Public Hearing Testimony

Family Health Care Decision Act

Submitted to:

New York State Assembly
Committee on Health

Presented by:

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On behalf of the New York Association for Homes and Services for the Aging (NYAHSA), I thank you for the opportunity to provide testimony on the Family Health Care Decision Act currently before the Assembly (A.5406-A) and the Senate (S.5807). This legislation would establish procedures and standards to allow family members and others close to a patient or resident to make medical treatment decisions on the patient's behalf when they are not able to make those decisions themselves.

My name is Carl Young, and I am the President of NYAHSA, a statewide organization of socially responsible, community-benefit organizations dedicated to providing high quality health care, housing, and community services to the elderly and people with special needs.

Founded in 1961, NYAHSA is the only statewide organization representing the entire continuum of not-for-profit, mission-driven and public continuing care. NYAHSA's nearly 650 members serve an estimated 500,000 New Yorkers annually. Those members include nursing homes, as well as adult care facilities, assisted living providers, continuing care retirement communities, senior housing facilities, adult day health care programs, and home care and community services providers serving people of all ages.

NYAHSA supports this proposal because it would allow medical treatment decisions to be made at the bedside by the resident's family or friends. Decisions would be made with advice from physicians and based upon the reasonably known wishes of the resident, or, in the absence of family or friends, by a person chosen for that purpose through a process carefully set forth in the bill. If the wishes of the resident are not reasonably known and can not be ascertained, the bill requires decisions to be made based on the best interests of the patient, including consideration of the patient's religious and moral values. For some kinds of decisions or in certain circumstances, the bill would require additional concurrence by a bioethics committee, with review by a physician.

Many residents of nursing homes have neither a living will nor a health care proxy. In the absence of these protections, health care providers and family members are forced to turn to the courts in order to make a treatment decision. Often that decision is sought more for the legal protection of those who must carry out the decision than for any heightened awareness of the appropriateness of the medical treatment. Courts are reluctant to make these kinds of decisions and are often unable to respond quickly. Furthermore, the adversarial nature of the court system can create further anxieties among family members or friends when discussing and resolving these sensitive issues.

While there are countless numbers of patients and residents who could be affected by the passage of this bill, I would like to focus my comments on how this legislation impacts the provider. Many residents who move into a nursing home are already unable to make medical decisions for themselves. In the absence of a living will or health care proxy, the provider must do all it can to sustain the resident's life – even if the resident's family or close friends know it is against the resident's wishes. Providers find themselves in the same situation even if a resident has a health care proxy but has failed to specifically designate that their proxy can make nutrition and hydration decisions.

If a provider takes action to sustain the life of the resident and the family or close friends decide to take the matter to court, then the provider must also then incur the costs of retaining counsel for the litigation. Nursing homes are already stretched thin and the added legal expense makes their situation that much worse. This proposal would put the medical decision making back into the hands of the people who are best able to know the resident's wishes -- their family and close friends. The bill also takes into consideration the possibility that family members may not agree as to what the resident's wishes are by providing for mediation.

One particular case serves to illustrate an example of the legislation's potential impact. "Mr. X" was a very elderly, demented nursing home resident without a health care proxy or living will. While hospitalized for an acute illness, he was unable to eat and a feeding tube was surgically inserted into his stomach. He returned to the nursing home and was eventually able to eat on his own. Nourishment via feeding tube was discontinued, and though he was able to eat some food, he did not consume enough to prevent becoming malnourished. The nursing home made every effort to provide supplemental nourishment and foods he particularly liked, and encouraged his devoted and attentive wife to assist him with his meals. Ultimately, however, all measures were failing, and the physician, in collaboration with the facility staff, determined that resumption of the tube feedings were necessary.

The resident's wife, who visited Mr. X daily for many hours, and his son who was also very attentive, strongly objected to resuming tube feedings. Their feeling was that Mr. X was in a natural and inevitable course of general decline due to his very old age, and that the feedings would only prolong his suffering. Furthermore, the wife recalled conversations with her husband during which he had made statements to the effect that he would never want futile artificial measures taken to prolong his life. The physician and staff acknowledged Mr. X's very poor prognosis, and philosophically concurred with his wife and son. Meetings of the facility's bioethics committee were held, and the facility's attorneys extensively reviewed the case. Their advice was that there did not exist sufficient "clear and convincing evidence" of Mr. X's wishes, and the facility was therefore legally obligated to "err on the side of life" and proceed with the tube feedings.

Mr. X's wife and son, while understanding the facility's position, were dismayed, frustrated, and angry at their powerlessness to effectively advocate on behalf of their loved one. They continued to request that the feedings be stopped, to no avail. Mr. X's condition slowly declined, and some months later he died.

Another example is that of "Mrs. Z". Mrs. Z. is also a very elderly and demented nursing home resident and she has no immediate family. She has suffered from recurring gall bladder inflammations and is hospitalized when her physician feels that the intervention of the acute care hospital is warranted in order to treat her inflammation. This generally consists of high doses of intravenous antibiotics along with sophisticated diagnostic testing.

The ultimate solution to Mrs. Z's gall bladder disease is the removal of her gall bladder. However, this cannot be performed during one of her acute episodes because it would be unsafe. It can only be safely performed when she is well. However Mrs. Z does not have a health care proxy and, since she suffers from severe dementia, she cannot provide her own informed consent. Since she has no immediate family, there is no one who can consent on her behalf. Since the gall bladder is not inflamed in between episodes, physicians cannot provide the consent because it is not a life or death emergency.

Therefore, Mrs. Z suffers with a disease for which there is a relatively easy cure but it is not available to her due to the nursing home's inability to provide consent for the surgery. The bill would outline a streamlined procedure to allow a relative or close friend to consent to surgery for Mrs. Z., rather than forcing the nursing home to go to court to seek a guardian.

NYAHSA believes that this legislation would institute a far more humane process than that which is currently available, without sacrificing either attention to standards or sensitivity to the moral values and religious beliefs of residents and their families, or those of the health care facility in which care is being provided. The bill is the product of several years of work by the Task Force on Life and the Law, and reflects the input of health care providers, consumers, academics, religious communities, and other interested persons. This legislation would provide important protections for patients and residents of nursing homes, their families and friends, and the health care providers who are forced to deal with these problems on a regular basis.

On behalf of NYAHSA, I would like to again thank you for the opportunity to provide these comments and invite committee members to use our organization as a resource. We are ready to help in any way that we can as you consider this important issue.