunities for fraud, misinformation and confusion. On average, 67 percent of nursing home residents have their care paid for by the Medicaid program; 9 percent are covered by Medicare. The federal government is paying upwards of \$50 billion/year for care. There must be accountability and transparency for how public dollars are being spent, especially given the serious findings of understaffed, inferior and deficient care. Nursing home chains are

proliferating, yet in NYS we have so far found it impossible to access ownership and investor interests in nursing homes. Nor do advocates and consumers – and possibly not even government – have any standard way of knowing how much money is actually being spent on direct care costs for their loved ones. Given the huge amount of state and federal dollars invested in nursing homes, financial transparency is critical to safeguarding the public’s investment in these facilities, and assuming that the NHRA requirements are satisfied.

4- Nursing home closures

In recent years, governmental long term care policies across the states have focused on a shift from institutional to home and community based care. FRIA supports home and community based options for those who have the full resources to live safely and independently. Yet even if our communities offered a full range of accessible, affordable housing and coordinated health and social services (which they currently do not) our communities would still need nursing homes that are staffed beyond minimum standards and that support a dignified life to accommodate those with dementia, those without family/friends to oversee care, those who prefer socialized living settings, and more. Further, the shift from institutions is partly in response to overly simplistic and idealistic notions of independence that blind many to the complex caregiving needs of seniors and their families/friends. It is also dollar-driven by the questionable belief that home and community based care costs less than nursing home care. Consequently, instead of implementing policies to protect our nation’s seniors in nursing homes, the nursing home model is being eroded by short-sighted state and federal policies.

For example, in New York, in 2004, Governor Pataki, like many other state officials, called for the closing of thousands of nursing home beds in the state. His statewide Commission to review the nursing home and hospital systems recommended that more than 3,000 nursing home beds statewide be cut. New York City alone will lose over 1,200 nursing home beds by 2008, despite its increasing senior population. Families are already hard-pressed to find nearby sub-acute and long term care beds upon hospital discharge or in response to health crises. Government needs to insist that strong protections be put in place to protect residents dislocated by voluntary and involuntary closures, that family/friends have the ‘say’ over where the resident will be transferred, and that there is oversight over to ensure that unbefriended residents are moved to appropriate facilities.

Conclusion

Although the issues presented by long term care are complicated and far reaching, enacting minimum safe staffing standards is not. Congress can better protect our seniors today by acting on this long overdue issue. It is that simple. If we fail to take the action that we all know is necessary, we are essentially saying that the frail elderly are disposable. We urge this committee to support this long-overdue and critical legislative effort.

We would be pleased to answer your questions or assist in any way we can as the Committees continue to review the urgent topics, staffing, enforcement, financial transparency, nursing home closures or any other topic that is raised as a result of the hearings.

Again, we thank Senator Kohl and the Senate Committee on Aging for your help and leadership, and for the opportunity to present some of our views.

Respectfully submitted,

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