



February 16, 1989

The Honorable John F. Russo
President
New Jersey Senate

The Honorable Charles Hardwick
Speaker
New Jersey Assembly

RE: Minority Report of the Commission on Legal and
Ethical Problems in the Delivery of Health Care
Concerning Advance Directives (Living Wills)

Dear Senator Russo and Assemblyman Hardwick:

Pursuant to N.J.S.A. 52:9Y-6, a dissenting minority of Commissioners on
your above Commission respectfully submit the enclosed Minority Report.

Thank you.

Very truly yours,

/s/ A Minority of Commissioners on the
New Jersey Commission on the Legal
and Ethical Problems in the Delivery
of Health Care

Enclosures

cc: Honorable Thomas H. Kean
cc: Honorable John Dorsey, Senate Minority Leader
cc: Honorable Willie Brown, Assembly Minority Leader

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Minority Report

New Jersey Commission on the Legal and Ethical Problems in the Delivery of Health Care:

Proposed Advance Directives for Health Care Act

To: The Honorable Thomas H. Kean, Governor;
New Jersey Senators; and
Members of the New Jersey Assembly

I. Background:

The undersigned Commissioners, appointed and serving as of December 31, 1988, on the New Jersey Commission on the Legal and Ethical Problems in the Delivery of Health Care ("Commission"), respectfully submit this Minority Report. This Report concerns the so-called 'Advance Directives for Health Care' legislation ("Proposal") proposed and forwarded to you at the end of 1988 by a bare majority of the Commissioners (viz., 14 of 27 Commissioners, one of whom eloquently stated his profound reservations in writing).

When the Commission was established, the Legislature specifically mandated by law (N.J.S.A. 52:9Y-6) that the Commission report to the Legislature what the current law is and how it is working. The Commission is required by law to submit to you, by December 31, 1988:

a. A report on the current status of the law in New Jersey and other jurisdictions regarding the termination of treatment, surrogate decision making, and related issues;

b. An examination of existing practices and procedures for decision making, such as Quinlan ethics committees and Grady and Conroy procedures, and a determination of how well they work and where change is needed. Successful approaches in decision making should be identified so that the wider use of these approaches by the health care profession and other professions may be encouraged;....
[emphasis supplied]

Though these empirical studies and reports are required by the Legislature and are logically preliminary to proposing any changes, the Commission has neither researched nor reported what the existing law is, or how it works in hospitals, where the majority of such decisions are made. The Proposal is, therefore, offered in a factual vacuum.

II. Suggestions:

We endorse the idea of legislation specifying the formal requirements of Living Wills and Durable Medical Powers of Attorney. "Advance Directives" is the Proposal's term for Living Wills and Durable Powers of Attorney. Despite the sincere efforts of our colleagues to produce a recommendation for you after three years of deliberation, the undersigned, however, must in good conscience dissent from several crucial facets of the Proposal. For reasons including those recited below, we respectfully submit that their Proposal should not be enacted.

II. A Safeguards:

The Commission has an ample staff of lawyers, philosophers and technical assistants. We are disappointed, as you also will be, that, despite the statutory mandate of N.J.S.A. 52:9Y-6, the Commission Staff has prepared a report describing neither other States' comparative precautions in this area nor current New Jersey law for foregoing life sustaining treatment. Not only does such New Jersey law exist,¹ but our State's jurisprudence in this area has been hailed internationally both for its wisdom and for being in the vanguard of this most sensitive and complicated area of the law. Indeed, one of our existing law's major features is a judicially designed system of safeguards to protect vulnerable patients from "the potential for abuse with unsupervised institutional decisionmaking."² Persons having Advance Directives are vulnerable to such risks, too.

The six main features of our current system of safeguards are simple, workable and proven, as well as commonsensical:

- 1) a requirement that life and death decisions for others be made under objective standards, rather than be left to the subjective biases, stress or limited knowledge of the particular decisionmaker;
- 2) a requirement that life and death decisions be restricted to those patients who are either terminally ill or in a persistent vegetative state (permanently unconscious);
- 3) a requirement that three physicians independently verify the diagnosis and prognosis and the treatment options available before a fatal decision can be made for a sick person;
- 4) a requirement that for any life and death decision to rest upon the patient's Living Will, that Living Will must contain clear and convincing evidence of the patient's wish (not, as the Proposal recommends, the "spirit" of that wish) to forego treatment;
- 5) a requirement that, even for a patient with a Living Will, the rights of that patient's caring family members be respected, to the extent of affording them a chance to contest the accuracy of the fatal decision being made;
- 6) a requirement that, where there is uncertainty about the patient's medical condition or wishes regarding life-sustaining medical treatment, such doubts should be resolved in favor of preserving life.

Just because a patient has made a Living Will does not mean that the patient is immune to the documented risks of neglect, misunderstanding or

indifference to his/her wishes. These risks affect all patients needing life-sustaining treatment which, of course, is sometimes difficult and expensive. Patients with Living Wills are no less deserving of protection than are others, though once the patient is no longer able to direct his/her own care the protection should focus on what the patient said in his/her Living Will.

Regrettably, the Proposal would either eliminate or radically impair each one of these six established, systematic protections for our most vulnerable citizens. Though it would abolish or dilute these six important safeguards, the Proposal has failed to evaluate how these permissive changes would affect the vulnerable and has failed to give due weight to the existing safeguards under New Jersey law. This tendency is deeply unfortunate and can have fatal consequences for particular patients whose lives will be prematurely ended. Of the Proposal's deadly implication for New Jersey as a whole, we must now: "Ask not for whom the bell tolls, it tolls for thee." [John Donne].

II. B Countervailing State Interests:

We firmly believe that patients have a right to direct their future health care, even to the point of providing in advance for what should be done if they later become intellectually compromised. We just as firmly agree with the New Jersey Supreme Court's holding that this right is not absolute.³ The Proposal does not contain a pregnancy exception typical of many other States' Living Will laws, nor does it set forth a general framework for tempering patient autonomy with respect for the important societal interest in protecting dependent third parties.

Section 1D of the Proposal pays lip service to the universally acknowledged social interest in preventing suicide and in protecting life, third parties and the integrity of the medical profession.⁴ However, there is no concrete procedure for deciding how and by whom these countervailing interests are to be balanced against the qualified right of the individual patient. Therefore, the patient's presumed "right to die" becomes paramount, even absolute. This is dangerous.

II. C Immunity:

The Proposal for decisionmaking is uniquely permissive among States' arrangements. It not only dispenses with the common requirement that a patient be terminally ill before a Living Will becomes operative, it furthermore grants blanket immunity to health care professionals and institutions that fail to use due care in dealing with the sick. Instead, anyone who acts "in good faith," however negligently or recklessly, becomes legally immune.

We fear, of course, the harm which can be done by those few who believe that euthanasia -- "mercy killing" -- is permissible for patients whose

quality of life fails to meet the ephemeral standards of these self-appointed "angels of mercy." However, we fear even more the inevitable emergence of a two-tiered system of health care: one of maximum diligence for those without a Living Will and one of "good enough" for those helpless, incapacitated patients who committed their most personal wishes to writing in a Living Will.

Imagine a patient with breathing difficulty who left a Living Will instructing that all beneficial treatment be attempted. The patient is now incapable of making and expressing his/her own medical treatment decisions and needs oxygen. The physician orders the therapy, but neglects to properly instruct the respiratory therapist. The patient dies, but, under the Proposal, no one can sue, because the malpractice is immunized, having occurred in "following" an advance directive. Likewise, under the Proposal, neither the negligent physician nor the technician can be professionally disciplined for their failure to follow the patient's wish to receive treatment.

Once we so weaken the legal and ethical standards of care owed by physicians to their patients, once we have so fundamentally altered the already inherently unequal relationship between the sick person and the health care establishment on whom the patient utterly depends, we will have profoundly impaired one of the most vital safeguards of all: the accountability of the healing professions. Without full professional and institutional accountability to patients who sign Living Wills, there will undoubtedly be a slow, but inexorable, degradation in the degree of personal responsibility felt to be owed to those having Living Wills.

When, as in the Commission's deliberations, ideas for "rationing" life-sustaining treatment for the infirm elderly are topical in policy discussions, we believe that the Proposal's grant of immunity represents unnecessary tampering with basic legal relationships. It is historically, legally and morally unwise.

II. D Due Process and Equal Protection of the Law:

Our concern with the negative aspects of the Proposal's grant of immunity leads naturally to another crucial problem, that of the Proposal's constitutional infirmities.

The Proposal would repeal overnight the six present safeguards for incompetent patients having Living Wills. At the same time, the Proposal grants immunity to those who negligently or recklessly make this fatal decision about the patient. Thus, the prospective patient's signing of an advance directive is tantamount to a tacit waiver of the protections available to others, including the right to sue his/her physician or health care agent for making an unjustified decision.

The right to life, the right to equal protection of the laws against homicide, the right to sue for redress of a grave mistake, the right of an incompetent to be represented by a guardian who will receive notice and

represent the incompetent's interests in proceedings which would prejudice the incompetent's basic rights -- these are fundamental civil and human rights under current New Jersey law and our system of government. Furthermore, classifying a patient without a hearing as unable to make life-and-death medical decisions for himself/herself is a constitutionally suspect categorization. That is, delegation by the State of New Jersey of such final decisions to ethics committees, physicians and designated health care representatives means that it has taken State action to approve abrogating those patients' basic rights. For protections to be deemed voluntarily surrendered through the mere act of signing a Living Will, the purported waiver must be knowing and intelligent.

Unless there is a clear written warning of the consequences, however, there is no assurance that patients who sign Living Wills will truly understand the fact that, under the Proposal, they have thereby effectively waived fundamental rights, including the constitutional rights of equal protection and due process of law. The argument that there is a waiver therefore fails, so another justification must be found for the Proposal depriving the subsequently incapacitated patient of his/her basic rights. The only other rationale justifying such a deprivation would be the theory that the Proposal represents the least restrictive alternative method of advancing important State interests. However, less restrictive means obviously exist. For example, the Legislature could enact statutes warning individuals of the rights they will automatically lose if they sign a Living Will. There could also be statutes which do not confer immunity on those who, though they act "in good faith," may not follow the patient's wishes.

The Proposal thus cannot pass constitutional muster. We believe that after three years of the Commission's protracted deliberations, enacting a constitutionally dubious statute would be inauspicious.

II. E Institutional Ethics Committees:

The Proposal reduces all safeguards to one: Institutional Ethics Committees. This bespeaks an unwarranted, almost blind, faith in "institutional ethics committees", an unproven and, at best, inexact mechanism for assuring the protection of patients' rights and the realization of patients' wishes. The Proposal has no authoritative empirical studies supporting its confidence in the unfettered discretion of the institutional ethics committees which would make life and death decisions. The Proposal also fails to include any guidelines for the composition, deliberative procedures or decisionmaking criteria of institutional ethics committees. Unless some substantive and procedural standards are specified, it is at least premature to rely exclusively on such an experimental method for life-and-death decisionmaking.

Ethics committees currently exist in some New Jersey health care institutions, but not commonly as dispute resolution bodies. Rather, where they actually function, they typically are consultative bodies, convened only at the request of the facility or its staff, usually to act as a forum for

discussion. For the Proposal to make ethics committees the referee of disputes about Living Will interpretation and authenticity places undue reliance on these institutional ethics committees. There are double dangers in making ethics committees into decisional bodies and in structuring their advice so that physicians, in fear of losing immunity, will be prone to follow the ethics committee's suggestions, however mistaken those suggestions may be. This exalted status for ethics committees envisioned by the Proposal is historically aberrant. It would undermine the accountability of physicians and, eventually, physicians' own best clinical judgment.

Under the Proposal, institutional ethics committee deliberations are not guided by any specified, binding legal rules. The absence of objective standards is an important departure from current law. The institutional ethics committees -- whose composition and style will vary from institution to institution -- will ipso facto provide no help for patients at home (including those many patients in home care-based hospices). Nor can the opinions of ethics committees' professional ethicists adequately substitute for the additional medical insight which would result were the Proposal to retain the current legal requirement for obtaining the opinion of a third qualified physician. Medical knowledge is, we believe, more important in resolving medical issues than are the opinions of self-styled "ethics experts." Finally, ethics committees cannot be convened by families who are interested in preventing a misdiagnosis or misinterpretation of a Living Will or a misplaced reliance on a forged or revoked Living Will. External overview, whether by family or by family and the State, must be possible, whether on a selective or an audit basis. Only this can give our citizens confidence that institutional ethics committees will not reach self-serving conclusions about patients too sick, too impaired, or too poor to demand quality care for themselves from those same institutions which control the committees.

Finally, families' pivotal role under the current system of safeguards would practically vanish under the Proposal. The diminution of their role undermines the most important ground of our principled treatment of the sick: trust in the knowledge and concern of close and caring family members. The functional replacement for families under the Proposal would be the institutional ethics committee. These committees will be creatures of the health care institutions sponsoring them. Patients' wishes will then be realized, not according to their own unique personal viewpoints and the caring understanding of their families, but according to the highly variable orientation of the large or small, public or private, secular or religious institutional setting within which the patient happens to be confined. This change borders on anarchy, not sound improvement on current law.

II. F Fluids and Nutrition:

New Jersey is in the midst of a great public debate about withholding and withdrawing food and water from patients. Some contend that hydrating and nourishing patients are merely varieties of medical treatment and, as such,

can be declined for any patient, regardless of the certainty of ensuing death. Others maintain that food and water do not treat an illness; they maintain life. The Commission's bare majority has not elucidated this issue, but, instead, provided a permissive recipe for immunity for those who would forego these essential forms of caring for patients.

In a sphere so profoundly controversial as food and water, where a judgment error will invariably be irreversibly fatal, we believe that it is reckless to provide a quick recipe for immunity, particularly one based on the decision of an institutional ethics committee. Here, especially, the Proposal is amiss in omitting at least a consultative role for close and caring family members. Perhaps such relatives should have even a kind of 'veto' power, which could be exercised in questionable circumstances to force uniform and impartial external review of this type of decision. Unlike the comparative haste and informality of an ethics committee, external, structured review would better ensure a fuller factual inquiry and a more reasoned decision. It would also better assure full representation of a patient's interest and for notice and opportunity for all interested parties to be heard.

We can imagine the retort that even the possibility of external review may entail delay and create an "adversarial" atmosphere. However, foregoing food and water is so ultimately prejudicial to the patient's presumptive self-interest that foregoing food and water should always be considered prima facie adverse to the patient. Formalizing the review process would simply ensure a more just and uniform result. At a minimum, such external review should be a precondition of any eventual immunity.

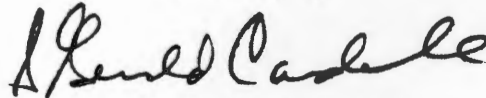
III. Conclusion:

The proposed Advance Directives for Health Care statute is flawed. We individually have additional objections; this Minority Report lists our shared criticisms. We are especially concerned that the Commission did not follow its statutory mandate to determine what present law is in all settings, including hospitals, and how the law works before proposing changes [N.J.S.A. 52:9Y-6].

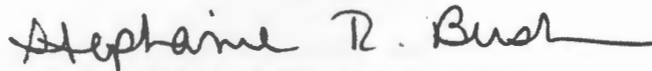
A member of the minority requested staff support for this minority position, but no staff support was forthcoming. On a subject of such substantial gravity, the Legislature needs to know the position of the minority of Commissioners, particularly where the majority is so numerically thin. The Commission adopted the final version of the Proposal only one business day before the Commission's December 31, 1988, deadline for transmitting its recommendation to the Governor and Legislature. Regrettably, this timing, combined with the lack of staff for our Minority Report position, makes it unavoidable that our Report be mostly critical.

Nevertheless, the undersigned would be pleased to cooperate with the Legislature in attempting to improve upon the Proposal. Above all, the Proposal needs simplification to make it workable by the non-lawyers who must apply it daily in the provision of health care to their patients. Necessary, proven safeguards must be reinstated. And the Proposal's tendency to unnecessarily grant immunity must be curbed. We earnestly hope that the Legislature will examine these important considerations in its own careful deliberations.

Respectfully Submitted, this 31st day
of January, 1989, by:



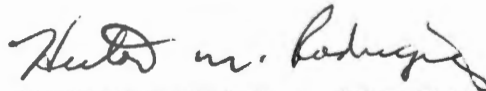
SENATOR GERALD CARDINALE



ASSEMBLYWOMAN STEPHANIE R. BUSH



ASSEMBLYMAN C. RICHARD KAMIN



OMBUDSMAN HECTOR M. RODRIGUEZ

BEING COMMISSIONERS ON THE COMMISSION ON THE
LEGAL AND ETHICAL PROBLEMS IN THE DELIVERY
OF HEALTH CARE

Footnotes

1 In re Quinlan, 70 N.J. 10, cert. denied sub nom. Garger v. New Jersey, 429 U.S. 922 (1976); In re Conroy, 98 N.J. 321 (1985); In re Farrell, 108 N.J. 335 (1987); In re Peter, 108 N.J. 365 (1987); and In re Jobes, 108 N.J. 394 (1987).

2 In re Conroy, 98 N.J. 321, 381.

3 "Nevertheless, the right to refuse life-sustaining medical treatment is not absolute. The State has at least four potentially counter-vailing interests in sustaining a person's life:

preserving life, preventing suicide, safeguarding the integrity of the medical profession and protecting innocent third parties. [Conroy, supra, 98 N.J. at 348-49 (citing Satz v. Perlmutter, supra, 362 So.2d at 162; In re Spring, 380 Mass. 629, 640, 405 N.E.2d 115, 123 (1980); Commissioner of Correction v. Myers, 379 Mass. 255, 261, 399 N.E.2d 452, 456 (1979); Saikewicz v. Superintendent of Belchertown State School, 373 Mass. 728, 738, 370 N.E.2d 417, 426 (1977); In re Torres, 357 N.W.2d 332, 339 (Minn.1984); In re Colver, 99 Wash.2d 114, 121, 660 P.2d 738, 743 (1983); President's Commission Report, supra, at 31-32; Note, "In re Storar: The Right to Die and Incompetent Patients," 43 U.Pitt.L.Rev. 1087, 1092 (1982).]

When a party declines life-sustaining medical treatment, we balance the patient's common-law and constitutional rights against these four state interests."

[In re Farrell, supra, at 348-349 (emphasis supplied)].

4 In re Farrell, supra., at 348-349; In re Conroy, supra, at 348-349.