CHAPTER 113

AN ACT establishing the New Jersey Advisory Council on End-of-Life Care in the Department of Health and Senior Services.

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey:*

1. The Legislature finds and declares that:

a. The current health care system in New Jersey often fails to meet the special needs of persons who are approaching the end of life by limiting the opportunity that they earnestly desire to spend their final months free of pain, in familiar surroundings, together with their friends and families, instead of being tethered to tubes and other medical apparatus in an intensive care unit or other acute care hospital setting;

b. At the same time, according to the *Dartmouth Atlas of Health Care* 2006 study on variations among states in the management of severe chronic illness, Medicare expenditures on many aspects of end-of-life care in New Jersey are among the highest of all states nationwide, and often greater than those in any other state, when measured by such indices as: days spent in a hospital per decedent during the last six months of life; days spent in an intensive care unit per decedent during the last six months of life; physician visits per decedent during the last six months of life; the percentage of deaths associated with an admission to intensive care; Medicare spending and resource inputs during the last two years of life; and standardized physician labor inputs per 1,000 decedents during the last two years of life;

c. Compared to the average American, New Jerseyans in the last six months of life spend 30% more days in the hospital, see physicians 43% more often, and spend 44% more days in the intensive care unit;

d. Expanded use of licensed hospice care programs, through more timely enrollment by persons in need of end-of-life care that responds to their needs and concerns, could help to avoid much of the expense for this type of care that is incurred in New Jersey;

e. In many cases, earlier referrals of persons with terminal conditions to hospice care could serve to improve their pain management and thereby enhance their quality of life and death, by providing high-quality palliative care while also meeting the counseling and spiritual needs of these patients and their families;

f. Persons who are near the end of life have unique needs for respectful and responsive care, and concern for their comfort and dignity should guide all aspects of their care so as to alleviate their physical and mental suffering as much as possible;

g. At a minimum, the end-of-life care that a person receives should encompass dignified and respectful treatment at all times and aggressive pain management as appropriate to that person’s needs;

h. As noted in the *Report of the New Jersey Legislative Commission for the Study of Pain Management Policy*, issued more than a decade ago, “the public policy of this State should support a compassionate and humane approach to caring for patients who are terminally ill which seeks to mitigate their physical pain and mental anguish and preserve as much of their peace and dignity as possible”;

i. As further observed in that report, “We are all stakeholders in the public interest to be served by the advancement of a kinder and gentler approach to caring for patients as they approach the end of life because we will all take that journey”; and

j. It is manifestly in the public interest for this State to establish an advisory body, the membership of which would comprise individuals with suitable qualifications for this purpose, to examine those issues that it deems appropriate for the consideration of its members relative to the quality and cost-effectiveness of, and access to, end-of-life care services for all persons in this State, and to propose recommendations for the consideration of State agencies, policymakers, health care providers, and third party payers.

2. There is established the New Jersey Advisory Council on End-of-Life Care in the Department of Health and Senior Services.

a. The advisory council shall include 21 members as follows:

(1) the Commissioners of Health and Senior Services and Human Services and the Ombudsman for the Institutionalized Elderly, or their designees, as ex officio members;

(2) two members each from the Senate and the General Assembly, to be appointed by the President of the Senate and the Speaker of the General Assembly, respectively, who in each case shall be members of different political parties; and

(3) 14 public members who are residents of this State, to be appointed by the Governor with the advice and consent of the Senate, including: one person who represents licensed hospice care programs in this State; two physicians licensed to practice in this State who have expertise in issues relating to pain management or end-of-life care, one of whom is an oncologist; two persons who represent general hospitals in this State, one of whom represents a religiously-affiliated hospital; one person who represents an organization in New Jersey that advocates on behalf of persons with mental illness; one person who represents an organization in New Jersey that advocates on behalf of persons with developmental disabilities; one person who represents nursing homes in this State; one registered professional nurse licensed to practice in this State; one attorney licensed to practice in this State who has expertise in health care law; one person who is employed as a patient advocate by a general hospital in this State; two members of the general public with expertise or interest in the work of the advisory council who are not licensed health care professionals, at least one of whom is a member of a minority racial or ethnic group; and one person representing academia who has expertise in biomedical ethical issues relating to end-of-life care and is not a licensed health care professional.

b. The public members of the advisory council shall serve without compensation but be reimbursed for any expenses incurred by them in the performance of their duties.

c. Legislative members shall serve during their terms of office. Vacancies shall be filled in the same manner as the original appointments were made.

d. The advisory council shall organize as soon as practicable after the appointment of its members. The Commissioner of Health and Senior Services or the commissioner’s designee shall serve as chairperson, and the advisory council shall select a vice-chairperson from among its members and a secretary who need not be a member of the advisory council.

e. The advisory council shall be entitled to call to its assistance and avail itself of the services of the employees of any State, county, or municipal department, board, bureau, commission, or agency as it may require and as may be available to it for its purposes.

f. The Department of Health and Senior Services shall, within the limits of its existing staff and resources, provide such staff support as the advisory council requires to perform its duties.

3. The purpose of the advisory council shall be to:

a. identify existing practices and programs in this State that have demonstrated measurable success in providing patient access to, and choice of, high-quality, cost-effective palliative care and end-of-life care services and ways to promote the expansion and dissemination of those practices and programs;

b. identify an effective mechanism for disseminating information to the general public, on as widespread a basis as is practicable, which information will assist patients and their families in making informed health care decisions with regard to palliative care and end-of-life care; and

c. develop goals and benchmarks for efforts, which may be undertaken by the Department of Health and Senior Services or other relevant entities acting singly or in collaboration with each other, to accomplish the purposes of: providing patient access to, and choice of, high-quality, cost-effective palliative care and end-of-life care services; and assisting patients and their families in making informed health care decisions with regard to such care.

4. The advisory council, no later than 18 months after the date of its organization, shall report to the Governor, and to the Legislature pursuant to section 2 of P.L.1991, c.164 (C.52:14-19.1), on the results of its activities, and shall include in that report such recommendations for administrative, legislative, and other action as it desires to present pursuant to section 3 of this act, including policy recommendations for the consideration of State agencies, policymakers, health care providers, and third party payers. In developing its recommendations, the advisory council shall have, as its overriding concern, to promote an end-of-life care paradigm in which patients' wishes are paramount and they are provided with dignified and respectful treatment that seeks to alleviate their physical pain and mental anguish as much as possible.

5. This act shall take effect immediately and shall expire upon the issuance of the report by the advisory council pursuant to section 4 of this act.

Approved August 18, 2011.