Problems and Approaches in Health Care Decisionmaking: The New Jersey Experience

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State of New Jersey
James J. Florio, Governor

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

May 1990

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Printed in the United States of America

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May 23, 1990

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The Honorable Robert N. Wilentz
Chief Justice of the Supreme Court
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Dear Governor Florio, President Lynch, Speaker Doria
and Chief Justice Wilentz:

On behalf of the Commission on Legal and Ethical Problems in the Delivery of Health Care (the New Jersey Bioethics Commission), we are pleased to transmit the Commission's report, "Problems and Approaches in Health Care Decisionmaking: The New Jersey Experience", as required by its enabling legislation (P. L. 1985, Chapter 363).

The Commission, created by the Legislature in 1985, was mandated to study the difficult ethical and legal dilemmas posed by modern advances in science and medicine, and on the basis of its findings, to make recommendations to the Legislature, the Governor and the citizens of New Jersey. Initially the Commission was asked to study appropriate ways of facilitating a process of health care decisionmaking which would be responsive to the rights and obligations of patients, their families and health care professionals. This report provides a comprehensive and current account of the Commission's deliberations and recommendations in this and other related areas. Included in this report are two legislative proposals approved by the Commission concerning the declaration of death and advance directives for health care. These proposals were passed by the New Jersey Senate in March of 1990, and are currently under consideration by the General Assembly.

In developing its recommendations, the Commission conducted an extensive review of the relevant medical, legal and ethical literature, as well as a comparison and analysis of legislative actions and landmark judicial decisions in New Jersey and elsewhere; held over 60 public meetings of the full Commission and its several Task Forces; and held 7 public hearings at which it received extensive testimony reflecting a broad spectrum of professional, moral and religious perspectives. In addition, the Commission received and considered numerous written submissions from many individuals and professional organizations. This process is well documented in the report.

As Chair and Vice-Chair, we would like to take special note of the spirit in which volunteer Commissioners went about their work. The Legislature envisioned a Commission which would reflect the viewpoints, backgrounds and beliefs of its diverse citizenry and which make it a rich and vibrant State. And, while our discussions have been serious and spirited, our disagreements often sharp, and our arguments passionate, they have been tempered by an equally strong conviction that only through respect for the beliefs of others would we find acceptable and lasting solutions to the difficult ethical problems which profoundly affect us all.

In closing, we would like to thank you for your support and for the privilege of serving on this Commission. We hope that our policy recommendations will in some measure alleviate many of the difficulties that face professionals, patients and their families. We look forward to working closely with you and your colleagues during our next triennial period.

Sincerely,

Daniel F. O'Connell, Esq.
Chair

Paul W. Armstrong, Esq.
Vice-Chair

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Executive Summary

The New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care (informally known as the New Jersey Bioethics Commission) was established in November of 1985 as a permanent legislative commission (P.L. 1985, Chapter 363). The Commission is mandated to "provide a comprehensive and scholarly examination of the impact of advancing technology on health care decisions [in order to] enable government, professionals in the fields of medicine, allied health care, law, and science, and the citizens of New Jersey and other states to better understand the issues presented, their responsibilities, and the options available to them." The Commission is directed to make recommendations for health policy to the Legislature, the Governor, and the citizens of New Jersey.

This triennial report is a compendium of the Commission's work over the past several years. The most significant aspects of the Commission's work, including the Commission's major conclusions and recommendations, are summarized below.

The New Jersey Bioethics Commission

Advances in medical science and technology in recent years have raised complex issues at the intersection of law, medicine and ethics, presenting fundamental societal questions potentially and profoundly affecting New Jersey's citizens and its health care community. New Jersey's national leadership role in addressing bioethical issues has been established by a series of landmark decisions of the New Jersey Supreme Court, beginning with *In re Quinlan*, which first addressed a patient's right to refuse life-sustaining treatment. While the judiciary has thrust New Jersey into the national spotlight, contemporary issues in bioethics also demonstrate the interrelated roles and responsibilities of the Legislature, the executive branch, the courts and state agencies in formulating public policy responses to the many dilemmas which regularly confront patients, families and health care institutions and which present new challenges for our health care system. Recognizing these interrelated responsibilities, and sensitive to the increasing public prominence and social significance of questions of death and dying, as well as the judiciary's call for comprehensive examination of these complex and multidisciplinary issues in the legislative forum, the Legislature created the New Jersey Bioethics Commission. The Commission is charged with continuing New Jersey's leadership responsibility.

The Commission's membership comprises a diverse and multidisciplinary body of 27 appointed members. The Commission's membership is designed to bring to the public policy process a broad spectrum of expertise, opinions and perspectives, including medicine, nursing, health care administration, law, ethics, theology, natural science, social science, the humanities, and public affairs. The Commission includes representatives of the executive and legislative

branches of state government, of major statewide professional and health care associations, and of New Jersey's professional and public communities. Thus, the composition of the Commission assures that a wide range of serious, diverse and competing points of view are ably and openly articulated, with vigorous representation of the many streams of opinion that characterize New Jersey's pluralistic traditions.

The Commission determined from the outset to recognize its role in the political process and its responsibility to be responsive to the pluralistic society it serves by conducting its deliberations and exploring the issues in full view of the public, holding all meetings open to the public with opportunity for comment. In addition, the Commission has held a number of public hearings and has received extensive testimony on a wide range of issues, reflecting a broad spectrum of professional, institutional, religious and moral perspectives. The Commission's work and recommendations are the product of extensive and open public deliberations seeking to craft balanced approaches to complex and difficult problems in a manner respectful of the diverse moral and religious views of a wide range of New Jersey's citizenry.

The Commission's Task Forces

The Commission also has the statutory authority to empanel ad hoc Task Forces to provide additional experience and expertise in the study of particular bioethical issues and to develop policy recommendations for the Commission's consideration. The Commission has created five Task Forces: New Reproductive Practices, Institutional Ethics Committees, Public and Professional Education, AIDS, and Protecting Vulnerable Patients. The Task Forces on New Reproductive Practices, Institutional Ethics Committees and Public and Professional Education are currently active and operational. All Task Force meetings are open to the public. Task Forces are advisory to the Commission and present their recommendations to the full Commission, which retains final authority and responsibility for recommendations ultimately forwarded to the Legislature and the Governor.

Death and Dying: Two Legislative Proposals

The Commission decided early in its history to focus its initial efforts on two areas--the declaration of death and advance directives for health care. The Commission's work resulted in two legislative proposals: The proposed New Jersey Declaration of Death Act (S-1208; A-1413), and the proposed New Jersey Advance Directives for Health Care Act (S-1211; A-2514). Both proposals have been introduced in the New Jersey Legislature, and both bills passed the New Jersey Senate in the 1990 session. The two bills await action in the General Assembly.

The Declaration of Death

Whole brain death, *i.e.*, the total and irreversible loss of all functions of the entire brain, including the brain stem, is recognized by statute or judicial decision as a legal standard for the declaration of death in 49 states and the District of Columbia. In 1988 the New Jersey Supreme Court adopted section one of the Uniform Determination of Death Act, establishing whole brain death as a legal standard for the declaration of death in New Jersey.

The Commission's proposed legislation would codify existing New Jersey case law by providing a statutory basis for declaring death on the grounds of total and irreversible loss of all functions of the entire brain, including the brain stem. In two important respects, the Commission's legislative proposal would go beyond existing New Jersey law and would make New Jersey's approach to the declaration of death unique among the laws of our sister states. First, in order to ensure certainty and uniformity in the manner by which whole brain death is determined, the proposal would mandate the adoption by law of uniform criteria for the declaration of death on the basis of neurological criteria, by requiring the Department of Health and the Board of Medical Examiners to adopt rules and regulations setting forth currently accepted medical standards, including criteria, tests and procedures, to govern such determinations. The proposal would require that these standards be periodically reviewed and updated to keep pace with developments in medical technology. Second, the proposal expresses an important commitment to respect for religious and moral values by expressly recognizing the legal right of an individual to claim an exemption from the application of neurological criteria for determining death if such a declaration would violate that individual's personal religious beliefs or moral convictions. If adopted, New Jersey would be the first state to recognize such an exemption in its statutory law.

Advance Directives for Health Care

The ability to control and direct decisions about one's own health care is highly valued in our society, and is a fundamental right protected by law. Advance directives allow individuals to exercise their rights to plan ahead for and control decisions about their health care in the event of subsequent loss of decisionmaking capacity. Advance directives also serve to relieve anxiety that one's wishes will not be respected when the ability to actively participate in one's own health care decisions is lost or impaired. Such documents provide needed direction and guidance to family members, physicians and others, thereby reducing uncertainty and the potential for disagreement, increasing confidence in treatment decisions, and easing the burdens which responsibility for the patient's care may impose.

Traditionally, two principal approaches to advance directives have been utilized: durable powers of attorney for health care (also known as "proxy directives") and instruction directives (commonly known as "living wills"). Proxy directives permit individuals to designate a health care representative with legal authority to make health care decisions on their behalf in the event of future loss of decisionmaking capacity. Instruction directives permit individuals to state their health care wishes in writing, thereby providing direction and guidance to those responsible for their health care in the event of future loss of decisionmaking capacity. Advance directives are recognized by statute in 43 states and the District of Columbia.

New Jersey currently has no legislation providing express legal recognition of advance directives. Under existing decisions of the New Jersey Supreme Court, advance directives are legal documents which should generally be respected by families and health care professionals. Furthermore, New Jersey's Power of Attorney Law gives individuals the right to designate another person to make future health care decisions on his or her behalf. Thus, both instruction

directives and durable powers of attorney for health care are legal documents under New Jersey law.

However, in the absence of statutory law there remains some uncertainty regarding the legal status of advance directives in New Jersey, as well as the obligations of health care professionals to honor such documents. There are no established formal requirements for valid execution of advance directives, nor is there a comprehensive framework for the recognition and implementation of advance directives. The Commission's legislative proposal addresses these and other issues involving the role of advance directives in health care decisionmaking.

The Commission's Recommendations and Legislative Proposal

The Commission's proposed Advance Directives for Health Care Act provides a carefully crafted and comprehensive approach to "living wills" and "medical durable powers of attorney" which would allow competent adults to specify in writing their treatment preferences and to entrust a family member or friend with legal authority to carry out their wishes and to make health care decisions on their behalf in the event of subsequent decisionmaking incapacity. The Commission's proposal goes beyond existing legislation in other states in a number of important respects, including its applicability to a broad range of health care decisions; its commitment to a shared decisionmaking process among patients, families, health care representatives, physicians and other health care professionals; its recognition that patients should be permitted to request the continued provision of life-sustaining measures as well as the foregoing of life-sustaining measures; its respect for the individual conscience of health care professionals; and its readiness to confront and address the appropriate role of societal interests and concerns regarding the foregoing of life-sustaining measures.

The Commission's most significant conclusions and recommendations are summarized below.

1) This State recognizes in its law and public policy the fundamental right of competent adults, in collaboration with their health care providers, to control decisions about their own health care. This right should not be lost in the event a patient loses decisionmaking capacity and is no longer able to actively participate in making his or her own health care decisions.

2) The State of New Jersey should recognize by statute the right of competent adults to plan ahead for health care decisions through the execution of advance directives.

   - The legislative proposal would provide that a competent adult (a "declarant") has the right to designate another person (a "health care representative") to make health care decisions on his or her behalf in the event of future decisionmaking incapacity; to state in writing his or her instructions and directions for health care in the event of future decisionmaking incapacity; or both. The Commission's recommendations are designed to encourage execution of an "integrated" advance directive, *i.e.*, one which

designates a health care representative and provides that person with written instructions and direction.

- The legislative proposal prescribes formalities for the execution of advance directives, as well as for the re-affirmation, modification or revocation of an advance directive.

- The Commission has proposed several standard forms for advance directives that may, but need not, be followed.

3) The Commission believes that the ethical norm of informed consent as shared decisionmaking best promotes the twin values of respect for patient self-determination and promotion of patient well-being in health care decisionmaking. The shared decisionmaking model views competent patients and health care professionals, and where appropriate, family members and health care representatives, as collaborative moral agents with complementary and interactive roles in the decisionmaking process, working together to establish greater mutual understanding and an effective basis for active patient participation in the decisionmaking process.

- When the patient's decisionmaking capacity is lost or impaired, the goals and process of shared decisionmaking can be approximated through the designation of a health care representative, charged with the responsibility to stand in the place of the patient and to implement the patient's expressed wishes and best interests.

4) The legislative proposal would provide that an advance directive becomes operative when (a) it is transmitted to the attending physician or the health care institution; and (b) it is determined that the patient lacks decisionmaking capacity.

5) The Commission recommends a decision-specific approach to the question of decisionmaking capacity. A determination that a patient lacks decisionmaking capacity should be based upon an evaluation of the patient's ability to understand and appreciate information regarding the nature and consequences of a particular health care decision, including the benefits and risks of the proposed health care and its alternatives, and to reach an informed decision.

- Patients should not be assumed to lack capacity on grounds of age or disability, nor should it be assumed that lack of capacity to make one health care decision means the patient lacks capacity to make other health care decisions.

- The Commission's legislative proposal recommends an informal (non-judicial) process for assessing a patient's decisionmaking capacity which places primary responsibility for such determinations with physicians.

6) Once operative, an advance directive designating a health care representative should confer upon that person the legal authority to make health care decisions on the patient's behalf, in accordance with the terms of the advance directive. This authority should be respected by physicians, health care professionals and health care institutions.

7) The health care representative and attending physician (and where appropriate, family and other members of the health care team) should seek to enhance patient capacity and to actively involve the patient with impaired capacity in the decisionmaking process, to the extent it is reasonable to do so. The patient's expressed wishes should be taken into account in the decisionmaking process.

- A patient's contemporaneously expressed wish that medically appropriate life-sustaining measures be provided should be respected, even if contrary to the decision of the health care representative or the terms of the patient's instruction directive.

8) In the absence of a designated health care representative, an instruction directive, once operative, should be respected by those responsible for the patient's care, and should be followed in accordance with its specific terms.

9) Health care institutions should establish an institutional mechanism for dispute resolution. In case of disagreement concerning the patient's decisionmaking capacity, the appropriate implementation of an advance directive, or other matters, recourse to this local process should be sought in the first instance.

10) The fundamental right to control decisions about one's own health care includes the right to forego life-sustaining measures. This right is not absolute, and is subject to certain interests of society, including the preservation of life, the prevention of suicide, the protection of innocent third parties, and safeguarding the integrity of the health care professions. Society also has an interest in ensuring the soundness of health care decisionmaking, including both protecting vulnerable patients from potential abuse or neglect and facilitating the exercise of informed and voluntary patient choice.

- The legislative proposal takes a situation-specific approach to decisions to forego life-sustaining measures, in accordance with the patient's advance directive, which identifies the circumstances in which such decisions should be authorized.

- The Commission believes that the foregoing of artificially provided fluids and nutrition for patients who lack decisionmaking capacity or are otherwise vulnerable raises important and distinctive problems for social policy that justify protective measures, beyond those applicable to the foregoing of other life-sustaining measures. Therefore, decisions to forego artificially provided fluids and nutrition are addressed separately from decisions to forego life-sustaining treatments.

- The Commission recommends that individuals explicitly state in an advance directive their wishes regarding the foregoing of artificially provided fluids and nutrition. The legislative proposal would authorize the foregoing of artificially provided fluids and nutrition in accordance with an explicit statement in the patient's advance directive.

- The Commission rejects on both legal and moral grounds the practice of active euthanasia, as by deliberate lethal injection.

11) Public policy should honor the personal and professional integrity of health care professionals while at the same time assuring that neither the rights of patients nor standards of professional care are compromised.

- Physicians, nurses, and other health care professionals should have the right to decline to participate in the withholding or withdrawal of life-sustaining measures on the basis of sincerely held personal or professional convictions. In the exercise of this right, health care professionals should facilitate appropriate, respectful and timely transfers of care, and should assure that the patient is not abandoned.

12) The Commission also believes that private religiously-affiliated health care institutions should have the right to adopt institutional policies and practices defining circumstances in which they will decline to participate in the withholding or withdrawal of life-sustaining measures. Such policies should be stated in writing and communicated to patients, families and health care representatives in a timely fashion.

13) Physicians, nurses and other health care professionals, and health care institutions, acting in good faith and in accordance with the requirements of the legislative proposal, and any rules and regulations established pursuant to the proposal, to carry out the terms of an advance directive, should be immune from legal liability and from discipline for unprofessional conduct. Health care representatives acting in good faith and in accordance with the requirements of the legislative proposal to carry out the terms of an advance directive should be immune from legal liability.

In sum, the Commission recommends the New Jersey Advance Directives for Health Care Act in order to assure respect for patients' previously expressed wishes when the capacity to participate actively in decisionmaking has been lost or impaired; to facilitate and encourage a sound decisionmaking process in which patients, health care representatives, families, physicians, and other health care professionals are active participants; to properly consider patients' interests both in self-determination and in well-being; and to provide necessary and appropriate safeguards concerning the termination of life-sustaining treatment for incompetent patients as the law and public policy of this State.

Commission Studies

Who should make medical treatment decisions raises fundamental questions about the proper roles of patients, families, physicians, institutional committees, courts and government agencies in health care decisionmaking. Public concerns about the potential abuse of vulnerable patients have led to the widely shared belief that in certain circumstances decisions ought not to be made exclusively within the privacy of the physician-patient-family relationship, and that some form of prospective review is warranted. Increasingly, the health care community and policymakers have looked to mechanisms such as institutional ethics committees or a state agency as an alternative to the courts. The Commission has studied several important areas in which committees, courts and state agencies have become involved in health care decisionmaking in New Jersey.

The Office of the Ombudsman for the Institutionalized Elderly

In *In re Conroy* (1985), the New Jersey Supreme Court created a role in reviewing life-sustaining treatment decisions for the Office of the Ombudsman for the Institutionalized Elderly (the "Ombudsman" or the "Office"). This role was further defined in the Court's decision in *In re Peter* (1987). By statute the Ombudsman's jurisdiction is limited to institutionalized residents of long-term care facilities who are 60 years of age or older.

The Ombudsman's role in reviewing life-sustaining treatment decisions has spawned considerable and continuing debate, and for a period of time sparked intense controversy. The scope and implementation of the Ombudsman's role has been a continuing subject of study for the Commission and its Task Force on Institutional Ethics Committees. The Commission has sought to respond to concerns within the health care community and to foster sound public policy approaches in this area through the development of formal policy recommendations and through its participation in the regulatory process.

The Commission strongly believes that a sound decisionmaking process respects patient wishes while providing necessary safeguards to protect patient well-being, and respects the integrity of the physician-patient-family relationship without undue and cumbersome intrusion. While society has a legitimate interest in safeguarding vulnerable patients against the improper foregoing of treatment, patients should also be protected against continued provision of unwanted and burdensome interventions.

In order to promote these sometimes competing goals and values, the Commission strongly believes that the Ombudsman's review process should ensure timely review without unnecessary delays, and should go significantly further in establishing and making public a system of priorities for the Ombudsman's involvement in reviewing decisions to forego life-sustaining treatment and for its use of resources in the process of this review. Such a system of priorities should include the identification of specific indicia of (potential) abuse or special vulnerability as prerequisites for full prospective review. Where prospective review is indicated, there should be expedited review in cases that pose minimal risks of actual abuse. Furthermore, the Commission believes that local ethics committees, either institutionally or regionally based,

can and should play a central role in the initial review process, and that the Ombudsman should develop ways it can rely on such committees for routine prospective review functions.

The Commission plans to build on these principles and recommendations in its continuing study of the respective roles of the Ombudsman and of ethics committees.

The Office of the Public Guardian for Elderly Adults

The Office of the Public Guardian for Elderly Adults (the "Public Guardian") is a state agency that provides guardianships, including medical guardianship services, for New Jersey's senior citizens over the age of 60 who have been adjudicated incompetent and who are without appropriate family members or friends acting on their behalf. With the dramatic increase in the number of New Jersey's elderly and growing awareness of the Public Guardian's role and functions, the Public Guardian will likely play an increasingly important part in the delivery of health care. The Commission has received testimony from the Public Guardian in the past, and hopes to work cooperatively with the Public Guardian in its future study of decisionmaking for incompetent and vulnerable patients who have not previously expressed their treatment preferences.

The "Baby Doe" Regulations in New Jersey

In the well-known "Baby Doe" case, the parents of an infant born with Down syndrome and a gastrointestinal malformation decided to forego surgery that would have corrected the malformation and might have saved the infant's life. In the aftermath of the "Baby Doe" case (and several other cases and studies), Congress amended the Child Abuse Prevention and Treatment and Adoption Reform Law (the "Child Abuse Amendments") (1984). The federal regulations designed to implement the Child Abuse Amendments became effective in 1985.

The Division of Youth and Family Services ("DYFS") is the child protective services agency in New Jersey charged with responsibility for implementing the law and regulations. Based upon its study to date, the Commission finds that the DYFS procedures provide a detailed response to the requirements for state implementation of the federal law and regulations, and that federal and state measures to respond to and deter instances of medical neglect of imperiled newborns have been largely successful. The Commission also believes that further study of this area, including in particular the role of Infant Care Review Committees, is warranted.

The Grady Procedures

In *In re Grady* (1981), the New Jersey Supreme Court addressed the issue of nonconsensual sterilization for a woman who lacked the capacity to make her own decision about the procedure. Finding that, among other reasons, historical abuses involving sterilization of incompetent persons warrant special safeguards in this area, the Court fashioned standards and procedures to protect the rights and best interests of patients when nonconsensual sterilization is considered by a court. In the Commission's view, the *Grady* procedures provide a carefully crafted and widely accepted scheme which properly protects the rights of persons incapable of consenting to sterilization procedures.

The Commission's Task Forces

New Reproductive Practices

Following the New Jersey Supreme Court's landmark decision in "Baby M", the Task Force on New Reproductive Practices was charged with the responsibility to study the practice of surrogacy. After examining the historical, legal and social context of surrogacy, including the social and psychological implications of the new reproductive practices, the meaning and impact of infertility, existing law in New Jersey and elsewhere, and theological and feminist perspectives on the practice of surrogacy, the Task Force began to develop an overall approach and to formulate specific policy recommendations for the Commission's consideration.

Two predominant themes have emerged from the Task Force's work. First, commercial surrogacy arrangements should be both illegal and unenforceable. Second, non-commercial surrogacy arrangements, though not to be prohibited, should be discouraged and the terms of such agreements should be unenforceable. Specifically, the Task Force and Commission jointly conclude and recommend that the State of New Jersey enact legislation to prohibit commercial surrogacy arrangements; to make illegal and unenforceable certain specified contractual provisions in a surrogacy contract; to make any surrogacy agreement unenforceable; to create a legal presumption in favor of the birth mother in the event of a custody dispute; to impose an obligation of support on the non-custodial parent in a surrogacy arrangement; and to create a presumption in favor of visitation by the non-custodial parent, unless it is demonstrated that visitation would be contrary to the best interests of the child.

As the Task Force approaches closure on a complete set of recommendations, additional issues to be addressed include the imposition of penalties for those who engage in commercial surrogacy arrangements, in particular broker/intermediaries; whether a "waiting period" should be established, and if so of what duration, to allow the birth mother to decide whether or not to relinquish custody; custody and support obligations where none of the parties want custody of the child; and the scope and practical implications of the principle that contractual undertakings purporting to restrict medical and lifestyle choices of the birth mother during pregnancy should be illegal and unenforceable. A report on surrogacy will be issued in the near future.

Institutional Ethics Committees

In the Commission's view, thorough study of the potential role of multidisciplinary ethics committees in the process of health care decisionmaking, an approach introduced by the *Quinlan* Court (1976), is especially important to New Jersey's health care system. The Task Force on Institutional Ethics Committees was mandated to study the operation and experience of existing ethics committees and the legal and regulatory environment in which they function; to evaluate the roles of ethics committees engaged in prospective case consultation in a variety of institutional settings; to analyze the potential interaction between ethics committees and the Office of the Ombudsman; and to develop recommendations for public policy, including where appropriate recommendations for legislative action.

Both the Task Force and the Commission believe that multidisciplinary ethics committees, acting in the capacity of consultant and advisor (not decisionmaker), can make a valuable

contribution to health care decisionmaking for individual patients. At this stage, the Commission and Task Force have jointly concluded that all hospitals and nursing homes in the State should be required to maintain or participate in an ethics committee that provides prospective case consultation, and that multi-institutional and regional approaches to the use of ethics committees should be developed. In addition, the Commission and Task Force believe that a statutory approach, supplemented by some combination of regulatory action, institutional guidelines and education, is needed to provide a clear, coherent and flexible framework for the establishment and operation of ethics committees. As the Task Force proceeds with its work, it will address a number of crucial issues, including committee membership and process; assuring appropriate confidentiality of committee proceedings; recordkeeping; the legal consequences of committee recommendations and the potential legal liability of participants in the decisionmaking process; and the possible interrelationship between ethics committees in long-term care and the Office of the Ombudsman. In its efforts to formulate specific recommendations for legislative action, the Task Force will evaluate ways in which a statutory response to particular issues can best facilitate a sound decisionmaking process while respecting institutional autonomy and assuring appropriate accountability.

Public and Professional Education

The Task Force on Public and Professional Education was established pursuant to the Commission's strong commitment to increasing awareness and promoting understanding of bioethical issues and the Commission's work among members of the health care community, policymakers, and the public. Focusing its initial efforts toward educational activities in support of the Commission's work in the area of death and dying, the Task Force has developed an informational pamphlet to enhance understanding of medical and legal aspects of whole brain death. The Task Force has also developed an educational brochure to assist individuals in preparing an advance directive. This brochure will include several sample advance directive forms.

The Commission's Future Agenda

As a permanent legislative study commission, the Commission is charged with the responsibility to examine emerging legal and ethical problems in health care, and to do so on a continuing basis. The Commission is keenly aware that New Jersey currently has the fourth largest number of reported cases of HIV infection of any state in the country. There is a critical need for New Jersey to respond to the complex medical, legal, ethical, social and economic issues posed by acquired immune deficiency syndrome (AIDS), and to do so in effective, sensitive and comprehensive fashion. In the next fiscal year, the Commission plans to make operational its Task Force on AIDS, inviting individuals with a broad spectrum of expertise, experience and perspectives to be a part of this process. In this effort the Commission hopes to work cooperatively with government agencies and the health care community to extend and combine collective resources and expertise in the effort to develop a coordinated approach to the AIDS crisis.

Recent surveys suggest that approximately 85% of New Jersey's citizens have not planned ahead for their health care needs by writing an advance directive. This statistic demonstrates

that, even with favorable action on the pending advance directives legislation and continuing educational efforts, the number of patients in New Jersey who lack decisionmaking capacity but have not clearly expressed their treatment preferences will remain substantial. When the patient's expressed wishes no longer present a firm basis for a treatment decision, complex issues, such as what it means to decide "in the patient's best interests" and the respective roles of family members, committees, state agencies, and the courts in health care decisionmaking, confront families, health care providers and policymakers. These fundamental issues comprise the core agenda of the Commission's Task Force on Protecting Vulnerable Patients. The Commission plans to make this Task Force operational in the next fiscal year, and to invite the participation of a diverse panel of experts in this process.

Thus, in addition to continuing the work and progress of the Task Forces on New Reproductive Practices, Institutional Ethics Committees, and Public and Professional Education, in the coming fiscal year the Commission plans to direct substantial efforts and resources to the important issues before the Task Forces on AIDS and Protecting Vulnerable Patients.

Organization of the Report

The report is organized in six Parts, with several Parts divided into Chapters. Part One discusses the Commission's history and process. The Commission's work on the declaration of death and advance directives for health care, with particular emphasis upon the Commission's legislative proposals, is discussed in Parts Two and Three, respectively. Part Four, titled Commission Studies, discusses the Office of the Ombudsman, the Public Guardian, the "Baby Doe" regulations, and *Grady* procedures. The work of the Commission's Task Forces on New Reproductive Practices, Institutional Ethics Committees, and Public and Professional Education is presented in successive chapters of Part Five. The report concludes with a discussion of the Commission's future agenda in Part Six. Important documents and materials are set forth in separate appendices to Parts Three and Four. The Appendix to the full report reproduces the Commission's enabling legislation and contains a number of Tables of additional information about the Commission, its Task Forces and process. Each Part of the report is intended to be as self-contained as possible in order to provide the reader with easy access to particular areas of interest.

Part One

The Commission's History and Process

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The Commission's History and Process

Recognizing the interrelated responsibilities of the Legislature, the executive branch, state agencies and the courts, and the developing public awareness and concern regarding bioethical issues, on February 25, 1985, legislation proposing the establishment of a permanent commission to study legal and ethical problems in the delivery of health care was introduced in the New Jersey General Assembly. This legislation (A-3316) was introduced by then-Speaker of the Assembly Alan J. Karcher, Assemblymen John Paul Doyle, George J. Otlowski, Thomas J. Deverin, Thomas W. Long, Martin A. Herman, Chuck Hardwick, Walter Kern, Thomas J. Shusted, Eugene H. Thompson, and Assemblywoman Angela L. Perun. A similar bill (S-2781) was introduced in the New Jersey Senate by the President of the Senate John F. Russo and Senator Carmen A. Orechio on February 28, 1985. On November 12 of that same year, the bill establishing the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care (informally known as the New Jersey Bioethics Commission), was signed into law by Governor Thomas H. Kean (Public Law 1985, Chapter 363).

The new law mandated the Commission "to provide a comprehensive and scholarly examination of the impact of advancing technology on health care decisions", and charged it with the responsibility of making recommendations for health policy to the legislature, the Governor, and New Jersey's citizens. The Commission's work is intended to enable health care professionals and the public "to better understand the issues presented, their responsibilities, and the options available to them."*

Why The Commission Was Created

Advances in medical science and technology in recent years have raised complex issues at the intersection of law, medicine and ethics. Moral dilemmas in medicine regularly confront patients, families and health care professionals. These issues present fundamental societal questions potentially and profoundly affecting New Jersey's citizens and its health care community. The Commission's enabling legislation recognizes that "New Jersey is a national leader in addressing the legal and ethical dilemmas in the delivery of health care posed by modern advances in science and technology", and charges the Commission with continuing this leadership responsibility.

New Jersey's national leadership role in the field of bioethics has been established by a series of decisions of the New Jersey Supreme Court, beginning with *Quinlan*[1] (1976), the first case to address a patient's right to refuse life-sustaining treatment. *Quinlan*, which involved a decision to withdraw a respirator from a young woman in a persistent vegetative state in a

* The Commission's enabling legislation is reproduced in Appendix A to the report.

hospital, focused unparalleled national and international attention on the issues surrounding decisions to forego life-sustaining treatment. Nine years later, in *Conroy*[2] (1985), the Court was confronted with a proposal to withdraw a nasogastric feeding tube from a severely debilitated and demented elderly patient in a nursing home. The Court's opinion in *Conroy* again thrust New Jersey into the national spotlight.

These cases demonstrate not only the intersection of law, medicine and ethics, but also the interrelationship of state judicial and legislative action. In each of these landmark cases, the Court expressly stated that its opinion was not intended to set forth guidelines for life-sustaining treatment decisions in a variety of other circumstances not before it, and acknowledged that such issues are more suitably addressed through the legislative process, where diverse viewpoints and disciplines can be brought together to fashion a comprehensive plan in a manner which accommodates the different needs and interests represented in New Jersey's pluralistic community.

Sensitive to the increasing public prominence and social significance of questions of death and dying and the need to foster sound decisionmaking processes while safeguarding the welfare of patients in a variety of health care settings, and responsive to the judiciary's call for legislative guidance, the Legislature recognized that controversial bioethical issues which raise fundamental questions about society's values ought not to be decided in a piecemeal fashion, such as through adversarial litigation on relatively narrow issues. These issues are best suited to more comprehensive legislative examination and resolution responsive to a broad spectrum of perspectives, interests and concerns within the health care community and the citizenry of New Jersey. This wisdom was recently echoed by New Jersey's Supreme Court in its trilogy of life-sustaining treatment decisions, *Farrell*[3], *Peter*[4], and *Jobes*[5] (1987). Similarly, in *Baby M*[6] (1988), the leading court case on the issue of surrogate parenting, the Court stated that the Legislature is the proper governmental body to explore society's "values and objectives...in [the] troubling, yet promising area" of new reproductive practices. It is the Legislature, not the courts, which is best suited to evaluate, adopt and implement thoughtful responses to these multi-faceted issues, to do so in a scholarly fashion, and to provide a comprehensive approach to improving the delivery of health care for the citizens of New Jersey.

Seeking to confront the many dilemmas posed by modern advances in science and medicine, and to continue New Jersey's role as a national leader in the field of bioethics, the Legislature created the Bioethics Commission as a permanent legislative commission to study these questions in a comprehensive and scholarly fashion, and to report its conclusions and recommendations to the Legislature and the Governor. In the fulfillment of its mandate, the New Jersey Bioethics Commission has a unique opportunity to work in partnership with the Legislature, the courts, state agencies, health care professionals and associations, and New Jersey's citizens in the complex effort to shape future law and policy for the State of New Jersey.

Commission Appointments

The New Jersey Bioethics Commission is composed of a diverse group of 27 appointed members. A majority of those appointed to the Commission elect a Chair and Vice-Chair from among its

members.* The Commission's membership includes representatives of the executive and legislative branches of state government, of major statewide professional and health care associations, and of New Jersey's professional and public communities. By law, the Commission includes two members of the General Assembly (one from each political party) and two members of the Senate (one from each political party); designees of the Commissioners of Health, Human Services, and Community Affairs; the Public Advocate; the Ombudsman for the Institutionalized Elderly; and representatives of the New Jersey Hospital Association, the New Jersey Association of Health Care Facilities, the New Jersey State Nurses Association, and the New Jersey Association of Non-Profit Homes for the Aging. In addition, there are fourteen public representatives appointed by the Governor (8 members), the Senate President (3 members), and the Speaker of the General Assembly (3 members). These individuals are appointed on the basis of their distinguished contributions in medicine, nursing, health care administration, law, ethics, theology, natural science, social science, the humanities, and public affairs.**

Thus, the Commission's membership is designed to comprise a large and diverse body, with a broad spectrum of expertise, opinions and perspectives. The composition of the Commission assures that a wide range of serious and competing points of view are ably, forcefully and openly articulated, with vigorous representation of the many streams of opinion that characterize New Jersey's pluralistic traditions. Significantly, health care providers attuned to the challenges and realities of daily health care practice are well-represented among the Commission's membership. As a consequence, the Commission's discussions and specific conclusions thus far have been characterized by a concern with the "workable", and with recognizing and addressing the frequent tension between ideals, values and commitments and the demands of established medical practices. While the Commission's goal of advancing the ways in which New Jersey responds to and thinks about legal and ethical questions posed by developments in modern medicine has suggested some new directions, and may impose some new or different obligations upon health care providers, patients, and families, the Commission's recommendations will be practical and responsive to the realities of the health care system.

The Commission's Process

The Commission determined from the outset to recognize its role in the political process and its responsibility to be responsive to the pluralistic society which it serves by opening all meetings to the public, with opportunity for public comment. The Commission is firmly committed to conducting its deliberations and exploring the issues in full view of the public. Pursuant to this commitment, the Commission has held several public hearings at which it has received extensive testimony on the wide range of issues before it, reflecting a broad spectrum of professional, institutional, religious and moral perspectives on the issues. Hearings typically are held both prior to systematic formulation of the Commission's proposals and following release

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* Daniel F. O'Connell, Esq. and Paul W. Armstrong, Esq. have served as Chair and Vice-Chair, respectively, since their election at the Commission's first meeting in April of 1986.

** A list of all past and current Commissioners is set forth in Table 1 of Appendix B to this report.

of draft working proposals. Thus, public participation and scrutiny contributes to the Commission's deliberative process, both in the preliminary formulation of the issues and in commentary upon the Commission's initial conclusions.

The Commission believes that its openness to public participation and scrutiny properly reflects the public policy role with which it has been charged by the Legislature. The open nature of the process has not only shaped the quality of the Commission's deliberations in a positive way, but also establishes a foundation for public confidence in the Commission's work. It is hoped that such confidence will provide a necessary basis for informed support among citizens and professional communities as the Commission's recommendations move toward legislative consideration, and thereafter, toward implementation in the hospitals, nursing homes, clinics and homes of New Jersey.

The Bioethics Commission decided early in its history to focus its initial efforts on two projects where the prospects for early legislative consideration and favorable action seemed especially promising: the declaration of death, and advance directives for health care. This decision was predicated on the belief that progress in these areas was both important in its own right, and would provide a necessary and appropriate foundation for confronting the still more difficult questions of ethics, law, and policy posed by decisionmaking for incompetent patients who have not clearly expressed their treatment preferences.

The Commission's recommendations on the topics of the declaration of death and advance directives for health care reflect an extended process of discussion and debate, which involved careful review of the relevant medical, legal and ethical literature, as well as comparison and analysis of legislative actions and judicial decisions in New Jersey, our sister states, and internationally. The Commission invited oral and written testimony from scholars, professional associations, religious and advocacy groups, and other members of the public, through formal public hearings and through oral comments and written submissions received over the period of extensive work on these projects. The Commission has received and considered numerous written submissions from many individuals and organizations.

The Commission submitted a proposed New Jersey Declaration of Death Act, and its accompanying Interim Report, to the Governor and the Legislature on June 15, 1988. On December 29, 1988, the Commission formally approved a proposed New Jersey Advance Directives for Health Care Act. The Commission's deliberations and process with respect to its two legislative proposals are described in greater detail in Parts Two and Three of the report. Both proposals have been introduced in the New Jersey Legislature and both passed the Senate in the 1990 session.

Commission Meetings

The Commission met 35 times between April of 1986 and March of 1990, at various locations throughout the State of New Jersey. Since its move to permanent quarters in July of 1988, the Commission has generally held all of its meetings at its offices in Princeton. All Commission meetings are open to the public and are attended by members of New Jersey's health

care organizations, interested groups, New Jersey's private citizens and the press. Notices of these meetings are placed in the New Jersey Legislative Calendar, and New Jersey's major newspapers are notified of the Commission meeting schedule and agenda.*

Public Hearings

The Commission has conducted seven public hearings since April of 1986. Six of these hearings were called to receive testimony in the area of death and dying from health care professionals and professional associations, advocacy groups, scholars, and other New Jersey citizens. These hearings were held on November 21, 1986 (in Atlantic City), December 17, 1986 (in Newark), January 21, 1987 (in Trenton), February 24, 1988 (in Trenton), April 13, 1988 (in Trenton) and November 29, 1988 (in Princeton). Several of these public hearings continued throughout the day. The Commission's first three public hearings invited general public input in the areas of death and dying. The final three invited specific responses to draft legislative proposals prior to final Commission consideration and approval. The February and April 1988 public hearings focused specifically on the Commission's proposals concerning the declaration of death and advance directives for health care. Prior to final approval of the proposed advance directives statute the Commission held an additional public hearing in November of 1988.

In addition, on May 11, 1988 in Newark, the Commission held a public hearing on the subject of surrogate motherhood. This full-day public hearing, held jointly by the Commission and its Task Force on New Reproductive Practices, was called to receive testimony on the medical, legal, ethical, social, religious and family dimensions of surrogate motherhood and public policy responses to it. **

Task Forces

The Commission has the statutory authority to empanel ad hoc Task Forces to study major bioethical issues and to prepare public policy recommendations for the Commission's consideration. The Commission has created five Task Forces: New Reproductive Practices, Institutional Ethics Committees, Public and Professional Education, AIDS, and Protecting Vulnerable Patients. The Task Forces on New Reproductive Practices, Institutional Ethics Committees, and Public and Professional Education are presently active and operational. Each of the currently active Task Forces meets at least eight to ten times per year. Like meetings of the full Commission, all Task Force meetings are open to the public and are noticed in the Legislative Calendar.

Commission Task Forces are established in an effort to take advantage of diversity of expertise in particular areas, and to allow broader input into the Commission's process from a larger segment of the health care community. Each Task Force consists of 12-20 members,

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* A list of Commission meetings appears in Table 6 of Appendix B to this report.

** A list of speakers who have offered testimony at the Commission's public hearings is set forth in Table 5 of Appendix B to this report.

which includes, in addition to a core group of Commissioners, additional individuals selected for their professional experience and expertise relevant to the topic under study. Leading national figures around the country have also been invited to serve as outside academic advisors to the Task Forces. All Task Force Chairs are members of the full Commission. In examining the bioethical issues under study, the Task Forces review extensively the relevant scholarly literature, including the writings of physicians, nurses, attorneys, theologians, and ethicists. Task Forces may conduct public hearings on selected topics, to ensure that the positions of various health care organizations, public agencies, advocacy groups, and the general public, are properly presented.

Task Forces are advisory to the full Commission and present their recommendations to the full Commission for approval. As a matter of both statutory requirement and Commission policy, the Commission retains final authority and responsibility for recommendations ultimately forwarded to the Governor and the Legislature. The work of these Task Forces is described in greater detail in Part Five of this Report.*

*The members of the Task Forces with capsule biographies are listed in Table 3 of Appendix B to this report.

Notes

1. *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, *cert. denied sub nom. Garger v. New Jersey*, 429 U.S. 922 (1976).
2. *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985).
3. *In re Farrell*, 108 N.J. 335, 529 A.2d 404 (1987).
4. *In re Peter*, 108 N.J. 365, 529 A.2d 419 (1987).
5. *In re Jobes*, 108 N.J. 394, 529 A.2d 434 (1987).
6. *In re Baby M*, 109 N.J. 396, 537 A.2d 1127 (1988).

Part Two

The Declaration of Death

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Chapter One
The Declaration of Death: An Introduction

Beginning in 1986, the Commission undertook a study of the determination of death on grounds of total and irreversible loss of all brain functions, including the brain stem (commonly referred to as "whole brain death"). Neurological criteria for determining death have been almost universally accepted by the lay public and by the medical and legal communities, and are recognized in virtually all states in the country as a legal standard for determining death. Yet, New Jersey has no statutory law recognizing brain death, and has only recently adopted this standard by decision of the highest court of the State.

In accordance with its enabling legislation the Commission began deliberations aimed at addressing this situation with a special focus on two issues of great importance for New Jersey's citizens. First, while most of the public now understands and accepts whole brain death as uncontroversial, some religious traditions continue to rely solely on the traditional criteria of irreversible cessation of heartbeat and breathing as the standard for determining death. In addition, some persons may object to the application of neurological criteria on secular grounds. A determination of death on grounds of neurological criteria would be a violation of the religious beliefs or moral convictions of these individuals. Accordingly, the Commission committed itself to exploring the most effective way of accommodating the diverse views of New Jersey citizens. Second, the Commission believed that it was important to ensure continued public confidence in the process by which health care practitioners determine death. As a consequence, the Commission undertook an analysis of the best means by which uniform up-to-date criteria for determining death in accordance with neurological criteria could be promulgated and implemented. The results of these deliberations and the Commission's proposed recommendations are discussed in detail in the analysis and commentary following this introduction.

Medical Background[1]

Since earliest times, death was determined when a patient's breathing and heartbeat permanently stopped. In the era prior to mechanical ventilators and other life-support systems, this event was usually quite clear to doctors and families. If a person stopped breathing or his or her heart stopped beating, it was certain that all cardiac, respiratory and brain functions would come to a halt. When these organs ceased to function the entire body would begin a process of disintegration and decay, thus confirming that the person was dead. If, on the other hand, a patient suffered complete loss of brain functions, cessation of heartbeat and breathing would quickly follow, due to the brain's central role in regulating these vital life functions. In either instance, there was little, if any, controversy over the question of when death had occurred.

Within the last 30 years, technological developments in life-support systems have resulted in extraordinary advances in our ability to care for seriously ill and injured patients. The

development of mechanical ventilators, cardiac pacemakers and mechanical or transplanted organs has contributed to our ability to prolong the lives of patients who formerly would invariably have died from their illness or injury. However, as the use of this complex technology became increasingly commonplace, health care providers had to confront some troubling medical circumstances. A patient might lose certain essential signs of life, such as brain activity, while other apparent signs of life such as heartbeat, circulation, and breathing, were capable of being artificially maintained for a short period of time (ordinarily from a few days to approximately two weeks until all organ systems begin to shut down). Emergency and intensive care personnel could often re-establish breathing and heartbeat for patients who had clearly sustained extensive brain damage and complete and irreversible loss of all brain functions.

As more cases like this began to appear, physicians realized that determining death for some patients was no longer as clear cut as it had once been prior to the development of modern medical technology. The traditional signs of death, complete cessation of heartbeat and respiration, were no longer appropriate indicators of death in patients who had suffered total and irreversible loss of brain functions, but whose cardiopulmonary functions were being maintained exclusively by mechanical means. The condition of these patients posed difficult questions for both health care providers and families. Should they continue to receive medical care as did other patients, even if such care was clearly futile? What should be said to family members about the condition of a loved one, and what were family members to think? Furthermore, the development of organ transplant technology raised additional questions. Upon death the suitability of a person's organs for use in transplantation rapidly diminishes. The most usable organs for transplant purposes are those taken from persons who have been declared dead on the basis of neurological criteria and whose organs can be kept viable, for a short time, by sustaining respiration and circulation through mechanical means. As a consequence of these factors, the medical community began a process of re-evaluating the traditional grounds and procedures by which death is determined.

Over the last 25 years the dilemma of how to deal with these formerly anomalous situations has been largely resolved. In 1968 a committee established by the Harvard Medical School issued a report recommending that the criteria of irreversible and complete loss of all functions of the entire brain be medically and legally recognized as sufficient grounds for declaring a person dead.[2] In 1981, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (the "President's Commission") issued a report on defining death, which recommended that whole brain death be adopted as the legal ground for declaring the death of an individual.[3] Included in the report of the President's Commission were several proposed approaches to legal recognition of whole brain death, including the Uniform Determination of Death Act (the "UDDA"). The President's Commission recommended that the UDDA be adopted by each state. In these and subsequent reports the criteria and procedures for determining brain death have undergone continuing study and further refinement. As a result there is now widespread national agreement among medical experts concerning the determination of death in the brain-damaged patient. These experts agree that the complete and irreversible loss of all functions of the entire brain, including the brain stem, constitutes death of the individual.

Legal Developments

The broad consensus existing today among the medical community that whole brain death is a proper basis for the declaration of death is mirrored in the legal community. As of December 1989, 49 states and the District of Columbia (all jurisdictions except South Dakota) have recognized whole brain death as a legal standard for the declaration of death, either through statutory law or judicial decision.

During the 1970's, a number of states enacted legislation recognizing brain death, based on a variety of statutory models. In light of the proliferation of competing models, efforts were made to develop a uniform proposal that would be broadly acceptable throughout the United States. These efforts resulted in the UDDA, approved by the President's Commission, the Uniform Law Commissioners, the American Bar Association, the American Medical Association, and several other groups. The UDDA has been the foundation for most subsequent legislative efforts. Between 1981 and 1989 the UDDA, or close variants of it, have been statutorily enacted in 23 states, replacing prior legislation in 10 of those states. Section one of the UDDA states:

> An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.[4]

As discussed below, Section one of the UDDA was recently adopted by the New Jersey Supreme Court as the law of this State.

New Jersey Law

The decision of the New Jersey Supreme Court in the case of *Strachan v. J.F.K. Memorial Hospital*,[5] decided in March 1988, constitutes the current law of New Jersey regarding the declaration of death. *Strachan* involved a 20 year old patient who shot himself in the head in an apparent suicide attempt and was admitted to the emergency room on Friday afternoon, April 25, 1980. Soon after admission, the patient was diagnosed as "brain dead".[6] This diagnosis was confirmed by a neurosurgeon and one of the attending physicians later that evening. The parents were asked to consent to donation of their son's organs. They decided not to consent to organ donation, and requested that the respirator be removed and the body released to them for burial.

The hospital had no procedures in place for documentation of the declaration of death upon the basis of neurological criteria nor for removal of the body from the life-support system upon the parents' request.[7] Following consultation with the hospital administrator and legal counsel, it was decided that additional tests should be performed, and the parents were again asked to consider organ donation.[8] After the diagnosis had again been confirmed over the weekend, the patient was officially pronounced dead on the following Monday, April 28. The body was then released, approximately three days after the patient was first determined to be dead. The parents subsequently instituted a lawsuit against the hospital and the hospital administrator for the emotional distress they suffered as a result of the hospital's failure to release the body for burial following the initial determination of death.

The central question addressed by the New Jersey Supreme Court was when death occurred, and, therefore, at what point in time there was a duty to release the dead body for burial. The Appellate Division had held that the patient was not legally dead until "he was officially pronounced dead, the respirator was turned off, and the death certificate was signed", and that since this had occurred on Monday, the day the body was released for burial, the hospital had acted properly.[9] The Supreme Court disagreed. The Court held that "section one of the UDDA provides the appropriate legal definition of death".[10] In reaching this conclusion, the Court noted the widespread adoption of brain death as a legal standard of death in other states. The Court thus concluded that the patient's death had occurred "considerably earlier" than Monday, April 28, the day that the body was released, and that the hospital had failed to act reasonably in fulfilling its obligation to release the dead body to the parents for burial.[11] *

Legal issues relating to brain death have also arisen in the context of insurance law in New Jersey. In *Cavagnaro v. Hanover Insurance Co.*,[12] the issue arose as to "whether hospital expenses incurred subsequent to confirmation of irreversible brain death are compensable under the New Jersey No Fault Act, *N.J.S.A.* 39:6A-4".[13] In *Cavagnaro*, the patient suffered severe injuries in a motor vehicle accident and was diagnosed as meeting the criteria for brain death. The clinical diagnosis was confirmed by an EEG, at which time the attending neurosurgeon determined that the patient was dead. Due to continuing family disagreements concerning organ donation, the patient's bodily functions were artificially maintained for twelve days at which time his blood pressure deteriorated and he was formally pronounced dead. It was uncontradicted that the patient's maintenance on life-support systems for this twelve day period "was designed solely to permit eventual organ transplant..."[14] The parents sought coverage under the personal injury protection of a motor vehicle insurance policy, for medical and hospital expenses incurred during that period.

The court held that the insurance coverage did not apply. While recognizing that brain death is a legal standard of death in New Jersey under *Strachan*, the court held that medical and hospital expenses "incurred in maintaining and continuing life-support systems after the confirmation of irreversible brain death" did not constitute "medical treatment" under the New Jersey No Fault Act. "Hospital expenses incurred after a determination of irreversible brain death are therefore not reimbursable from personal injury protection insurance coverage."[15] **

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* Several years earlier in *State v. Watson*, 191 N.J. Super. 464, 467 A. 2d 590 (1983), the Appellate Division held that a defendant was properly convicted under New Jersey's homicide statute for causing the "brain death" of his victim. In that case, the defendant had sought to upset his conviction of murder on grounds that his acts "were not the proximate cause of the death of the decedent", and that the actions of the decedent's family and the physician in authorizing and effectuating the removal of machinery sustaining some of the victim's bodily functions were the "supervening cause of death". The Appellate Division, in accordance with numerous decisions in other jurisdictions, firmly rejected those arguments, and adopted a definition equating death with brain death.

** Although the *Cavagnaro* case did not present any issue of personal religious or moral objection to the application of neurological criteria for the determination of death, the decision does highlight the desirability of clear statutory language to resolve payment disputes in such circumstances. The Commission's statutory proposal provides that health and life insurance and governmental benefits programs would apply to costs incurred when life-

The Commission's Proposal

The Commission's proposed New Jersey Declaration of Death Act codifies existing New Jersey case law by providing a statutory basis for declaring death on the grounds of total and irreversible loss of all functions of the entire brain, including the brain stem ("whole brain death"). In two important respects, the proposal would be unique among whole brain death laws currently in force by statute or court decision across the country.

First, the proposal would mandate the adoption by law of uniform criteria for the determination of whole brain death in New Jersey, by requiring the Department of Health and the Board of Medical Examiners to jointly adopt rules and regulations setting forth currently accepted medical standards, including criteria, tests and procedures, to govern such determinations. While state legislation and judicial decisions nationally have adopted a requirement that a determination of death be made "in accordance with accepted medical standards", no statutes or cases establish the criteria for such determinations nor do they establish a mechanism for adoption of uniform criteria. By mandating a regulatory approach, the Commission's proposal would require adoption of uniform criteria based upon currently accepted medical standards, while allowing the flexibility needed to periodically review and update criteria and procedures to keep pace with developments in medical technology.*

Second, the proposal expresses an important commitment to respect for religious and moral values, by recognizing the legal right of an individual to claim an exemption from the application of neurological criteria for determining death if such a declaration would violate that individual's personal religious beliefs or moral convictions. It also requires that a health care provider seek to ascertain the individual's personal religious beliefs or moral convictions, by making reasonable efforts in good faith to contact persons who maintained a close relationship with the individual (*e.g.*, family member, personal physician, religious leader, or friend), and by reviewing the individual's medical records, including any existing advance directive. This approach recognizes that for some people, the continuing flow of breath and blood through the body, even if such respiration and circulation are artificially supported, is itself constitutive of life. For those holding this view, a declaration of death under these circumstances would be violative of personal religious beliefs or moral convictions.

The importance of respect for religious beliefs and moral convictions in this area is underscored by Governor Kean's conditional veto of legislation introduced in 1982 to enact the UDDA. Governor Kean stated his objection as follows:

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support is continued for a patient with a personal religious or moral objection to the declaration of death on the basis of neurological criteria.

* The Commission's proposal would afford the Department of Health and Board of Medical Examiners the additional flexibility of proceeding by interpretive guidelines. The Commission fully supports amendments to the New Jersey Declaration of Death Act which delete this option and require that criteria, tests and procedures be promulgated by regulation.

> Although I agree with the intent and purpose of this bill, I am concerned that it may violate the First Amendment "freedom of religion" rights of certain citizens of New Jersey. According to the tenets of certain longstanding, bona fide religions, death occurs only upon the cessation of cardiac and respiratory activity, and not the cessation of brain activity. In order to protect the religious rights of all New Jersey citizens, I believe this bill should include an exemption clause for those who do not accept a legislative definition of death which contravenes tenets of their bona fide religious beliefs.[16]

The Commission's proposal provides a practically and symbolically important accommodation of religious, moral and cultural diversity in this pluralistic state. If the Commission's proposed statute is adopted, New Jersey would be the first state to recognize such an exemption in its statutory law.*

The Commission formally approved its recommendation of the Proposed New Jersey Declaration of Death Act on June 8, 1988. The Commission's legislative proposal was formally transmitted to Governor Kean and the New Jersey Legislature on June 15, 1988, in the form of the Commission's First Interim Report (reproduced below). The proposal is analyzed in detail in a commentary to the legislative proposal (also reproduced below). A product of extensive and open public deliberations, the proposal reflects the Commission's approach to bioethical issues: an open-minded search for responses to complex and difficult problems in a manner that respects the diverse moral and religious views of a wide range of New Jersey's citizenry.

Current Status of Legislation

The Commission's proposal was originally introduced in the Senate (S-2659) on June 16, 1988, sponsored by Commission member Senator Gabriel Ambrosio, and in the General Assembly (A-3399) on June 20, 1988, sponsored by Commission member Assemblyman Richard Kamin and former Commission member Assemblyman David Schwartz, with the support of Commission member Assemblywoman Stephanie Bush.

The Senate Judiciary Committee conducted hearings on S-2659 on May 8 and June 8, 1989. The bill was reported out of Committee, as amended, on June 22, 1989, and passed the Senate, as amended in Committee, on August 14, 1989. A-3399 was amended by its sponsors on December 15, 1989, to conform with Senate amendments to S-2659, and following a public hearing, was reported out of the Assembly Judiciary Committee on December 18, 1989. No further action was taken by the General Assembly in the 1989 legislative session.

The New Jersey Declaration of Death Act has been pre-filed in the Senate and Assembly for the 1990 session as S-1208 and A-1413, respectively. S-1208 was reported out of the Senate Judiciary Committee on January 25, 1990, and was passed by the New Jersey Senate on March 29, 1990.

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* New York State does formally recognize a religious exemption, although at the regulatory rather than the statutory level. Title 10 *NYCRR* Section 400.16.

Notes

1. This section is based on medical testimony presented by Dr. Jerry Belsh at a public hearing before the New Jersey Bioethics Commission held in Trenton, New Jersey, on April 13, 1988. The Commission would like to acknowledge Dr. Belsh's assistance in preparing this section of the report.

2. Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, "A Definition of Irreversible Coma", *Journal of the American Medical Association* 205 (1968): 337.

3. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Defining Death: A Report on the Medical, Legal and Ethical Issues in the Determination of Death* (U.S. Govt. P.O. 1981).

4. 12 *U.L.A.* 236 (Supp. 1983).

5. *Strachan v. John F. Kennedy Memorial Hospital*, 109 N.J. 523, 538 A.2d 346 (1988).

6. The term "brain dead" as used in the decision means "whole brain death".

7. Had the Commission's proposed statute been in effect at the time of the *Strachan* case, the hospital would have been required to have had procedures in place.

8. 538 A. 2d at 347.

9. *Strachan v. John F. Kennedy Memorial Hospital*, 209 N.J. Super. 300, 507 A.2d 718 (1986).

10. 538 A. 2d at 351.

11. The Court held that the parents were entitled to damages, and that they were not required to prove physical injury to recover damages for emotional distress. Finding that the jury instruction had been improper, the Court remanded the case to the trial court on the issue of damages. 538 A. 2d at 354.

12. *Cavagnaro v. Hanover Insurance Company*, No. L-079332-86, slip op. (Superior Court of New Jersey, August 10, 1989).

13. *Id.* at 1-2.

14. *Id.* at 6.

15. *Id.* at 6-7.

16. Executive memorandum from Governor Thomas Kean to the New Jersey Senate, January 9, 1984.

Chapter Two
First Interim Report: New Jersey Declaration of Death Act

June 15, 1988

The Honorable Thomas H. Kean
Governor, State of New Jersey
State House
Trenton, New Jersey 08625

Dear Governor Kean:

On behalf of the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care, I am pleased to transmit the Commission's legislative proposal for a New Jersey Declaration of Death Act.

As you know, the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care was established as a permanent commission by Public Law 1985, Chapter 363, approved on November 12, 1985. The Commission was directed by this legislation to "provide a comprehensive and scholarly examination of the impact of advancing technology on health care decisions." Among the questions specifically directed to the Commission's attention was the determination of death.

The Commission's founding statute provides for a comprehensive report to the Governor, the Legislature and the public every three years. The first such report is due on December 31, 1988. The legislation provides, however, that the Commission "may submit interim reports as it deems desirable." Recognizing the urgency to the citizens of New Jersey of clarifying the legal standards for declaring death, and noting further the call for such action in the Report of the New Jersey Task Force on Transplant Organ Retrieval, the Commission designated this topic for early action and is pleased to forward its recommendations in the form of a first interim report, well in advance of the December 1988 statutory deadline. We trust that this action will facilitate early legislative consideration of the Commission's statutory recommendations.

The Commission's Process

The Commission's recommendations are the result of an extended process of study, discussion and debate. The Commission and its staff have carefully and extensively reviewed the relevant scientific, medical, legal and ethical literature, including the work on this topic of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and

Behavioral Research, the New York State Task Force on Life and the Law, the Hastings Center, and recognized scholars in the field. We have collected, compared and analyzed legislative actions and judicial decisions in New Jersey, in our sister states, and internationally. The Commission has invited oral and written testimony from scholars, members of relevant professional communities, and members of the public, both at the outset of its work and again (for two days of public hearing) following public circulation of a statutory proposal unanimously approved in principle by the Commission. The revised statutory proposal reflects a number of clarifications adopted in response to this extensive public input.

The Commission's process merits brief additional description. All of the Commission's meetings and discussions on the topic of declaring death took place in meetings open to the public. Following a series of public hearings conducted around the State in 1986 and early 1987 to seek initial public input, the Commission directed its staff to conduct a comprehensive and scholarly review of the question and to develop statutory alternatives sensitive to the needs of New Jersey's citizenry. These alternatives were considered by the Commission at several open meetings. On December 16, 1987, the Commission unanimously adopted a statutory proposal. The Commission then made this proposal available to the public and scheduled a public hearing to invite response, in order to assure the presentation and consideration of the diverse views and perspectives of New Jersey's citizens and professional communities.

The Commission heard extensive testimony in response to its proposal at a well publicized and heavily attended public hearing on February 24, 1988. In order to accommodate all those wishing to speak, the hearing was continued for a second full day on April 13, 1988. The Commission offered to provide additional time for brief statements by members of the public at its regular meetings of March 9 and June 8, and invited additional submissions of written and videotape materials. All materials received were made a part of the Commission's official record and copies were forwarded to Commission members. During the course of this extensive public process, the Commission heard from representatives of major religious communities (including official representatives of Orthodox Jewish and Catholic communities), from New Jersey medical experts and major State professional associations, from organizations and individuals concerned with public policy in this area, and from other interested citizens.

As a result of concerns expressed at one or both of the 1988 public hearings, the Commission conducted additional inquiries and made several modifications to its December 16 proposal. In particular, in response to anecdotal accounts of errors or mishaps under previously utilized (and sometimes misapplied) standards for the determination of "brain death", the Commission invited additional testimony from several distinguished neurological experts at major teaching hospitals in New Jersey, who carefully reviewed currently accepted medical standards and existing practices in New Jersey for the determination of "brain death". This expert testimony, supplementing extensive medical literature and expert testimony and experience from other American jurisdictions previously reviewed by the Commission, provides a strong, on-the-record basis of support for the careful, cautious approach adopted by the Commission.

During the course of this public hearing process, the legal environment of the Commission's deliberations was significantly altered by the decision of the New Jersey Supreme Court in the case of *Strachan v. J.F.K. Memorial Hospital*, announced on March 16, 1988. In that decision, the Supreme Court judicially adopted "whole brain death", as set forth in Section One of the Uniform Determination of Death Act, as a legal standard for declaring death in New Jersey. The Court's decision was fully consistent with the recognition of whole brain death contained in the Commission's December 16 proposal. The Court did not, however, have occasion in *Strachan* to consider a range of additional issues at the heart of the Commission's deliberative process and statutory recommendations. While supporting the basic recognition of whole brain death contained in the Supreme Court's decision, the Commission continues to believe that more comprehensive legislative action is required to protect the rights and interests of New Jersey's citizens in this important and complex area.

The Commission's Proposal

As discussed in more detail below, the result of the Commission's process is an innovative proposal that builds on the work of other legislatures, study commissions, scholars, and the *Strachan* decision, but takes a number of additional steps which we believe are well suited to the special requirements of our State, its diverse citizenry, and its pluralistic traditions. We believe that this proposal enhances New Jersey's recognized role as a national leader in addressing the problems posed by advances in medicine and technology.

The Commission's legislative proposal adopts the concept popularly known as "brain death" as a new, legitimate medical basis, supplementing traditional cardio-respiratory criteria, for declaring the death of an individual. In so doing, the Commission's proposal accepts the central principle underlying the Uniform Determination of Death Act. That Act has been endorsed by the President's Commission, the American Medical Association, the American Bar Association, and the National Conference of Commissioners on Uniform State Laws, and enacted in many states over the past decade. The Commission's proposal, however, goes beyond this basic recognition of brain death to address a number of specific concerns that we believe have not been fully attended to in other jurisdictions, and which the Supreme Court was not called upon to address in *Strachan*. While a full account of the Commission's analysis and considerations will await the publication of the Commission's December 1988 report, we believe it would be helpful to specify here the major innovations contained in our proposal and a brief statement of the basis for our approach.

Most significantly, the Commission's proposal is based on the conviction that society has entered a transitional period, during which its understanding of the meaning of death, and the criteria for determining the fact that death has occurred, are responding to continuously changing scientific understandings and medical techniques. While criteria for declaring death are rooted in scientific understanding and medical technology, the Commission also recognizes inevitable social and philosophical components in the process by which society adapts its understanding, its medical practices, and its law, to these new developments. In particular, the Commission notes that some of these recent developments pose particular challenges to certain religious understandings and traditions and to the conscientious moral beliefs of some individuals.

Concerns for Religious and Moral Convictions

The Commission has wrestled, over many months, with the difficult questions of whether and how society can simultaneously recognize the import of these new scientific and medical developments and yet accommodate important and constitutionally-valued religious and moral convictions. After considerable study and discussion, the Commission is convinced that society's general interests in uniformity in this area may yield, to a limited degree, in order to respect more fully the religious and moral convictions of those individuals who desire that their deaths be declared solely in accordance with long-accepted traditional criteria based on the irreversible cessation of cardiac and respiratory activity.

Accordingly, the proposed legislation contains a number of features designed to recognize this interest and to require reasonable efforts, in good faith, by health care professionals to assure that these personal wishes can be expressed, ascertained and respected in the relatively few cases in which the situation arises. The proposal recognizes, at the same time, the need for practical and sensitive procedures to attend the declaration of death, and seeks to reach a reasonable accommodation of these potentially competing interests. The result is a proposal that establishes an exemption based on religious or moral convictions, yet affords a degree of flexibility to health care institutions to allow appropriate responses to local circumstances, free of the specter of potential liability.

In light of the novelty of the Commission's inclusive approach and the potential need for further practical refinements following the accumulation of greater experience with its operation, the proposal provides that these procedures should be reviewed and evaluated on a periodic basis, allowing for necessary administrative adjustments consistent with the overall statutory approach, and, if necessary, for legislative reconsideration of that approach.

If adopted, this proposed statute would make New Jersey the first state in the nation to seek to accommodate these diverse interests in its statutory law. New York State has recently adopted a more limited version of this approach, although at the regulatory rather than the statutory level. We believe legislative action is more appropriate.

Concerns for Accurate Diagnosis

The proposed statute also recognizes other concerns that have been raised regarding the accuracy and reliability of medical tests and procedures for declaring death on the basis of neurological criteria. In particular, rather than relying on unspecified "accepted medical standards", as provided by the Uniform Determination of Death Act, the proposed statute directs the State Department of Health, acting jointly with the State Board of Medical Examiners, to review up-to-date medical information and to adopt regulations or interpretive guidelines formally recognizing currently accepted medical procedures, tests and criteria to govern the declaration of death, including any special provisions appropriate for specific population groups such as children and infants.

The Commission's extensive review of the medical literature, coupled with the testimony

of recognized neurological experts at several of New Jersey's leading hospitals, provides assurance that existing medical standards, if well understood and carefully followed by properly trained medical personnel, provide a very high degree of diagnostic and prognostic accuracy, as is properly required on such a matter. Of fundamental importance to such determinations is a carefully conducted and repeated clinical examination, including a medical history and testing to rule out such potentially confounding factors as the presence of drugs, alcohol, or hypothermia, which may "mimic" certain features of brain death. The Commission's research reveals some variations among specialists and institutions with respect to laboratory or other confirmation of the fundamental clinical diagnosis. As might be expected, the existing medical literature provides scientific support for several responsible, yet distinct approaches, and continuing medical research and technological developments are likely to lead to further evolution in approved practices. Given the likelihood of such evolution, and of continuing differences of view within the medical profession on the ideal approach in particular circumstances, the Commission believes it would be inappropriate and counter-productive to "lock-in" any particular methodology at the statutory level.

Following consultations with the State Department of Health and the State Board of Medical Examiners, the Commission is confident that these agencies, working collaboratively, can identify protocols for the determination of death that will assure the necessary reliability and accuracy, and with it, a sound basis for public confidence. These agencies are also well equipped to undertake the statutorily required periodic updating of these tests and criteria in accordance with continuing advances in medical understanding and technology.

Concerns about Alternative Standards

It should be noted that the proposed statute requires that such procedures be directed solely toward the determination of irreversible cessation of *all* functions of the *entire* brain. It does *not* provide for recognition of so-called "higher brain" or "neocortical" death. This reflects a conviction by the Commission that consideration of such an approach would be premature at this time. Although there has been a good deal of philosophic support, and some legal argument, favoring acceptance of a "higher brain" concept of death, this position has been advanced primarily in theoretical terms. While the courts, including the New Jersey Supreme Court, have treated patients in a so-called "persistent vegetative state" (a form of permanent unconsciousness) as constituting a distinct category of patients for purposes of certain treatment decisions, no American court or legislature has yet accepted the argument that such patients should be regarded as legally dead. Further, the best available evidence regarding scientific understanding of brain function and medical prognostic abilities (including, in particular, the capacity to rule out, with the very high requisite degree of certainty, the possibility of recovery of some degree of consciousness) indicates that serious consideration of the "higher brain" concept of death is not warranted at the present time.

It should also be noted that the Commission's statutory proposal would not provide any basis for permitting the use of so-called "anencephalic" newborns as organ donors, since, to the best of our knowledge following extensive research, there do not currently exist any validated medical standards for the reliable determination of brain death in the immediate neonatal period.

Nor does the Commission's proposal accept or endorse the medically dubious assertion that such infants should be regarded as entirely "brain absent", and therefore "brain dead". To date, the Commission has not considered the ethical implications or the legal ramifications of proposals to authorize the use of anencephalic newborns as organ donors in the absence of a legally valid determination of death.

Final Observations

The proposed statute was endorsed, in principle, by a unanimous vote of the twenty-one Commissioners present and voting at the Commission's meeting of December 16, 1987. As previously noted, the Commission's proposal was then made available to the public for detailed review and comment, including two full days of public hearings on February 24, 1988 and April 13, 1988. Certain technical corrections, responsive to testimony received, were approved by the Commission at its meetings of March 9, 1988 and June 8, 1988. The proposed New Jersey Declaration of Death Act in its present and final form was formally approved by the Commission on June 8, 1988, with 20 members present and voting in favor, one member expressing general support for the proposal but voting opposed on a technical ground,* and one abstention. Of the Commission's three legislative members unable to be present for the final vote, two have expressed support for the proposal, and one is opposed.** Given the number of innovations reflected in this legislative proposal, the diversity of views and perspectives reflected in the Commission's membership, and the thoroughgoing study, analysis and discussion preceding this final action, the Commission is particularly pleased that the proposal has received this overwhelming endorsement. We trust that this consensus support will lend credibility and conviction to the recommended approach during the process of legislative consideration.

The Commission will provide a full written account of the background and rationale for its approach to the issue of declaring death in its triennial report, to be submitted to the

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* Commissioner Elmer M. Matthews requests that the following statement explaining his negative vote be included in this report:

"Although I am in agreement with the remainder of the proposed legislation, including the religious and moral exemption, my negative vote was predicated on the fact that it is my feeling that the language of Section 4(B) which requires the State Department of Health jointly with the Board of Examiners to adopt, and from time to time revise, regulations *or* interpretive guidelines should be limited to the authority to issue regulations alone. Under the Administrative Procedures Act, granting to the named agencies the authority to issue interpretive guidelines would give such guidelines the force of regulatory authority without the public notice and public participation provisions of that act. An interpretive guideline should be just that. Both agencies presently have the capacity to issue such guidelines but those guidelines do not have the force or legal effect of a regulation. I feel that it is imperative that all actions taken by the agencies under this section should be on proper notice to avoid any semblance of suspicion that activity is being shielded from public knowledge. The same criticism, of course would extend to the last sentence of paragraph 4(B)."

** Senator Gerald Cardinale is the sole Commission member expressing substantive opposition to the Commission's proposal. Senator Cardinale introduced his own bill on brain death (S-2631) on June 3, shortly prior to the Commission's final action on this matter.

Governor, the Speaker of the General Assembly, and the President of the New Jersey Senate by the end of 1988. Recognizing the great public interest in this issue, and reflecting the strong conviction of the Commissioners that this matter is now ripe for legislative action, we have determined to transmit the statutory proposal at this time and to recommend legislative consideration and approval at the earliest possible date. We are pleased to have been of service in considering this important issue and look forward to working with you and your colleagues in securing the legislative adoption of this proposal.

Respectfully,

Daniel F. O'Connell, Esq.
Chairman

Proposed New Jersey Declaration Of Death Act

Approved by the New Jersey Bioethics Commission
June 8, 1988

AN ACT concerning the declaration of death.

Be it enacted by the Senate and General Assembly of the State of New Jersey:

Section 1: PURPOSE

The death of an individual shall be declared in accordance with the provisions of this Act.

Section 2: RECOGNITION OF TRADITIONAL CARDIO-RESPIRATORY CRITERIA

An individual who has sustained irreversible cessation of all circulatory and respiratory functions, as determined in accordance with currently accepted medical standards, shall be declared dead.

Section 3: RECOGNITION OF MODERN NEUROLOGICAL CRITERIA

Subject to the standards, procedures and exemptions established in accordance with Sections 4, 5 and 6 of this Act, an individual whose circulatory and respiratory functions can be maintained solely by artificial means, and who has sustained irreversible cessation of all functions of the entire brain, including the brain stem, shall be declared dead.

Section 4: STANDARDS AND PROCEDURES FOR DECLARATION OF DEATH BASED UPON NEUROLOGICAL CRITERIA

A. A declaration of death upon the basis of neurological criteria pursuant to Section 3 of this Act shall be made by a licensed physician professionally qualified by specialty or expertise, in accordance with currently accepted medical standards and such additional requirements, including appropriate confirmatory tests, as are provided pursuant to this Act.

B. Subject to the provisions of this Act, the State Department of Health, jointly with the State Board of Medical Examiners, shall adopt, and from time to time revise, regulations or interpretive guidelines setting forth 1) requirements, by specialty or expertise, for physicians authorized to declare death upon the basis of neurological criteria; and 2) currently accepted medical standards, including criteria, tests and procedures, to govern declarations of death upon the basis of neurological criteria. The initial regulations and interpretive guidelines shall be issued within 120 days of the enactment of this Act.

C. If the individual to be declared dead upon the basis of neurological criteria is or may be an organ donor, the physician who makes the declaration that death has occurred shall not be the organ transplant surgeon, the attending physician of the organ recipient, nor otherwise an individual subject to a potentially significant conflict of interest relating to procedures for organ procurement.

D. If death is to be declared upon the basis of neurological criteria, the time of death shall be upon the conclusion of definitive clinical examination(s) and any confirmation necessary to determine the irreversible cessation of all functions of the entire brain, including the brain stem.

Section 5: EXEMPTION TO ACCOMMODATE PERSONAL RELIGIOUS BELIEFS OR MORAL CONVICTIONS: POLICY

The death of an individual shall not be declared upon the basis of neurological criteria pursuant to Sections 3 and 4 of this Act when such a declaration would violate the personal religious beliefs or moral convictions of that individual, and when that fact has been communicated to, or should, pursuant to the provisions of Section 6, reasonably be known by, the licensed physician authorized to declare death. In such cases, death shall be declared, and the time of death fixed, solely upon the basis of traditional cardio-respiratory criteria pursuant to Section 2 of this Act.

Section 6: EXEMPTION TO ACCOMMODATE PERSONAL RELIGIOUS BELIEFS OR MORAL CONVICTIONS: IMPLEMENTATION

A. Prior to declaring an individual dead upon the basis of neurological criteria pursuant to Sections 3 and 4 of this Act, the licensed physician authorized to declare death, or another responsible person designated for this purpose, shall make reasonable efforts, in good faith, to determine whether such a declaration would violate the personal religious beliefs or moral convictions of that individual. Such efforts shall include, as is appropriate under the circumstances, review of available medical records (including advance directives for health care) and reasonable efforts to contact a person or persons (such as a family member, personal physician, religious leader, or friend) who maintained a close

association with the individual sufficient to render that person knowledgeable concerning the nature and content of the individual's personal religious beliefs or moral convictions.

B. If a claim of exemption is reasonably advanced on the individual's behalf under this Act, a physician or other health care provider charged with responsibility for the treatment and care of that individual shall 1) refrain from declaring such individual dead upon the basis of neurological criteria; and 2) refrain from discontinuing, solely upon the basis of the individual's neurological status, mechanical or other artificial means employed to maintain the individual's circulatory or respiratory functions.

Section 7: IMMUNITIES

A licensed health care practitioner, hospital, or other health care provider who acts in good faith and in accordance with currently accepted medical standards to execute the provisions of this Act and any rules, regulations or guidelines issued by the State Department of Health or the State Board of Medical Examiners pursuant to this Act, shall not be subject to criminal or civil liability or to discipline for unprofessional conduct with respect to those actions. Such immunities shall extend to conduct in conformity with the provisions of this Act following enactment of this Act but prior to its effective date.

Section 8: EFFECT ON INSURANCE AND HEALTH BENEFITS

Changes in pre-existing criteria for the declaration of death effectuated by the legal recognition of modern neurological criteria shall not in any manner affect, impair or modify the terms of, or rights or obligations created under, any existing policy of health insurance, life insurance or annuity, or governmental benefits program. No health care practitioner or other health care provider, and no health service plan, insurer, or governmental authority, shall deny coverage or exclude from the benefits of service any individual solely because of that individual's personal religious beliefs or moral convictions regarding the application of neurological criteria for declaring death.

Section 9: REPORTING AND MONITORING

A. The State Department of Health shall establish such rules, regulations, policies and practices as may be necessary to collect annual reports from health care institutions, and to gather such additional data as is reasonably necessary, to oversee and evaluate the implementation of this Act, including provisions relating to the exemption procedure established by Sections 5 and 6 of this Act. The Department of Health shall seek to minimize the burdens of record-keeping imposed by such rules, regulations, policies and practices, and shall seek to assure the appropriate confidentiality of patient records.

B. The State Department of Health, the State Board of Medical Examiners, and the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care shall jointly evaluate the implementation of this Act and report to the State Legislature, including recommendations for any changes deemed necessary, after a period of not more than five years from the effective date of this Act.

Section 10: SEVERABILITY

If any provision of this Act or its application to any individual or circumstance is held invalid, the invalidity shall not affect other provisions or applications of this Act which can be given effect without the invalid provision or application, and to this end the provisions of this Act are severable.

EFFECTIVE DATE: This Act shall take effect 180 days from its enactment.

Chapter Three
Proposed New Jersey Declaration Of Death Act With Commentary

The proposed New Jersey Declaration of Death Act was approved in final form by the New Jersey Bioethics Commission on June 8, 1988, and transmitted on June 15, 1988, to the Governor and Legislature.

AN ACT concerning the declaration of death.

Be it enacted by the Senate and General Assembly of the State of New Jersey:

Section 1: PURPOSE

The death of an individual shall be declared in accordance with the provisions of this Act.

Comment

The purpose of this Act is to establish a fixed statutory basis for the declaration of death. The legislative standards for declaring that death has occurred are set forth in sections 2 and 3 of the Act. These are the sole legal bases for declaring the death of an individual. In this regard, the Act clarifies existing judicial precedent and establishes a statutory basis for New Jersey law.

Section 2: RECOGNITION OF TRADITIONAL CARDIO-RESPIRATORY CRITERIA

An individual who has sustained irreversible cessation of all circulatory and respiratory functions, as determined in accordance with currently accepted medical standards, shall be declared dead.

Comment

Section 2 recognizes the traditional criteria for the declaration of death, the irreversible cessation of all circulatory and respiratory functions. It is anticipated that these traditional criteria will continue to govern in the vast majority of cases in which death must be declared. In section 2, as throughout the Act, the term "declaration" of death is used. ("Declaration" is used synonymously with "pronouncement".) This is quite deliberate. The Act is intended to establish legally applicable standards for those authorized to declare that death has occurred; it does not attempt to "define" death in religious, metaphysical or philosophical terms. Upon the declaration of an individual's death by a qualified practitioner in accordance with the established legal standard, the individual is properly treated as legally dead. This section is not intended to modify either existing law relating to the qualifications of practitioners (including nurses) currently authorized to declare death according to cardio-respiratory criteria or existing practices relating to determination of the "time of death" when death is declared upon the basis of cardio-respiratory criteria.

Section 3: RECOGNITION OF MODERN NEUROLOGICAL CRITERIA

Subject to the standards, procedures and exemptions established in accordance with Sections 4, 5 and 6 of this Act, an individual whose circulatory and respiratory functions can be maintained solely by artificial means, and who has sustained irreversible cessation of all functions of the entire brain, including the brain stem, shall be declared dead.

Comment

Section 3 recognizes modern neurological criteria, popularly known as "whole brain death", as a legal basis for declaring death. The "whole brain death" standard complements the traditional cardio-respiratory criteria for the declaration of death recognized in section 2, by providing that modern neurological criteria are to be applied when the individual's circulatory and/or respiratory functions can only be maintained by artificial means. The provision thus explains the relationship between the traditional cardio-respiratory and modern neurological standards for declaring death, an explanation lacking in the Uniform Determination of Death Act ("UDDA") and in several other statutory formulations.

Section 3 defines the neurological basis for declaring death as the "irreversible cessation of all functions of the entire brain, including the brain stem." This follows the formulation of the UDDA, and rejects approaches based upon brain stem function alone (the British approach) or higher brain function alone. Irreversible loss of *all* brain functions must be established for death to be declared under the Act. In rejecting so-called "higher brain" or "neocortical" death as a legal basis for declaring the death of an individual, the Act declines to permit a determination that a patient in a "persistent vegetative state" (such as Karen Quinlan) is legally dead.

The Act does not provide any legal basis for permitting the use of so-called "anencephalic" newborns as organ donors, since there do not currently exist any validated medical standards for the reliable determination of whole brain death in the immediate neonatal period. The Act also does not provide any basis for the medically dubious assertion that such infants should be regarded as entirely "brain absent", and therefore "brain dead".

Section 4: STANDARDS AND PROCEDURES FOR DECLARATION OF DEATH BASED UPON NEUROLOGICAL CRITERIA

A. A declaration of death upon the basis of neurological criteria pursuant to Section 3 of this Act shall be made by a licensed physician professionally qualified by specialty or expertise, in accordance with currently accepted medical standards and such additional requirements, including appropriate confirmatory tests, as are provided pursuant to this Act.

B. Subject to the provisions of this Act, the State Department of Health, jointly with the State Board of Medical Examiners, shall adopt, and from time to time revise, regulations or interpretive guidelines setting forth 1) requirements, by specialty or expertise, for physicians authorized to declare death upon the basis of neurological criteria; and 2) currently accepted medical standards, including criteria, tests and procedures, to govern declarations of death upon the basis of neurological criteria. The initial regulations and interpretive guidelines shall be issued within 120 days of the enactment of this Act.

C. If the individual to be declared dead upon the basis of neurological criteria is or may be an organ donor, the physician who makes the declaration that death has occurred shall not be the organ transplant surgeon, the attending physician of the organ recipient, nor otherwise an individual subject to a potentially significant conflict of interest relating to procedures for organ procurement.

D. If death is to be declared upon the basis of neurological criteria, the time of death shall be upon the conclusion of definitive clinical examination(s) and any confirmation necessary to determine the irreversible cessation of all functions of the entire brain, including the brain stem.

Comment

Section 4 establishes certain standards and procedures for the declaration of death upon the basis of neurological criteria.

Section 4(A) states two basic statutory requirements: that a declaration of death upon the basis of neurological criteria is to be made by a licensed physician professionally qualified by specialty or expertise to make this determination, and that the declaration is to be made in accordance with currently accepted medical standards. Section 4(A) also contemplates that additional specific requirements, including such confirmatory tests as may be appropriate in particular circumstances, may be established by the State Department of Health and the State Board of Medical Examiners, pursuant to the express regulatory authority conferred by the Act.

Section 4(B) authorizes and requires the Department of Health, acting jointly with the Board of Medical Examiners, to establish appropriate professional qualifications for physicians authorized to declare death upon the basis of neurological criteria, and to designate and periodically update accepted medical standards for such declarations. In so providing, the Act encourages significantly greater certainty and uniformity in the standards and practices to be employed in declaring death than is typical of other state statutes, or provided by the UDDA (which relies upon unspecified "accepted medical standards"). At the same time, the Act provides for periodic updating in accordance with changes in medical science and technology, without requiring unduly burdensome and perhaps unrealistic changes in the governing statute. All such changes must be consistent with the statutory standard of whole brain death.

The Act would permit the Department of Health and the Board of Medical Examiners to act either through a formal regulatory process, in accordance with the "Administrative Procedure Act", *N.J.S.A. 52*: 14B-1 *et seq.*, or through a less formal process of interpretive guidelines. The Act's authorization of interpretive guidelines is considered an appropriate approach, since the primary task, at least in some cases, is simply to recognize current and well-established medical standards already published in the medical literature. The Legislature may wish to consider, however, requiring a formal regulatory process rather than this less formal approach. Although somewhat more cumbersome to implement, such a legislative determination would be consistent with the basic purpose of this provision.

The initial regulations or interpretive guidelines are to be issued within 120 days of enactment of the Act. This period should be adequate in the case of interpretive guidelines, but may prove ambitious for formal regulatory action, unless preparations are underway at the time the Act is adopted. It should be recognized that death is now being declared in accordance with whole brain death criteria in New Jersey (and throughout the United States and much of the world), on the basis of accepted medical standards, in the absence of any statutory or regulatory specification.

The Department of Health and Board of Medical Examiners are mandated to update standards on a periodic basis in accordance with developments in medical understanding and technology. Such updating may be especially significant with respect to the development and availability of confirmatory techniques in areas that are currently less well understood, such as brain death in newborns and infants.

Standards for the declaration of death. The regulations or guidelines are to address both the professional qualifications of persons authorized to declare death on the basis of neurological criteria, and the medical standards to be employed in making such determinations. Unlike the case with traditional criteria for declaring death, in which non-physicians have long played a role, neurological criteria for declaring death require highly specialized expertise. It is anticipated that legal authorization will be limited to licensed physicians with highly specialized training (*e.g.*, neurologists and neurosurgeons), and perhaps those with special experience (senior intensivists). Specification of necessary credentials is thought best left to the regulatory authorities.

With respect to currently accepted medical criteria for declaration of death on the basis of modern neurological criteria, there is extensive recent medical literature addressing the relevant clinical procedures and appropriate confirmatory tests, when indicated. The original Harvard criteria, published in 1967, have since been superseded by the Report of the Medical Consultants on the Diagnosis of Death to the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (the "President's Commission"), published in 1981. More recent literature extends these tests to population groups not fully covered by the earlier literature, such as children and older infants. The literature establishes the need to develop sound medical histories and to rule out complicating conditions, such as drug sedation or hypothermia, which may confound certain clinical or confirmatory tests. The literature also distinguishes between those cases in which repeated clinical examinations provide a proper and sufficient basis for the declaration of death, and those cases in which one or another confirmatory test should be employed.

The literature also reflects certain professional disagreements concerning the indications for and relative advantages and disadvantages of alternative confirmatory tests. Once again, detailed specification of the range of approaches appropriate to New Jersey, consistent with the basic statutory standards established by the Act, is thought best left to the regulatory authorities. The Act would permit specification of particular criteria, tests and procedures when, and to the degree that, the regulatory authorities conclude that such specificity is necessary and appropriate. Efforts to require particular confirmatory tests at the statutory level are bound to be unduly rigid and to quickly become outmoded as medical technology continues to advance. Section 4(B) is intended to accord some flexibility to the regulatory authorities in establishing standards in order to allow the medical standards to address particular clinical circumstances and respond to continuing scientific advances in this area.

Conflicts of interest. Section 4(C) requires that, in addition to meeting standards of professional qualification established pursuant to section 4(B), any physician who is to declare death not be involved in a conflict of interest relating to organ procurement and transplantation. This is intended both to protect the patient to be declared dead from any hypothetical possibility that such conflicting obligations might impair the physician's judgment or otherwise result in error, and to assure necessary public confidence in the integrity of such determinations. This section also provides a clear legal basis for physicians to decline inappropriate participation in potentially difficult situations of conflicting obligations.

While not conflating the standards for declaring death with an individual's suitability as a potential organ donor, section 4(C) does recognize, realistically, that individuals who meet neurological criteria for the declaration of death constitute the primary pool of potential donors of organs for transplantation purposes. Cognizant of this reality, and of the need for justified public confidence, the Act specifically identifies and disqualifies the organ transplant surgeon, and the attending physician of a patient in need of an organ for transplantation, from making the declaration of death. This reflects the fact that such physicians may be subject to potentially conflicting obligations to two patients--the patient to be declared dead (the potential donor) and the patient in need of an organ transplant (the potential recipient). In addition, the last clause of section 4(C) provides for disqualification of others

involved in organ procurement who are not in either of these categories, but who are subject to some other "potentially significant" conflict of interest. Only physicians not subject to a potentially significant conflict of interest with respect to organ procurement may make the declaration of death.

Time of death. Section 4(D) provides statutory direction for fixing the time of death in cases in which death is declared on the basis of neurological criteria. Neither this section, nor any other provision of the Act, modifies existing law or practice regarding the time of death in cases in which traditional cardio-respiratory criteria are employed.

Because the signs of "brain death" are neither as dramatic nor as readily apparent as the vital signs associated with cessation of breathing and heartbeat, there has been some confusion regarding the appropriate moment for fixing the time of death in such cases. The principal candidates are, first, the time at which the patient first meets the initial clinical criteria for irreversible cessation of all brain functions, and second, the time at which the repeated clinical examinations, together with the completion of any appropriate confirmatory tests, establish a definitive diagnosis of death.

Neither the UDDA, nor the report of the President's Commission, specifically resolves this issue. There are advantages and disadvantages to each approach. The Act opts for the second approach because it stresses the importance of careful, repeated clinical examinations as a necessary prerequisite to so significant a diagnosis, and because it avoids unnecessary and anomalous after-the-fact determinations that a patient was legally dead during the interval (typically 6-24 hours, sometimes longer) between the initial clinical diagnosis and the subsequent, definitive diagnosis. This approach also avoids potentially confounding disputes over the applicability of private and public health care coverage during that interval. Were time of death resolved in a different manner, there might be confusion over whether insurance coverage might cease prior to the actual declaration of death.

Section 4(D) does not apply in cases in which the exemption to accommodate personal religious beliefs or moral convictions applies (sections 5 and 6 of the Act), in which event death is to be declared solely upon the basis of traditional cardio-respiratory criteria, and the time of death fixed accordingly.

Section 5: EXEMPTION TO ACCOMMODATE PERSONAL RELIGIOUS BELIEFS OR MORAL CONVICTIONS: POLICY

The death of an individual shall not be declared upon the basis of neurological criteria pursuant to Sections 3 and 4 of this Act when such a declaration would violate the personal religious beliefs or moral convictions of that individual, and when that fact has been communicated to, or should, pursuant to the provisions of Section 6, reasonably be known by, the licensed physician authorized to declare death. In such cases, death shall be declared, and the time of death fixed, solely upon the basis of traditional cardio-respiratory criteria pursuant to Section 2 of this Act.

Comment

Section 5 provides an exemption from the applicability of neurological criteria for declaring death when such a declaration would violate the personal religious beliefs or moral convictions of the individual concerned. In such cases, the traditional criteria of irreversible cessation of circulatory and respiratory functions are to be applied.

This exemption constitutes a distinctive feature of this Act's approach to the declaration of death. It is founded on a particular understanding of the respective roles of medical and scientific, and of social and

philosophical, factors in the process by which society adapts to new developments in medical science and technology.

Clearly, the identification of medical criteria for determining that certain bodily functions have ceased, and that such cessation is irreversible, must be based upon scientific understanding and medical techniques and technology. Such understandings have changed over time, and will continue to evolve and advance. However, the acceptance of particular medical criteria as the social and legal basis for declaring the death of an individual, although necessarily rooted in scientific understanding, is not itself a medical and scientific choice. Rather, it is a societal decision which rests on social, philosophical and legal criteria, which may themselves be informed by religiously-influenced understandings. As stated by the President's Commission, whose report on *Defining Death* provides the foundation for the UDDA and for brain death statutes in many jurisdictions, "the society as a whole must judge that these technical standards and the opinions they reflect conform to the society's settled values and accepted conceptions of human existence and personal rights."

The approach taken in this Act is distinctive in its response to the recognition that the legal adoption of modern neurological criteria for the declaration of death poses special challenges to the well-established and long-accepted beliefs and practices of some of New Jersey's diverse and pluralistic populace. Some of these individuals are members of communities whose religious traditions identify life with continued respiratory activity, even if that activity is artificially supported; others have more personally defined conscientious moral objections to the application of modern neurological criteria, which may include concerns (not accepted by most within the medical community) regarding the means by which those criteria are applied and confirmed. The question is whether continued application of long-established traditional standards for determining the death of individuals holding such personal religious beliefs or moral convictions would be so antithetical to the public order as to require the profound beliefs of those individuals to be disregarded. The Act is predicated on a deep conviction that the societal need for uniformity in the application of modern neurological criteria is not so absolute as to preclude a reasonable effort to accommodate the important and constitutionally-valued religious and moral convictions of those individuals who desire that their deaths be declared solely in accordance with long-accepted traditional criteria of the irreversible cessation of cardio-respiratory functions. The Act does not recognize any "novel" or "individually determined" standard for the declaration of death; it merely continues the application of the traditionally recognized criteria in the traditional way in accordance with the beliefs and convictions of a group of New Jersey citizens.

Section 5 provides that the exemption applies to situations in which the individual's religious beliefs or moral convictions have actually been communicated to, or should reasonably be known by, the physician authorized to declare death. Reasonable means of obtaining such information are specified in section 6.

Section 6: EXEMPTION TO ACCOMMODATE PERSONAL RELIGIOUS BELIEFS OR MORAL CONVICTIONS: IMPLEMENTATION

A. Prior to declaring an individual dead upon the basis of neurological criteria pursuant to Sections 3 and 4 of this Act, the licensed physician authorized to declare death, or another responsible person designated for this purpose, shall make reasonable efforts, in good faith, to determine whether such a declaration would violate the personal religious beliefs or moral convictions of that individual. Such efforts shall include, as is appropriate under the circumstances, review of available medical records (including advance directives for health care) and reasonable efforts to contact a person or persons (such as a family member, personal physician, religious leader, or friend) who maintained a close association with the individual sufficient to render that person knowledgeable concerning the nature and content of the individual's personal religious beliefs or moral convictions.

B. If a claim of exemption is reasonably advanced on the individual's behalf under this Act, a physician or other health care provider charged with responsibility for the treatment and care of that individual shall 1) refrain from declaring such individual dead upon the basis of neurological criteria; and 2) refrain from discontinuing, solely upon the basis of the individual's neurological status, mechanical or other artificial means employed to maintain the individual's circulatory or respiratory functions.

Comment

Section 6 provides for implementation of the exemption from application of neurological criteria for the declaration of death recognized by section 5. Pursuant to section 6(A), before an individual may be declared dead on the basis of neurological criteria, reasonable efforts must be made, in good faith, to ascertain whether the individual's personal religious beliefs or moral convictions would be violated by the application of neurological criteria for the declaration of death. The Act is flexible in permitting such efforts to be carried out either by the physician authorized to declare death or by another responsible person designated for that purpose by the health care institution, such as a nurse, social worker, or other person experienced in bereavement counseling.

The key terms of section 6(A) provide that "reasonable efforts" are to be made "in good faith" by the responsible person to determine whether application of neurological criteria would violate the individual's religious beliefs or moral convictions. Section 6(A) provides specific illustrations of how this obligation may properly be met.

In this regard, it should be noted that declarations of death on the basis of neurological criteria rarely require action on an emergency basis. Medical protocols require a repeated clinical examination following a waiting period, during which time "reasonable efforts" may proceed to determine whether the individual would object to such a declaration. Since the patient is, by definition, not conscious in such situations, the responsible person must look to other reliable sources of relevant information, including family members or others who know the patient, as well as documentary evidence of the patient's wishes. Documentary sources include available medical records, which may include an advance directive prepared by the patient at an earlier time to express directions on health care issues. Religious communities may choose to develop sample forms for use by their members, and may wish to maintain their own registries for consultation in time of need.

Reasonable efforts should also be made to contact those who are likely to be familiar with the patient's religious beliefs and moral convictions regarding the declaration of death, such as family members, a personal physician, a religious leader or other close friends. The focus of such inquiries is on the beliefs and convictions of the patient, not those of the family member or others speaking on behalf of the patient. Recognizing the difficult and sensitive nature of conversations in such circumstances, section 6(A) is intended to afford a measure of flexibility and discretion to those responsible for conducting such inquiries. The provision does not require a formal "informed consent" to the declaration of death; nor does it require that families receive detailed or legalistic recitations of the exemption established by the Act. The conversation should be structured in a manner appropriate to the circumstances and the sensibilities of the family. Greater detail will be appropriate when the conversation reveals that there may be reason to believe that the exemption is potentially applicable. It is important in such cases that family members and others clearly understand that they are being asked about the beliefs of the patient; they are not being asked for their own consent to declaring the patient dead or to withdrawing life-sustaining treatments.

Section 6(B) provides the steps to be followed when a claim of exemption has been reasonably advanced on the individual's behalf. The term "reasonably advanced" is intended to mean that, in order for the exemption to apply, available sources of information about the individual's beliefs should be trustworthy and reliable, and should provide a reasonable basis for concluding that the declaration of death upon the basis of neurological criteria would indeed violate the individual's personal religious beliefs or moral convictions. Absolute certainty is not

required under this standard.

When a claim of exemption has been reasonably advanced, section 6(B) provides that the individual shall not be declared dead on the basis of neurological criteria, and that life-support mechanisms used to maintain the individual's circulatory and respiratory functions (such as a respirator) should not be discontinued solely on the ground of the individual's neurological status. Thus, physicians and other health care providers responsible for the individual's care should generally continue to provide cardio-respiratory support until it is determined, in accordance with currently accepted medical standards, that irreversible cessation of all circulatory and respiratory functions has occurred, and that death should be declared in accordance with the traditional cardio-respiratory criteria recognized by section 2.

While this section is not intended to establish priorities for allocation of scarce medical technologies in situations of emergency or triage, neither is it intended to preclude the application of existing decisionmaking processes generally applicable in emergency settings, insofar as such decisions might apply to any irreversibly comatose, terminally ill patients, regardless of whether they meet "brain death" criteria.

Section 7: IMMUNITIES

A licensed health care practitioner, hospital, or other health care provider who acts in good faith and in accordance with currently accepted medical standards to execute the provisions of this Act and any rules, regulations or guidelines issued by the State Department of Health or the State Board of Medical Examiners pursuant to this Act, shall not be subject to criminal or civil liability or to discipline for unprofessional conduct with respect to those actions. Such immunities shall extend to conduct in conformity with the provisions of this Act following enactment of this Act but prior to its effective date.

Comment

Section 7 provides a good faith immunity for health care professionals and institutions who act in accordance with accepted medical standards to carry out the provisions of the Act and any rules, regulations or guidelines issued pursuant to the Act. Immunity extends to physicians, nurses, hospitals and other health care providers, and applies to criminal or civil liability and to discipline for unprofessional conduct. This section does not absolve from liability or from professional discipline those whose actions are contrary to accepted professional standards or the requirements of the Act.

This section is intended to make clear to physicians, hospitals and other health care providers that non-negligent actions undertaken in compliance with the Act are insulated from potential liability. Physicians should be confident that they may exercise sound professional judgment in making declarations of death in accordance with the requirements of this Act and good medical practice. This statutory grant of immunity is intended to calm existing concerns of unfounded and burdensome entanglements in legal proceedings, and to obviate any perceived need to seek advance approvals from committees or courts prior to making a declaration of death in accordance with the provisions of the Act.

These immunities are intended to become immediately effective upon the passage of this Act, and to apply to conduct in accordance with the requirements of the Act and currently applicable law.

Section 8: EFFECT ON INSURANCE AND HEALTH BENEFITS

Changes in pre-existing criteria for the declaration of death effectuated by the legal recognition of modern neurological criteria shall not in any manner affect, impair or modify the terms of, or rights or obligations created under, any existing policy of health insurance, life insurance or annuity, or governmental benefits program. No health care practitioner or other health care provider, and no health service plan, insurer, or governmental authority, shall deny coverage or exclude from the benefits of service any individual solely because of that individual's personal religious beliefs or moral convictions regarding the application of neurological criteria for declaring death.

Comment

Section 8 provides that neither the recognition of modern neurological criteria for the declaration of death, nor the exercise of the right of exemption from the application of neurological criteria to declare an individual's death, shall be a legally valid ground for the denial, impairment or modification of rights or obligations under the terms of existing policies of health insurance, life insurance or annuity, or any governmental benefits program. Section 8 also prohibits health care practitioners and health care providers, health service plans, insurers, and governmental authorities from employing such personal religious beliefs or moral convictions as a basis for the denial of coverage or for exclusion from the benefits of service. This section is intended to protect the free exercise of personal religious beliefs or moral convictions regarding the declaration of death, and to preclude insurers or care providers from cutting off benefits or services or conditioning their cost or availability upon the exercise or non-exercise of this right. An individual's ability to procure or to receive health care, health insurance or health coverage is not to be denied on the basis of the individual's personal religious beliefs or moral convictions regarding the declaration of death.

Section 9: REPORTING AND MONITORING

A. The State Department of Health shall establish such rules, regulations, policies and practices as may be necessary to collect annual reports from health care institutions, and to gather such additional data as is reasonably necessary, to oversee and evaluate the implementation of this Act, including provisions relating to the exemption procedure established by Sections 5 and 6 of this Act. The Department of Health shall seek to minimize the burdens of record-keeping imposed by such rules, regulations, policies and practices, and shall seek to assure the appropriate confidentiality of patient records.

B. The State Department of Health, the State Board of Medical Examiners, and the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care shall jointly evaluate the implementation of this Act and report to the State Legislature, including recommendations for any changes deemed necessary, after a period of not more than five years from the effective date of this Act.

Comment

Given the innovative features of this Act and concerns that have been expressed regarding aspects of its implementation, Section 9 requires the collection of data necessary to evaluate the Act's effectiveness in achieving

its intended objectives and provides a mechanism for proposing any necessary changes. The Department of Health is directed to collect reports, on an annual basis, from health care institutions regarding their experience with the implementation of the Act. While minimizing unnecessary paperwork, this process should provide an empirically sound basis for recognizing and correcting any difficulties, including any confusions regarding medical standards for the declaration of death upon the basis of neurological criteria or regarding the implementation of the exemption provision established by sections 5 and 6 of the Act.

Section 9(B) provides that evaluation of the effectiveness of the Act shall be undertaken jointly by the Department of Health, the State Board of Medical Examiners and the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care. These three bodies are directed to report their conclusions to the New Jersey State Legislature, including recommendations for any changes that may be necessary to better achieve the objectives of the Act. The initial report is to be made to the Legislature within not more than five years from the effective date of the Act. In the event serious difficulties arise, an earlier report would be possible.

The requirement that the initial report be made to the Legislature within five years of the effective date of the Act has no automatic effect upon the continued validity of the Act; the Act does not contain a formal "sunset" provision.

Section 10: SEVERABILITY

If any provision of this Act or its application to any individual or circumstance is held invalid, the invalidity shall not affect other provisions or applications of this Act which can be given effect without the invalid provision or application, and to this end the provisions of this Act are severable.

Comment

Section 10 states that should a particular provision of the Act be held invalid, the other provisions that can be given effect without the invalid provision will continue to have legal force and effect. The invalidity of one provision will not invalidate the entire Declaration of Death Act. Section 10 follows widely used language enacted by a number of state legislatures and approved by the Uniform Law Commissioners in the Uniform Rights of the Terminally Ill Act (1985).

EFFECTIVE DATE: This Act shall take effect 180 days from its enactment.

Comment

Since the Act envisions a regulatory process to establish medical standards, time is allowed for this process to be completed and communicated to the relevant professional communities before the Act becomes fully effective. However, since declarations of death are now taking place in New Jersey pursuant to court decision, it is intended that the Act's immunity provisions be immediately effective with respect to conduct in conformity with the provisions of this Act (including respect for the exemption provision).

Statement of Commissioner Matthews

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June 9, 1988

Alan J. Weisbard, Esq.
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Dear Alan:

At the meeting of the Commission yesterday, I voted in the negative on the Declaration of Death Act and promised to forward to you a concise statement particularizing the reason for my negative vote.

Although I am in agreement with the remainder of the proposed legislation, including the religious and moral exemption, my negative vote was predicated on the fact that it is my feeling that the language of Section 4(B) which requires the State Department of Health jointly with the Board of Examiners to adopt, and from time to time revise, regulations or interpretive guidelines should be limited to the authority to issue regulations alone. Under the Administrative Procedures Act, granting to the named agencies the authority to issue interpretive guidelines would give such guidelines the force of regulatory authority without the public notice and public participation provisions of that act. An interpretive guideline should be just that. Both agencies presently have the capacity to issue such guidelines but those guidelines do not have the force or legal effect of a regulation. I feel that it is imperative that all actions taken by the agencies under this section should be on proper notice to avoid any semblance of suspicion that activity is being shielded from public knowledge. The same criticism, of course would extend to the last sentence of paragraph 4(B).

I would appreciate the particularization being included in the letter of transmittal to the Governor and the legislature.

Very truly yours,

Elmer M. Matthews

EMM/mmc

Statement of Commissioner Murphy

When the Bioethics Commission took final action on its Proposed New Jersey Declaration of Death Act on June 8, 1988, I chose to abstain. I did so in order to signal a specific reservation to what I regard as an otherwise thoroughly admirable and supportable draft. This statement is an attempt to make clear the precise reasons for my reservation.

My concern is based entirely on pragmatic considerations. It in no way reflects any reservations about the basic concepts of exemption based on religious beliefs or moral convictions.

The problem lies in implementation of the proposed statute's provision that physicians "shall make reasonable efforts...to determine whether (declaration of death based on neurological criteria) would violate the personal religious beliefs or moral convictions of (the patient)". In my view, this requirement will prove unworkable in many "real life" clinical situations. My experience as a clinician and educator of clinicians-in-training suggests that, faced with this statutory obligation, many physicians who might otherwise proceed with relative assurance will instead exhibit uncertainty, confusion and hesitancy, with adverse effects for newly bereaved family members.

These implementation provisions are not likely to cause serious problems in major medical centers where there is already extensive experience with brain death determination and specialized personnel for dealing with the families of patients who are or may soon become brain dead. Rather, it is in smaller hospitals and with physicians relatively inexperienced in these matters that I anticipate an exacerbation of an already difficult situation. Both my clinical experience and available research demonstrate that families of newly dead patients need, more basically than anything else, clear information conveyed in understandable terms and in timely fashion. This is already difficult, particularly for health professionals who are themselves fearful of death, of emotionality and of real or imagined malpractice liabilities. I am concerned that such health professionals, faced with the requirement to inquire into "the personal religious beliefs or moral convictions" of patients not known to them, will respond with avoidance, circumlocution and awkwardness of manner. Already distraught family members, I fear, will have an already difficult situation made more difficult, both intellectually and emotionally. Most of all, I am afraid that some bereaved families will get the impression that it is up to them to determine when their loved one is dead.

Again, that is not the point of the religious exemption and in experienced hands, it need not be the impression conveyed to vulnerable family members. However, I anticipate that this provision of the proposed statute will almost inevitably be unworkable because it mistakenly presumes the relevant experience in most "real world" settings.

I would rather trust the advocacy of families and friends of patients known to have had "personal religious beliefs or moral convictions" which would be violated by a declaration of death based on neurological criteria. Though I can imagine the possibility of such beliefs not being asserted on behalf of critically ill patients undergoing diagnosis for brain death, this risk seems fairly remote. In my view, the proposed statute guards against this remote risk by imposition of a requirement that is very likely to add to the burdens of many. This seems disproportionate and unnecessary and, therefore, unwise.

Part Three

Advance Directives For Health Care

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Chapter One
Advance Directives for Health Care: Introduction and Summary

The ability to control and direct decisions about one's own health care is highly valued in our society, and is a fundamental right protected by law. Yet, there are times when serious illness, injury, or simply advancing age, can lead to the loss of a person's capacity to participate effectively in making decisions about his or her health care. As a consequence, decisions must be made on the patient's behalf by others, who may have limited knowledge of the patient's values and of what the patient would choose under the circumstances. Making health care decisions for patients who lack decisionmaking capacity may pose difficult questions, as well as imposing emotional and psychological burdens, for those responsible for the patient's care, such as a family member, physician, friend, or, in some instances, a court-appointed guardian.

As a vehicle for expressing an individual's treatment preferences and health care objectives, and for appointing a trusted family member or friend with the legal authority to make decisions on one's behalf, an advance directive extends patient self-determination and control even after capacity to make one's own health care decisions has been lost or impaired. At the same time, by providing a written statement of a patient's previously expressed wishes, an advance directive can help to reduce uncertainty and to relieve some of the burdens of decisionmaking which may fall on those responsible for the patient's care.

Traditionally, two principal approaches to advance directives have been utilized: durable powers of attorney for health care (also known as "proxy directives") and instruction directives (commonly known as "living wills"). Proxy directives permit individuals to designate a health care representative with legal authority to make health care decisions on their behalf in the event of future loss of decisionmaking capacity. Instruction directives permit individuals to state their health care wishes in writing, thereby providing direction and guidance to those responsible for their health care in the event of future loss of decisionmaking capacity. While 43 states and the District of Columbia now recognize advance directives in their statutory law, New Jersey currently has no legislation providing express legal recognition of advance directives.

The absence of a statute expressly recognizing advance directives has not, however, inhibited the New Jersey Supreme Court from addressing some of the important questions concerning the role of advance directives in health care decisionmaking. Under *In re Conroy*[1] and *In re Peter*,[2] advance directives are legal documents which should generally be respected by families and health care professionals. In *Conroy*, the Court held that "whether or not they are legally binding..., advance directives are relevant evidence of the patient's intent" that provide important guidance to those responsible for the patient's care.[3] In *Peter*, the Court held that under New Jersey's Powers of Attorney Law, *N.J.S.A.* 46:2B, an individual has the right to

authorize the conveyance of authority to another person to make future health care decisions on his or her behalf, *i.e.*, a right to designate a health care representative.[4] Thus, both instruction directives and durable powers of attorney for health care are legal documents under New Jersey law.

At the same time, there remains some uncertainty regarding the legal status of advance directives in New Jersey, as well as the obligations of health care professionals to honor such documents. In the absence of statutory law, there are no established formal requirements for valid execution of advance directives, nor is there a comprehensive framework for the recognition and implementation of advance directives. In addition, many health care professionals appear to be uncertain of the legal status of advance directives, and seem reluctant to rely upon the Court decisions.

The Commission's enabling legislation directs the Commission to examine the use of "advance directives, such as living wills, [and] durable powers of attorney, and [to make] a determination of the approach best suited for New Jersey." In view of this mandate, and recognizing the importance of establishing appropriate guidelines for the execution and implementation of advance directives; of providing clear guidance to both the public and to health care professionals regarding their legal rights and obligations; of establishing a comprehensive framework for a sound decisionmaking process that promotes respect for patients' previously expressed wishes and protects patients' well-being when the capacity to actively participate in one's own health care decisions has been lost or impaired; and cognizant of the important role of statutory law as a vehicle for public and professional education, the Commission made the study of advance directives and development of proposed legislation one of its top priorities. Part Three of the report discusses the Commission's deliberations and recommendations in this area, with particular focus on the Commission's "Proposed New Jersey Advance Directives for Health Care Act."

The Commission's Process

The Commission's recommendations are the result of an extensive public process of study, discussion and debate. The Commission began its deliberations in mid-1986, and scheduled a series of public hearings around the State in 1986 and early 1987 to seek initial input from the public and the professional community. The Commission then directed its staff to conduct an ongoing, comprehensive review of the issues, and to begin to develop a statutory proposal sensitive to the needs of New Jersey's citizenry. The evolving proposal took shape over many months and was considered by the Commission at an extended series of meetings, all of which were open to the public. Several particularly difficult or controversial topics, such as the foregoing of artificially provided fluids and nutrition and the appropriate scope of institutional conscience to decline to participate in the foregoing of life-sustaining measures in certain circumstances, were revisited by the Commission on numerous occasions to assure the fullest consideration of diverse perspectives and to seek principled accommodation of differing points of view. Several related topics, including the respective roles of the Office of the Ombudsman for the Institutionalized Elderly (the "Ombudsman") and of institutional and regional ethics committees in health care decisionmaking in hospitals, nursing homes, and other settings, were

addressed at length by the Commission and by its Task Force on Institutional Ethics Committees.*

In developing its legislative proposal, the Commission and its staff extensively reviewed relevant medical, legal and ethical literature. The Commission's proposal went through an exhaustive process of review in the course of its development. At each stage of its development, Commissioners had the opportunity to express their concerns and to offer suggestions and revisions. Copies of working drafts of the proposal were circulated to professional associations, advocacy groups, experts from the academic community, and individual citizens who expressed interest in the Commission's work. The Commission's proposal has benefited from oral and written commentary submitted by professional associations, health care practitioners, religious and advocacy groups, scholars, and other members of the public, received over the course of more than two years of intensive work on this project. In many instances these suggestions proved to be particularly valuable and were incorporated into the Commission's final recommendations.

By early 1988, midway through the deliberations, a draft of the proposal was completed and the Commission conducted a public hearing to seek further input from the public and professionals. The hearing was held on February 24, 1988, following which an updated draft incorporating many of the suggested changes was prepared and reviewed. In order to assure the fullest opportunity for consideration of the diverse views of New Jersey's citizens and professional communities, a revised proposal, developed over the course of several meetings, was made available to the public and was the subject of another public hearing on November 29, 1988. At this hearing the Commission received extensive testimony; in accordance with Commission policy, all materials received were made a part of the Commission's official record and were forwarded to Commission members.

Following this process of public discussion and debate, the Commission met on December 14, 1988 to review the proposal in its entirety. The Commission discussed the proposal on a section-by-section basis, considering a number of changes suggested by those who had submitted oral or written testimony, as well as by members of the Commission. Those Commissioners present voted nearly unanimously (with three abstentions) to approve the legislative proposal in principle, with conforming changes to be incorporated into a final revised version of the legislative proposal. On December 29, 1988, the Commission again considered the proposal on a section-by-section basis, and gave final approval to its proposed New Jersey Advance Directives for Health Care Act. A total of 17 Commissioners stated their support for the proposal, 2 abstained, and 5 were opposed.** Following this meeting, copies of the legislative proposal were

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* As discussed in other parts of the report, the respective roles of the Ombudsman and of ethics committees in health care decisionmaking are the subject of continuing Commission and Task Force work.

** Twelve Commissioners voting in favor of the proposal submitted a separate statement supporting the characterization of artificially provided fluids and nutrition as medical treatment. Those Commissioners who abstained submitted a statement of "Rationale for Abstaining from Full Support of the Proposal." Those Commissioners who opposed the proposal submitted a "Minority Report." These documents are included in the

transmitted to the Governor, the Senate President, the Speaker of the General Assembly, other legislative leaders, the media and the New Jersey public.

What follows is a brief summary of the principal features of the Commission's recommendations.

The Commission's Recommendations and Legislative Proposal

The Commission's proposed Advance Directives for Health Care Act provides a carefully crafted and comprehensive approach to "living wills" and "medical durable powers of attorney" which would allow competent adults to specify in writing their treatment preferences and to entrust a family member or friend with legal authority to carry out their wishes and to make health care decisions on their behalf in the event of subsequent decisionmaking incapacity. The Commission's proposal goes beyond existing legislation in other states in a number of important respects, including its applicability to a broad range of health care decisions; its commitment to a shared decisionmaking process among patients, families, health care representatives, physicians and other health care professionals; its recognition that patients should be permitted to request the continued provision of life-sustaining measures as well as the foregoing of some forms of life-sustaining measures; its respect for the individual conscience of health care professionals; and its readiness to confront and address the appropriate role of societal interests and concerns regarding the foregoing of life-sustaining measures. In the Commission's view, the proposed legislation sets a new standard in this difficult area, enhancing New Jersey's reputation as a national leader in addressing legal and ethical dilemmas in the delivery of health care.

The Commission's conclusions and recommendations are summarized below.*

1) This State recognizes in its law and public policy the fundamental right of competent adults, in collaboration with their health care providers, to control decisions about their own health care. This right should not be lost in the event a patient loses decisionmaking capacity and is no longer able to actively participate in making his or her own health care decisions.

2) The State of New Jersey should recognize by statute the right of competent adults to plan ahead for health care decisions through the execution of advance directives.

Appendix to this Part.

* It should be noted that the Commission's proposed legislation is intended to apply to decisionmaking for incompetent patients who have previously executed an advance directive. The Commission has not yet fully considered a number of issues relating to decisionmaking for incompetent patients without advance directives, including the circumstances in which life-sustaining measures may be withheld or withdrawn from such patients and the respective roles of family members, physicians, ethics committees and state agencies in making such decisions. As discussed in Part Six, the Commission has committed itself to giving priority to these issues in the next phase of its work. Pending the completion of that process, the Commission does not intend that its proposed Advance Directives for Health Care Act be construed to limit any patient rights conferred by existing law, and believes that existing law should continue to govern in circumstances not governed by this proposed legislation.

- The legislative proposal would provide that a competent adult (a "declarant") has the right to designate another person (a "health care representative") to make health care decisions on his or her behalf in the event of future decisionmaking incapacity; to state in writing his or her instructions and directions for health care in the event of future decisionmaking incapacity; or both. The Commission's recommendations are designed to encourage execution of an "integrated" advance directive, *i.e.*, one which designates a health care representative and provides that person with written instructions and direction.

- The legislative proposal prescribes formalities for the execution of advance directives, as well as for the re-affirmation, modification or revocation of an advance directive.

- The Commission recommends that individuals explicitly state in an advance directive their wishes regarding the foregoing of artificially provided fluids and nutrition.

- Health care institutions should provide appropriate informational materials concerning advance directives to all interested patients, families and health care representatives, and should assist patients interested in discussing and executing an advance directive.

- The Commission has proposed several standard forms for advance directives that may, but need not, be followed.

3) The Commission believes that the ethical norm of informed consent as shared decisionmaking best promotes the twin values of respect for patient self-determination and promotion of patient well-being in health care decisionmaking. The shared decisionmaking model views competent patients and health care professionals, and where appropriate, family members and health care representatives, as collaborative moral agents with complementary and interactive roles in the decisionmaking process, working together to establish greater mutual understanding and an effective basis for active patient participation in the decisionmaking process.

- When the patient's decisionmaking capacity is lost or impaired, the goals and process of shared decisionmaking can be approximated through the designation of a health care representative, charged with the responsibility to stand in the place of the patient and to implement the patient's expressed wishes and best interests.

- The legislative proposal is designed to foster a shared decisionmaking process among the health care representative, physician, and (where capable) the patient.

4) The legislative proposal would provide that an advance directive becomes operative when (a) it is transmitted to the attending physician or the health care institution; and (b) it is determined that the patient lacks decisionmaking capacity.

- Health care institutions should adopt policies designed to determine whether a patient has executed an advance directive.

5) The Commission recommends a decision-specific approach to the question of decisionmaking capacity. A determination that a patient lacks decisionmaking capacity should be based upon an evaluation of the patient's ability to understand and appreciate information regarding the nature and consequences of a particular health care decision, including the benefits and risks of the proposed health care and its alternatives, and to reach an informed decision.

- Patients should not be assumed to lack capacity on grounds of age or disability, nor should it be assumed that lack of capacity to make one health care decision means the patient lacks capacity to make other health care decisions.

- The Commission's legislative proposal recommends an informal (non-judicial) process for assessing a patient's decisionmaking capacity which places primary responsibility for such determinations with physicians.

6) Once operative, an advance directive designating a health care representative should confer upon that person the legal authority to make health care decisions on the patient's behalf, in accordance with the terms of the advance directive. This authority should be respected by physicians, health care professionals and health care institutions.

- The health care representative should exercise the patient's right to give informed consent to or refusal of health care.

- In the exercise of this authority, the health care representative's primary responsibility should be to implement the patient's expressed wishes.

- The health care representative should have the authority to exercise informed discretion and judgment, and to make health care decisions in the patient's best interests.

7) The health care representative and attending physician (and where appropriate, family and other members of the health care team) should seek to enhance patient capacity and to actively involve the patient with impaired capacity in the decisionmaking process, to the extent it is reasonable to do so. The patient's expressed wishes should be taken into account in the decisionmaking process.

- A patient's contemporaneously expressed wish that medically appropriate life-sustaining measures be provided should be respected, even if contrary to the decision of the health care representative or the terms of the patient's instruction directive.

8) In the absence of a designated health care representative, an instruction directive, once operative, should be respected by those responsible for the patient's care, and should be followed in accordance with its specific terms.

9) Health care institutions should establish an institutional mechanism for dispute resolution. In case of disagreement concerning the patient's decisionmaking capacity, the appropriate implementation of an advance directive, or other matters, recourse to this local process should be sought in the first instance.

10) The fundamental right to control decisions about one's own health care includes the right to forego life-sustaining measures. This right is not absolute, and is subject to certain interests of society, including the preservation of life, the prevention of suicide, the protection of innocent third parties, and safeguarding the integrity of the health care professions. Society also has an interest in ensuring the soundness of health care decisionmaking, including both protecting vulnerable patients from potential abuse or neglect and facilitating the exercise of informed and voluntary patient choice.

- The Commission's legislative proposal takes a situation-specific approach to decisions to forego life-sustaining measures, in accordance with the patient's advance directive, which identifies the circumstances in which such decisions should be authorized.

- The Commission believes that the foregoing of artificially provided fluids and nutrition for patients who lack decisionmaking capacity or are otherwise vulnerable raises important and distinctive problems for social policy that justify protective measures, beyond those applicable to the foregoing of other life-sustaining measures. Therefore, decisions to forego artificially provided fluids and nutrition are addressed separately from decisions to forego life-sustaining treatments.

- The Commission rejects on both legal and moral grounds the practice of active euthanasia, as by deliberate lethal injection.

11) The Commission believes that honoring a patient's wishes, as expressed in an advance directive, that life-sustaining treatment be withheld or withdrawn should be authorized in the following circumstances:

- When the treatment is experimental, likely to be ineffective or futile in prolonging life, or likely merely to prolong an imminent dying process.

- When the patient is permanently unconscious.
- When the patient is in a terminal condition.
- When the above circumstances are not present, but the patient has a serious and irreversible illness or condition, and the likely risks and burdens of the treatment may reasonably be judged to outweigh the likely benefits, and imposition of the treatment on an unwilling patient would be inhumane. In this latter circumstance a local or regional reviewing body (such as an ethics committee), or a public agency (such as the Ombudsman), should be consulted prior to implementing the decision.

12) The Commission believes that honoring a patient's wishes, as explicitly stated in an advance directive, that artificially provided fluids and nutrition be withheld or withdrawn should be authorized in the following circumstances:

- When the artificial provision of fluids and nutrition is likely to be ineffective or futile in prolonging life, or is likely merely to prolong an imminent dying process.
- When the patient is permanently unconscious.
- When the patient is in a terminal condition, and the likely risks and burdens of the least burdensome treatment modality likely to be effective may reasonably be judged to outweigh its likely benefits, and imposition of the intervention on an unwilling patient would be inhumane. In this latter circumstance, a local or regional reviewing body (such as an ethics committee), or a public agency (such as the Ombudsman), should be consulted prior to implementing the decision.

13) The Commission believes that public policy should honor the personal and professional integrity of health care professionals while at the same time assuring that neither the rights of patients nor standards of professional care are compromised.

- Physicians, nurses, and other health care professionals should have the right to decline to participate in the withholding or withdrawal of life-sustaining measures on the basis of sincerely held personal or professional convictions. In the exercise of this right, health care professionals should facilitate appropriate, respectful and timely transfers of care, and should assure that the patient is not abandoned.

14) The Commission also believes that private religiously-affiliated health care institutions should have the right to adopt institutional policies and practices defining circumstances in which they will decline to participate in the withholding or withdrawal of life-

sustaining measures.

- Such policies should be stated in writing and communicated to patients, families and health care representatives in a timely fashion. When the patient's wishes cannot be accommodated, the health care institution should effect an appropriate, respectful and timely transfer of care to another health care institution appropriate to the patient's needs, and should assure that the patient is not abandoned.

15) Physicians, nurses and other health care professionals, and health care institutions, acting in good faith and in accordance with the requirements of the legislative proposal, and any rules and regulations established pursuant to the proposal, to carry out the terms of an advance directive, should be immune from legal liability and from discipline for unprofessional conduct. Health care representatives acting in good faith and in accordance with the requirements of the legislative proposal to carry out the terms of an advance directive should be immune from legal liability.

- Willful contravention of the requirements of the legislative proposal should be subject to legal liability, regulatory action, or proceedings for professional misconduct.

In summary, in order to assure respect for patients' previously expressed wishes when the capacity to participate actively in decisionmaking has been lost or impaired; to facilitate and encourage a sound decisionmaking process in which patients, health care representatives, families, physicians, and other health care professionals are active participants; to properly consider patients' interests both in self-determination and in well-being; and to provide necessary and appropriate safeguards concerning the termination of life-sustaining treatment for incompetent patients as the law and public policy of this State, the Commission recommends the New Jersey Advance Directives for Health Care Act.

Current Status of Legislation

The New Jersey Advance Directives for Health Care Act was introduced in the Senate (S-3320), sponsored by Commission member Senator Gabriel Ambrosio and by Senators Matthew Feldman and Paul Contillo, on February 9, 1989. The proposal was introduced in the General Assembly (A-4536), sponsored by Assemblywoman Elizabeth Randall, on May 15, 1989, and as A-4671, sponsored by former Commission member Assemblyman David Schwartz and Assemblyman Gerard Naples, on June 15, 1989.

The Senate Judiciary Committee held public hearings on S-3320 on May 8 and June 8, 1989, and reported the bill out of Committee, as amended, on June 22, 1989. S-3320 passed the Senate on August 14, 1989. Although received by the General Assembly in August 1989 and referred to the Assembly Judiciary Committee, no hearings were held in the Assembly on the New Jersey Advance Directives for Health Care Act during the 1989 session.

The bill was pre-filed in the Senate for introduction in the 1990 session as S-1211, sponsored by Senator Gabriel Ambrosio. Reported out of the Senate Judiciary Committee on January 25, 1990, S-1211 passed the New Jersey Senate on March 29, 1990. The companion bill, A-2514, has been introduced by Assemblywoman Elizabeth Randall and Assemblyman Gerard Naples.

Overview of Part Three

As discussed above, the Commission's work concerning the role of advance directives in health care decisionmaking has addressed a wide range of issues and the Commission's recommendations have been developed over a period of many months. The next Chapter of this Part sets forth the general legal context which has informed the Commission's deliberations. This discussion is followed in subsequent chapters by analysis of the underlying principles and basic approach of the Commission's conclusions and recommendations, and by a section-by-section commentary and analysis of the proposed legislation. The Proposed New Jersey Advance Directives for Health Care Act, along with three sample forms for advance directives, is contained in the Appendix to Part Three. The Appendix also contains the Commission's policy statements concerning do not resuscitate orders and decisions to forego artificially provided fluids and nutrition, adopted in December 1988, several separate statements submitted by Commissioners, and the Minority Report submitted by five members of the Commission.

Notes

1. 98 N.J. 321, 486 A.2d 1209 (1985).
2. 108 N.J. 365, 529 A.2d 419 (1987).
3. 98 N.J. at 361 n.5, 486 A.2d at 1229 n.5.
4. 108 N.J. at 378-79, 529 A.2d at 426.

Chapter Two
Advance Directives: The General Legal Context

Whether, and in what circumstances, a patient may refuse life-sustaining medical treatment are issues that first came to national attention in the New Jersey Supreme Court's seminal opinion in *In re Quinlan*[1] (1976). Today, the problems associated with terminating life-sustaining treatment for seriously ill patients, especially incompetent patients, confront families and health care professionals regularly, and have become a central concern in the care of the dying. Advances in medical science and technology make it possible to prolong life in circumstances in which many would prefer to refuse treatment and choose a less burdensome dying process. These advances have continued to outpace development of legal rules and guidelines to govern treatment decisions at the end of life. Since *Quinlan*, numerous courts across the country have been called upon to address these difficult questions and to establish a much-needed legal context for decisions to forego life-sustaining treatment.

The New Jersey Supreme Court has had occasion to address these issues in four opinions subsequent to *Quinlan*. The Court's decision in *Conroy*[2] (1985) is also widely acknowledged as a landmark opinion. The *Farrell*[3], *Peter*[4] and *Jobes*[5] trilogy (1987) builds upon the earlier *Quinlan* and *Conroy* cases, and continues New Jersey's reputation as a national leader in this area. These decisions along with several lower court opinions, give New Jersey the richest body of case law in the nation addressing the right to refuse life-sustaining treatment.

Since New Jersey currently has no statutory law in this area, the legal context for decisions to forego life-sustaining treatment is found in the case law, primarily the five decisions of the New Jersey Supreme Court. In its opinions the Court has shown a strong commitment to patients' rights to forego life-sustaining treatment, and has recognized that in the absence of legislative guidance, the Court has a responsibility to establish guidelines and procedures to assist patients, families and health care professionals in making these difficult and complex decisions. The Court has established both substantive standards and procedures to govern how and by whom these decisions may be made. This chapter of the report discusses the existing legal context for decisions to forego life-sustaining treatment. The central focus of the discussion is the approach taken by the New Jersey Supreme Court and the standards and procedures set forth in its opinions to govern decisionmaking in this area.

The Right to Refuse Life-Sustaining Treatment

A patient's right to refuse life-sustaining treatment is well-established under New Jersey law. This right is grounded in both the common law right of self-determination and the constitutional right of privacy. The common law has long recognized the individual's right to control one's own body and to be free from nonconsensual bodily invasions. In matters of medical treatment, the right to make choices about one's own health care is protected by the

doctrine of informed consent. In essence, the law of informed consent requires that physicians obtain consent from patients prior to performing a treatment or procedure, and is designed to ensure that patients receive information about their medical condition and the risks, benefits and burdens of treatment options necessary to reach an informed decision.* The right to refuse treatment is the logical corollary of the right to consent to treatment. Thus, the common law right of self-determination encompasses the right to accept or to refuse medical treatment, including life-sustaining treatment.[6]

In *Quinlan*, the Court held that a patient has a fundamental constitutional right to refuse life-sustaining treatment, grounded in the right of privacy under the federal and state constitutions. Finding the legal underpinnings for the right of privacy in the United States Supreme Court's decisions in the area of procreation,[7] the *Quinlan* Court held that "this right is broad enough to encompass a patient's decision to decline medical treatment under certain circumstances."[8] The Court also held that the right of privacy is protected by the New Jersey state constitution.[9] In *Conroy*, the Court rested its decision regarding the right to refuse life-sustaining treatment on the common law right of self-determination, but did not reject the constitutional basis of the right.[10] The recent decision in *Farrell* recognizes both the common law and constitutional bases for the right to refuse life-sustaining treatment, and re-affirms the constitutional right of privacy as a fundamental right to be protected against unwanted interventions and invasions of bodily integrity.[11]

While courts in several other jurisdictions have also embraced the constitutional right of privacy,[12] often courts elsewhere have preferred not to address the constitutional question and have recognized the common law basis of the right to refuse treatment.[13] Whether grounded in common law or constitutional law, courts uniformly have recognized a patient's right to refuse life-sustaining treatment as a fundamental tenet of respect for patient autonomy and self-determination.**

The majority of refusal-of-treatment cases have involved incompetent patients, raising the issue whether incompetent patients have the same right to refuse life-sustaining treatment as competent patients. The New Jersey Supreme Court, like other courts across the country,[14] has consistently held that a patient does not lose his or her right to refuse treatment in the event of incompetency and that this right may be exercised by another on the patient's behalf. This issue was first addressed in *Quinlan*, where the Court held that Karen Quinlan, a young woman in a persistent vegetative state, had the right to refuse the respirator which artificially sustained her life, and appointed her father as the legal guardian with authority to exercise this right on his

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* The New Jersey law of informed consent is discussed in the next chapter, in the context of the shared decisionmaking model of informed consent.

** The Commission does not view its role as that of an arbiter of constitutional law, and has not sought to take a position regarding the scope of the constitutional right of privacy as applied to medical treatment decisions. The Commission recognizes that pursuant to the decisions of the New Jersey Supreme Court the right to refuse life-sustaining treatment is constitutionally protected, and has sought to foster the exercise of these rights within the framework of a sound decisionmaking process.

daughter's behalf.[15] In reaching this conclusion, the Court stated that if a decision to forego life-sustaining treatment is

> a valuable incident of [Karen's] right of privacy, as we believe it to be, then it should not be discarded solely on the basis that her condition prevents her conscious exercise of the choice. The only practical way to prevent destruction of the right is to permit the guardian and family of Karen to render their best judgment, subject to the qualifications hereinafter stated, as to whether she would exercise it in these circumstances.[16]

As summarized in the recent *Peter* decision, "(a)ll patients, competent or incompetent, with some limited cognitive ability or in a persistent vegetative state, terminally ill or not terminally ill, are entitled to choose whether or not they want life-sustaining medical treatment."[17]

While the legal underpinnings of the patient's right to refuse life-sustaining treatment are not affected by loss of competency, the conditions for the exercise of this right differ substantially when the patient is incompetent. The procedures to be followed in making the decision on behalf of an incompetent patient, as well as the conditions in which termination of treatment has been authorized, are discussed below.

The Nature of Life-Sustaining Treatments

Recent cases have raised the issue whether the patient's right to refuse life-sustaining treatment is dependent upon or limited by the nature of the medical treatment in question. Of particular concern has been whether artificially provided fluids and nutrition constitutes medical treatment which a patient is entitled to refuse on the same basis as other forms of treatment, such as a respirator. This issue was first addressed by the New Jersey Supreme Court in *Conroy*, which involved a request to withdraw a nasogastric feeding tube from an 84 year old woman with serious and irreversible physical and mental impairments and a life expectancy of one year or less. In *Conroy*, the Court found that "artificial feedings such as nasogastric tubes, gastrostomies, and intravenous infusions...are medical procedures." While noting the symbolic meaning of fluids and nutrition, the Court held that analytically, artificially provided fluids and nutrition is equivalent to artificial breathing by means of a respirator. "Both prolong life through artificial means when the body is no longer able to perform a vital bodily function on its own."[18] Therefore, the Court held that "(a) competent patient has the right to decline any medical treatment, including artificial feeding, and should retain that right when and if he becomes incompetent."[19] This position was re-affirmed in *Peter*[20] and in *Jobes*.[21] Courts in other jurisdictions that have addressed this issue have reached the same conclusion, and have made no distinction between artificially provided fluids and nutrition and other forms of life-sustaining treatment.[22]

Countervailing Societal Interests

Courts across the country, including New Jersey, have recognized that the right to refuse life-sustaining treatment is not absolute. The patient's common law and constitutional rights must be balanced against potentially countervailing state interests. Courts have uniformly identified four countervailing state (societal) interests which may limit the patient's right to refuse life-sustaining treatment: preserving life, preventing suicide, safeguarding the integrity

of the medical profession, and protecting innocent third parties.[23] While characterized by the courts as "state interests", since these considerations generally do not arise from specific state regulations or statutes, they are perhaps more properly viewed as "countervailing considerations to the exercise of the right of self-determination", based upon societal concerns and values.[24]

The most significant of these societal interests is the preservation of life, understood to embrace "an interest in preserving the life of the particular patient, and an interest in preserving the sanctity of all life."[25] In general, the societal interest in preserving life weakens and the individual's right to choose grows as the degree of bodily invasion from the proposed medical intervention(s) increases and the patient's prognosis dims.[26] Although identified as a distinct concern, the societal interest in preventing suicide is "motivated by, if not encompassed within", the societal interest in preserving life.[27] Judicial decisions in New Jersey and other states have consistently held that a patient's refusal of life-sustaining treatment is not properly viewed as direct and purposeful self-destruction motivated by an intent to die.[28] Where the termination of life-sustaining treatment allows the underlying disease or condition to take its course, the patient's death is primarily a result of the underlying disease or condition, and not of a self-inflicted injury.[29] Furthermore, respecting the patient's refusal of life-sustaining treatment respects the patient's intent, not to die, but to refuse medical intervention and to choose a personally preferred dying process.[30*]

With respect to society's interest in maintaining the integrity of the medical profession, courts have been primarily concerned with whether the patient's refusal of life-sustaining treatment is consonant with existing norms of medical ethics. In its recent opinions, the New Jersey Supreme Court has looked to well-established medical authorities for guidance, including official policy statements from the American Medical Association, the New Jersey State Board of Medical Examiners, and others. Medical authorities strongly support the physician's professional obligation to respect a patient's right to self-determination, including refusal of life-sustaining treatment. The medical profession also acknowledges that when the patient is incompetent, this right may be exercised on the patient's behalf by a family member, health care representative or legally appointed guardian.[31] Thus, while the Court has recognized that respect for patient rights does not compel health care professionals to violate generally accepted professional standards,[32] the patient's right to refuse life-sustaining treatment generally takes precedence over countervailing concerns regarding the integrity of health care professionals.[33 **]

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* In the early case of *John F. Kennedy Memorial Hosp. v. Heston*, 58 N.J. 576, 279 A.2d 670 (1971), the Court authorized a life-saving blood transfusion for a young accident victim who was a Jehovah's Witness. The Court based its conclusion, in part, on the view that there was no distinction between self-destruction and self-determination. Therefore, the refusal of life-saving treatment was tantamount to (attempted) suicide, and the State's interest in the preservation of life was held to warrant the transfusion. *Heston* was expressly overruled on this point in *Conroy*, 98 N.J. at 351, 486 A.2d at 1224. *See* Norman L. Cantor, "*Conroy*, Best Interests, and The Handling of Dying Patients", *Rutgers Law Review* 37 (1985): 550-51.

** As discussed in the next chapter, one response to a sincere conflict between patient wishes and a health care professional's personal and professional conscience is to seek an appropriate transfer of care to another health care professional or institution prepared to honor the patient's right to refuse treatment.

The fourth countervailing consideration consistently cited by courts is the societal interest in protecting innocent third parties from harm. Although not a significant factor in the majority of treatment refusal cases, in some instances this interest has been held to justify requiring competent adults to undergo medical procedures. For example, competent adults have been compelled to accept medical treatment to protect the public health,[34] to protect the patient's minor children against emotional and financial abandonment,[35] or to protect the life of an unborn child.[36] In the latter two circumstances, the interest in protecting minor children is most compelling where the parent's prospect for recovery is good and the parent's death would put the child's security or life at risk. Accordingly, in *Anderson* (1964) the New Jersey Supreme Court found that the interests of an unborn infant were sufficiently compelling to order a life-saving blood transfusion for a pregnant woman.[37] In contrast, these factors were not present in *Farrell*, where the Court held that a 37 year old competent woman who suffered from amyotrophic lateral sclerosis (ALS, also known as Lou Gehrig's Disease) should have been allowed to refuse a respirator, noting that her two teenage sons supported her decision, would not be threatened by her death and would be well cared for by her husband.[38] Thus, with the exception of those cases in which a parent's preventable death posed serious risk of harm to the child, the Court has consistently found that the patient's right to refuse life-sustaining treatment prevails over these four countervailing societal interests.

Determining Competence*

The patient's competence to make his or her own health care decisions is the touchstone for determining who has authority to make a decision to forego life-sustaining treatment, as well as the standards to be applied and the procedures to be followed in making such decisions. Generally, adults are presumed competent.[39] In *Farrell*, the Court prescribed a non-judicial process for determining a patient's competence intended to bolster this presumption and to avoid the need for court determinations of competency. At the same time the procedure is intended to protect against hasty decisions made under the emotional strain of a sudden illness or major catastrophe.[40]

The *Farrell* procedure requires that the attending physician's assessment of a patient's competence be confirmed by two independent (non-attending) physicians who have examined the patient. In the words of the Court, "(a) competent patient has a clear understanding of the nature of his or her illness and prognosis, and of the risks and benefits of the proposed treatment, and has the capacity to reason and make judgments about that information."[41] In addition, the non-attending physicians are to confirm that the patient has been provided with the information necessary to understand what is involved in the decision and to make an informed refusal, *i.e.*, that the patient has been fully informed about his or her prognosis, the treatment options, and the

* This section of the report uses the terms "competent" and incompetent", in consonance with the language of the Court. Other parts of the report use the terms "decisionmaking capacity" and "lack of decisionmaking capacity" adopted by the Commission.

risks involved, including the likely outcome if life-sustaining treatment is discontinued.[42*] It should be noted that the Court has not established the standard to be applied in assessing the patient's competence, in other words, what level of decisionmaking abilities a patient must possess to have sufficient understanding of relevant information and to reason and make judgments about that information. The standard to be applied is left to the exercise of professional judgment under the particular clinical circumstances.

Although the procedure established in *Farrell* was developed to protect a patient who was at home, this procedure also applies to patients in hospitals and nursing homes.[43]

Competent Patients

Under the law of New Jersey and other states, a competent patient's right to refuse life-sustaining treatment generally outweighs any countervailing societal interest. As stated by the Court in *Conroy*, the state's interest in preserving life does not outweigh the patient's interest in self-determination where "the life the state is seeking to protect...is the life of the same person who has competently decided to forego the medical intervention."[44] In such cases, "the state's indirect and abstract interest in preserving the life of the competent patient generally gives way to the patient's much stronger personal interest in directing the course of his own life."[45] The well-recognized principle of respect for patient self-determination, first articulated in cases involving incompetent patients, was recently applied in *Farrell*, which involved the right of a competent, terminally ill patient with advanced ALS to have a life-sustaining respirator withdrawn. Re-affirming its earlier opinions, the Court held that "a competent patient like Kathleen Farrell can choose to have her life-supporting treatment discontinued."[46]

With the exception of those rare cases in which the protection of innocent third parties outweighs respect for the patient's wishes, the competent patient's interest in controlling decisions about his or her own medical care, in accordance with personal values and objectives, generally prevails over countervailing considerations. Under New Jersey law, the competent patient's right to refuse life-sustaining treatment in accordance with his or her own subjective values and objectives is not expressly limited by the patient's medical condition or prognosis. In other words, the Court has not found there to be specific medical circumstances in which the patient's interests would not prevail over countervailing societal interests. Nonetheless, it is important to recognize that most cases nationally have involved incompetent patients, and in several of the cases involving competent patients, the patient has been terminally ill.[47] While some courts have upheld a competent patient's right to refuse life-sustaining treatment when not terminally ill,[48] a judicial consensus on this issue has not yet clearly emerged.[49] (There also is no clear judicial consensus on the meaning of the term "terminal illness.") While recognizing a broad right of self-determination for the competent patient, the New Jersey Supreme Court has not had occasion to address the non-terminally ill competent patient's refusal of life-sustaining

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* Approximately one year after its decision in *Farrell*, the Court modified the New Jersey law of informed consent in *Largey v. Rothman*, 110 N.J. 204, 540 A.2d 504 (1988). *Largey*, discussed in the next chapter, overruled the Court's adoption of a "professional standard" of disclosure twenty years earlier in favor of a "reasonable patient standard."

treatment.*

Incompetent Patients

Decisions to forego life-sustaining treatment for incompetent patients present several difficult issues, including the standard to be applied in terminating treatment, the identity of the decisionmaker, and the procedures to be followed in making such decisions. The New Jersey Supreme Court has sought to protect the relevant interests by crafting a decisionmaking process intended to facilitate respect for patient rights without the need for judicial intervention, while at the same time protecting patients from potential abuse or neglect. The importance of procedural safeguards is especially true of the Court's approach to decisionmaking for incompetent patients. In establishing appropriate procedures to be followed in making decisions to forego life-sustaining treatment, the Court has recognized that society has an interest in ensuring a sound process for health care decisionmaking which fosters the exercise of the patient's right to decide while safeguarding societal concerns, in particular the preservation of life. (Since this societal interest does not purport to limit the patient's right to decide, it is not properly characterized as countervailing, but it is nonetheless a central theme of the Court's approach.)

In addition, a continuing concern, originally expressed in *Quinlan*, has been the adverse effect that perceived risk of legal liability has on physicians' willingness to participate in the withholding or withdrawal of life-sustaining treatment. The perceived risk of legal entanglements has contributed to the practice of "defensive medicine", and at times has led to the institution of legal proceedings to seek a declaration of rights and responsibilities and legal protection from the court prior to making a decision to forego life-sustaining treatment. The Court's approach has generally been to respond to professional concerns about legal consequences, and to seek to minimize the perceived need to pursue judicial involvement, by according immunity from civil and criminal liability for those who follow in good faith the guidelines established by the Court.

The termination-of-treatment cases presented to the Court thus far have involved patients who are either terminally ill (defined in *Conroy* to mean a life-expectancy of approximately one year or less[50]) or in a persistent vegetative state (PVS). The New Jersey Supreme Court, like numerous courts elsewhere which have addressed these issues, has expressly recognized the incompetent patient's right to refuse life-sustaining treatment when terminally ill or in a persistent vegetative state.[51] While the incompetent patient's right to refuse life-sustaining

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* In *In re Quackenbush*, 156 N.J. Super. 282, 383 A.2d 785 (1978), the court held that a 72 year old competent patient who suffered from severe gangrene in both legs had the right to refuse a life-saving amputation. While the probability of recovery from the proposed surgery (amputation of both legs above the knee and possibly amputation of both legs entirely) was good, and the risks of surgery limited, without the operation the patient's prognosis was that he would die within about three weeks. Finding that the surgery would involve extensive bodily invasion, the court upheld "[the patient's] right of privacy to decide his own future regardless of the absence of a dim prognosis." *Id.* at 290, 383 A.2d at 789.

treatment has not been expressly limited to these two medical circumstances, the Court has not had specific occasion to address the scope of this right in other medical circumstances.[52] As a consequence, the Court has established both substantive and procedural guidelines for decisionmaking with these two types of patients primarily in mind. The trilogy makes clear, however, that the Court's decisions are grounded in certain fundamental principles and concerns which govern how, and by whom, decisions to forego life-sustaining treatment should be made.

Substantive Standards

Like numerous courts in other states, the New Jersey Supreme Court has recognized that a decision to forego life-sustaining treatment for an incompetent patient may be made in accordance with the patient's wishes, as expressed at a time when the patient was competent,[53] or, in an appropriate case, in accordance with the patient's best interests.[54] The *Quinlan* Court adopted the "substituted judgment" standard to guide *how* decisions about life-sustaining treatment should be made, and has consistently followed this approach to decisionmaking for PVS patients. In *Conroy* the Court held that life-sustaining treatment may be withheld or withdrawn from an incompetent patient pursuant to the "subjective", "limited-objective", or "objective" tests, sometimes referred to as the "*Conroy* tests".[55] These two "objective" tests involve analysis of the patient's best interests, and are sometimes referred to as comprising two strands of a "best interests" standard.[56] In analyzing these substantive criteria it is important to look beyond these terms to the underlying concepts.

Though stated as separate tests, the substantive standards for decisionmaking are best viewed as involving "a continuum of subjective and objective information about the patient that will support a reliable decision."[57] Consistent with a commitment to self-determination, first and foremost, "the goal of decisionmaking for incompetent patients should be to determine and effectuate, insofar as possible, the decision that the patient would have made if competent."[58] That is, the decision should be based upon the patient's own, subjective values and expressed wishes. The term "substituted judgment" usually means that the surrogate decisionmaker effectuates, to the extent possible, the formerly competent patient's wishes. In its purest form, the substituted judgment standard is the *Conroy* subjective test by another name. This subjective standard applies to decisionmaking for all patients, whether competent or incompetent, regardless of the patient's medical condition or life-expectancy.[59] By looking to the patient's previously expressed wishes to govern the decision, the substituted judgment and subjective standards respect patient self-determination at a time of subsequent incompetency.

In seeking to make a substituted judgment on the patient's behalf, those responsible for the patient's care should look to the prior statements and expressed wishes of the formerly competent patient. All available evidence of the patient's wishes should be considered, including, for example, prior oral or written statements regarding life-sustaining treatments, the patient's philosophical values and religious beliefs, and the patient's prior consistent pattern of conduct regarding medical care.[60]

Often the best evidence of the patient's wishes will be an advance directive.[61] As discussed earlier, though not formally recognized as "legally binding", under existing New

Jersey law instruction directives are legal documents that generally should be honored by those responsible for the patient's care. As stated in *Conroy*, "(w)hether or not they are legally binding...advance directives are relevant evidence of the patient's intent."[62] The designation of a health care representative, pursuant to the New Jersey Powers of Attorney Law, conveys to that person legal authority to make health care decisions on the patient's behalf.[63] Where an advance directive, or other information about the patient's previously expressed wishes, such as a clear oral statement, provides clear and convincing evidence that the patient would refuse life-sustaining treatment under the present circumstances, the patient's previously expressed wishes should be honored, in accordance with the procedures for decisionmaking set forth in the case law.

The reliability (or probative value) of the patient's prior expressions will necessarily vary in particular cases, depending upon such factors as the remoteness in time, consistency, specificity and thoughtfulness of prior statements and actions.[64] A patient's previously expressed wishes will not always demonstrate informed foresight regarding future medical conditions, nor provide specific direction with respect to the foregoing of life-sustaining treatment in the current medical circumstances. In some cases information about the patient's statements, while competent, will provide "trustworthy" but not "clear" evidence of the patient's wishes. Under *Conroy's* limited-objective test, a decision to forego life-sustaining treatment may be made where trustworthy evidence of the patient's wishes, in conjunction with evaluation of the patient's best interests, supports such a decision. While *Conroy* involved a terminally ill patient, in cases involving PVS patients, the Court has taken essentially the same approach to the continuum of subjective and objective information relevant to a decision to forego life-sustaining treatment under the rubric of substituted judgment. For example, in *Jobes* the Court held that where there was trustworthy, but not clear, evidence of the patient's wishes, family members could exercise substituted judgment to determine whether a feeding tube should be withdrawn on the patient's behalf.[65] And in *Peter*, the Court stated that the decisionmakers "need only "render their best judgment" as to what medical decision the patient would want them to make."[66] However, as discussed below, the Court's approach to objective factors relevant to the patient's best interests differs significantly depending upon whether the patient is terminally ill (or more generally, sentient) or PVS. With respect to "Conroy-type" patients, the *Conroy* objective tests apply, while with respect to PVS patients the *Quinlan* guidelines govern.*

The objective tests set forth in *Conroy* are designed for patients who, like Claire Conroy, are awake and conscious and have at a minimum some limited capacity for interaction with their environment, though mental capacities may be severely impaired.[67] Under the limited-objective test, life-sustaining treatment may be withheld or withdrawn "when there is some trustworthy evidence that the patient would have refused the treatment, and the decision-maker is satisfied that it is clear that the burdens of the patient's continued life with the treatment outweigh the benefits of that life for him".[68] In balancing the burdens and benefits of continued treatment, if the net burdens of prolonged life for the patient, measured in terms of the suffering of

* The substituted judgment approach is discussed further below in connection with the role of family members in decisionmaking.

unavoidable pain, "markedly outweigh any physical pleasure, emotional enjoyment, or intellectual satisfaction that the patient may still be able to derive from life", then life-sustaining treatment may be withheld or withdrawn.[69]

The pure-objective test recognizes that as evidence of the patient's intent weakens and becomes less trustworthy, the basis for decisionmaking (and for the exercise of substituted judgment) shades into a best interests (objective) analysis. Where there is little or no indication of the patient's treatment preferences while competent, to speak of patient self-determination as a basis for decisionmaking is not meaningful. In such cases, *Conroy* authorizes application of the pure-objective test. Like the limited-objective test, the pure-objective test involves a balancing of the net burdens and benefits for the patient of continued treatment. As formulated by the Court, under the pure-objective test "the net burdens of the patient's life with the treatment should clearly and markedly outweigh the benefits that the patient derives from life. Further, the recurring, unavoidable and severe pain of the patient's life with the treatment should be such that the effect of administering life-sustaining treatment would be inhumane."[70]

What primarily distinguishes the limited-objective from the pure-objective test is the presence in the former case of some trustworthy indication of the patient's wishes. Each objective test shares the same analysis of objective elements relevant to the patient's best interests and requires a balancing of the burdens and benefits to the patient of continued provision of life-sustaining treatment and prolonged life. Where a decision to forego life-sustaining treatment is not supported by some trustworthy evidence of the patient's wishes and the pure-objective test is applied, stronger evidence that such a decision is in the patient's best interests is required. Namely, *Conroy* holds that the patient's recurring, unavoidable and severe pain should be such that prolonging the patient's life would be inhumane.[71] With respect to both objective tests, the *Conroy* Court emphasized that it is best to err, if at all, on the side of preserving life.[72] Furthermore, if the patient has previously expressed a wish to be kept alive, this wish should be respected even if the patient will continue to experience severe pain.[73]

Of particular note in the Court's approach to decisionmaking in the patient's best interests is the centrality of pain and suffering, and their converse, physical pleasure, emotional enjoyment and intellectual satisfaction, as the relevant objective factors to be assessed. Fearing discrimination against vulnerable institutionalized elderly patients, the Court has expressly rejected the termination of treatment "based on assessments of the personal worth or social utility of another's life, or the value of that life to others."[74] To satisfy the balancing tests for Conroy-type patients, that the patient is suffering "unavoidable and severe" physical pain is an essential burden. Absent this circumstance, the best interests tests are not satisfied, and life-sustaining treatment may not be withheld or withdrawn.*

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* Whether "unavoidable and severe pain" should be an essential burden under *Conroy's* objective tests has been a source of dialogue within the Court. Justice Handler, in his concurring opinions in *Conroy* and *Jobes*, has argued that this test is too restrictive, and that such criteria as dependency, humiliation, or dignity will be relevant factors for some patients in the balancing of burdens and benefits of continued treatment. *See Conroy*, 98 N.J. at 399, 486 A.2d at 1249-50 (Handler, J., concurring); *Jobes*, 108 N.J. at 442-43, 529 A.2d at 459 (Handler, J., concurring).

Conroy's benefits-burdens analysis does not apply to PVS patients. By definition, patients in a persistent vegetative state have no cognitive or interactive capacities; thus they do not experience the benefits or burdens to be assessed under *Conroy's* objective tests. As a calculus of pain, suffering and enjoyment, the limited-objective and pure-objective tests have no meaning as applied to PVS patients. Rather, the relevant objective consideration for the PVS patient is the possibility of return to a cognitive sapient state. Consequently, the Court has looked to *Quinlan* for the approach to decisionmaking for PVS patients and, as discussed below, has made confirmation of the patient's prognosis a central feature of the process.[75]

Existing law provides limited guidance regarding the circumstances in which life-sustaining treatment may be withheld or withdrawn in the patient's best interests. While a best interests standard was recognized in *Conroy*, the Court ultimately held that there was insufficient evidence before it of the benefits and burdens of the patient's life to satisfy either of the objective tests.[76] The pure-objective test was applied in the lower court decision of *In re Visbeck.*[77] In *Visbeck*, the Court addressed whether a feeding tube should be surgically implanted in the stomach of a 90 year old incompetent and terminally ill patient who had suffered a severely disabling stroke. Since there was no evidence of the patient's wishes, the court looked to the pure-objective test. Although severely physically and mentally impaired, Mrs. Visbeck had "significant awareness of her surroundings and...some limited ability to respond to them...markedly better than the mental condition [of] Claire Conroy."[78] She was not in pain, nor was implantation of the feeding tube likely to cause significant pain. Finding that "there is a positive quality to [the patient's] life in terms of awareness, responsiveness and minimal comfort", the court ordered that the feeding tube be implanted.[79]

Further development of the best interests tests and how they should be applied in particular cases looms on the horizon as an important issue for the future.*

Who Decides: Process and Procedure

Central to the Court's approach to shaping decisionmaking procedures for life-sustaining treatment cases is its respect for the ideal of informed self-determination of the competent patient, and a recognition that ideally such self-determination should develop out of an interaction among patient, family, and physician, the oft-cited triad of traditional participants in the health care decisionmaking process. With respect to incompetent patients, the Court has established specific guidelines designed to assure sound procedures to protect patients' rights and safeguard patients against possible abuse. An additional and continuing concern has been to

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See also In re Visbeck, 210 N.J. Super. 527, 529, 510 A.2d 125, 131 (N.J. Super. Ch. Ct. 1986) (stating that the pain standard is too limited, and fails to take into account the meaning to patients of such factors as severe loss of mental and physical capacities, dependency and loss of privacy). As this area of jurisprudence develops, it is worth posing the question whether *Conroy's* central focus on the patient's physical pain and suffering is properly suited to certain types of patients, for example, patients with advanced Alzheimer's disease.

* The Commission plans to study decisionmaking in the patient's best interests in its future work, through its Task Force on Protecting Vulnerable Patients.

devise procedures which will permit physicians to exercise sound professional judgment in terminating life-sustaining treatment without undue fear of legal entanglements or liability which may constrain that judgment and move physicians (or institutions) to practice "defensive medicine", delay important decisions or seek judicial intervention to clarify their rights and responsibilities. With this balancing of interests and objectives in mind, the Court has examined the roles and responsibilities of family and physician, and of others who may be designated as surrogate decisionmakers (such as health care representatives and legally appointed guardians), as well as the potential roles for less familiar participants in decisionmaking, such as ethics committees and the Office of the Ombudsman for the Institutionalized Elderly. While recognizing that "(t)he importance of the family in medical treatment decisions is axiomatic,"[80] the Court has also mandated the involvement of consulting physicians, committees and, in the nursing home setting, the Ombudsman for the Institutionalized Elderly.[81]

The Physician-Patient-Family Relationship

The New Jersey Supreme Court has consistently held that life-sustaining treatment decisions should generally be made within the context of the privacy of the physician-patient-family relationship. The Court's opinions express a fundamental commitment to the traditional role of family members, acting in collaboration with physicians, to make health care decisions on behalf of their loved ones. At the same time, the Court has carved out appropriate and complementary roles for other participants in the process of health care decisionmaking.

Originally expressed in *Quinlan*, the central role of family in decisionmaking for incompetent patients is most forcefully stated in *Jobes*:

> Almost invariably the patient's family has an intimate understanding of the patient's medical attitudes and general world view and therefore is in the best position to know the motives and considerations that would control the patient's medical decisions....Family members are best qualified to make substituted judgments for incompetent patients not only because of their peculiar grasp of the patient's approach to life, but also because of their special bonds with him or her. Our common human experience informs us that family members are generally most concerned with the welfare of a patient. It is they who provide for the patient's comfort, care, and best interests...and they who treat the patient as a person, rather than a symbol of a cause.[82]

The Court has consistently held that most often family members are best situated to implement the substantive standards for decisionmaking, in particular when a decision is to be based (in whole or in part) upon the patient's own values and prior expressions. It is family members (and close friends) who are most likely to exercise informed judgment regarding the patient's wishes and to do so out of strongly felt concern for the patient's well-being. As a consequence, the Court has generally deferred to family members to exercise substituted judgment on behalf of incompetent loved ones. This commitment to the role of family and to the integrity of the physician-patient-family relationship is echoed by numerous courts in other states.[83]

In New Jersey, health care professionals generally may look to close and caring family members, or to designated surrogates (*e.g.*, a health care representative), without need for appointment of a guardian.[84] Those family members with a close degree of kinship--a spouse, parents, adult children, or siblings--are normally appropriate persons to make a substituted judgment and should be looked to by health care professionals without need for a formal guardianship appointment. In general, if there are no close and caring family members acting on the patient's behalf, and the patient has not designated a health care representative, then a guardian must be appointed.[85] A guardian should also be appointed in those rare cases in which "a health-care professional becomes uncertain about whether family members are properly protecting a patient's interests."[86]

Although the Court's opinions are marked by attention to the legal role and responsibilities of family members, physicians continue to play a central and essential role in life-sustaining treatment decisions as collaborators in the process of decisionmaking with crucial medical expertise and important responsibility for life-sustaining treatment decisions. Of particular concern to the Court has been the impact of this responsibility upon physicians' willingness to participate in implementing decisions to forego life-sustaining treatment. In response to professional concerns about potential legal liability for making such decisions, the Court has established procedural guidelines intended, in part, to free physicians from unwarranted apprehension regarding legal consequences which too often constrains the exercise of sound professional judgment.[87] The Court has responded to this perceived state of affairs in the medical profession in several ways, including the involvement of a "hospital "Ethics Committee" or like body of the institution" to confirm a PVS patient's prognosis.[88] Such committees have the potential to diffuse professional responsibility for decisionmaking and to calm concerns over legal consequences.[89] The Court has expressed the hope that its opinions "might be serviceable to some degree in ameliorating the professional problems under discussion."[90]

Medical confirmation

Informed and reasoned decisions about life-sustaining treatment depend upon accurate diagnosis and assessment of the patient's medical condition. In order to assure sound decisionmaking and to protect vulnerable patients, in particular incompetent patients, against the inappropriate foregoing of treatment, the Court has mandated confirmation of the patient's medical condition and prognosis before a decision to forego life-sustaining treatment may be made. Under *Quinlan*, a hospital committee, commonly referred to as a "prognosis committee", should be consulted to confirm that a patient is in a persistent vegetative state. If a committee is not available, as may be the case in the nursing home setting, two independent (non-affiliated) physicians should perform this function.[91] The consulting physicians, like the prognosis committee, should be qualified to diagnose PVS, namely, they should be "knowledgeable in neurology".[92] Similarly, in *Conroy* the Court required that the patient's medical condition be evaluated by two independent physicians, and that the attending physician's determination that the patient is terminally ill with a life-expectancy of approximately one year or less be confirmed before a decision to forego life-sustaining treatment would be permitted.[93] While *Conroy* involved a terminally ill patient in a nursing home, this same requirement of medical

confirmation has been applied in the hospital setting,[94] and has been endorsed, for example, by the New Jersey State Board of Medical Examiners.[95]

Special Considerations in Nursing Homes: The Role of the Ombudsman for the Institutionalized Elderly

The Court's concern with the special vulnerability of elderly incompetent nursing home residents in *Conroy* occasioned the establishment of a role for the Office of the Ombudsman for the Institutionalized Elderly (the "Ombudsman") in life-sustaining treatment decisions. The nature and scope of that role was further refined by the Court in *Peter*, which addressed Ombudsman review in cases involving elderly PVS patients and clarified the Ombudsman's role when close family members or a health care representative are involved in decisionmaking on the patient's behalf. By statute the Ombudsman's jurisdiction extends to cases involving patients 60 years of age or older who are residents of nursing homes or certain other long-term care facilities in New Jersey.[96]

In *Conroy* the Court found that, due to "significant differences in the patients, the health care providers, and the institutional structures of nursing homes and hospitals," the *Quinlan* procedure "is not entirely appropriate" for patients who are residents of nursing homes.[97] Among the important factors noted by the Court which make the nursing home patient population more vulnerable than patients in hospitals are the advanced age, disabilities and mental impairments of the typical nursing home patient, the relative absence of close and caring family members, the more limited role of physicians in nursing home care, and the frequent absence of "ethics" or "prognosis" committees to review the patient's medical condition and proposed treatment decisions in the institutional settings.[98] With these concerns in mind, the Court sought to fashion appropriate procedural safeguards for incompetent nursing home patients for whom a decision to forego life-sustaining treatment is contemplated.

Citing New Jersey's outstanding efforts over several decades to constructively address the needs of its elderly citizens and families,[99] the Court seized upon the 1983 amendments to the Ombudsman's enabling legislation, finding that the statute provides "a vehicle for safeguarding the rights of elderly, institutionalized, incompetent patients both to receive medical treatment and to refuse life-sustaining medical treatment under certain circumstances."[100] Specifically, those amendments charge the Ombudsman with responsibility to protect elderly institutionalized patients against "abuse." The term "abuse" is defined, in relevant part, as "the willful infliction of physical pain, injury or mental anguish; unreasonable confinement; or *the willful deprivation of services which are necessary to maintain a person's physical and mental health.*"[101]

In *Conroy* and *Peter* the Court set forth procedures to be followed when a decision to withhold or withdraw life-sustaining treatment from an incompetent patient 60 years of age or older in a nursing home is contemplated. Any person, such as a family member, guardian, attending physician, or the nursing home administrator, who believes that a decision to forego life-sustaining treatment for a patient would effectuate the patient's wishes or best interests, or conversely, who reasonably believes that such a decision would be an abuse of that patient, should notify the Ombudsman's Office of the proposed decision.[102] The Ombudsman is directed

to treat every notification of a proposal to forego life-sustaining treatment as a possible "abuse," and to undertake an investigation. Pursuant to statute, a report of this investigation is to be made "within 24 hours to the Commissioner of Human Services and to any government agency that regulates or operates the facility."[103]

Conroy also holds that before a decision to forego life-sustaining treatment may be implemented, two independent physicians must confirm that the patient is terminally ill. Thus, in addition to information provided by the attending physician and nurses concerning the patient's medical condition, two independent physicians, unaffiliated with the nursing home or the attending physician, must be obtained by the Ombudsman to confirm the patient's medical condition and prognosis.[104] * The person responsible for the patient's care (in *Conroy* the patient's nephew and court-appointed guardian), the attending physician and the Ombudsman must concur in the decision to forego life-sustaining treatment (in accordance with the substantive standards discussed above).

In *Peter*, the Court established further guidelines regarding the scope of the Ombudsman's role where the patient has designated a surrogate decisionmaker (a health care representative) or has a close and caring family member acting on his or her behalf. In such cases, the Ombudsman is directed to secure two independent confirmations of the patient's medical condition, and to determine whether the patient has designated a family member or close friend as health care representative. In the absence of such a designation, the Ombudsman should determine whether there is a close and caring family member acting on the patient's behalf. In these circumstances, when the patient's medical condition has been confirmed, the Ombudsman "should defer any decisions concerning life-support to the designated decisionmaker, [or] (i)n the absence of a designated decisionmaker...[to] a close family member."[105] In the absence of either a health care representative or close family member acting on the patient's behalf, a guardian must be appointed to represent the patient's interests, and the Ombudsman would be charged with responsibility for reviewing the guardian's decision.[106]

As discussed above, the primary goal of decisionmaking should be to effectuate the patient's wishes. In *Conroy*, the Court held that where the basis for the contemplated decision involves assessment of the patient's best interests, *i.e.*, application of the limited-objective or pure-objective tests, "the patient's spouse, parents and children, or, in their absence, the patient's next of kin, if any -- must also concur in the decision to withhold or withdraw life-sustaining treatment."[107] However, the holding in *Peter* suggests that decisions grounded in these objective tests made by a close family member or a health care representative need not be agreed upon among the several members of the patient's family, at least where the patient is in a persistent vegetative state.[108]

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* In *Conroy*, the Court stated the following guidelines concerning responsibility for the costs of these medical consultations: "Depending upon the circumstances of a particular case, the physicians may be compensated by the patient's estate, the guardian, the family, or the nursing home. If the funds from these sources are insufficient, the guardian [or the family] may seek reimbursement from the Ombudsman or possibly from Medicare." 98 N.J. at 384, 486 A.2d at 1242.

It is important to emphasize that the Court has held that a decision to forego life-sustaining treatment for a patient pursuant to the patient's wishes or best interests is not an "abuse", and is not properly characterized as a "willful deprivation of services."[109] Nor is the fact that the Ombudsman has been notified of a contemplated decision to forego life-sustaining treatment and has become involved in the decision indicative of abuse or any wrongdoing. Furthermore, participants in the decisionmaking process who act in good faith to follow the procedures established by the Court to implement a decision to forego life-sustaining treatment would be immune from civil and criminal liability.[110]

Summary of Procedural Guidelines for Incompetent Patients

In its decisions to date, the New Jersey Supreme Court has mandated specific procedures for (i) PVS patients in hospitals; (ii) PVS patients in nursing homes; and (iii) terminally ill patients in nursing homes. The Court's procedural guidelines vary principally by reference to two factors--the nature of the patient's underlying condition and the setting in which the patient is being cared for.[111] In summary, the Court has established the following procedural guidelines to govern decisions to forego life-sustaining treatment for incompetent patients:

1. *PVS patients*

   A) *Hospital Patients and Non-Elderly Nursing Home Patients (Quinlan and Jobes)*: When the family, health care representative (if one has been appointed), guardian (if one has been appointed), and the attending physician agree that life-sustaining treatment should be withheld or withdrawn, the patient's medical condition must be confirmed by a "prognosis committee", or where such a committee is not available, by two independent (non-attending) physicians. (If the attending physician does not concur, the surrogate decisionmaker has the right to transfer responsibility for the patient's care to a different physician.)[112] The prognosis committee (or the consulting physicians) must confirm that there is no reasonable possibility that the patient might recover from the present comatose condition to a cognitive sapient state. If the committee (consultants) concur in this determination, life-sustaining treatment may be withheld or withdrawn.

   B) *Elderly Nursing Home Patients (Peter)*: If the patient is 60 years of age or older and is a resident of a nursing home, then the Ombudsman is to be involved in a prospective review of the decision. When a person, such as a family member, health care representative, guardian, attending physician or nursing home administrator, believes that a decision to withhold or withdraw life-sustaining treatment would effectuate the patient's wishes or best interests, the Ombudsman should be notified of the proposed decision. The Ombudsman should secure the appointment of two independent physicians, not affiliated with the nursing home or the attending physician, to confirm that the patient is in a persistent vegetative state, with no reasonable possibility of recovering to a cognitive sapient state. Provided the patient's medical condition is confirmed, if the person responsible for the patient's care, such as a family member, health care representative (if one has been appointed), or guardian (if one has been appointed), and the attending physician agree that the foregoing of life-sustaining treatment would effectuate the patient's wishes or best interests, and the Ombudsman concurs in this decision, life-sustaining treatment may be withheld or withdrawn. Where the Ombudsman

determines that a close and caring family member, or a designated decisionmaker, is acting on the patient's behalf, the Ombudsman should generally defer to their decision to forego life-sustaining treatment. In the absence of a close family member or a designated health care representative, a guardian must be appointed.

2. *Terminally Ill, Incompetent, Elderly Nursing Home Patients (Conroy)*

When a person, such as a family member, health care representative, guardian, attending physician or nursing home administrator, believes that a decision to withhold or withdraw life-sustaining treatment would effectuate the patient's wishes or best interests, the Ombudsman should be notified of the proposed decision. The Ombudsman should secure the appointment of two independent physicians, not affiliated with the nursing home or the attending physician, to confirm the patient's medical condition and prognosis. Provided the patient's medical condition is confirmed, if the person responsible for the patient's care, such as a family member, health care representative (if one has been appointed), or guardian (if one has been appointed), and the attending physician agree that the foregoing of life-sustaining treatment would effectuate the patient's wishes or best interests, in accordance with the subjective, limited-objective, or pure-objective tests, and the Ombudsman concurs in this decision, life-sustaining treatment may be withheld or withdrawn. Where the limited-objective or pure-objective test provides the basis for the decision, the family (*i.e.*, the patient's spouse, parents and children or, in their absence, the next of kin, if any), must also concur in the decision.

With respect to each of the procedures described above, the Court provides that all participants who follow the Court's guidelines (both substantive and procedural) in good faith to implement a decision to withhold or withdraw life-sustaining treatment shall be immune from criminal and civil liability for such actions.

The Role of Ethics Committees: An Emerging Trend*

The most innovative element of the Court's approach to the procedural aspects of decisionmaking with respect to life-sustaining treatment was its introduction of the concept of involving multidisciplinary ethics committees as legally significant participants in the process. The concept was first presented in the *Quinlan* case in response to the belief that

> there must be a way to free physicians, in the pursuit of their healing vocation, from possible contamination by self-interest or self-protection concerns which would inhibit their independent medical judgments for the well-being of their dying patients.[113]

Relying heavily on a law review article written by a physician[114] the Court presented the concept of a multidisciplinary committee, accessible to those who provide medical care as a forum for dialogue regarding the ethical dilemmas posed by individual cases, and thereby to provide

* The existing and potential roles of ethics committees in health care decisionmaking are examined at greater length in Part Five of the report, which discusses the work of the Commission's Task Force on Institutional Ethics Committees.

assistance and safeguards for patients and health care professionals. Such committees would promote exploration of all the options available to a patient. The feature which most appealed to the Court in *Quinlan* was the anticipated ability of such a committee to diffuse professional responsibility for life and death decisions.[115]

The precise nature of the role that the *Quinlan* Court hoped ethics committees would play is not clear, due largely to a contrast between the role suggested by the law review article cited in the case and subsequent interpretations of the duties actually required of the committee in the case. This contrast can best be understood in light of the fact that in *Quinlan*, the Court itself performed the legal and ethical analysis of the dilemmas presented by Karen's situation -- there was no reason to ask a multidisciplinary ethics committee to reconsider these questions. However, as the Court noted, it did not have before it up-to-date evidence of Karen's medical condition and prognosis. Having concluded that in this type of case, "the focal point of decision should be [her] prognosis,"[116] the task actually assigned to the committee was the narrow one of confirming that "there is no reasonable possibility of Karen's ever emerging from her present comatose condition."[117] As discussed above, the Court made committee confirmation of a PVS patient's prognosis a mandatory part of the process.

Although a broader role for ethics committees, beyond that of prognosis confirmation, is only suggested under *Quinlan* and its progeny, it is clear from the *Quinlan* opinion that the Court aspired to accomplishing more than resolving the issues presented by the specific case at hand.[118] In the aftermath of *Quinlan*, ethics committees and more narrowly focused prognosis committees have been established in an increasing number of hospitals and long-term care facilities. The Court and individual justices have continued to advocate the involvement of institutional ethics committees in termination of treatment cases as an aid and advisor to physicians and families, hospitals and other health care facilities,[119] and to exhort others to pursue this agenda. For example, the Court's continuing desire to expand reliance on such committees is reflected in Justice Pollock's concurrence in *Jobes*, which calls upon health care facilities, including nursing homes, to give serious consideration to making available the services of an ethicist or ethics committee.[120] In endorsing statements by the President's Commission regarding the nature of ethics committee participation in a consultative or reviewing role, Justice Pollock echoes the view originally presented in *Quinlan*, that when ethics committees serve in such a role, they do not supplant the principal decisionmakers (that is, families and practitioners), but they do provide for efficient review without regularly incurring the liabilities of judicial review.[121] Thus, utilization of ethics committees can serve the underlying objectives of establishing a legal framework for decisionmaking that permits those faced with life-sustaining treatment dilemmas to make choices unhindered by fear of legal entanglements and to do so without routine resort to the courts for protection.[122]

Conclusion

The Supreme Court of New Jersey has deservedly gained a national reputation for its life-sustaining treatment decisions. Yet, the Court has noted with regret that these difficult issues came before it principally because, in the absence of legislative guidance, a series of individuals felt the need to resort to the judiciary for assistance and protection in making traditionally private

life and death medical decisions. While the Court has readily accepted its responsibility to participate in such decisions when called upon to do so, and to set forth guidelines to govern how and by whom such decisions should be made, it has also readily acknowledged that judicial involvement is generally inappropriate and "impossibly cumbersome".[123] Recognizing that the complex issues involved are "not...well-suited for resolution in an adversary judicial proceeding",[124] the Court has sought to develop and clarify procedures for decisionmaking which discourage routine reliance on the judicial system. At the same time, the Court has frequently stated its view that these issues are "more suitably addressed in the legislative forum, where fact finding can be less confined,...the subject [can] be dealt with comprehensively and the interests of all institutions and individuals [can] be properly accommodated",[125] and has invited the Legislature to pursue the development of sound decisionmaking procedures, which are respectful of traditional rights and values yet reflect an openness to innovation.

Notes

1. 70 N.J. 10, 355 A.2d 647, *cert. denied sub nom. Garger v. New Jersey*, 429 U.S. 922 (1976).

2. *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985).

3. *In re Farrell*, 108 N.J. 335, 529 A.2d 404 (1987).

4. *In re Peter*, 108 N.J. 365, 529 A.2d 419 (1987).

5. *In re Jobes*, 108 N.J. 394, 529 A.2d 434 (1987).

6. *Farrell*, 108 N.J. at 348, 529 A.2d at 410; *Conroy*, 98 N.J. at 347, 486 A.2d at 1222.

7. 70 N.J. at 39-40, 355 A.2d at 663, (citing *Eisenstadt v. Baird*, 405 U.S. 438 (1972); *Stanley v. Georgia*, 394 U.S. 557 (1969); *Griswold v. Connecticut*, 381 U.S. 479 (1965)).

8. 70 N.J. at 40, 355 A.2d at 663.

9. Art. I, par. 1, of the CONSTITUTION OF NEW JERSEY (1947) provides:
> All persons are by nature free and independent, and have certain natural and unalienable rights, among which are those of enjoying and defending life and liberty, of acquiring, possessing, and protecting property, and of pursuing and obtaining safety and happiness.

10. 98 N.J. at 348, 486 A.2d at 1223; Stewart G. Pollock, "Life and Death Decisions: Who Makes Them and By What Standards?", *Rutgers Law Review* 41 (Fall 1989): 530-31 ("Pollock") ("Without rejecting the constitutional right, the court shifted the basis of its decision to the common-law right of self-determination in *Conroy*.")

11. In *Farrell* the Court states: "While we held that a patient's right to refuse medical treatment even at the risk of personal injury or death is primarily protected by the common law, we recognized that it is also protected by the federal and state constitutional right of privacy." 108 N.J. at 348, 529 A.2d at 410 (citing *Conroy*, 98 N.J. at 348, 486 A.2d at 1223; *Quinlan*, 70 N.J. at 38-42, 355 A.2d at 662-64).

12. *See, e.g., Gray v. Romeo*, 697 F.Supp. 580 (D.R.I. 1988); *Rasmussen v. Fleming*, 154 Ariz. 207, 741 P.2d 674 (1987); *Corbett v. D'Allesandro*, 487 So. 2d 368 (Fla. App.), *rev. denied*, 492 So. 2d 1331 (Fla. 1986). The constitutional basis of the right to refuse life-sustaining treatment was presented to the United States Supreme Court for the first time in the case of *Cruzan v. Harmon*, 760 S.W.2d 408 (Mo. 1988) (*en banc*), *cert. granted*, 109 S. Ct. 3240 (1989). The Court heard oral arguments in the case on December 5, 1989, and a decision is expected in the summer of 1990. It should be noted that should the United States Supreme Court limit the scope of the federal constitutional right of privacy in this area, such a ruling would not affect the constitutional underpinnings of the right to refuse treatment in states, like New Jersey, which have held there to be a constitutionally protected right to refuse treatment under the State constitution.

13. *See, e.g., Conservatorship of Drabick*, 200 Cal. App. 3d 185, 245 Cal. Rptr. 840 (Ct. App. 1988); *In re Estate of Longeway*, 133 Ill.2d 33, 549 N.E.2d 292 (1989); *In re Gardner*, 534 A.2d 947 (Me. 1987); *Matter of Westchester County Medical Center(O'Connor)*, 72 N.Y.2d 517, 534 N.Y.S.2d 886, 531 N.E.2d 607 (1988).

14. *See, e.g.*, the cases cited *infra* note 51.

15. 70 N.J. at 41-42, 355 A.2d at 664.

16. *Id.* at 41, 355 A.2d at 664.

17. 108 N.J. at 372, 529 A.2d at 423.

18. 98 N.J. at 373, 486 A.2d at 1236.

19. *Id.* at 374, 486 A.2d at 1236.

20. 108 N.J. at 382, 529 A.2d at 428.

21. 108 N.J. at 427, 529 A.2d at 451.

22. *See, e.g., Rasmussen v. Fleming*, 154 Ariz. 207, 741 P.2d 674 (1987); *Conservatorship of Drabick*, 200 Cal. App. 3d 185, 245 Cal. Rptr. 840 (Ct. App. 1988); *McConnell v. Beverly Enterprises-Connecticut*, Inc., 209 Conn. 692, 553 A.2d 596 (1989); *Corbett v. D'Allessandro*, 487 So. 2d 368 (Fla.Dist.Ct.App.), *rev. denied*, 492 So. 2d 1331 (Fla. 1986); *Brophy v. New England Sinai Hosp.*, 398 Mass. 417, 497 N.E.2d 626 (1986).

23. *See, e.g., Conroy*, 98 N.J. at 348-49, 486 A.2d at 1223.

24. Pollock, *supra* note 10, p. 515 (quoting Note, "Artificial Nutrition and the Terminally Ill: How Should Washington Decide?", *Wash. L. Rev.* 61 (1986): 433-34 n.102); *see also* David C. Blake, "State Interests in Terminating Medical Treatment", *Hastings Center Report* 19(3) (May/June 1989): 5-13.

25. *Farrell*, 108 N.J. at 349, 529 A.2d at 411; *Conroy*, 98 N.J. at 349, 486 A.2d at 1223.

26. *Quinlan*, 70 N.J. at 41, 355 A.2d at 664; *accord Rasmussen v. Fleming*, 154 Ariz. 207, 741 P.2d 674, 683 (1987); *In re Colyer*, 99 Wash. 2d 114, 660 P.2d 738, 743 (1983).

27. *Conroy*, 98 N.J. at 350, 486 A.2d at 1224; *see Farrell*, 108 N.J. at 349-50, 529 A.2d at 411 (quoting *Conroy*).

28. *Conroy*, 98 N.J. at 350-51, 486 A.2d at 1224; *Farrell*, 108 N.J. at 350, 529 A.2d at 411; *see, e.g., Bartling v. Superior Court*, 163 Cal. App. 3d 186, 209 Cal. Rptr. 220, 225-26 (1984); *In re Gardner*, 534 A.2d 947, 955-56 (Me. 1987).

29. *Conroy*, 98 N.J. at 351, 486 A.2d at 1224; *Farrell*, 108 N.J. at 350, 529 A.2d at 411.

30. *Conroy*, 98 N.J. at 351, 486 A.2d at 1224 ("Recognizing the right of a terminally ill person to reject medical treatment respects that person's intent, not to die, but to suspend medical intervention at a point consonant with the 'individual's view respecting a personally preferred manner of concluding life.'") (quoting Note, "The Tragic Choice: Termination of Care for Patients in a Permanent Vegetative State," *New York University Law Review* 51 (1976): 310).

31. *See, e.g.*, American Medical Association Council On Ethical And Judicial Affairs, *Current Opinions*, secs. 2.20, 2.21 (1989).

32. *Farrell*, 108 N.J. at 351, 529 A.2d at 412.

33. *See* Pollock, *supra* note 10, pp. 516-17.

34. *Jacobson v. Massachusetts*, 197 U.S. 11 (1905) (enforcing compulsory smallpox vaccination law).

35. *Application of President & Directors of Georgetown College*, 331 F.2d 1000, 1008 (D.C. Cir.), *cert. denied*, 377 U.S. 978 (1964) (ordering a blood transfusion for a mother because of her "responsibility to the community to care for her infant").

36. *Raleigh Fitkin-Paul Morgan Memorial Hosp. v. Anderson*, 42 N.J. 421, 201 A.2d 537, *cert. denied*, 377 U.S. 985 (1964).

37. *Id.*

38. *Farrell*, 108 N.J. at 352, 529 A.2d at 413; *see* Pollock, *supra* note 10, p. 518.

39. *Farrell*, 108 N.J. at 356, 529 A.2d at 415.

40. *Id.*

41. *Id.* at 354 n.7, 529 A.2d at 413 n.7.

42. *Id.* at 356, 529 A.2d at 415.

43. *Id.* at 356 & n.8, 529 A.2d at 415 & n.8. Thus, the non-judicial process under *Farrell* supersedes the Court's prior holding in *Conroy*, 98 N.J. at 381, 486 A.2d at 1240, which required a court determination of the patient's (in)competence.

44. *Conroy*, 98 N.J. at 349, 486 A.2d at 1223.

45. *Id.* at 350, 486 A.2d at 1223.

46. *Farrell*, 108 N.J. at 359, 529 A.2d at 416.

47. In addition to *Farrell* and *In re Requena*, 213 N.J.Super. 475, 517 A.2d 886 (Super. Ct. Ch. Div.), *aff'd.*, 213 N.J.Super. 443, 517 A.2d 869 (App. Div. 1986), *see Tune v. Walter Reed Army Medical Hosp.*, 602 F. Supp. 1452 (D.D.C. 1985) (patient with terminal cancer); *Camp v. White*, 510 So.2d 166 (Ala. 1987) (patient with chronic, obstructive pulmonary disease); *Satz v. Perlmutter*, 362 So. 2d 160 (Fla.Dist.Ct.App. 1978) (patient with ALS).

48. *Bouvia v. Super. Ct. of Los Angeles County*, 179 Cal. App. 3d 1127, 225 Cal. Rptr. 297 (Ct. App. 1986) (patient with severe cerebral palsy and quadriplegia had right to refuse artificially provided fluids and nutrition); *Bartling v. Super. Ct. of Los Angeles County*, 163 Cal. App. 3d 186, 209 Cal. Rptr. 220 (Ct. App. 1984) (patient with lung cancer and chronic respiratory failure had right to refuse a respirator); *State v. McAfee*, 385 S.E.2d 651 (Ga.1989) (patient with quadriplegia had right to refuse a respirator); *In re Culham*, No. 87-340537-AZ, slip op. (Cir. Ct. Mich., Dec. 15, 1987) (patient with non-terminal ALS had right to refuse a respirator).

49. While some courts have upheld the competent patient's right to refuse treatment when not terminally ill but suffering from an incurable, irreversible illness or disease process, *see* cases cited *supra* note 48, a more difficult issue on the horizon involves the competent patient's refusal of life-sustaining treatment in circumstances where the patient is not terminally ill and the proposed treatment does offer hope of cure or recovery from the underlying illness or disease process.

50. 98 N.J. at 364, 486 A.2d at 1231.

51. *See, e.g.*, *Gray v. Romeo*, 697 F. Supp. 580 (D.R.I. 1988) (PVS); *Rasmussen v. Fleming*, 154 Ariz. 207, 741 P.2d 674 (1987) (PVS); *McConnell v. Beverly Enterprises-Connecticut, Inc.*, 209 Conn. 692, 553 A.2d 596 (1989) (PVS); *In re Gardner*, 534 A.2d 947 (Me. 1987) (PVS); *Brophy v. New England Sinai Hosp., Inc.*, 398 Mass. 417, 497 N.E.2d 626 (1986) (PVS); *John F. Kennedy Memorial Hosp. v. Bludworth*, 452 So. 2d 921 (Fla. 1984) (permanent brain damage and acute respiratory failure); *In re Spring*, 380 Mass. 629, 405 N.E.2d 115 (1980) (end-stage kidney disease); *In re Guardianship of Grant*, 109 Wash.2d 545, 747 P.2d 445 (1987) (incurable terminal neurological disorder).

The Missouri Supreme Court's decision in *Cruzan v. Harmon*, 760 S.W.2d 408 (1988), reversing the trial court's judgment, is unique among its sister states in holding that the family of a PVS patient could not authorize removal of life-sustaining treatment on the patient's behalf. The Cruzan case is now pending before the United States Supreme Court (No. 88-1503). *See supra* note 12.

52. *But see, Quinlan*, 70 N.J. at 54 n.10, 355 A.2d 671 n.10 ("The declaratory relief we here award is not intended to imply that the principles enunciated in this case might not be applicable in divers other types of terminal medical situations...not necessarily involving the hopeless loss of cognitive or sapient life.").

53. *Peter*, 108 N.J. at 377-79, 529 A.2d 425-27; *Conroy*, 98 N.J. at 360-62, 486 A.2d at 1229-30.

54. *Conroy*, 98 N.J. at 365, 486 A.2d at 1231-32.

55. *Id.* at 364-65, 486 A.2d at 1231-32.

56. Norman L. Cantor, *Legal Frontiers of Death and Dying* (Indiana Univ. Press 1987), p. 69; *Conroy*, 98 N.J. at 365, 486 A.2d at 1232.

57. Pollock, *supra* note 10, p. 518.

58. *Conroy*, 98 N.J. at 360, 486 A.2d at 1229.

59. *Peter*, 108 N.J. at 377-78, 529 A.2d at 425.

60. *Jobes*, 108 N.J. at 414-15, 529 A.2d at 444; *Conroy*, 98 N.J. at 361-62, 486 A.2d at 1230. *Conroy* overrules the decision in *Quinlan* to disregard evidence of statements made by the patient to friends regarding life-sustaining treatment decisions for other seriously ill patients. 98 N.J. at 362, 486 A.2d at 1230.

61. *Peter*, 108 N.J. at 378, 529 A.2d at 426.

62. *Conroy*, 98 N.J. at 361 n.5, 486 A.2d at 1229 n.5.

63. *Peter*, 108 N.J. at 378-79, 529 A.2d at 426. The New Jersey Powers of Attorney statute authorizes conveyance of durable power of attorney authority which may be exercised "notwithstanding later disability or incapacity of the principal." *N.J.S.A.* 46:2B-8(a) (West 1972). The statute does not expressly authorize conveyance of authority to make health care decisions. Therefore, it is advisable that those who wish to designate a health care representative under current New Jersey law specifically delegate to their chosen representative authority to make health care decisions, including (if desired) authority to refuse life-sustaining treatment. *See Peter*, 108 N.J. at 379, 529 A.2d at 426.

64. For a more in-depth discussion of the probative value of patients' prior statements, *see Conroy*, 98 N.J. at 362-63, 486 A.2d at 1230.

65. *Jobes*, 108 N.J. at 412-15, 529 A.2d at 443-45 (citing *Quinlan*, 70 N.J. at 41, 355 A.2d at 664). In contrast, in *Matter of Westchester County Medical Center (O'Connor)*, 72 N.Y.2d 517, 534 N.Y.S.2d 886, 531 N.E.2d 607 (1988), the court required that the patient's wishes be established by clear and convincing evidence.

66. *Peter*, 108 N.J. at 377, 529 A.2d at 425 (citing *Quinlan*, 70 N.J. at 41, 355 A.2d at 664).

67. *Conroy*, 98 N.J. at 364-65, 486 A.2d at 1231-32; *Peter*, 108 N.J. at 374, 529 A.2d at 424.

68. *Conroy*, 98 N.J. at 365, 486 A.2d at 1232.

69. *Id.*

70. *Id.* at 366, 486 A.2d at 1232.

71. *Id.*; *see* Bernard Lo & Laurie Dornbrand, "The Case of Claire Conroy: Will Administrative Review Safeguard Incompetent Patients?", *Annals of Internal Medicine* 104(6) (June 1986): 870.

72. 98 N.J. at 368, 486 A.2d at 1233.

73. *Id.* at 366-67, 486 A.2d at 1232.

74. *Id.* at 367, 486 A.2d at 1232-33.

75. In *Jobes* the Court did not reach the question of how a best interests standard might be applied when a substituted judgment standard proves unworkable, such as for a never-competent patient or a patient without family or friends who has left no evidence of his or her wishes. 108 N.J. at 424, 529 A.2d at 449. Certain passages in the Court's opinions suggest, however, that the foregoing of life-sustaining treatment for a PVS patient would satisfy a pure best interests analysis. *See Quinlan*, 70 N.J. at 41-42, 355 A.2d at 664 ("this decision should be

accepted by a society the overwhelming majority of whose members would, we think, in similar circumstances, exercise such a choice in the same way for themselves or for those closest to them."); *Peter*, 108 N.J. at 380, 529 A.2d at 427 ("we find it difficult to conceive of a case in which the state could have an interest strong enough to subordinate a patient's right to choose not to be sustained in a persistent vegetative state.").

76. 98 N.J. at 386, 486 A.2d at 1243.

77. 210 N.J. Super. 527, 510 A.2d 125 (N.J. Super. Ch. Ct. 1986).

78. *Id.* at 537, 510 A.2d at 130.

79. *Id.* at 542, 510 A.2d at 133. *See also In re Clark*, 210 N.J. Super. 548, 510 A.2d 136 (N.J. Super. Ch. 1986) (ordering an enterostomy for a 45 year old patient who suffered a stroke, was seriously malnourished, and was severely mentally and physically impaired, but who was not in significant pain and derived some benefit from life and would be able to live for a number of years if artificial feeding was provided).

80. *Jobes*, 108 N.J. at 416, 529 A.2d at 445 (quoting *Farrell*, 108 N.J. at 355, 529 A.2d at 414).

81. To some, the Court's approach goes too far in impinging on the historically private realm of family life. *See, e.g.*, Nancy J. Moore, ""Two Steps Forward, One Step Back": An Analysis of New Jersey's Latest 'Right-To-Die' Decisions", *Rutgers Law Journal* 19 (Summer 1988): 955.

82. *Jobes*, 108 N.J. at 416, 529 A.2d at 445 (quotations and citations omitted).

83. For in-depth analysis of the role of the family in health care decisionmaking *see* Nancy K. Rhoden, "Litigating Life and Death", *Harvard Law Review* 102 (1988): 375-446; Newman, "Treatment Refusals for the Critically Ill: Proposed Rules for the Family, the Physician and the State", *New York Law School Journal of Human Rights Annual* III (1985): Part One; *see also* Judith Areen, "The Legal Status of Consent Obtained From Families of Adult Patients to Withhold or Withdraw Treatment", *Journal of the American Medical Association* 258 (2) (July 10, 1987): 229-235 (summarizing existing law).

84. *Jobes*, 108 N.J. at 420, 529 A.2d at 447. *See* Pollock, *supra* note 10, p. 537 ("*Jobes* eliminated the guardianship requirement [previously set forth in *Conroy*] where the patient has close family members, or where the patient has left clear and convincing evidence that another relative or a friend is to make surrogate medical decisions.").

85. *Jobes* suggests that in some cases, other relatives, such as a cousin, aunt or uncle, niece or nephew, may, in the judgment of the responsible health care professional, function in the capacity of nuclear family, and "can and should be treated as a close and caring family member." 108 N.J. at 419, 529 A.2d at 447. *Peter* holds that a close friend should function in this capacity if specifically designated as the patient's surrogate decisionmaker; otherwise a guardianship appointment should be sought. 108 N.J. at 384, 529 A.2d at 429.

86. *Jobes*, 108 N.J. at 419, 529 A.2d at 447.

87. *Quinlan*, 70 N.J. at 46, 355 A.2d at 666 ("[t]he modern proliferation of substantial malpractice litigation and the less frequent but even more unnerving possibility of criminal sanctions would seem, for it is beyond human nature to suppose otherwise, to have bearing on the practice and standards as they exist.").

88. *Id.* at 54, 355 A.2d at 671.

89. *Id.* at 49, 355 A.2d at 668 (citing Karen Teel, "The Physician's Dilemma: A Doctor's View: What the Law Should Be", *Baylor Law Review* 27 (1975): 8-9 ("Teel").

90. 70 N.J. at 49, 355 A.2d at 668.

91. *Jobes*, 108 N.J. at 422, 529 A.2d at 448.

92. *Id.*

93. 98 N.J. at 384, 486 A.2d at 1242.

94. *See In re Visbeck*, 210 N.J. Super. 527, 541, 510 A.2d 125, 132-33 (N.J. Super. Ch. Ct. 1986).

95. *See* "New Jersey State Board of Medical Examiners Policy Statement on Decisions to Withhold or Withdraw Medical Treatment" (revised August 1989).

96. *N.J.S.A.* 52:27G-2(i), 27G-2(f) (West 1983).

97. *Conroy*, 98 N.J. at 375, 486 A.2d at 1237.

98. *Id.* at 375-77, 486 A.2d at 1237-38.

99. *Id.* at 377-79, 486 A.2d at 1238-39.

100. *Id.* at 379, 486 A.2d at 1239.

101. *N.J.S.A.* 52:27G-2(a) (West 1983) (emphasis added).

102. *Conroy*, 98 N.J. at 383, 486 A.2d at 1241-42.

103. *Id.* at 384, 486 A.2d at 1242 (citing *N.J.S.A.* 52:27G-7.2(a) (West 1983)).

104. *Peter*, 108 N.J. at 384, 529 A.2d at 429. The Ombudsman's authority to appoint consulting physicians derives from *N.J.S.A.* 52:27G-5(b) (West 1977). In *Conroy*, the Court had recommended, but not required, that the Ombudsman assume responsibility for appointing the confirming physicians. 98 N.J. at 384, 486 A.2d at 1242.

105. *Peter*, 108 N.J. at 384, 529 A. 2d at 429.

106. *Id.* Some have interpreted *Peter* to establish separate guidelines for the Ombudsman's role which apply only for PVS patients and do not modify or build upon *Conroy*.

107. 98 N.J. at 384-85, 486 A.2d at 1242.

108. 108 N.J. at 384-85, 529 A.2d at 429.

109. 98 N.J. at 381, 486 A.2d at 1240.

110. *Id.* at 385, 486 A.2d at 1242. *Conroy* states that "in the absence of bad faith" no participant in the process shall be liable; in contrast, the trilogy provides immunity when the procedures are followed "in good faith". *See, e.g., Jobes*, 108 N.J. at 422, 529 A.2d at 448.

111. Although the Court believes that "the processes of surrogate decisionmaking should be substantially the same regardless of where the patient is located" (*In re Jobes*, 108 N.J. at 421, 529 A.2d at 448), the attributes of each setting are sufficiently different that variations in the applicable procedures are required.

112. *Quinlan*, 70 N.J. at 54, 355 A.2d at 671.

113. *Id.* at 49, 355 A.2d at 668.

114. Teel, *supra* note 88, pp. 8-9.

115. *Quinlan*, 70 N.J. at 50, 355 A.2d at 669.

116. *Id.* at 51, 355 A.2d at 669.

117. *Id.* at 54, 355 A.2d at 671.

118. *Id.* at 49-50, 355 A.2d at 668.

119. *Peter*, 108 N.J. at 383 n.13, 529 A.2d at 428 n.13.

120. 108 N.J. at 450-53, 529 A.2d at 463-64 (Pollock, J., concurring).

121. *Id. See also Peter*, 108 N.J. at 383 n.13, 529 A.2d at 428 n.13 (citing with approval the possibility of nursing homes utilizing a prognosis committee of an affiliated acute care institution and encouraging the Department of Health to consider the feasibility of developing regional prognosis committees for nursing homes).

122. *See Jobes*, 108 N.J. at 450-53, 529 A.2d at 463-64 (Pollock, J., concurring).

123. *Quinlan*, 70 N.J. at 50, 355 A.2d at 669.

124. *Farrell*, 108 N.J. at 343, 529 A.2d at 407-08.

125. *Id.*

Chapter Three
Advance Directives For Health Care: Underlying Principles and Basic Approach

As discussed above, following extensive deliberations over the course of close to two years, the Commission approved and recommended a legislative proposal on advance directives for health care. Much of the general legal context underlying the Commission's deliberations is set forth above. This chapter discusses the underlying principles and basic approach to the area of advance directives on which the Commission's recommendations and legislative proposal are based.

The Norm of Informed Consent as Shared Decisionmaking

The State of New Jersey recognizes, in its law and public policy, the personal right of competent adults to make voluntary, informed choices to accept, to reject, or to choose among alternative courses of health care, including life-sustaining measures, on the basis of their own values and in furtherance of their own goals.* This right is embodied in the process of informed consent, and is grounded in the twin values and objectives of respect for patient self-determination and promotion of patient well-being in health care decisionmaking. The Commission's recommendations are grounded in a strong commitment to these twin values.

On both legal and ethical grounds, the Commission concludes that the normative ethical model of health care decisionmaking is the process of informed consent, interpreted not as a legal doctrine but as an ethical norm of shared decisionmaking. The Commission's approach adopts the shared decisionmaking model of the physician-patient relationship as developed in the work of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (the "President's Commission")[1], and extends this model to the circumstance in which the patient lacks decisionmaking capacity. In so doing, it makes the health care representative a central figure in the process of shared decisionmaking, by allowing the health care representative to stand in the place of the patient in this process with authority to give informed consent to and refusal of medical treatment and care. The Commission's recommendations are designed to structure and facilitate a process of shared decisionmaking in which health care professionals, patients, health care representatives and families are viewed (and view themselves) as moral agents with complementary and collaborative roles in the delivery of health care. While the proposed legislation focuses primarily upon the responsibilities of physicians and health care representatives, the ethical norm of shared decisionmaking views nurses, social workers and other health care professionals as members of the health care team with joint and complementary roles in a process of collaborative decisionmaking respectful of patient self-determination and seeking to promote patient well-being.

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* See the discussion of the relevant case law above.

The Ethical Norm of Shared Decisionmaking

While there exists lively debate and disagreement concerning the necessary and sufficient elements of informed consent, there is general agreement that for a consent or refusal to be effective or valid, at least three elements should be present. First, the patient should have decisionmaking capacity. Second, the patient should act voluntarily (including being free from coercion, manipulation or undue influence). Third, the patient should understand the nature of his or her condition and the risks and benefits of proposed treatment alternatives, including the alternative of no treatment. In order to promote effective and meaningful patient decisionmaking, health care professionals have an affirmative obligation to assist patients in the informed consent process through provision of relevant information concerning the patient's condition and treatment alternatives (including risks, benefits and associated uncertainties), to enhance patients' capacity for meaningful participation in the decisionmaking process, and to safeguard the voluntariness of patients' decisions (including efforts to assure that the patient is not coerced, manipulated or unduly influenced by others). These three elements of informed consent capture the core requirements for the patient to make an informed decision to accept or refuse particular medical interventions. However, these core elements provide only a partial picture of what the interactive nature or model of the physician-patient relationship should be if it is to promote and facilitate effective patient participation in the process of informed consent.[2]

In the Commission's view, the patient's right to and interest in both self-determination and well-being with respect to medical treatment decisions, expressed through effective participation in the process of informed consent, is best advanced by the shared decisionmaking model of informed consent. Shared decisionmaking presumes that physicians will continue to make available to patients (as has been the case under existing law and medical practice) certain fundamental types of information regarding the patient's medical circumstances and the risks, benefits and burdens of treatment options, and that physicians will continue to protect the voluntariness of patient decisions. The shared decisionmaking model goes beyond this informational exchange and expresses a norm of a fundamentally interactive and collaborative physician-patient relationship. This model views both competent patients and health care professionals as collaborative moral agents with appropriate, complementary and interactive roles in the decisionmaking process.

Shared decisionmaking recognizes that each party commonly brings to the physician-patient relationship special knowledge that the other lacks. While the physician possesses medical knowledge and skills, as well as a set of professional values and goals, without which the patient cannot make an informed decision, the patient possesses knowledge of his or her own personal values and goals without which the risks, benefits and burdens of proposed treatment options, and therefore the patient's true wishes and best interests, cannot be meaningfully evaluated.[3] Shared decisionmaking encourages both patients and physicians to discuss the patient's personal values and goals, as well as his or her particular needs and concerns, including, for example, personal fears or religious beliefs which at times influence, and perhaps at other times determine, the treatment decision. Through a process of conversation, both patients and physicians are afforded meaningful opportunities to work together to enhance mutual understanding of what each uniquely contributes to the decisionmaking process and to the

physician-patient relationship, thereby creating a more effective basis for active patient participation in health care decisionmaking. This process of dialogue also provides a stronger basis for the physician to come to understand and respect the patient as a person and the values and objectives underlying the treatment decisions of that person, and encourages patients and physicians to pursue and define a mutually agreeable relationship premised upon mutual respect and communication.

The norm of shared decisionmaking is also intended to promote the related, and intrinsically important, value of trust within the physician-patient relationship. The recent history of health care is marked by, among other things, the effects of the increasingly complex consumer-oriented and often litigious society in which we live. A number of factors, including the evolution of medical malpractice law (where significant disparities have emerged between the philosophical basis of informed consent and its legal reality, resulting in part from the nature of the adversarial litigation process), the growth in medical malpractice claims, rising insurance costs, economic constraints, extensive specialization and fragmentation in medical care, and an increasingly mobile society in which long-standing relationships with a family physician are no longer the norm, have all contributed to significant and continuing changes in the nature of the physician-patient relationship. These factors and perceptions contribute to a contractual consumer-oriented conception of the physician-patient relationship characterized by an arm's length encounter between physicians and patients, in which the patient is reduced to the consumer and the physician is reduced to the provider of medical services, the "body mechanic".[4] Furthermore, the attitude of health care professionals in general toward the provision of health care has come to be heavily influenced by a familiar and pervasive (though often exaggerated) fear of legal liability. As a consequence, the fundamental bond of trust between physician and patient, historically a hallmark of medicine, has been challenged.

Neither the perception of the patient as consumer nor that of the physician as technician or body mechanic promotes the mutual respect and collaborative interaction characteristic of a *fiduciary* relationship. As a non-adversarial, non-contractual model of the physician-patient relationship, shared decisionmaking seeks to restore and promote a norm of trust within that relationship. Willingly engaged in a continuing dialogue based upon mutual respect and participation, it is hoped that the essential bond of trust within the physician-patient relationship will be developed and nurtured in a way mutually satisfactory to physicians, patients, health care representatives and families, and that participants in the decisionmaking process will increasingly be able to view their interactive relationships as caring, collaborative, and fiduciary in nature. The Commission's recommendations are intended to afford physicians, patients, families and health care representatives substantial latitude and flexibility in developing, defining, and redefining the nature of this relationship.

Finally, the process of dialogue and interaction characteristic of shared decisionmaking is properly sensitive to the clinical realities of medical practice and health care decisionmaking. Clearly, many treatment decisions involve discrete events in which a few (or even one) conversations occur at particular times (perhaps in a single day) and consent to treatment is obtained. This episodic conception of health care decisionmaking underlies the core elements of

informed consent, with their emphasis on the physician's disclosure of information (along with the physician's recommendations) and the patient's authorization of a course of treatment. Yet, health care often involves a continuous *process* of interaction among patients, families and health care professionals over time. It is common for treatment plans to evolve and change over time as the patient's condition evolves and tests and treatments provide additional or new information relevant to a treatment decision. Moreover, patient care frequently involves a continuing and dynamic process in which patients, families and health care providers are confronted with a number of decisions of greater and lesser consequence in response to evolving medical circumstances. Understanding health care as a continuous process is especially appropriate to care of the chronically ill, and of patient care in nursing homes and other long-term care facilities. Shared decisionmaking is better suited to the process-oriented nature of health care, for it encourages continuing dialogue and facilitates mutual understanding between physician and patient over the course of the patient's treatment and care.[5]

The Legal Norm of Informed Consent

In contrast to the ethical norm of shared decisionmaking, it is the legal norm of informed consent and the model of the physician-patient relationship which it promotes that is most familiar to health care professionals. The Commission believes that the law of informed consent falls short of fulfilling its professed commitment to the protection and promotion of meaningful patient self-determination, and provides at best an imperfect approximation of the ideal for the physician-patient relationship. Therefore, this section briefly summarizes the law of informed consent in New Jersey and identifies the most important features which distinguish the ethical norm of shared decisionmaking from the legal norm of informed consent.*

Under the law of New Jersey, like that of most states, failure to obtain a patient's informed consent is a species of professional medical malpractice law and is governed by rules and principles of negligence law.[6] Under traditional negligence principles, to recover damages the plaintiff-patient must prove four elements of the cause of action: 1) that the physician owed a duty of care to the patient; 2) breach of that duty; 3) injury or harm; and 4) that breach of the physician's duty was the cause of harm to the patient.[7] To recover damages for a physician's provision of treatment (most often the cases have involved a surgical procedure) without consent, a patient must show that the physician has violated a duty. The law has framed this duty in terms of a duty to disclose medical information, often with a heavy emphasis on the disclosure of risks associated with proposed treatment alternatives.[8] The patient must also show that as a result of the nondisclosure of a particular risk, the patient consented to a procedure or course of treatment to which he or she would not have given consent if properly informed of this risk. Rephrased, the patient must show "that the physician violated a legally established duty to disclose a particular risk, that the undisclosed risk materialized in a physical injury, and that the

* Since the focus of the Commission's recommendations is health care decisionmaking for patients who lack decisionmaking capacity, and specifically the role of advance directives for health care, a thorough examination of the legal and ethical implications of the informed consent of the competent patient (the patient with decisionmaking capacity) in the physician-patient relationship is beyond the scope of this report.

failure to disclose "caused" the patient to consent to a procedure which otherwise would have been rejected."[9] *

The recent decision of the New Jersey Supreme Court in *Largey v. Rothman*[10] reviews the law of informed consent. In *Largey*, the patient's principal contention was that the physician had negligently failed to warn her of the risk of lymphedema presented by the excision of lymph nodes during a biopsy of the breast, and that her consent to the operation was therefore uninformed. Thus, the central legal issue before the Court was the appropriate standard by which to measure the physician's duty of disclosure.[11] In *Largey*, the Court adopted the so-called "objective reasonable patient" standard of disclosure, overruling its decision twenty years earlier in *Kaplan v. Haines*[12] which had adopted a "reasonable physician" standard (a so-called "professional standard").[13]

The physician's duty of disclosure is intended to "enable the patient to make an evaluation of the nature of the treatment and of any attendant substantial risks, as well as of available options in the form of alternative therapies."[14] A risk is "material" to the patient's decisionmaking process, and therefore must be disclosed, "when a reasonable patient, in what the physician knows or should know to be the patient's position, would be 'likely to attach significance to the risk or cluster of risks' in deciding whether to forego the proposed therapy or to submit to it."[15] Thus, the extent of the physician's duty to disclose information to the patient is not determined by what the reasonable physician would disclose under the circumstances (or by customary medical practice, another application of the professional standard),[16] nor by the personal, specific and perhaps idiosyncratic informational needs of the particular patient, but rather by what the hypothetical reasonable or prudent patient likely would need to know to make an informed decision under the circumstances.[17] In reaching this conclusion, the New Jersey Supreme Court joins a long line of courts which have followed the rationale of *Canterbury v. Spence*,[18] the leading case adopting the reasonable patient standard of disclosure.**

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* The doctrine of informed consent which has evolved as a species of negligence law should be distinguished from the legal doctrine of battery which has played, and to a lesser extent continues to play, a role in structuring the physician-patient relationship. A battery is any intentional touching or invasion of bodily integrity without consent. The theory of battery and the basis of recovery in a legal action is predicated upon the physician's intentional invasion of the patient's right to bodily integrity. W. Page Keeton, Dan B. Dobbs, *et al.*, *Prosser and Keeton on Torts* (West Publishing 5th ed. 1984), pp. 39-42. In contrast to a claim of negligence, which typically focuses upon the adequacy of the physician's disclosure in fulfillment of a duty to provide medical information and to obtain the patient's *informed* consent, a claim of battery most often alleges that no consent was given at all, or that the actual procedure performed was substantially different from the procedure to which the patient gave consent. Although some states have abolished the patient's right to sue for battery where the physician allegedly failed to obtain consent, most states, including New Jersey (*see Perna v. Pirozzi*, 92 N.J. 446, 457 A.2d 431 (1983)), still permit an action in battery.

** Adoption of the *Canterbury* approach to informed consent suggests an unresolved tension between the Court's position on informed consent and its expressed commitment to thoroughgoing self-determination in its treatment refusal decisions. In *In re Conroy*, 98 N.J. 321, 486 A.2d 1209, 1229 (1985), for example, the Court emphatically states: "The standard we are enunciating is a subjective one, consistent with the notion that the right that we are seeking to effectuate is a very personal right to control one's own life. The question is not what a reasonable or

For the present purposes, only a few brief points of comparison between the New Jersey law of informed consent and the norm of shared decisionmaking are warranted.[19] There are several respects in which the law of informed consent, with its emphasis upon the physician's duty of disclosure, in particular the duty to disclose risks of proposed treatment alternatives, promotes an essential core interaction within the physician-patient relationship. The law plays an important role in seeking to assure (albeit not always successfully) that a patient is provided all relevant information and gives an *informed* consent. Absent a professional duty of disclosure, patient self-determination would have little meaning. To its credit, the law of New Jersey has gone a step in the right direction in its commitment to self-determination by definitively rejecting the more traditional professional standard of disclosure in favor of a standard which focuses on the informational needs of patients.

However, the legal model fails in significant respects to fully promote the values underlying the norm of shared decisionmaking. By focusing upon the informational needs of the hypothetical reasonable patient the law requires the physician to make a judgment about what the ordinary reasonable or prudent person in the patient's circumstances would likely need to know to make a treatment decision. The law does not require disclosure of information attentive to the particular and personal needs of patients whose values, objectives, fears and concerns may not be identical with those of the average reasonable or prudent patient acting under the same or similar circumstances. Yet, fundamentally important informational needs of patients may differ in accordance with highly personal beliefs or unusual family circumstances. Thus, the reasonable patient standard of disclosure does not fully encourage physician disclosure responsive to the personal values, goals and concerns of each patient, or to the especially personal nature of the evaluation of risks, burdens and benefits essential to reaching a treatment decision.[20] The reasonable patient standard of disclosure represents only a partial and imperfect fulfillment of the law's professed goal of self-determination.

In the Commission's view, however, the most significant distinguishing feature of the two models is the way in which each structures the physician-patient relationship. The law's emphasis upon a duty of disclosure, whatever the legal standard, promotes an interaction of disclosure and consent which has done little to foster a continuing process of conversation and communication between physician and patient. Rather than advancing a relationship of shared moral agency, the law more often fosters an interaction in which physician and patient are viewed (and view themselves) as parties to a contract in which each is alternately vested with independent moral agency and authority. Disclosure without mutual communication is not designed to be attentive to particular and personal patient needs and may fail to explore and

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average person would have chosen to do under the circumstances but what the particular patient would have done if able to choose for himself." This commitment to patient self-determination was reaffirmed and emphasized in the Court's trilogy of refusal-of-treatment decisions in *Farrell*, *Peter*, and *Jobes*. This tension was recognized in *Cheung v. Cunningham*, 214 N.J. Super. 649, 520 A.2d 832 (1987), where the court, following *Conroy's* commitment to self-determination, rejected the *Canterbury* approach in favor of a more individuated patient-oriented standard of disclosure attentive to the informational needs of the individual patient. *Cheung* was overruled on this point in *Largey*, 540 A.2d at 511.

enhance the patient's level of understanding of the available treatment options, their associated risks and benefits. In short, the physician-patient relationship is often characterized by physicians "talking at and not with patients."[21] As a consequence, both patient self-determination and patient well-being are compromised. Furthermore, a relationship in which health care providers, in particular physicians, feel overly (and sometimes misguidedly) constrained to focus upon compliance with a legal duty of full disclosure, but are not encouraged to go further to engage in shared conversation and collaboration with the patient, does little to foster a bond of trust between physician and patient. The ethical norm of shared decisionmaking responds to these shortcomings of the legal norm by suggesting a different model of interaction and communication between physicians and patients based upon shared moral agency and collaboration in the process of health care decisionmaking.*

The Commission's recommendations represent an innovative effort to build upon the conceptual foundation of shared decisionmaking by applying this ethical norm to the difficult problem of health care decisionmaking for the patient who lacks decisionmaking capacity. As discussed in the next section, the Commission's recommendations and proposed legislation are designed to establish a framework for a sound decisionmaking process which promotes the objectives of advance directives, most importantly assuring respect for patients' expressed wishes even after capacity to actively participate in health care decisionmaking has been lost or impaired. The meaning of shared decisionmaking and the respective roles of the health care representative, physician and others is further examined in subsequent sections of this chapter.

Advance Directives: An Integrated Approach

Advance directives allow individuals to express their wishes and control their own health care decisions in the event of future loss of decisionmaking capacity. In this event, the process and results of shared decisionmaking in which the patient's values and objectives continue to play a substantial role can be approximated through the execution of an advance directive. To this end, the patient's designated health care representative is viewed as the central figure in the decisionmaking process with both the right and responsibility to work collaboratively with health care professionals and to give informed consent or refusal on the patient's behalf. As discussed below, in the Commission's view the goals of a shared decisionmaking process and the objectives of advance directives are best achieved through execution of an integrated advance directive, *i.e.*, designation of a health care representative coupled with a written instruction directive. The legislative proposal is intended to encourage (but not to require) individuals to take this integrated approach to writing an advance directive.

The Objectives of Advance Directives

Advance directives serve several important and interrelated objectives. The primary (and

* The law of informed consent also suggests a conception of health care decisionmaking as a set of isolated events which precipitate occasions for physician disclosure and patient consent. While this is certainly true of many physician-patient encounters, as discussed above, the delivery of health care is often more process-oriented, involving a number of decisions in response to evolving medical circumstances.

most familiar) objective of advance directives is to allow individuals to exercise their rights to plan ahead for and control decisions about their own health care in the event of subsequent loss of decisionmaking capacity. As a legally recognized mechanism for expressing one's wishes and making those wishes "count" in the process of health care decisionmaking, an advance directive extends patient autonomy and control. Since individuals ordinarily are the best judges of their own interests, in terms of their own values and goals, by extending patient autonomy advance directives also promote the equally important end of patient well-being. In turn, advance directives often serve to relieve patient anxiety or concern that unwanted medical treatments will be provided, or desired treatments withheld, when the patient is no longer able to make informed decisions.

In addition to these fundamental patient-centered objectives, advance directives serve the interests and goals of other participants in the decisionmaking process. Absent written directions or other statements expressing the patient's wishes, family members and physicians can have a difficult time determining which course of treatment and care is consonant with the patient's wishes and best interests. Advance directives provide needed direction and guidance, thereby reducing uncertainty, relieving (at least to some extent) possible guilt feelings among loved ones, and reducing family disagreement and strife which may occur when difficult decisions are confronted. Advance directives also can relieve physician anxiety concerning potential legal liability, particularly where a health care representative has been designated with legal authority to give informed consent or refusal. Thus, by informing physicians, family and others responsible for the patient's future health care of the patient's wishes, advance directives can increase family and physician confidence in treatment decisions and can ease the burdens which responsibility for the patient's care may impose.[22]

The Commission's approach to advance directives is designed to promote these important values and objectives, and to do so by fostering the related and independently important goal of structuring a sound decisionmaking process when the patient is no longer able to actively participate in health care decisionmaking. By establishing a statutory framework for the writing and implementation of advance directives, including legally recognized formalities for execution of such documents, the legislative proposal would both enable and encourage advance planning for future health care needs. Statutory law also functions as an important educational vehicle, and should alleviate both public and professional uncertainty under existing law regarding the legal status of advance directives and professional obligations to honor such documents.

An Integrated Approach

At present, 43 states and the District of Columbia have advance directives legislation.[23] State statutes, commonly referred to as "living will" laws, provide for two types of advance directives--an instruction directive, popularly known as a living will,* and a medical durable

* The Commission has avoided use of the term "living will", and refers to documented instructions for health care as an "instruction directive". This is a deliberate effort to avoid ambiguous and possibly confusing references to a "living will" as a document commonly and narrowly understood to instruct the withholding or withdrawal of life-sustaining treatment. The term "living will" also is commonly identified with a specific model document

power of attorney, also known as a "proxy directive". Since California first authorized living wills by statute in its 1976 "Natural Death Act",[24] the majority of states have followed the instruction directive approach. The recent trend has been to authorize proxy directives, either in a separate medical durable power of attorney statute,[25] or in a proxy provision of a living will statute.[26*]

The Commission's conclusions are in accord with this recent trend, and with the conclusions of the President's Commission[27] and the New York State Task Force on Life and the Law,[28] in giving priority to the durable power of attorney for health care as the essential means of achieving the objectives of advance directives. The Commission's approach goes further than existing legislation in other states in combining elements of both types of advance directives into an integrated "package". This type of advance directive "package" is envisioned as the preferred means of promoting the twin values of patient self-determination and well-being (grounded in the patient's own values and objectives) in the event of the patient's decisionmaking incapacity. Accomplishing the important objectives of advance directives will require careful planning and judgment in the preparation of advance directives. The Commission plans to make strong efforts through public and professional education to encourage, support and facilitate this integrated approach.

The value of this integrated approach and the special role for the health care representative is revealed by examining some of the advantages and disadvantages of either approach alone. While the Commission believes that both proxy directives and instruction directives should be legally recognized means for advance health care planning, and provides for this in its legislative proposal, the deficiencies of each type of document alone, in particular the instruction directive, evidences the value of an integrated approach.

Instruction Directives

Widespread legal recognition of instruction directives has become an important vehicle for patients to exercise the right to control their own health care decisions when capacity to decide is lost or impaired. Experience demonstrates, however, that the instruction directive alone may fail to adequately achieve the central goals of patient self-determination and patient well-being (as well as the other objectives of advance directives). Criticism of instruction directives based upon this experience has focused upon the difficulties of interpreting and applying static written directives, and upon the related concern that since instruction directives are often written remotely in time from the current circumstances, they may fail to provide a sound basis for

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(promulgated by a private organization).

* All 50 states have general durable power of attorney laws. These statutes generally apply to delegation of authority to make personal, business or financial decisions. Although some durable power of attorney laws expressly apply to health care decisions, unlike health care proxy laws, none provide further guidance nor establish conditions for the exercise of this authority. New Jersey's durable power of attorney law, *N.J.S.A.* 46:2B-8 *et seq.*, does not refer to health care decisions. However, under *In re Peter*, 108 N.J. 365, 529 A.2d 419 (1987), that statute does authorize use of a durable power of attorney to delegate authority to make health care decisions.

contemporaneous decisions.[29]

Instruction directives most often are written well in advance of the time when they become operative, often when the individual is in good health and without the information and insight derived from actual experience of a serious illness. In formulating an instruction directive an individual typically is called upon to anticipate or foresee an indeterminate range of medical conditions, along with treatment options for each, which may occur in the future. Even where the patient is well informed and possesses a good understanding of medical information concerning a particular illness or illnesses at the time an instruction directive is executed, medical circumstances may not turn out to be exactly as contemplated. The patient's illness may involve unforeseen complications or other factors; thus the available treatment options, as well as the patient's prognosis, may have changed since execution of a patient's written instructions. New therapeutic options may become available, changing the patient's prognosis from that previously contemplated. Indeed, the progress of medicine in the 20th century suggests that what is state of the art medicine in 1990 will not be state of the art medicine (and may even be obsolete) by the year 2000. In short, individuals cannot be expected to possess perfect foresight which anticipates all aspects of their future health care needs, nor to always express their wishes in clear and unambiguous language.

Since an instruction directive is by nature a static written document, it cannot embody contemporaneous decisions, nor does it possess the flexibility needed to adjust its content and meaning to the actual medical circumstances with which the patient is later confronted. Thus, there are intrinsic limitations to the use of instruction directives to anticipate and respond to future medical circumstances.* The most familiar practical problem with instruction directives is that they too often are ambiguous or otherwise difficult to apply when they become operative. This results in part from the writing being remote in time, but also from the language used in the typical instruction directive. Most familiar are documents instructing that the patient not receive "extraordinary" or "heroic" measures.[30] Yet, the meaning of these terms is necessarily relative to and dependent upon the patient's current medical condition and treatment options.[31] Further, the meaning attached to such terms by the patient may be different from the interpretation of health care professionals, who "are often going to interpret the key words according to what they already think it best to do. In this way they might at times do less than the patient might have wished, and at other times much more."[32]

To some extent greater specificity and detail in instruction directives, as well as avoiding ambiguous terms, would address practical concerns about interpretation and increase respect for patient wishes. The Commission believes that specific instructions regarding particular medical circumstances and particular life-sustaining measures, such as cardiopulmonary resuscitation (CPR) and artificially provided fluids and nutrition, would be especially useful and should be

* One suggested (partial) response to this problem is to require an individual to periodically re-execute or reaffirm an advance directive. The Commission rejects a legal requirement of re-execution or reaffirmation on the ground that such a requirement would unduly limit the goal of patient self-determination. The Commission does, however, recommend that an individual periodically review and reaffirm or modify his or her advance directive.

encouraged. However, specificity assists only within the practical limits imposed by the need to anticipate a wide range of future contingencies.[33]

Given these intrinsic limitations, an instruction directive may not adequately approximate the contemporaneous understanding and deliberation characteristic of the informed consent process. An individual will not be fully informed in advance of each of an indeterminate range of contingencies, nor able to provide clear written instructions for each with sufficient confidence that at the time these wishes are to be followed they will still reflect informed and accurately expressed choices. Thus, whether an instruction directive truly promotes self-determination in accordance with the patient's informed wishes will vary with the extent to which the directive anticipates the patient's medical condition and provides clear guidance for health care decisions.

Furthermore, as with informed consent, it is assumed that patients ordinarily are the best judge of their own interests and act to promote their own best interests. Respect for self-determination most often serves the end of patient well-being. Yet, this assumption is generally less valid when health care professionals are called upon to implement an instruction directive.[34] Future health care choices ordinarily evaluate the benefits, risks and burdens of what medicine has to offer based upon today's medicine, and upon current perceptions of the meaning of such abilities as physical activity, job performance, or family involvement, and the experience of various sources of pleasure and enjoyment. Where what medicine has to offer has changed radically, prior written directives may run contrary to the patient's present interests. At times, instruction directives will need to be interpreted more flexibly than the document itself allows, and in some cases should be overridden to protect patient well-being.[35]

In sum, concerns about instruction directives rest on recognition of the limitations of a static written document which attempts to provide specific direction and guidance for future health care decisions. These concerns bespeak the need for flexibility in implementing the patient's wishes and promoting well-being in a manner responsive to the patient's current medical circumstances and interests. They also raise the question of who should have authority to interpret the patient's prior instructions. These concerns have been the major impetus underlying the recent trend favoring use of the proxy directive.

Proxy Directives: Designation of a Health Care Representative

The contemporaneous role of the health care representative responds to the difficulties which may arise with instruction directives. Most often we look to close and trusted loved ones to act on our behalf when unable to make our own health care decisions. Whether family member, friend or trusted advisor[36], the key factor is that one's health care representative know the patient and his or her values and that there be a bond of trust between patient and health care representative.[37]

A personally selected and legally authorized representative will ordinarily be quite familiar with the patient's values, objectives and previously expressed wishes. Charged with the responsibility of "standing in the shoes" of the patient, the health care representative will be well-situated to understand and faithfully implement the patient's wishes in a flexible and realistic

way, duly attentive to the patient's actual and contemporaneous medical circumstances. The health care representative can resolve potential ambiguities or uncertainties in the patient's instruction directive by bringing to bear personal knowledge of the patient in the current interpretation of the written instructions, and can do so in a manner responsive to medical circumstances and treatment options not previously contemplated by the patient. As a consequence, the need to anticipate an indeterminable range of future contingencies, a problem with instruction directives, is largely alleviated by the presence of the health care representative.

Furthermore, with the presence of the health care representative, "(h)ealth care professionals can rely on the [representative's] interpretation with greater confidence, both that they are honoring the patient's wishes, and that they are acting lawfully."[38] Thus, the contemporaneous role of the health care representative provides greater assurance that the patient's wishes will be honored. In most cases, the health care representative is also the best person to decide, based upon his or her personal knowledge of the patient, that the instruction directive is contrary to the patient's best interests and should not be followed. Finally, the continuing role of the health care representative assures continuity of care and of decisionmaking authority during the course of the patient's care, and allows numerous collateral decisions which may not be addressed in an instruction directive to be made as clinical circumstances develop over time. For these reasons, a health care representative is generally best situated to understand and evaluate the patient's values and objectives in a flexible and realistic way, duly attentive to the patient's actual and contemporaneous medical circumstances, including changing medical information and possible courses of treatment and care, and to give due weight to these factors in reaching a treatment decision.

The proxy directive does, however, raise some important concerns. A proxy directive alone usually gives broad authority to the health care representative without the benefit of specific direction. Yet, this approach may not adequately assure that the health care representative is informed and knowledgeable about the patient's wishes. In addition, absent written direction from the patient regarding treatment preferences, health care professionals may have little independent basis to judge whether the representative is faithfully stating and implementing the patient's wishes. Furthermore, in particular cases the health care representative may not advance the patient's wishes and best interests. In some instances, the psychological and emotional burdens of decisions at the end of life, as well as personal values, may unduly influence even the most devoted family members.[39] In rare cases, the health care representative may have a significant conflict of interest or may act out of self-interest or ill motive.

While few argue that these concerns undermine the validity of proxy directives, many believe that the possibility for the health care representative to improperly exercise or abuse his or her discretion warrants procedural safeguards which can be invoked in particular cases to provide additional review where serious concerns arise. The Commission shares this concern, and recommends that health care institutions establish local review mechanisms (a dispute resolution process) to which those responsible for the patient's care can look in the event of disagreement or conflict.

The Integrated Approach

The Commission believes that an integrated directive is an effective response to the shortcomings of using either an instruction directive or a proxy directive alone. Informed by both written and personal knowledge of the patient's wishes, values and objectives, the contemporaneous role of the health care representative provides the flexibility in the decisionmaking process necessary to ensure an effective role for the patient's wishes attentive to current medical circumstances. As discussed more fully below, the legislative proposal seeks to structure a decisionmaking process which fosters the implementation of advance directives while providing appropriate safeguards for review in cases of disagreement or possible wrongdoing.

Requesting Life-Sustaining Measures

One additional point about the Commission's approach to the nature of advance directives warrants emphasis here. The Commission has been particularly attentive to the importance of facilitating the use of advance directives to direct the provision of life-sustaining measures, as well as to forego such measures. The majority of advance directive laws recognize the individual's right to direct that life-sustaining measures be withheld or withdrawn, usually in the narrow circumstances of terminal illness (as variously defined by statute) and sometimes in the case of permanent unconsciousness. Although none of these statutes prohibit individuals from requesting life-sustaining measures, and there seems little reason to believe at this time that an advance directive affirmatively requesting that the patient be kept alive would not be respected,[40] only a handful of state statutes expressly authorize use of advance directives for this purpose.[41] The Commission believes that statutory law in this area should expressly recognize and facilitate use of advance directives to state specific instructions that life-sustaining measures be provided. This aspect of the Commission's legislative proposal forthrightly acknowledges the range of values within our pluralistic society, and fosters patients' rights to choose continued life in various circumstances, in accordance with their own values and objectives. This feature of the proposal also anticipates that emerging trends in health care, including greater awareness that continued treatment may not always be in the patient's best interests; growth of the hospice model of supportive care; and social and economic constraints to limit treatment, control the costs of care, and adjust present day allocations of health care resources, may increasingly constrain health care delivery in the direction of limiting treatment. Express statutory recognition of the right to request treatment seeks to assure respect for patient wishes in this regard in the face of competing demands on the health care system.

Triggering an Advance Directive: Decisionmaking Capacity

Once an advance directive has been transmitted to the attending physician or to the health care institution, it becomes legally operative only upon a determination that the patient lacks capacity to make a particular health care decision on his or her own behalf.* So long as the

* As discussed below, in order to facilitate transmittal and communication of advance directives, the proposed legislation would impose upon physicians a duty to make affirmative inquiry of patients and families to determine whether the patient has executed an advance directive, and would also require health care institutions to adopt policies and practices necessary to establish routine inquiry to determine whether patients have advance directives.

patient retains capacity with respect to a particular health care decision, the patient continues to possess the legal and moral right to make his or her own health care decisions, and neither the designated health care representative nor the instruction directive is legally operative. Where it is determined that the patient lacks capacity to make a particular health care decision, the locus of decisionmaking authority changes.* A determination that the patient lacks capacity to make a particular health care decision "triggers" the operation of an advance directive, and the legal and moral role of the health care representative in the decisionmaking process.**

Capacity as Decision-Specific

As used by the Commission, decisionmaking capacity is primarily a functional and decision-specific concept. Judgments of incapacity require a context within which the individual's abilities are to function. Ordinarily, when we speak of someone as lacking capacity, we judge the person to be without capacity to perform a particular task or function, or to make a particular range of decisions, but not to be generally incapacitated. A person could have capacity to manage one's financial affairs, to drive a car, or to perform one's job, or might possess capacity to perform some but not all of these tasks or functions (for example, to drive a car but not to manage personal finances).[42]

Similarly, a patient may possess the capacity to make some treatment decisions but not others. For example, a patient may be able to engage in the relatively simple deliberative process required to accept routine pain medication, yet lack the ability to effectively deliberate about a proposed surgical intervention, including the risks, benefits and burdens of the procedure and the demands of possible changes in lifestyle following a successful surgery. In fact, the majority of patients for whom decisionmaking capacity is compromised or lacking possess some level of interactive abilities and have "impaired capacity". Total lack of decisionmaking capacity is much more the exception than the rule. Many patients whose mental abilities are impaired experience intermittent periods of lucidity and mental function and may possess decisionmaking capacity one day, yet clearly lack that ability the next ("fluctuating capacity"). This may be due, for example, to the patient's medical condition (such as organic brain syndrome), to certain effects of the patient's illness (such as severe pain or fatigue), or to the effects of treatment (such as the effects of pain medication on mental alertness and function). Other patients are able to

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* In the absence of an advance directive, a determination that the patient lacks decisionmaking capacity raises somewhat different issues regarding the authority and role of family members in making decisions on the patient's behalf. The absence of an advance directive may also raise the often difficult questions of how to determine the patient's true wishes with respect to treatment, and, if the patient's wishes cannot be determined, what treatment decision is in the best interests of the patient. Although these issues are beyond the scope of this report, as discussed in Part Six of the report, the Commission will address these important issues in the next phase of its work.

** The Commission's approach to the problem of decisionmaking capacity is intended at this time to apply in the context of advance directives for health care, and should not be interpreted as recommending changes in existing law or practice in other areas where a different process, such as a formal court determination, may be required. The Commission plans in its future work to examine the problem of decisionmaking capacity in other contexts.

exercise the requisite abilities to make some treatment decisions but not other more complex or consequential decisions ("diminished capacity").

The reality of fluctuating or diminished capacity among seriously ill patients further emphasizes the importance of viewing decisionmaking capacity as a decision-specific (and time-specific) concept. A patient's incapacity to make one health care decision does not mean that the patient necessarily lacks capacity to make another health care decision. If, for example, a patient has sufficient capacity to accept or reject pain medication, that decision should be respected. Yet, that same patient may lack capacity to consent to or refuse surgery, due, for example, to lack of cognitive ability to understand the associated risks or to psychological factors such as fear or denial.[43] Decisionmaking capacity should be understood and applied as a matter of functional ability to make a particular health care decision. Decisionmaking capacity does not depend upon the patient's general mental status, nor upon particular patient characteristics, such as age or disability.

Capacity and competence. Use of the terms "capacity" and "incapacity" rather than the terms "competence" and "incompetence" is deliberate. The term competence is frequently thought of as a legal concept, most often associated with a threshold determination by a court of a person's capacity to make particular types of decisions, usually business or financial decisions. A person ordinarily is presumed competent; a finding of incompetence divests the individual of the legal authority to make one's own decisions and manage one's own affairs, and reposes this authority in another, usually a family member or other court-appointed guardian. In the context of health care decisionmaking, the concepts of competence and incompetence are sometimes employed to separate patients into two sharply differentiated groups: Those from whom consent must be obtained (absent, for example, medical emergency) and those who, in blunt terms, can be and often are ignored in the decisionmaking process. Value judgments based on practical or policy reasons, most often protection of the patient's interests, are thought to warrant designation of another to assume decisionmaking authority on behalf of the incompetent patient.[44] The Commission's decision-specific approach to the problem of decisionmaking capacity rejects the concept of competence (capacity) as one which separates patients into two sharply differentiated groups, and avoids use of the terms "competence" and "incompetence" which convey this meaning.

Defining and Assessing Decisionmaking Capacity

The concepts of decisionmaking capacity and incapacity are at best vaguely defined in existing statutory and common law. The Commission's approach seeks to capture the essential features of our common understanding of what it means to make health care decisions.

Health care decisionmaking for the typical patient ordinarily involves several interrelated elements. First, to possess sufficient capacity to make a health care decision, the patient must *possess and be able to act upon personal values, preferences and goals*, including objectives for treatment. These values, preferences and goals may be somewhat idiosyncratic, and need not correspond precisely to mainstream views of health care professionals or the wider society, though generally the patient's personal views should be "intelligible" to others in terms of shared

values or a shared sense of the good.

Second, the patient must possess the capacity *to understand and to evaluate information* relevant to his or her medical condition, including (in lay terms) diagnosis, prognosis, and the risks, benefits and burdens (and associated uncertainties) of the proposed treatment alternatives (including the option of no treatment). The patient who does not comprehend and appreciate the nature of his or her medical condition and the nature of the treatment options cannot be said to give informed consent or to make an informed refusal with respect to that particular treatment decision.

Third, the patient must possess the capacity *to reason and deliberate* about available medical information and a course of treatment within the context of personal values, preferences and goals. The critical factors here are that the decision, including the relative importance assigned to the risks, benefits and burdens of the treatment alternatives, is grounded in and informed by the patient's personal values and objectives, and that the decision results from a rational deliberative process that is based upon intelligible (even if not universally shared) reasons. Thus, the critical factor is *not* whether others, particularly health care professionals, necessarily agree with the content of the patient's decision. Of particular importance in this context, a patient's decision to reject a burdensome intervention and to accept a shorter life expectancy when confronted with a serious life-threatening disease, or to reject an undesired prolongation of a burdensome dying process, is not in and of itself conclusive evidence of decisionmaking incapacity.[45]

Assessing the patient's decisionmaking capacity requires a delicate balancing between the health care professional's twin obligations to respect patient self-determination (in terms of the patient's values and treatment objectives) and to promote patient well-being. Judgments of decisionmaking capacity should seek as much as possible to avoid two types of errors. On the one hand, an unfounded determination of incapacity results in denying the patient the legal and moral right to have his or her personal and contemporaneous wishes respected. On the other hand, uncritical compliance with the patient's wishes where decisionmaking capacity is questionable may at times carry serious consequences for the patient's well-being.[46] Thus, these twin duties may include protecting seriously compromised patients from the harmful consequences of poorly thought through or irrational decisions which result from diminished capacity and do not necessarily reflect full or true autonomy.[47] Both unfounded determinations of incapacity, with their resulting failure to respect truly autonomous patient decisions, and uncritical compliance with a patient's stated preferences, without adequate evaluation of the patient's decisionmaking capacity, can be seriously harmful to the patient's true autonomy and best interests.

Initiating the inquiry. Since decisionmaking capacity is the touchstone of the patient's retention of decisionmaking authority, and (where capacity is lacking) of the legal and moral role of the health care representative in the decisionmaking process, physicians and other health care professionals should be alert to the possibility of decisionmaking incapacity. In practice, some assessment of the patient's decisionmaking capacity often occurs implicitly within the context

of the physician-patient relationship. As a general matter, physicians should raise the question of capacity and engage in a more thorough assessment when substantial deficits in capacity are apparent.[48] Physicians should be alert to particular factors warranting a closer look at the patient's decisionmaking capacity, and should seek out and be attentive to relevant input from other health care professionals responsible for the patient's care.

Decisionmaking capacity ordinarily is questioned by physicians only when patients make decisions that are medically contraindicated or with which the physician disagrees. This practice has been widely criticized, particularly in the context of decisions about life-sustaining treatment, as a potential mechanism to deprive patients of their moral and legal right to self-determination when the physician disagrees with the patient's decision. Here it is important to distinguish initiating an inquiry concerning decisionmaking capacity from making a judgment of incapacity and the criteria for such a judgment. There is good reason to view refusal of life-sustaining treatment in the face of a contrary recommendation by the physician as a ground for further inquiry into the patient's decisionmaking capacity. Since a physician's recommendation of treatment ordinarily is in the medical interests of the patient, it will often appear that the patient's refusal of life-sustaining treatment is or may be contrary to the patient's interests. Thus, while refusal of life-sustaining treatment is not itself sufficient ground for a determination of incapacity, a patient's decision to refuse life-sustaining treatment should be a call to further conversation between physician and patient before such a decision is implemented.

Physicians should also protect patient self-determination and well-being by being alert to patient decisions made for highly unusual or bizarre reasons, or due to pathologic conditions, and by seeking to determine whether such reasons or influences have impaired the patient's ability to properly assess the risks, benefits and burdens of proposed treatment alternatives. In fact, this makes explicit what often occurs in practice. Patient preferences and decisions based upon highly unusual or bizarre reasons are a red flag to physicians that decisionmaking capacity is questionable and should be more closely considered.[49]

Standards of capacity

A *standard* of decisionmaking capacity refers to the level of abilities requisite to a particular decision a patient must be able to act upon in order to be judged to possess decisionmaking capacity. As discussed above, the relevant abilities are those of being able to understand, evaluate and act upon relevant medical information within the context of personal values and objectives to make a particular health care decision. Yet, this definition itself provides no means of measuring what level of these abilities is sufficient to possess decisionmaking capacity. To what degree must a patient be able to understand and reason about relevant medical information? To be able to evaluate risks and benefits in terms of his or her own values and treatment objectives? To communicate intelligible reasons for particular choices to others? Conversely, what degree of inability to perform these tasks constitutes decisionmaking incapacity?

In the Commission's view, no single articulable standard or standards of (in)capacity provides a fully satisfactory or absolute guide for judgments of capacity.[50] Therefore, a legally

mandated standard for the determination of incapacity is considered inappropriate and is not recommended. The best approach to the problem is to recall the two values at stake in capacity determinations--self-determination and well-being--and to seek in assessing decisionmaking capacity to minimize the harmful consequences that may result from errors in either direction. (Other values, such as maintaining the integrity of the medical profession and the fostering of trust between patients and physicians also are involved in choosing an appropriate approach to a standard of capacity.)

Following the President's Commission, it is recommended that a variable or "sliding-scale" concept of standards of decisionmaking capacity be adopted to guide physicians in this often difficult task.[51] This approach recognizes that the level of ability required for the exercise of decisionmaking capacity will vary with the task of making particular health care decisions and with the significance and irreversibility of the consequences of particular choices. For example, while a decision to accept or reject minor surgery may require evaluation of relatively simple medical information, a decision to accept or reject open heart surgery or chemotherapy often requires evaluation of more complex medical information. This approach also recognizes that as the risks attendant upon certain types of treatment decisions increases, the obligation to promote and protect patient well-being demands that the physician be more circumspect in respecting patient decisions. In short, when the consequences for patient well-being are serious, such as in the case of a patient's decision to refuse life-sustaining treatment, there is a greater need to be certain that the patient's decision is made with sufficient decisionmaking capacity. Thus, the variable scale approach acknowledges that the necessary level of decisionmaking abilities ought to increase as the complexity of relevant medical information increases and/or as the potential detriment to patient well-being increases relative to particular health care decisions.[52] This more demanding standard of decisionmaking capacity should not, however, be interpreted as a recommendation that patients who refuse life-sustaining treatment be found to lacks decisionmaking capacity. To the contrary, the definition and criteria of decisionmaking capacity make clear that neither the outcome of a treatment decision nor disagreement of that decision with the physician's treatment recommendation is itself ground for a finding of incapacity.

The Commission rejects several alternative and inflexible views of decisionmaking capacity. First and foremost, a judgment of incapacity based upon the patient's general mental status is unacceptable, short of extreme circumstances. Patients should not be presumed to lack capacity merely on the basis of fitting into a category, such as being elderly, mentally ill, retarded or cognitively disabled. Many patients whose decisionmaking capacity is affected by old age or disability nonetheless possess sufficient capacity to make some or all of their own health care decisions, and such decisions are morally, and may be legally, entitled to respect.[53] Of course, at least one category of patients, the permanently unconscious, clearly lacks decisionmaking capacity. But within the total patient population, the permanently unconscious patient is rare.*

* Young children raise some different concerns about status and decisionmaking capacity. The Commission's recommendations with respect to decisionmaking capacity are not intended to affect the existing legal framework governing the role and limits of parental authority in making health care decisions for children.

The Commission also rejects the so-called "minimalist" standard, which requires of the patient in all cases only the ability to express a preference; and the so-called "maximalist" standard, which requires the patient in all cases to reach the "correct decision" (an outcome or content standard). The minimalist position fails to recognize the complexity of various medical decisions, and overemphasizes the instrumental value of self-determination (respect for a patient's decision because it is thought, incorrectly, to best advance the patient's own conception of his or her interests) at the expense of patient well-being. In contrast, the maximalist or outcome-based position overemphasizes the value of purportedly objective judgments of the rightness of decisions (in particular the value of medical judgments) at the expense of patient self-determination, especially that aspect of respect for self-determination which requires honoring decisions based upon the patient's personal treatment objectives with which the physician may disagree.[54]

Special Concerns

That decisionmaking capacity means the ability to understand, evaluate and act upon relevant information within the context of personal values and objectives, and that the necessary level of ability may vary relative to the demands of a particular decision, expresses the core meaning of decisionmaking capacity. Yet, a determination of decisionmaking capacity should not necessarily be limited to evaluation of these abilities alone. Several types of special concerns are identifiable from clinical experience.

Psychological factors and disorders. In some cases psychological factors or disorders, such as hidden fears or denial may impair decisionmaking capacity. Some patients may appear to understand and evaluate relevant information, and to do so within the context of personal values and objectives, yet underlying psychological factors, such as fear of surgery or of abandonment by family members, may strongly influence the patient's weighing of the risks and benefits of proposed treatment alternatives.[55] Evidence of underlying psychological factors, in particular of a psychological disorder, should be taken as a call to further conversation between physician and patient.[56] But this is not in itself ground for a determination of incapacity. Individual beliefs and preferences associated with personal fears and concerns may be real and important to the patient and provide an intelligible reason for a treatment decision worthy of respect (at least considered in conjunction with other relevant information), even though considered irrational by the physician.

Chronic illness and disability. A patient's evaluation of the risks, benefits and burdens of proposed treatment alternatives ordinarily involves a look into the future; an assessment of what life will be like should a particular treatment be accepted or refused. In some cases this look into the future means a life with chronic illness or disability requiring (perhaps radical) adjustments in lifestyle and behavior. Patients confronted (sometimes suddenly) with a treatment option carrying with it the demands of radical adjustments in future occupational, familial or personal pursuits may be unaware of the full range of information and options needed to make an informed judgment to commit (or not to commit) oneself to a future life with chronic illness or disability, including, for example, the nature and availability of rehabilitative treatment and therapy and of other support services.

Those responsible for the patient's care should seek to enhance the capacity of such patients to make *informed* choices from among reasonable and available treatment options. In particular, efforts should be made to assure that the decisionmaking process includes discussion of the availability, benefits and burdens of rehabilitative treatment, therapy and services. While these efforts should be appropriate under the circumstances (for example, it would be inappropriate for patients who are permanently unconscious or who are imminently dying), participants in the decisionmaking process are strongly encouraged to be sensitive to the role a patient's perception of a future life with chronic illness or disability may play in his or her treatment decision, and to seek to enhance the patient's capacity to knowingly confront and assess these concerns. Health care institutions should, in consultation with physicians, assure that relevant information is discussed with the patient and health care representative where it would promote the patient's self-determination and well-being.*

It is important to recognize, however, that as is the case with underlying psychological factors which may impair decisionmaking capacity, a patient's decision to refuse treatment, including life-sustaining treatment, based upon his or her evaluation of the burdens and benefits of a future life with chronic illness or disability is not itself ground for a determination of incapacity. The patient's decision may be grounded in personal values and objectives which, though not necessarily shared by all, are intelligible and entitled to respect. Rather, where the issue of future life with chronic illness or disability is relevant and appears to impair the patient's decisionmaking capacity, this should be taken as a call to further conversation and more thorough evaluation of decisionmaking capacity.

Developmental disabilities. Some patients may lack full decisionmaking capacity due to developmental disabilities, such as impaired ability to communicate effectively. Involvement of the patient in the decisionmaking process and assessment of the patient's decisionmaking capacity may require not only special efforts on the part of the physician, but also specialized training or experience. In some cases the communication process can be enhanced by special attention to the nature of the patient's disability and to the potential use and benefit of treatments or assistive devices designed to alleviate impediments to the patient's abilities to communicate, though not necessarily treating the patient's illness or disease. (For example, the ability to communicate of a patient in an advanced stage of amyotrophic lateral sclerosis (ALS) often is enhanced by use of a letter board.) A disability affecting the patient's participation in the decisionmaking process ought to serve as a call to the physician to pay particular attention to ways to improve the patient's ability to deliberate and communicate effectively, before reaching a determination that the patient lacks decisionmaking capacity. Patients with developmental disabilities should not be categorized as incapacitated based upon this status in the absence of more particularized assessment of the abilities required for effective participation in the particular health care decision.

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* The Commission's legislative proposal would require health care institutions to adopt such policies and practices as are necessary to educate patients, families and health care representatives about the availability, benefits and burdens of rehabilitative treatment, therapy and services. Educational efforts should include information about family and social services, vocational assessment and management, and the use of assistive devices.

Enhancing Decisionmaking Capacity

Respect for patient self-determination includes the obligation to enhance the patient's capacity for self-determination. Physicians and health care representatives should seek to enhance the patient's decisionmaking capacity not only by being attentive to the concerns discussed above, but also by engaging the patient in a meaningful and continuing dialogue even though decisionmaking capacity may be impaired. (Of course, these efforts should be appropriate to the patient's abilities and medical circumstances.) In fact, the patient with diminished or fluctuating capacity presents one of the strongest cases for shared decisionmaking and communication. It is only through the process of communication on a regular and interactive basis that the physician will be able to properly determine whether the patient's expressed preferences are based on an understanding of relevant medical information, intelligible reasons, and a sound reasoning process grounded in the patient's personal values and objectives. Mutual communication and interaction will better allow the patient's preferences to be expressed and given appropriate weight in health care decisions, and will facilitate respect for those preferences (decisions) expressed at times of decisionmaking capacity. The Commission believes that both physicians and health care representatives are morally obligated to enhance patient capacity and to facilitate appropriate patient participation in decisionmaking. The legislative proposal would make this explicit by imposing affirmative obligations to actively involve the patient with impaired capacity in the decisionmaking process.

Who Should Determine Capacity

The Commission recommends an informal (non-judicial) process which places primary responsibility for making a determination of incapacity with physicians. A determination of the patient's decisionmaking capacity should be made initially by the attending physician, and confirmed by one or more qualified physicians (unless incapacity is clear and confirmation unnecessary, such as with the permanently unconscious patient).*

While this approach represents a departure from the more traditional formal requirement of a court determination of "competence" understood in a more global, less decision-specific sense, an informal process furthers several important objectives. An informal process has the advantage of being adaptable to existing medical practices and to the need for flexibility in response to changing medical circumstances, particularly for those patients with impaired capacity whose decisionmaking abilities may change daily, if not more frequently. It will generally be the attending physician who is best situated to make this judgment, and to do so on a regular basis. (This may vary to some extent, however, with the nature of the institutional setting.) Placing initial responsibility in the hands of the attending physician reflects the realities and demands of the clinical context in which judgments of capacity must take place. This process also recognizes an important sphere of privacy for the physician-patient-health care representative relationship upon which court intervention severely intrudes. In addition, the Commission's approach seeks to resolve (at least where the patient has executed an advance

* In no event, however, should a physician designated as the patient's health care representative make the determination of decisionmaking incapacity. This is expressly prohibited by the legislative recommendations.

directive) an ambiguity between formal legal requirements and existing medical practice. In actuality, determinations of incapacity frequently are made informally, especially where family members are involved in the decisionmaking process and concur in the physician's judgment that the patient lacks decisionmaking capacity. It is only in rare cases of conflict that formal court determinations of the patient's (in)capacity are sought.[57]

Notice and Documentation

Given the important consequences of decisionmaking incapacity, it is important that the patient and health care representative be promptly notified of such a determination and that this judgment be properly documented. As the responsible professional closest to the patient and health care representative, the attending physician should assure that the patient (where able to comprehend this information) and the health care representative are promptly notified. Notice of incapacity should include an explanation of the patient's condition and the cause and extent of incapacity, as well as stating the right of the patient and health care representative to seek review through an institutional dispute resolution mechanism should either disagree with the physicians' judgments. A patient's decisionmaking incapacity should also be properly documented in writing and entered in the patient's medical records by all physicians who examine the patient. The physicians' opinions should include the nature, cause, extent and probable duration of the patient's incapacity.

At times it may be appropriate to notify the health care representative prior to a formal determination of incapacity to better enable the representative to become involved in the patient's care. And in some cases, it may be desirable for the health care representative, with the approval of the patient, to participate in the decisionmaking process in the informal capacity of friend and facilitator, absent a record determination of incapacity. The legislative proposal is intended to allow these kinds of responses to the problem of incapacity while safeguarding patient interests by requiring written notice and documentation.

Implementing An Advance Directive: The Decisionmaking Process

Once operative, an advance directive designating a health care representative confers upon the health care representative legal authority to participate in the decisionmaking process, and to make health care decisions on the patient's behalf. The health care representative has the right to give informed consent to or refusal of health care, subject to the terms and limitations of the advance directive. Physicians, other health care professionals, and health care institutions are obligated to honor the patient's designation of a health care representative and the patient's instruction directive, and to participate in good faith in the decisionmaking process established by the legislative proposal, in accordance with their respective roles. While the legislative proposal would establish some mandatory guidelines for the decisionmaking process, the recommended framework for decisionmaking is intended to allow participants in the process a large degree of flexibility in developing the nature of their interactions and relationships. Absent a life-threatening emergency, the decisionmaking process should be structured to permit adequate time for the health care representative to come to understand and reflect upon a treatment decision before it is implemented. Health care decisions, especially those involving withholding

or withdrawal of life-sustaining measures, should not be made with unnecessary haste or without thorough consideration of the reasonable treatment options.

The Health Care Team

The Commission's recommendations accept and endorse a central role for the physician in health care decisionmaking. At the same time, the central role of the physician should not obscure or diminish the moral role and obligations of other health care professionals. While the physician by professional training and experience possesses the knowledge, skills and judgment necessary to diagnose the patient's condition and offer treatment options, and bears ultimate responsibility for treatment decisions, other members of the health care team play important and active roles in implementing those decisions and in caring for patients. In today's health care system, other members of the health care team, including nurses, social workers, clergy and others, often have more daily contact with patients, and at times families, than do physicians, and have essential roles in the delivery of health care. Increasingly, nurses (and occasionally other health care professionals) have primary responsibility for the daily care of patients, particularly in nursing homes and in home health care,[58] and nurses often view their role, at least in part, as that of a patient advocate.[59] This may be especially true in long-term and chronic care settings where, in contrast to the primarily episodic nature of care typical of acute-care hospitals, the goal often is to construct a complete care plan in a structured residential setting. Moreover, a stronger emphasis on chronic rather than acute care and on supportive care and patient comfort contributes to nurses and other health care professionals having a more prominent role in patient care in long-term care facilities, while the presence of physicians is comparatively less than in the hospital setting.[60] Consequently, nurses, social workers, clergy and other health care professionals may possess important knowledge and insight into the patient's medical condition, as well as the patient's (and at times the health care representative's or family's) beliefs, wishes, feelings or fears.

The model of shared decisionmaking adopted by the Commission views physicians, nurses, social workers and other health care professionals as members of a health care team with appropriate and complementary roles, engaged jointly with patients, health care representatives and families in a process of collaborative decisionmaking respectful of patient self-determination and seeking to promote patient well-being. The model of shared decisionmaking recognizes the importance of communication and active participation involving all members of the health care team as a means to enhance the quality of the decisionmaking process and the quality of the patient's care.

Developing a Treatment Plan

Patient care ordinarily should involve development of a treatment plan designed to serve the patient's objectives and well-being and agreed upon by the health care representative and attending physician. Patient care, in particular chronic and long-term care, often involves a series of decisions of greater and lesser consequence as the patient's condition evolves over time. Within the context of this process, informed consent or refusal regarding a particular course of treatment will involve discrete events in which the physician and health care representative discuss particular treatment options and arrive at a treatment decision. A treatment plan fosters

a consistent approach to a series of decisions grounded in the patient's overall treatment objectives and best interests.

While a treatment plan should be tailored to the needs of each individual patient, and should be flexible and responsive to changes in the patient's clinical circumstances, certain important questions concerning approaches to patient care commonly arise and provide some general guidelines. As health care professionals are well aware, the potential effectiveness of a particular treatment cannot always be predicted with certainty. A familiar concern for the seriously ill and dying patient is that a course of treatment will prove ineffective or that its benefit for the patient will decline as the patient's prognosis dims or the progression of illness worsens. Conversely, treatment thought inadvisable at one stage of the progression of a patient's condition may become advisable at a later stage. Neither health care representatives nor physicians should feel that once a treatment is started it cannot be discontinued. In some cases time-limited trials may be medically and ethically appropriate. This approach should be discussed with the health care representative and the patient. Implementation of a particular treatment on a trial basis provides the opportunity to better evaluate the benefits and burdens of the treatment. Furthermore, a trial period may assure patients, health care representatives, and families that all reasonable options have been explored, thereby helping to alleviate anxiety, uncertainty, or emotional distress about foregoing life-sustaining measures. Patients, health care representatives and physicians should understand that if implementation of a treatment on a trial basis proves ineffective or unduly burdensome it can be withdrawn, and should not feel that a treatment once started cannot be stopped, and therefore should not be tried at all.[61]

Sometimes overlooked is the fact that what appear to be single-issue decisions, such as to forego life-sustaining measures, often involve important collateral decisions, such as whether to treat an intercurrent illness or infection. A decision about life-sustaining measures will form the basis for a treatment plan, but may not be the only decision of consequence to be made a part of the treatment plan. In making decisions at the end of life it is important to recognize that the withholding or withdrawal of a particular life-sustaining measure does not mean the cessation of patient care. A decision to forego one form of treatment, such as by entering of a DNR order, does not necessarily mean cessation of other forms of treatment, such as antibiotic therapy. Furthermore, health care professionals responsible for the patient's care are obligated to continue to provide supportive care intended to alleviate pain and discomfort for the patient, and to provide symptomatic relief, in accordance with agreed upon objectives for the patient. This may mean such measures as careful attention to the use of sedatives and other medication designed to relieve pain, hygienic care, and turning and positioning of the patient. While administering of pain medication should strike an appropriate balance between the patient's interests in pain relief and in mental alertness and ability to communicate, there may be occasions when it is appropriate to sedate the patient even to the point of unconsciousness if that is the course of treatment agreed upon with the health care representative (and to the extent possible, the patient).[62]

Implementing the Patient's Wishes

As emphasized throughout this report, good decisionmaking respectful of patient self-determination and well-being requires that the patient's values and objectives be brought to bear

in the contemporaneous evaluation of medical information, including risks and benefits of treatment options. The patient's expressed wishes should always provide a central foundation for a treatment plan. At the same time, physicians and health care representatives should guard against focusing excessive attention on the written advance directive at the expense of the discussion and communication central to the physician-patient-health care representative relationship.[63]

The legislative proposal establishes specific guidelines for implementation of the patient's wishes pursuant to an advance directive. First and foremost, the health care representative should look to the patient's instruction directive. Where the instruction directive provides a clear basis for the treatment decision to be made, it should be followed in accordance with its terms. This is perhaps the closest possible approximation of the patient's stated wishes and of the patient's exercise of self-determination under circumstances of decisionmaking incapacity.

As discussed earlier, the task of determining what the patient would want under the current medical circumstances will not always be an easy one, as the instruction directive may not provide clear direction or may not clearly anticipate the patient's current circumstances. In seeking to advance the patient's interests in self-determination and well-being, the health care representative should consider all available evidence of the patient's wishes, including prior oral or written statements made by the patient to family members, friends, health care professionals or religious leaders, and personal knowledge of the patient and his or her values and objectives.

In this effort, it is important that the health care representative not be rigidly constrained by unduly mechanistic interpretation of the specific terms of the instruction directive, and that there be room for the exercise of reasonable and informed discretion. As evidenced by the deficiencies of instruction directives, any predetermined mechanistic method for determining the patient's wishes would be unworkable. Furthermore, in light of changed medical circumstances or therapeutic advances, rigid compliance with the specific terms of an instruction directive may prove to be contrary to the patient's interests in both self-determination and well-being. Where an instruction directive is determined by the health care representative, in the exercise of reasonable judgment, to be unclear or ambiguous as applied under the current medical circumstances, the health care representative should have legal authority to use reasonable judgment in good faith to seek to effectuate the spirit of the instruction directive and the wishes of the patient. Of particular importance, the health care representative should have the authority to consent to a new and potentially life-saving treatment where this new therapeutic option was not (and could not have been) contemplated by the instruction directive, even though such consent may appear contrary to the terms of the instruction directive.[64]

The Patient's Best Interests

The importance of flexibility and discretion in interpreting and applying the patient's previously expressed wishes demonstrates that the health care representative should have authority to act in the patient's best interests, based upon what is known of the patient's wishes. Furthermore, the patient's choice of a family member or trusted friend as health care representative ordinarily expresses the patient's judgment that the representative is familiar with

the patient's own values and wishes, and that this knowledge will be given due consideration by the representative in reaching a treatment decision in the patient's best interests. It is likely that individuals who make the effort to designate a health care representative ordinarily want their chosen representatives to be able to exercise their considered but not overly constrained judgment to determine and evaluate what is known of the patient's wishes and to act in the patient's best interests. Thus, unless otherwise indicated by the terms of the designation, it should be presumed that a patient intends his or her health care representative to have legal authority to exercise some scope of discretion to act in the patient's best interests, duly attentive to the patient's own wishes and the need to adapt and apply those wishes to currently existing medical circumstances.*

Involving the Patient In the Decisionmaking Process

As noted at several points above, the duty to respect patient self-determination entails the duty to promote and enhance the patient's capacity for self-determination through active participation in the decisionmaking process. The obligation to involve the patient who lacks full decisionmaking capacity in the decisionmaking process is an obligation to enhance patient self-determination through shared decisionmaking among the patient, health care representative, and others.[65] Equally important, efforts to enhance the patient's decisionmaking capacity further the goal of patient well-being by recognizing that autonomy is one of the most important goods or values of the persons and by assuring that the patient's expressed wishes will be more effectively considered in the decisionmaking process.[66] In developing a treatment plan and reaching specific decisions about treatment, the physician and the health care representative should jointly seek to involve the patient as an active participant in the decisionmaking process, and to take the patient's wishes into account. Nurses and other members of the health care team can and should have appropriate roles here as well. While this is not possible for some patients (such as the permanently unconscious or the severely demented), many patients with impaired decisionmaking capacity do possess some ability to reason and communicate about their medical condition, concerns, fears and wishes. The patient who is able to communicate views about his or her condition or treatment, including the feelings of pain and discomfort or apprehension about invasive procedures, should have the chance to make those views known, even if he or she lacks another ability, such as understanding of treatment risks and alternatives, requisite to ultimate decisionmaking authority.

Obviously essential to the enhancement of patient capacity is careful attention to the provision of relevant information, and appropriate efforts to assure the voluntariness of patients' decisions. Meaningful communication with the patient means more than providing the patient

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* Here, the authority of the health care representative to act in the patient's best interests rests on the understanding that such a judgment will in fact be grounded in and consistent with the available evidence of the patient's own values and objectives. In contrast to this approach, the term "best interests" is often understood to refer to an objective or independent third party judgment of what will best promote the patient's well-being, in circumstances where the patient's wishes are known. The Commission plans in its future work to address issues involving decisionmaking for incompetent patients who have not previously expressed their wishes, including what it means to make decisions "in the patient's best interests" in this context.

with relevant information and listening to the patient. The health care professional is affirmatively obligated, at least morally and professionally, not only to evaluate but also to enhance patient capacity; to promote patient autonomy not merely by respecting autonomous decisions and by being alert to whether a patient's expressed wishes are truly autonomous, but also by seeking to restore autonomy by confronting and treating obstacles to effective patient participation in the decisionmaking process. At times skillful conversation with the patient and health care representative can work to address the patient's hidden fears or concerns, to confront deficits in patient understanding or reasoning, or otherwise to break down barriers to effective patient participation. Efforts to enhance the patient's decisionmaking capacity may make it unnecessary to deprive the patient of decisionmaking authority and therefore unnecessary to look to the patient's health care representative for the legal and moral authority to make a treatment decision.

For example, physicians, nurses and other health care professionals should be alert to the usefulness of treating conditions which impair the patient's mental functioning (including altering the use of pain medication to lessen its effects upon mental alertness), and to the use of assistive devices to alleviate impediments to effective patient communication. Family members, health care representatives, nurses, social workers and others will often possess significant insight regarding psychological or emotional obstacles to effective patient participation in decisionmaking. Mutual collaboration among the participants in the health care process will at times reveal effective avenues to enhancing or restoring patient autonomy, and to more active and meaningful patient participation in the decisionmaking process. Thus, even where the patient does not fully regain decisionmaking capacity (which may often be the case), and therefore lacks the legal authority to make a particular health care decision, overcoming barriers to effective patient participation is an important step toward assuring that the patient's expressed wishes will count in the decisionmaking process.

Capacity to make some decisions but not others. Situations in which the patient has capacity to make some treatment decisions on his or her own behalf but not others present special questions about the locus of decisionmaking authority and the proper role of patients and health care representatives. Although ordinarily the health care representative will have already become involved in the decisionmaking process, where the patient regains capacity to make a particular health care decision, the patient has the ultimate legal and moral authority to make that treatment decision, and the patient's decision should be respected by both physicians and health care representatives. However, it is not intended that this situation be viewed as one of sequential authority which shifts back and forth between the patient and the health care representative. Where the patient possesses capacity to make a particular treatment decision, the health care representative should continue, absent objection by the patient, to be involved in the decisionmaking process as an advisor and active participant. The continuing role of the health care representative will facilitate continuity of care, as the health care representative may bear responsibility for making future treatment decisions on the patient's behalf. It also will improve the quality of the decisionmaking process, for the health care representative will continue his or her role and contribution as a participant in the process of developing and implementing a treatment plan for the patient. Thus, physicians and other health care professionals should

continue to actively involve the health care representative in the ongoing process of decisionmaking in the course of the patient's care (unless the patient objects), even though the health care representative may not have authority to give informed consent to that particular treatment.

Respecting contemporaneous patient wishes. While the patient's previously expressed wishes (most often contained in an advance directive) provide important guidance and will at times be determinative of the course of treatment, a central goal of actively involving the patient in the decisionmaking process is to assure that the patient's contemporaneous wishes are taken into account. Of particular importance, the Commission recommends in its legislative proposal that the patient's contemporaneously expressed wish that potentially effective life-sustaining measures be provided should be respected, even if the health care representative might otherwise request discontinuing the treatment, or the patient's instruction directive (or other evidence of the patient's previously expressed wishes) directs the withholding or withdrawal of life-sustaining measures. Physicians and health care representatives should act on the presumption that a patient's contemporaneously expressed wish to continue to receive potentially effective life-sustaining measures is to be respected, regardless of the patient's degree of decisionmaking capacity. This recommendation is grounded in a commitment to respect for human life, as well as recognition of the possibility that the patient will have a change of mind as death approaches (and perhaps becomes a less abstract idea and a more real experience). This provision of the proposal also safeguards against foregoing of life-sustaining measures too early or without full consideration of the circumstances and options.

The Health Care Representative Alone. While the Commission strongly recommends that individuals who choose to designate a health care representative follow the integrated approach and provide the person selected with an instruction directive stating their wishes, an individual should be free to choose to entrust another with the legal authority to make decisions in his or her interests, and to choose not to direct or constrain the exercise of that authority with an instruction directive. The health care representative may also be called upon to make a treatment decision in the patient's best interests without the benefit of an instruction directive where an individual has chosen to revoke an instruction directive (perhaps due to a change of mind or a desire to reconsider its contents), or has simply neglected to prepare one. In some cases the instruction directive may provide little or no guidance for the decision to be made; in effect a situation in which the health care representative must act without benefit of an instruction directive. In these circumstances, the health care representative should have the legal authority to base a treatment decision on the best interests of the patient, based upon personal knowledge or other evidence of the patient's wishes. In so doing, the health care representative should exercise reasonable discretion to interpret and apply the available evidence of the patient's wishes, and to make a treatment decision consistent with what is known about the patient's wishes.

An Instruction Directive Alone. The Commission also strongly believes that instruction directives should be statutorily recognized documents for advance planning, and provides for such recognition in its legislative proposal. Some choose not to designate a health care representative,

perhaps preferring not to impose the burdens of decisionmaking on loved ones. For others who have lost loved ones over the years, including many nursing home residents, the health care representative may not be a realistic option. These individuals should have their written instructions respected as a legally valid expression of their wishes for their future health care. The Commission also recognizes that many New Jersey citizens have or will execute instruction directives prior to favorable legislative action on the Commission's proposal, and the new law's effective date. Changes in law effected by the proposed legislation should not be applied retroactively. Previously executed instruction directives should continue to be honored by family members and health care providers.

Although the Commission has been concerned with the potential difficulties of interpreting and applying prior written instructions, the instruction directive will at times provide clear and unambiguous guidance to legally appointed guardians, family members, physicians, or others responsible for making a treatment decision on the patient's behalf. Under these circumstances, the instruction directive should be honored, in accordance with its specific terms.

On the other hand, as discussed above, an instruction directive alone may not provide clear direction to those responsible for the patient's care and treatment. In these circumstances there is a danger that the instruction directive will not be given due weight or will even be disregarded. This should not be the case; the patient's prior efforts to plan ahead and to control the course of his or her future health care should be given appropriate weight. The responsible decisionmaker(s) should endeavor to exercise reasonable judgment to effectuate the wishes of the patient, giving due weight to both the specific terms and to the spirit or general intent of the instruction directive. In order to assure faithful interpretation and implementation of the patient's expressed wishes, the legislative proposal would require that departure form the specific terms of the directive be based upon a clear articulation of factors (most significantly the patient's present medical circumstances) which were not foreseen or contemplated by the instruction directive, and which therefore warrant a different course of treatment than that stated in the instruction directive. Here, those responsible for the patient's care should be most attentive not only to whether the instruction directive is unclear but also to whether it is contrary to the patient's best interests.

In the absence of a health care representative, shared decisionmaking may be less meaningful. Nonetheless, physicians and other health care professionals have equally important obligations to actively involve family members (where present) and patients in the decisionmaking process. Strong efforts should be made to enhance patient capacity and to consider the contemporaneously expressed wishes of the patient. It is worth emphasizing here that the patient's fears and concerns should be considered and addressed, and the patient's contemporaneously expressed wishes for continued life should be respected, consistent with accepted medical standards.*

* The Commission's proposal does not specifically address the applicability of an advance directive in cases of pregnancy. While this situation is likely to be extremely rare in practice, it should be noted that the Commission's recommendations are fully consistent with a woman's ability to direct, in an advance directive, continued treatment

Process and Review

The Commission's legislative proposal is structured to allow well-considered decisions to be made within the privacy of the physician-patient-health care representative relationship, without the need for judicial involvement, while providing appropriate and not unduly burdensome procedures to assure sound decisionmaking and protect against premature decisions or possible abuse. As has traditionally been the case, in the first instance the physician-patient-health care representative relationship plays a critical role in safeguarding the patient's interests. It is the responsibility of the attending physician (and other members of the health care team), both legally and ethically, to scrutinize both the decision and the decisionmaker to assure that decisions are made in accordance with sound medical practice and legal and ethical norms, and to safeguard the patient against possible errors in judgment or wrongdoing. Health care providers, especially physicians, should be attentive to these concerns throughout the course of the patient's care.

It is expected that in most cases discussions with the patient, health care representative and family will reveal any suspicion of improper judgment, undue influence or other wrongdoing. Where discussion fails to resolve misunderstandings or disagreements, or suspicion of wrongdoing remains, the Commission recommends resort to an institutional dispute resolution mechanism. This may be especially important with respect to disagreements about the patient's decisionmaking capacity or the implementation of an advance directive, but may involve other matters as well. The legislative proposal is designed to allow health care institutions to develop the precise nature of the dispute resolution process. The process might involve, for example, consultation with a single individual, such as an "ethics consultant," or with an institutional ethics committee.

An intra-institutional dispute resolution mechanism serves the important function of being easily accessible and informal without the need to involve more formal and burdensome resort to the courts when disagreements arise. It is anticipated that effective communication and shared decisionmaking, and occasional recourse to a non-adversarial and informal consultation process will minimize occasions of real conflict. Of course, if disagreement persists, judicial review or review by a government agency, such as the Ombudsman, may be appropriate.

Decisions to Forego Life-Sustaining Measures: Scope and Limitations

As discussed earlier, the right to individual control over future health care decisions in the event of subsequent loss of decisionmaking capacity, including the right to refuse life-sustaining measures, is widely recognized as a fundamental right and is the public policy of this

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in the event of pregnancy. In the absence of any explicit written provision contemplating pregnancy, the legislative proposal recognizes the possibility that instruction directives may fail to foresee or contemplate certain medical conditions (which may include pregnancy), and provides for an appropriate response in interpreting the advance directive in such cases. The Commission believes these general provisions are adequate to handle those rare circumstances that may be presented where health care decisions must be made on behalf of a pregnant woman who has lost decisionmaking capacity.

State. At the same time, this right is not absolute, and is subject to certain interests of society. The Commission's legislative proposal rests upon careful and considered deliberation regarding the appropriate role of societal interests as sources of limitation upon the duty of health care providers and of society to comply with patients' expressed wishes. The basic principles underlying the Commission's deliberations with respect to these issues are discussed elsewhere in this Part, in particular the general legal context for decisions to forego life-sustaining measures. This section briefly summarizes the Commission's conclusions and recommendations in this area, as set forth in sections 15 and 16 of its legislative proposal. A more detailed discussion of the central features of the Commission's approach is presented in the Commentary on the proposed legislation (chapter 4).

The Commission's legislative proposal takes a situation-specific approach to the circumstances in which the foregoing of life-sustaining measures in accordance with a patient's advance directive should be authorized. The proposal sets forth the procedures to be followed in each type of circumstance before such a decision is implemented. Of particular concern has been the foregoing of artificially provided fluids and nutrition, an issue discussed and debated at length by the Commission. For reasons discussed below, and presented at greater length in a separate policy statement, the proposed legislation gives greater weight to societal interests with respect to the foregoing of artificially provided fluids and nutrition, and takes a parallel, but not identical, approach to the circumstances in which the proposal would authorize the withholding or withdrawal of life-sustaining measures other than artificially provided fluids and nutrition. Thus, section 15 of the legislative proposal addresses decisions to forego life-sustaining treatments, other than artificially provided fluids and nutrition, while section 16 of the proposal addresses decisions to forego artificially provided fluids and nutrition.

It is important to note that the right recognized by the Commission is properly characterized as a right to decide, including the right to refuse unwanted medical interventions. The Commission's legislative proposal should not be construed to recognize a so-called "right to die." Furthermore, the Commission expressly rejects on both legal and moral grounds the practice of "active euthanasia" (sometimes referred to as "mercy killing"), *i.e.*, the intentional causing of the patient's death. The withholding or withdrawal of life-sustaining measures in accordance with the patient's advance directive and the provisions of the legislative proposal would be both legally and morally permissible. However, patients have no right to request a lethal injection, nor is any physician or health care provider obligated or authorized to engage in the practice of active euthanasia.

Decisions to Forego Life-Sustaining Treatment

The Commission believes that a number of conclusions, embodied in section 15 of its legislative proposal, are justified. These conclusions are substantially in accord with widespread societal consensus regarding the circumstances in which a patient's expressed wishes to forego life-sustaining treatment should be respected.

First, when the life-sustaining treatment is experimental and not a proven therapy, or is likely to be ineffective or futile in prolonging life, or is likely merely to prolong an imminent

dying process, the patient's wishes as expressed in an advance directive that life-sustaining treatment be withheld or withdrawn should be honored.[67]

Second, when the patient is permanently unconscious, *i.e.*, the patient has suffered total and irreversible loss of consciousness and capacity for interaction with the environment, and the provision of life-sustaining treatment serves only to maintain bodily functions in the absence of a realistic prospect for return to a cognitive sapient state, the patient's wishes as expressed in an advance directive that life-sustaining treatment be withheld or withdrawn should be honored.[68] Permanent unconsciousness, including but not necessarily limited to the conditions of persistent vegetative state and irreversible coma, should be diagnosed in accordance with currently accepted medical standards and with reasonable medical certainty, and should be confirmed by a second qualified physician.

Third, when the patient is in a terminal condition, the patient's wishes as expressed in an advance directive that life-sustaining treatment be withheld or withdrawn, should be honored. The legislative proposal defines "terminal condition" as the terminal stage of an irreversibly fatal illness, disease or condition. Recognizing the range of differing views concerning the definition of "terminal" condition, as well as the inherent difficulties involved in requiring physicians to state precise prognoses of a patient's life expectancy, the legislative proposal would not require a determination of a specific life expectancy as a precondition for a diagnosis that the patient has a terminal condition. Rather, the Commission recommends that a prognosis of a life expectancy of six months or less serve as a guideline; a patient whose life expectancy is determined to be six months or less is clearly "terminal" for purposes of the legislative proposal. This guideline was adopted in part to correspond to federal and state law governing reimbursement of health care costs, for example under Medicare and hospice regulations. However, this is only a guideline, and a patient with a longer life expectancy may still have a terminal condition within the meaning of the proposal.[69]

The Commission also believes that a patient's wishes to forego life-sustaining treatment as expressed in an advance directive should be honored in a fourth circumstance. When none of the above circumstances apply, but the patient has a serious irreversible illness or condition, and the likely risks and burdens associated with the medical intervention to be withheld or withdrawn may reasonably be judged to outweigh the likely benefits to the patient from such intervention, and imposition of the medical intervention on an unwilling patient would be inhumane, the patient's wishes as expressed in an advance directive that life-sustaining treatment be withheld or withdrawn should be honored.[70] In the Commission's view, this fourth circumstance presents a more morally problematic situation in which societal interests in favor of preserving life may carry greater weight. Therefore, additional procedural safeguards are warranted before a decision to forego life-sustaining treatment is implemented.

In such cases, prior to implementing the decision, the legislative proposal would require consultation with a local reviewing body, such as an institutional or regional ethics committee, or with a public agency with authority to review the proposed decision, such as the Ombudsman or a court. Thus, in specified circumstances in which the patient has executed an advance

directive, the Commission recommends a prospective case consultation role for an ethics committee or similar reviewing body. In the Commission's judgment, this process of local review provides appropriate protection for patients in the specified circumstance, while being less burdensome, intrusive and time-consuming than past experience with other review processes, such as the Ombudsman or the courts. At present, properly established and functioning ethics committees could serve this prospective case consultation function. Where such committees exist in facilities within the jurisdiction of the Office of the Ombudsman, the proposed legislation would establish a legally recognized alternative to Ombudsman review for a limited class of cases.*

Decisions to Forego Artificially Provided Fluids and Nutrition

The Commission believes that the withholding or withdrawal of artificially provided fluids and nutrition (such as by nasogastric tube, gastrostomy tube, jejunostomy tube, or intravenous infusion) from patients who lack decisionmaking capacity or are otherwise vulnerable raises important and distinctive problems for public policy that justify protective measures, beyond those recommended for the foregoing of other life-sustaining measures. For this and other reasons set forth at length in a separate policy statement, "Foregoing of Artificially Provided Fluids and Nutrition" (reproduced in the Appendix to this Part), the Commission's proposed legislation addresses decisions to forego artificially provided fluids and nutrition distinctly from decisions to forego other life-sustaining measures. The legislative proposal takes a situation-specific approach (in section 16) to the withholding and withdrawal of artificially provided fluids and nutrition.

It should be noted that a range of strongly held views regarding this issue exist among members of the Commission. Twelve Commissioners, all of whom support the Commission's legislative proposal, submitted a written statement, expressing their views, along with numerous authorities, "that life-prolonging medical treatment includes artificially or technologically supplied nutrition and hydration." In contrast, three Commissioners who abstained from supporting the proposal submitted a written statement, expressing their views "that the withdrawal or withholding of life-sustaining treatment or artificially provided fluids and nutrition should be limited to terminal cases arising from irreversible pathology from which death is imminent." (These separate statements are reproduced in the Appendix to this Part.)

The Commission believes that decisions to forego artificially provided fluids and nutrition should be based upon an explicit statement in the patient's advance directive instructing the withholding or withdrawal of artificially provided fluids and nutrition. This position is responsive to special public policy concerns regarding the foregoing of artificially provided fluids and nutrition. This provision of the proposed legislation also recognizes that at times patients' advance directives have provided unclear or ambiguous guidance with respect to the patients' wishes about artificially provided fluids and nutrition. The legislative proposal is designed to

* The proposed legislation addresses the role of institutional and regional ethics committees only in this narrow context. The Commission's work regarding the respective roles of ethics committees and of the Ombudsman in a broader context are discussed separately in other parts of the report.

assure that the patient's wishes in this regard are stated explicitly, and that such decisions are based upon clear evidence of the patient's wishes and are not subject to uncertainty or ambiguity.

The Commission believes that the following conclusions, embodied in section 16 of its legislative proposal, are justified.

First, when the artificial provision of fluids and nutrition is likely to be ineffective or futile in prolonging life, or is likely merely to prolong an imminent dying process, the patient's wishes as explicitly stated in an advance directive that artificially provided fluids and nutrition be withheld or withdrawn should be honored.

Second, when the patient is permanently unconscious, and the provision of artificial fluids and nutrition serves only to maintain bodily functions in the absence of realistic prospect for return to a cognitive sapient state, the patient's wishes as explicitly stated in an advance directive that artificially provided fluids and nutrition be withheld or withdrawn should be honored. Permanent unconsciousness, including but not necessarily limited to the conditions of persistent vegetative state and irreversible coma, should be diagnosed in accordance with currently accepted medical standards and with reasonable medical certainty, and should be confirmed by a second qualified physician.

Third, when the patient is in a terminal condition, and the likely risks and burdens of the least burdensome treatment modality likely to be effective may reasonably be judged to outweigh the likely benefits of such intervention, and imposition of the intervention on an unwilling patient would be inhumane, the patient's wishes as explicitly stated in an advance directive that artificially provided fluids and nutrition be withheld or withdrawn should be honored. In the Commission's view, this third circumstance presents a more morally problematic situation in which societal interests in favor of preserving life may carry greater weight. Consequently, the substantive approach here is more restrictive of the medical circumstances in which foregoing of artificially provided fluids and nutrition should be authorized than is true of the Commission's approach to decisions to forego life-sustaining treatment. Additional procedural safeguards are also warranted in this circumstance. Therefore, in such cases, prior to implementing the decision, the legislative proposal would require prospective case consultation with a local reviewing body, such as an institutional or regional ethics committee, or with a public agency, such as the Ombudsman or a court. A local reviewing body would be a legally recognized alternative to Ombudsman review in these limited circumstances for cases within the Ombudsman's jurisdiction.

Under the Commission's proposal, absent an explicit instruction that artificially provided fluids and nutrition be withheld or withdrawn, such a decision would not be authorized. It is important to note, however, that the Commission does not intend that decisions to forego artificially provided fluids and nutrition absent an explicit instruction be prohibited or unlawful, nor that patients who have not provided such explicit instructions be provided artificial fluids and nutrition regardless of the patient's medical circumstances or without an assessment of the risks, burdens and benefits of the intervention. In some circumstances it may be appropriate to infer

the patient's wishes from other more general language in an advance directive or from other evidence of the patient's wishes. In such cases, the Commission's legislative proposal would neither authorize nor prohibit a decision to forego artificially provided fluids and nutrition, and therefore would confer no immunity for such actions; but those responsible for the patient's care should be aware that they may look to other existing law to determine the legal basis for a decision to forego and for immunity from legal liability when such decisions are properly made.*

The Commission has sought to achieve a judicious balancing of patients' rights and interests in refusing life-sustaining measures and potentially countervailing societal interests. At the same time, the Commission also recognizes that in particular cases the patient's rights and expressed wishes may conflict with strongly held views of health care professionals. As discussed below, the legislative proposal seeks to protect and accommodate the personal and professional integrity of health care professionals without compromising patient rights and well-being.

Patient Rights and Professional Integrity

In some cases, patient wishes directly conflict with claims of professional and less often institutional conscience. Such conflicts have at times become intractable and have led to lengthy and burdensome litigation. This is perhaps more true where decisions to forego life-sustaining measures are at issue than in any other situation. Responsive to the need to provide a better mechanism for dealing with potential conflicts without the need for judicial intervention, and to do so in a way respectful of both patient rights and professional integrity, the Commission recommends express statutory recognition of a right of professional conscience and of institutional conscience (for private religiously-affiliated health care institutions). The exercise of this right would also entail obligations to assure timely, appropriate and respectful transfers of care to assure that the patient's wishes are honored.

Professional Conscience

By virtue of their professional status and role, health care professionals have fundamental obligations to respect patient autonomy and to protect and promote patient well-being. These duties are at the core of medical ethics. At the same time, health care professionals are not obligated to comply with any and all patient wishes, and have a right, within limits, to remain true to certain personal and professional moral and religious convictions. This claim is perhaps most compelling where it involves decisions to forego life-sustaining measures. Where foregoing life-sustaining measures is in issue, the claim of professional conscience has been advanced as a limiting principle; one which justifies, in appropriate circumstances, the withdrawal of the health care professional from implementing a particular course of treatment or from the care of a particular patient. The right to decline or withdraw from care of a patient, for reasons of conscience, honors the personal and professional integrity of the health care professional.

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* For a current analysis of existing law, see the discussion of The General Legal Context.

Decisions about life-sustaining measures often demand judgments based upon deeply held moral or religious convictions, and consequently, are among the most difficult and controversial of decisions which patients and physicians sometimes have to make. Health care professionals, in particular physicians and nurses who are primarily responsible for implementing treatment decisions, are often strongly influenced by personal and professional commitments to moral values, including in some cases personal religious beliefs. Strongly and sincerely held differences in values and objectives between the physician or nurse and the patient or family member, as well as confusion about professional obligations, has sometimes led to provision, or (less often) withholding, of treatment contrary to the wishes of the patient or family, and at times to protracted litigation. Perhaps most familiar is the situation in which the physician, steadfastly motivated by traditional pressures for aggressive treatment to sustain life which has marked many years of professional training, insists upon continuation of aggressive modes of treatment in circumstances in which the patient or family members believe that needless suffering is being imposed to no good end, and contrary to their wishes.

A right of conscientious withdrawal from the care of a particular patient is generally recognized (perhaps most often for physicians), under common law and professional codes of responsibility.[71] In the Commission's view, public policy properly sensitive to the professional integrity of physicians and nurses should expressly recognize, through the mechanism of law, the legitimate interests of physicians, nurses and other health care professionals in being permitted to act in consonance with their own moral or religious convictions regarding life-sustaining measures, subject to legal and ethical constraints, including the rights of patients and families.* Thus, the Commission recommends specific statutory recognition of the legal right of physicians, nurses, and other health care professionals acting in good conscience, on grounds of sincerely held personal or professional moral convictions, to decline to participate in a decision to withhold or withdraw life-sustaining measures.

A health care professional's claim of conscience should be based upon the personal significance of engaging in actions, such as implementing treatment decisions, which it is sincerely believed would be in violation of his or her personal or professional convictions, including moral values or religious beliefs.[72] The health care professional who is troubled by his or her participation in the course of treatment requested by the patient or health care representative should strive to distinguish questions of values and principles from personal distaste or prejudice. The health care professional should abstain from making moral judgments about patients, and should guard against allowing any personal moral judgments to affect his or her professional judgment.[73] Health care professionals should also guard against permitting perceptions motivated by fear of potential legal liability or unfavorable publicity to obscure the differences between conscientious professional or moral judgment and self-interest. To refuse to care for patients out of bias, self-interest or fear of legal consequences is to abandon both

* Decisions to forego life-sustaining measures can be especially difficult for nurses, particularly where close personal feelings about the patient have developed. Being primarily responsible for the continued and highly personal care of the patient (including supportive and hygienic care), nurses have a special role in the implementation of decisions about life-sustaining measures.

patients and the central mission of health care.

Transfers of care. Where significant disagreement persists, it may be best for the patient, health care representative, and the health care professional(s), to dissolve their relationship and to effectuate a respectful transfer of care to another health care professional, or another health care institution, better able to serve the needs and interests of the patient. In these circumstances, public policy should honor the personal and professional integrity of health care professionals while assuring that neither the rights of patients nor the highest standards of professional care are compromised. Thus, the Commission recommends specific obligations of health care professionals intended to assure respectful and appropriate transfers of care where such claims of professional conscience are made. In no event should patients be abandoned.[74]

The first obligation is to inform the patient and the health care representative, as well as a responsible member of the staff (such as the chief of the medical staff or the head of nursing) of the desire to withdraw from care of the patient. The patient and health care representative should be informed of the options for transfer to another health care professional or another health care institution, and of the process involved in effectuating a transfer.

In the exercise of the right of professional conscience (or in withdrawing from care of a patient for any other reason), the physician or nurse should take necessary and proper steps to initiate and cooperate in effecting appropriate transfers of care and to assure that patients are not abandoned. With the consent of the patient or health care representative, the responsible health care professional should assist in the orderly, respectful and timely transfer of the patient to the care of another health care professional or, where necessary, another health care institution. The health care professional must continue to care for the patient (but is not required to withdraw life-sustaining measures) until transfer is effected.[75] The health care institution should oversee and facilitate the transfer process, including assuming that the patient is not abandoned.

Continuity of care and patient well-being are best (and perhaps only) achieved where the patient is transferred to the care of another physician or nurse who does not have a fundamental conscientious disagreement with the patient or the health care representative regarding philosophy of care or the desired course of treatment. Since physicians and nurses will differ in their personal and professional commitments to particular moral values and religious beliefs, and in their views of what constitutes appropriate care in particular cases, transfer to another health care professional who shares (more or less) the treatment philosophy and objectives of the patient should ordinarily be possible and mutually agreeable to patients, health care representatives and the responsible health care professionals. However, where transfer of care cannot be effectuated (for example, where another appropriate health care professional willing to accept care cannot be found), or cannot be agreed upon, the physician or nurse may not withdraw from the case, and must, at a minimum, continue to provide necessary care. Under no circumstances may the patient be abandoned or endangered. If disagreement persists, resolution through institutional means (a dispute resolution mechanism) should be pursued. If this proves unsatisfactory, judicial resolution may be necessary.

Institutional Conscience

Among the most difficult emerging issues involved in debates about life-sustaining measures is whether health care institutions should be entitled to decline to participate in the implementation or effectuation of certain courses of treatment or non-treatment, contrary to the wishes of the patient or the patient's health care representative. This question has been most pressing with respect to the foregoing of life-sustaining measures, particularly artificially provided fluids and nutrition. The Commission has devoted lengthy discussion to the issue of whether the law should recognize a right of "institutional conscience" in this area, and if so, what the scope of such a right should be.

The question of institutional conscience is not fully resolved under existing New Jersey law. This issue was recently presented to the New Jersey Supreme Court in the *Jobes* case. In *Jobes*, the nursing home claimed that it had adopted an institutional policy against removal of the jejunostomy tube from Nancy Jobes, a patient in a persistent vegetative state, and that it was legally entitled to rely upon that policy in refusing to comply with the family's request for removal of the feeding tube made on the patient's behalf. The New Jersey Supreme Court found that the nursing home's policy had never been formalized, that the patient and family had not been informed of this policy at the time of admission, and that transfer to another institution was not a reasonable alternative under the circumstances. Reversing the opinion below, the Court rejected the nursing home's argument and held that the nursing home could not refuse to participate in the withdrawal of the feeding tube.[76] However, the Court did not rule on the issue of whether such a policy might be respected if the health care institution properly gave timely notice of the policy to patients and families, such as at the time of admission.[77]

Some have argued against such a right of institutional conscience, claiming that "(h)ospitals are corporations that have no natural personhood, and hence are incapable of having either "moral" or "ethical" objections to actions."[78] The same has been said of other types of health care institutions. In contrast, others have argued that all health care institutions should have the right to establish institutional policies to be accorded plenary effect when in conflict with patients' expressed wishes.[79] Debate within the Commission has also focused upon whether legal recognition of an "institutional conscience" should extend to all distinctively private institutions, or should be limited to religiously-affiliated or sponsored private institutions, whose "consciences" are grounded in a religious tradition or philosophy.

It is the Commission's view that some health care institutions do hold strong formal commitments to a particular philosophy of care, or to particular principles, and that such formal commitments can forcefully shape the character of the institution. At times the character of an institution may be exemplified by the actions of health care professionals that are permitted, encouraged and openly practiced, in contrast to those which are proscribed or prohibited, or perhaps covertly practiced. Indeed, a particular health care institution may take on such a character, perhaps through its religious or distinctive secular charter, policies and practices, that it personifies or embodies a particular institutional philosophy of care. This institutional philosophy of care may parallel, for the individual institution and its professional staff, the personal convictions, identity and integrity of the individual physician or nurse.[80] (Of course,

while the right is described as an institutional right, its exercise and benefits are intended to honor the integrity of the health care workers who share, both individually and collectively, that institution's formal commitments to particular principles and to a particular philosophy of care.)

As a general matter, it is anticipated that those institutions grounded in certain religious traditions are the most likely candidates to embody an institutional philosophy of care which adopts a particular position with respect to the foregoing of life-sustaining measures. It is in fact the case that religiously-affiliated institutions have often been most active in formulating ethical codes and policies which establish governing principles of care for the institution. Such codes and policies often draw upon well-developed moral and religious traditions, and are perhaps entitled to special consideration under the free exercise of religion clause of the Constitution. Courts have, for example, been particularly attentive to the special character of religious institutions in the context of providing abortions and abortion-related services. On the other hand, it is possible that non-religious institutions may develop distinctive secular understandings of their mission or philosophy of care. This is particularly evident in the case of hospice-type care, but may extend more broadly. Representatives of private non-religiously sponsored or affiliated health care institutions have been critical of any public policy that would deny them discretionary authority afforded to religious institutions, claiming that such a policy would be unfair and perhaps in violation of the norms of the establishment clause of the first amendment of the Constitution.

The Commission believes that private religiously-affiliated health care institutions should have a legally recognized right of institutional conscience regarding the foregoing of life-sustaining measures. This conclusion rests ultimately not on philosophical or constitutional grounds, nor on a conclusion about which health care institutions have "consciences", but on a prudential judgment about the practical impact of such a right. Given the reality that effectuating transfers of care in controversial cases has often been difficult for patients and families, and the concern that private institutions might invoke claims of conscience to avoid potentially troublesome situations, the Commission is reluctant to over-extend legal recognition of institutional conscience and to risk unduly diminishing the number of institutional settings in which patients and families can properly expect their rights and wishes to prevail. A broadly stated right might also eliminate any realistic expectation of prompt and respectful institutional transfer in cases of potential notoriety or perceived legal risks. Such a position would accept too readily the possibility that the doors of all health care institutions would be closed to patients in need, thereby abandoning those whose treatment objectives may present difficult ethical choices or may be out of the mainstream. Furthermore, it would be contrary to law and to public policy to permit public health care institutions, whether hospitals, nursing homes or other types of facilities, to selectively refuse admission, and thereby to discriminate against patients, based upon differences in patients' treatment objectives or philosophies. Therefore, the Commission recommends in its legislative proposal that private religiously-affiliated health care institutions have a legal right, parallel to that of physicians and nurses, to decline, through the adoption of institutional policies and practices, to participate in the withholding or withdrawal of particular life-sustaining measures, in specified circumstances.

Transfers of care. Situations in which patients, health care representatives or families are erroneously led to believe that the patient's wishes are likely to be honored by the health care institution and its physicians, nurses and others should be avoided. A private religiously-affiliated health care institution wishing to exercise and rely upon its right of institutional conscience should be required to state its policies and practices in writing, and to communicate them to patients, families and health care representatives in a timely fashion. Generally, this will mean prior to or upon admission and acceptance of care. Proper notice to patients, health care representatives and families should reduce opportunities for conflict (and instances of litigation), serving to assist placement of patients in health care settings committed to pursuing treatment objectives compatible with the patient's own.

As a realistic matter, however, potential disagreements about treatment objectives cannot always be anticipated. As the course of a patient's medical condition progresses, patients, health care representatives and health care professionals need to continually evaluate and perhaps revise earlier treatment objectives, at times in response to unanticipated changes in the patient's condition. In some cases this will mean that a disagreement about treatment objectives arises under circumstances where this was not, and perhaps could not have been, previously contemplated. Transfer may be the best alternative for all concerned.

As part of its responsibility to provide quality compassionate care for all patients, the health care institution should assure that patients are never abandoned nor treated disrespectfully. These obligations apply with equal, and perhaps even greater, force where a conflict arises between a patient's treatment objectives and the written policy of the health care institution. If disagreement among the patient, health care representative, physician and institution cannot be resolved in a mutually satisfactory manner, including through resort to an institutional mechanism (such as an institutional ethics committee), the facility administrator or other responsible person should discuss the alternative of transfer to another institution with the patient and health care representative.

Any decision to transfer care should give priority to the patient's well-being. Thus, a decision to transfer care should give due weight to risks involved for the patient, including whether the patient's condition is sufficiently stable so that transfer will not cause excessive pain or suffering, or endanger the patient's well-being.[81] This requires more than just professional judgment about the patient's medical condition. It also requires a judgment about the psychological and emotional strain transfer may place on the patient, considering such factors as adjustment to new physicians and nurses, and a new and perhaps very different health care environment. The geographical location of the transfer institution, which may make it more or less convenient for family and friends to visit, also is an important consideration.[82] Where an appropriate transfer cannot be effectuated, or the health care representative (or the patient) do not consent to transfer, continuing disagreement over treatment may necessitate court intervention. In order to minimize the difficulties that may be involved where transfer is desired, it is recommended that those private religiously-affiliated health care institutions who choose to formally adopt a policy limiting their obligations to participate in the withholding or withdrawal of life-sustaining measures maintain a list of possible transfer institutions which have not adopted

similar policies and which may be appropriate to the patient's needs. Appropriate referral patterns should be established in advance of emergencies or incidents of conflict.*

Legal Consequences and Concerns for Implementation

Immunities

The Commission strongly shares the concern of many that unfounded fears of legal liability too often interfere with the ability of physicians (and other health care professionals) to exercise sound judgment in the best interests of their patients.[83] Although often unfounded, such fears are a reality, and appear to make health care professionals uncertain and uncomfortable about the relationship between legal constraints and medical practice, contributing to a concern for legal liability or entanglements that too often improperly influences medical decisionmaking. While changes in medicine, law and social policy make it inevitable that there will be legal uncertainties in particular cases, "appropriate and compassionate care should have priority over undue fears of criminal or civil liability."[84]

Concern (and sometimes fear) for legal liability among physicians, and at times other health care professionals, is perhaps more pervasive today than ever before. High malpractice settlements and judgments and rising insurance costs in a highly litigious society have heightened concern over legal liability, both actual and potential (including the threat of a lawsuit). Although prosecutions for criminal conduct have been extremely rare,** and there is, according to some prosecutors and commentators, little likelihood of prosecution or conviction for withholding or withdrawing, or for providing, life-sustaining treatment,[85] fear of criminal proceedings (including the possibility of adverse publicity) may remain a concern for some physicians, and perhaps for other health care professionals.[86]

At times physicians or other health care professionals may respond to the perceived threat of legal intervention by practicing "defensive medicine," such as by ordering additional tests, or by avoiding documentation of certain decisions.[87] Similarly, facility administrators often adopt an institutional posture in favor of "defensive medicine," by seeking to minimize legal entanglements, including the costs of involvement in legal proceedings and potential for adverse publicity. Administrators also must responsibly address compliance with regulations and

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* The Commission's specific recommendations regarding institutional transfers of care are directed to situations of serious and possibly irresolvable conflict between the patient's treatment objectives and the formal commitments and policy of private religiously-affiliated health care institutions. While the Commission's recommendations may provide ethical guidance applicable in other circumstances, the Commission does not intend in this report to address problems which may arise with transfers of care in a variety of other circumstances.

** The President's Commission (1982) noted that "(r)eported criminal prosecutions of health care professionals for killing patients are almost nonexistent." *Deciding to Forego*, pp. 34-35. Known cases have almost always involved active interventions to cause death, not withdrawals of treatment pursuant to patient or family wishes. *Barber and Nejdl v. Superior Court*, 195 Cal. Rptr. 484, 147 Cal. App.3d 1032 (Cal.Ct.App. 1983), is the only known case in which physicians were prosecuted for withdrawing life-sustaining treatment from a patient, there a patient in a permanent vegetative state. In *Barber and Nejdl*, the court issued a peremptory writ dismissing the complaint prior to trial, and prohibiting any further attempts to bring criminal charges against the physicians.

financial constraints. At times these responsibilities will mean that the interests of patients are viewed as secondary and in some cases are compromised.[88] Consequently, the administrator of the health care institution may be unwilling to permit a treatment decision for a patient which creates even minimal uncertainty about its legal implications. Pressures to practice defensive medicine or to be unduly cautious are sometimes enforced by hospital or nursing home attorneys whose primary goal in assessing applicable law is to minimize risks of legal liability and of involvement in legal proceedings (including procedural entanglements and adverse publicity), whether actual or imagined. Perhaps most familiar (and most relevant here) is the situation in which the physician, motivated by perceived legal risks, and perhaps also by traditional commitments to aggressive treatment, resists a request for discontinuation of life-sustaining measures from the patient or family who believe that continued provision of the treatment is unduly intrusive and burdensome and needlessly prolongs suffering. An increasingly familiar result of this type of conflict has been a lawsuit, sometimes brought by physicians or health care institutions seeking an advance statement of immunity from liability from the court for withdrawing life-sustaining measures.[89]

Although effective changes in knowledge and attitudes about the law-medicine relation would be a preferable response to these concerns, and hopefully will evolve over time, in present circumstances the Commission agrees with the conclusion of the *Quinlan* Court that "there must be a way to free physicians, in the pursuit of their healing vocation, from possible contamination by self-interest or self-protection concerns which would inhibit their independent medical judgments for the well-being of their dying patients."[90] To this end, the Commission recommends statutory immunity from legal liability and from discipline for unprofessional conduct for physicians and other health care professionals who act in good faith and in accordance with accepted medical standards to honor advance directives and to implement treatment decisions consistent with the requirements of the legislative proposal (and any applicable rules and regulations). The Commission also recommends a parallel grant of statutory immunity from legal liability for health care institutions.[91]

Immunity from legal liability is intended to improve the decisionmaking process, including fostering recognition of and compliance with advance directives, by freeing physicians and other health care professionals from actual or perceived constraints imposed by fear of legal liability, or burdensome entanglements in legal proceedings even where the likelihood of liability is extremely low. Statutory recognition of good faith immunity should minimize the impact of legal uncertainty upon the quality of patient care, and should obviate the perceived need to seek advance judicial grants of immunity that have motivated some lawsuits, and have led to unnecessary and burdensome litigation inimical to the interests of patients and families. While the purpose of statutory immunity is to better enable physicians, nurses, administrators, and other health care professionals to more freely engage in a sound decisionmaking process without undue apprehension about legal consequences or legal intervention, health care professionals should not construe the grant of immunity as absolute. The proposal's good faith immunity insulates from potential liability and disciplinary action non-negligent actions undertaken in compliance with the proposal's requirements and applicable regulations. Health care professionals would be expected to act in accordance with accepted professional standards and the proposal's requirements at all

times.

To encourage and enforce fulfillment of professional obligations, the legislative proposal authorizes (but does not require) the Department of Health to establish rules and regulations pursuant to the "Administrative Procedure Act,"[92] to oversee and assure compliance with the legislative proposal. While the exercise of regulatory authority is directed to enforcement of the obligations of health care institutions to facilitate implementation of advance directives, the Department would also have generalized authority to establish rules and regulations as may be necessary to oversee and enforce compliance of health care institutions with any and all other obligations under the proposal. The proposal also states that those acting in willful contravention of requirements established by or pursuant to the proposed legislation may be subject to legal liability, regulatory action, or proceedings for professional misconduct. In this regard, the Department of Health would be given authority to enforce penalties against health care institutions for willful failure to follow the proposal's requirements.

Implementation of Advance Directives: Professional and Institutional Responsibilities

Respect for advance directives requires that a patient's advance directive become known to health care providers. Physicians and institutions should have affirmative obligations to assure that appropriate inquiry is made of the patient, family or others to determine whether a patient has executed an advance directive. Patients and families should not be expected to readily volunteer such information. The Commission recommends that health care institutions be required to adopt formal policies and practices to provide for routine inquiry at the time of admission, and on a periodic basis thereafter, concerning the existence of advance directives, as well as any other information necessary to locate the patient's advance directive and to contact the patient's health care representative. Institutional policy should incorporate a complementary and independently important obligation of inquiry on the part of the attending physician. Information about advance directives, including a copy of the document, should be entered in the patient's medical records.

An "active policy" which places the burden of inquiry with health care professionals facilitates communication about advance directives, making them known to physicians earlier in the course of the patient's care and enabling physicians and health care representatives to thoroughly discuss the patient's wishes in developing a treatment plan. Early communication also serves to anticipate and avoid the possibility of a future (and perhaps unanticipated) medical crisis in which the patient loses decisionmaking capacity and an advance directive is discovered too late to be useful. An active policy serves an important educational function as well, as initial conversation can become the vehicle for further dialogue about these issues. In contrast, a "passive policy" which places with patients and families responsibility to notify physicians and institutions of an advance directive would be much less successful in revealing the existence of advance directives, and is less likely to foster continuing discussion among patients, families and physicians.[93]

While inquiry at the time of admission is generally recommended, institutional policies and professional conduct should be flexible and sensitive to the interests of patients and families.

For example, provision of needed emergency care should not be delayed by such an inquiry, nor should patients or family members be subjected to unnecessary stress where a conversation about advance directives could just as easily, and with less emotional burden, take place at a later time.

Review and Monitoring

Given the somewhat complex and innovative features of the Commission's recommendations and some of the concerns that have been expressed regarding several of its features, the legislative proposal contains several provisions designed to monitor and review the proposal's implementation and effectiveness, and to respond to future difficulties which may arise. The legislative proposal specifically directs the Department of Health to collect data necessary to evaluate the proposal's effectiveness in achieving its intended objectives and provides a mechanism for proposing any necessary changes. The Department is directed to collect reports, on an annual basis, from health care institutions regarding their experience with the implementation of advance directives pursuant to the proposal, including the extent to which advance directives are being honored by health care providers, the way in which the decisionmaking process is working, and identification of particular concerns, such as protection against possible abuse. It is expected that this process will provide an empirically sound basis for recognizing and correcting any difficulties. Evaluation of the effectiveness of the proposal would be undertaken jointly by the Department of Health and the Bioethics Commission, with a report to be made to the Legislature within five years of the effective date of the new law (or earlier if necessary), including recommendations for any changes that may be needed to better achieve the proposal's objectives.

Education

Heightened public awareness concerning the problems associated with long-term care health care, as well as with acute care crises, has contributed to widespread public interest in advance planning for health care decisions. Nevertheless, at the present time only a small minority of individuals in New Jersey have completed some type of advance directive in the form of either a living will or durable power of attorney for health care. This fact may be attributable in part to the absence of a State law providing statutory grounds for legal recognition of advance directives. Yet, even in the many states where such laws exist the total number of people who have written advance directives does not exceed a small minority of the total eligible population.[94] The reasons for this are complex and involve social and psychological factors, ranging from a lack of information about advance directives as a tool for advance health care planning, to avoidance of candid discussion of the subject among individuals, family members and health care providers, particularly when it involves questions concerning life-sustaining treatment decisions.

The Commission believes that increased use of advance directives and their effective implementation will improve the quality of care for the citizens of New Jersey. It is also aware that if New Jersey is to be successful in increasing the numbers of people who write directives, there will be a need to provide citizens and professionals with information to help them better understand their rights, responsibilities and available options under the proposed legislation. This

process can only be achieved by concerted educational efforts on the part of public and private organizations. The Commission's mandate speaks strongly to the need to develop educational activities; and the Commission has expressed this commitment in the provisions of its advance directives proposal and in its creation of a special Task Force on Public and Professional Education.

Ideally, individuals will learn about advance directives prior to an experience of serious illness or injury to either themselves or a loved one. In fact, however, many people will not consider planning ahead until confronted by a condition which requires them to enter a hospital or other long-term care facility. For some, the experience of illness, including the prospect of future mental incapacity, may be a motivating factor in prompting action. For others, such as residents of long-term care facilities, the opportunity for learning about the use of advance directives outside an institutional setting is simply not present. For those who have already executed a directive, the actual experience of illness may provide the occasion for a more informed understanding of medical circumstances and conditions and therefore induce a desire to re-evaluate one's previously expressed wishes. For these reasons the Commission's proposal recognizes that health care institutions have a special responsibility to engage in educational efforts addressing the needs of both patients and health care providers. To this end, the proposed legislation recommends that health care institutions be required to provide information and assistance to patients, families and health care representatives concerning advance directives; and to inform health care professionals of their rights and responsibilities under the proposed legislation.

The Commission also strongly believes that practical and ethical considerations argue that educational efforts should not be left until a crisis arises, nor should health care institutions bear the sole responsibility for education. Efforts should be undertaken immediately to begin the process of educating interested citizens, health care providers and other professionals, such as attorneys and social workers, in the writing and implementation of advance directives. These educational efforts will require developing materials for use by patients, physicians and nurses, health care representatives and other professionals concerned with the care and/or treatment of a patient. It is important to address the specific informational needs of the various participants in the health care process in an effective way. Thus, responsibility for developing programs which have lasting impact also lies with those institutions responsible for the education and training of professionals. Education and training of nurses, doctors, other health care professionals, lawyers and others should include curricula or "clinical" activities which focus on increasing the student's understanding of the function of advance directives as tools which assist individuals in planning for their future health care and which can also provide them with guidance concerning the wishes of a patient under their care. Perhaps more importantly, programs of continuing professional education should be developed which provide post-graduate educational opportunities for working professionals.

The Commission has begun meeting these educational needs by focusing its initial efforts on developing an informational brochure on advance directives for public distribution. The purpose of the brochure is to explain to citizens and professionals the Commission's view of the

nature and function of advance directives. The brochure (presently in draft form) includes material selected to encourage informed reflection in the writing of an advance directive. It describes the various options a person can choose in creating a directive which best reflects his or her wishes and circumstances, and discusses the strengths and limitations of durable powers of attorney for health care, instruction directives and integrated directives. The brochure also will contain sample advance directive forms, all of which are consistent with the requirements of the Commission's proposed statute, as well as existing case law in New Jersey. (These forms are attached to the Commission's legislative proposal, reproduced in the appendix to this Part of the report.) In addition, the Commission is developing materials designed to assist individuals to identify and articulate their preferences and values in the writing of an advance directive. After completion of this project, the Commission will address the needs of professionals who may be called upon to assist individuals in preparing a directive, as well as development of informational materials to address special concerns regarding implementation of advance directives.

Notes

1. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research ("President's Commission, *Making Health Care Decisions*"), *Making Health Care Decisions*, Vol. 1 (U.S. Govt. P.O. 1982).

2. For in-depth discussion and analysis of the doctrine of informed consent, *see* Paul S. Appelbaum, Charles W. Lidz & Alan Meisel, *Informed Consent: Legal Theory and Clinical Practice* (Oxford Univ. Press 1987) ("Appelbaum, Lidz & Meisel"); Ruth R. Faden & Tom L. Beauchamp, *A History and Theory of Informed Consent* (Oxford Univ. Press 1987) ("Faden & Beauchamp"); Jay Katz, *The Silent World of Doctor and Patient* (The Free Press 1984) ("Katz"). For a concise discussion of the elements of informed consent, *see* Tom L. Beauchamp & James F. Childress, *Principles of Biomedical Ethics* (Oxford Univ. Press, 3d ed. 1989), chapter 3 ("Beauchamp & Childress").

3. *See* Allen Buchanan & Dan W. Brock, "Deciding for Others," *Milbank Quarterly* 64 (Supp. 2) (1986): 28-29 ("Buchanan & Brock").

4. For insightful discussions of metaphors and models of the physician-patient relationship, *see* James F. Childress, *Who Should Decide: Paternalism in Health Care* (Oxford Univ. Press 1982), chapt. 1; Mark Siegler, "Searching for Moral Certainty in Medicine: A Proposal for a New Model of The Doctor-Patient Encounter," *Bulletin of the New York Academy of Medicine* 57(1) (Jan.-Feb. 1981): 56-69; William F. May, "Code, Covenant, Contract, or Philanthropy," *Hastings Center Report* 5 (Dec. 1975): 29-38; Robert M. Veatch, "Models for Ethical Medicine in a Revolutionary Age," *Hastings Center Report* 2 (June 1972): 5-7.

5. *See* Appelbaum, Lidz & Meisel, *supra* note 2, pp. 152-58 (contrasting an event model of health care decisionmaking with a process model, and arguing that a process model is more consistent with clinical realities and better promotes active patient participation in the decisionmaking process).

6. President's Commission, *Making Health Care Decisions*, *supra* note 1, pp. 21-22; *see also Making Health Care Decisions*, Vol. 3 (App. L.) (surveying state law of informed consent).

7. Appelbaum, Lidz & Meisel, *supra* note 2, pp. 115-16.

8. Katz, *supra* note 2, chapt. 3; Alan J. Weisbard, "Informed Consent: The Law's Uneasy Compromise With Ethical Theory," *Nebraska L. Rev.* 65(4) (1986): 751 ("Weisbard") ("[i]n its attempt to translate the moral ideal of informed consent into a set of workable legal rules adapted to the technical requirements of the litigation process, the law has transformed that ideal into little more than a legal "duty to warn" of risks of medical treatment.").

9. Weisbard, *supra* note 8, p. 758.

10. 110 N.J. 204, 540 A.2d 504 (1988).

11. *Id.* at 205, 540 A.2d at 506.

12. 96 N.J. Super. 242, 232 A.2d 840 (1967), *aff'd per curiam*, 51 N.J. 404, 241 A.2d 235 (1968). *See Largey*, 110 N.J. at 207-14, 540 A.2d at 505-09. 540 A.2d at 505-09.

13. *Largey* was recently re-affirmed by the New Jersey Supreme Court in *Niemiera v. Schneider*, 114 N.J. 550, 561, 555 A. 2d 1112, 1119 (1989), which held that the physician is a "learned intermediary" who has a duty as part of the informed consent process to warn the patient of the risks of pharmaceutical products, in accordance with the "prudent patient" standard of disclosure.

14. *Largey*, 110 N.J. at 208, 540 A.2d at 506. *Accord Perna v. Pirozzi*, 92 N.J. 446, 457 A.2d 431 (1983) (the duty of disclosure is intended to enable the patient to "evaluate knowledgeably the options available and the risks attendant upon each") (quoting *Canterbury v. Spence*, 464 F.2d 772, 780 (D.C.Cir.), *cert. denied*, 409 U.S. 1064 (1972)).

15. *Largey*, 110 N.J. at 211-12, 540 A.2d at 508 (quoting *Canterbury v. Spence*, 464 F.2d at 787).

16. This standard is summarized in the decision of the appellate division in *Calabrese v. Trenton State College*, 162 N.J. Super. 145, 392 A.2d 600 (1978), *aff'd*, 82 N.J. 321, 413 A.2d 315 (1980). Quoting *Natanson v. Kline*, 187 Kan. 186, 354 P.2d 670, 672-73 (1960), the leading case stating the professional standard of disclosure, the *Calabrese* court stated: "(W)hen the facts concerning the actual disclosures made to the patient are ascertained...the expert testimony of medical witnesses is required to establish whether such disclosures are in accordance with those which a reasonable medical practitioner would make under the same or similar circumstances." *Calabrese* 162 N.J. Super. at 155, 392 A.2d at 605-06.

17. *Largey*, 110 N.J. at 211-12, 540 A.2d at 508.

18. 464 F.2d 772 (D.C. Cir.) *cert denied*, 409 U.S. 1064 (1972). Two earlier decisions of the appellate division had previously adopted the *Canterbury*-style reasonable or prudent patient-oriented standard. *See Nicholl v. Reagan*, 208 N.J. Super. 644, 649, 506 A.2d 805, 809 (1986); *Skripek v. Bergamo*, 200 N.J. Super. 620, 663, 491 A.2d 1336, 1343-47 (1985).

19. The law of informed consent has been the subject of a vast literature. In addition to the sources cited *supra* note 2, *see, e.g.*, Robert A. Burt, *Taking Care of Strangers: The Rule of Law in Doctor-Patient Relations* (The Free Press 1979); Alexander M. Capron, "Informed Consent in Catastrophic Disease Research and Treatment," *U.Pa.L.Rev.* 123 (1974): 340-438; Jon R. Waltz & Thomas W. Scheuneman, "Informed Consent to Therapy," *Nw.U.L.Rev.* 64 (1970): 628-50; Marjorie M. Shultz, "From Informed Consent to Patient Choice: A New Protected Interest," *Yale Law Journal* 95(2) (Dec. 1985): 219-99.

20. *See, e.g.*, President's Commission, *Making Health Care Decisions*, *supra* note 1, chapt. 1; Katz, supra note 2, chapt. 3.

While a few courts have adopted an individuated patient-oriented standard more protective of the patient's particular informational needs, this stronger commitment to the core value of patient self-determination is a minority view in the law of informed consent. *See, e.g.*, *Scott v. Bradford*, 606 P.2d 554 (Okla. 1979); *McPherson v. Ellis*, 305 N.C. 255, 287 S.E.2d 892 (1982). *Scott* adopts a *Canterbury*-style analysis, but rejects Canterbury's "reasonable man" approach to causation as limiting the injured patient's protection and as "backtracking on its own theory of self-determination." 606 P.2d at 559. The court's adoption of an individuated standard is suggested by its statements that the scope of a physician's communications must be measured by *his patient's need* to know enough to enable *him* to make an intelligent choice," and that risk is material and must be disclosed "if it would be likely to affect *patients'* decisions," *Id.* at 558 (emphasis added), but is left somewhat obscure by the absence of a characterization of its own position as either subjective or objective. *McPherson* rejects the objective standard of causation and expressly adopts a subjective individuated standard, stating that a patient's "supposedly inviolable right to decide for himself what is to be done with his body is made subject to a standard set by others." 287 S.E.2d at 897. However, the precedential impact of *McPherson* may be limited by the fact that the cause of action arose prior to the effective date of state legislation limiting the scope of informed consent claims. *See Dixon v. Peters*, 306 S.E.2d 477 (N.C. Ct. App. 1983).

21. Jay Katz, "Disclosure and Consent: In Search of Their Roots," in Aubrey Milunsky & George J. Annas, eds., *Genetics and the Law II* (Plenum Press 1980), p. 122. *See* President's Commission, *Making Health Care Decisions*, *supra* note 1, p. 30.

22. Kent W. Davidson, Chris Hackler, et al., "Physicians' Attitudes on Advance Directives," *Journal of the American Medical Association* 262 (17) (Nov. 3, 1989): 2415-2419.

23. ALA. CODE secs. 22-8A-1 to 8A-10 (1984); ALAS. STAT. secs. 18.12.010-.100 (1986); ARIZ. REV. STAT. ANN. secs. 36-3201-3210 (1986); ARK. STAT. ANN. secs. 20-17-201 to 17-218 (Supp. 1989); CAL. HEALTH & SAFETY CODE secs. 7185-7195 (West Supp. 1990); COLO. REV. STAT. secs. 15-18-101 to 18-113 (1987 & Supp. 1989); CONN. GEN. STAT. ANN. secs. 19a-570 to 19a-575 (West Supp. 1988); DEL. CODE ANN. tit. 16, secs. 16-2501-2509 (1983); D.C. CODE ANN. secs. 6-2421 to 6-2430 (1989); FLA. STAT. ANN. secs. 765.01-.15 (West 1986); GA. CODE ANN. secs. 31-32-1 to 32-12 (1985 & Supp. 1988); HAW. REV. STAT. secs. 327D-1 to D-27 (Supp. 1987); IDAHO CODE secs. 39-4501 to 39-4508 (1985 & Supp. 1988); ILL. ANN. STAT. Ch. 110-1/2, paras. 701-710 (Smith-Hurd Supp. 1988); IND. CODE ANN. secs. 16-8-11-1 to 11-22 (Burns Supp. 1989); IOWA CODE ANN. secs. 144A.1-.11 (1989); KAN. STAT. ANN. secs. 65-28, 101 to -28, 109 (1985); KY., H.B. No. 113 (Senate Committee Substitute) (1990); LA. REV. STAT. ANN. secs. 40:1299.58.1-.10 (West Supp. 1988); ME. REV. STAT. ANN. tit. 22, secs. 2921-2931 (Supp. 1988); MD. HEALTH-GEN. CODE ANN. secs. 5-601 to 5-614 (Supp. 1988); MINN., Bill No. S.F. 28 (1989); MISS. CODE ANN. secs. 41-41-101 to 41-121 (Supp. 1988); MO. ANN. STAT. secs. 459.010-.055 (Vernon Supp. 1988); MONT. CODE ANN. secs. 50-9-101 to 9-104, 9-111, 9-201 to 9-206 (1987); NEV. REV. STAT. ANN secs. 449.540-690 (Michie 1987); N.D., House Bill No. 1481 (1989); N.H. REV. STAT. ANN. secs. 137-H:1 to H:16 (Supp. 1988); N.M. STAT. ANN. secs. 24-7-1 to 7-11 (1986); N.C. GEN. STAT. secs. 90-320 to 90-322 (1985); OKLA. STAT. ANN. tit. 63 secs. 3101-3111 (West Supp. 1988); OR. REV. STAT. secs. 97.050-.090 (1984 & Supp. 1986); R.I. GEN. LAWS secs. 23-4.10.1-.2 (1989); S.C. CODE ANN. secs. 44-77-10 to 77-160 (Law. Co-op. Supp. 1987); S.D., H.B. No. 1233 (1990); TENN. CODE ANN. secs. 32-11-101 to 11-110 (Supp. 1988); TEX. REV. CIV. STAT. ANN. art. 4590h-1 (Vernon Supp. 1988); UTAH CODE ANN. secs. 75-2-1101 to 2-1118 (Supp. 1988); VT. STAT. ANN. tit. 18, secs. 5251-5262 (1987) and tit. 13, secs. 1801 (1974 & Supp. 1988); VA. CODE ANN. secs. 54.1-2981-2992 (1988 & Supp. 1989); WASH. REV. CODE ANN. secs. 70.122.010-70.122.905 (Supp. 1989); W. VA. CODE secs. 16-30-1 to 30-10 (1985) and H.B. No. 4197 (Enrolled Committee Substitute) (1990); WIS. STAT. ANN. secs. 154.01-.15 (West Supp. 1988); WYO. STAT. secs. 35-22-101 to 22-109 (1977 & Supp. 1988).

24. CAL. HEALTH & SAFETY CODE secs. 7185-7195 (West Supp. 1990).

25. CAL. CIV. CODE secs. 2430-2444 (West 1974 & Supp. 1988); D.C. CODE ANN. secs. 21-2201-2213 (Supp. 1989); ILL. ANN. STAT. ch. 110 1/2, paras. 804-1 - 804-12 (Smith-Hurd Supp. 1988); IDAHO CODE sec. 39-4505 (Supp. 1988); IND. CODE ANN. secs. 16-8-12-6 (Burns Supp. 1989); MINN., Bill No. S.F. 28 (1989); NEV. REV. STAT. secs. 449.800-860 (1987); R.I. GEN LAWS secs. 23-4.10.1-.2 (1989); VT. STAT. ANN. tit. 14, secs. 3451-3467 (Supp. 1988).

26. ARK. STAT. ANN. sec. 20-17-202(e) (Supp. 1987); DEL. CODE ANN. tit. 16, sec. 2502(b) (1983); FLA. STAT. ANN. secs. 765.05(2), 765.07 (1986); IOWA CODE ANN. sec. 144A.7 (West Supp. 1988); LA. REV. STAT. ANN. sec. 40:1299.58.3(c)(1) (West Supp. 1988); TEX. REV. CIV. STAT. ANN. art. 4590h-1 (Vernon 1989); UTAH CODE ANN. sec. 75-2-1106 (Supp. 1988); VA. CODE ANN. sec. 54.1-2984 (1988 & Supp. 1989); WYO. STAT. sec. 35-22-103 (1988).

27. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* (U.S. Govt. P.O. 1983) ("President's Commission, *Deciding to Forego*"), p. 153.

28. New York State Task Force on Life and The Law, *Life-Sustaining Treatment: Making Decisions and Appointing a Health Care Agent* (1987) ("New York State Task Force") The New York State Task Force recommended a health care proxy act, but did not recommend enactment of living will legislation. *See* pp. 80-83.

29. *See generally*, Buchanan and Brock, *supra* note 3.

30. *See* Albert R. Jonsen, Mark Siegler, *et. al*, *Clinical Ethics* (MacMillan Publishing 1986), pp. 79-82 ("Jonsen & Siegler") (discussing the interpretation of living wills).

31. New York State Task Force, *supra* note 28, pp. 75-76; David A. Peters, "Advance Medical Directives: The Case for the Durable Power of Attorney for Health Care," *Journal of Legal Medicine* 8(3) (1987): 444-46 ("Peters").

32. Sissela Bok, "Personal Directions for Care at the End of Life," *New England Journal of Medicine* 295 (7) (Aug. 12, 1976): 368.

33. Peters, *supra* note 31, p. 446.

34. Buchanan and Brock, *supra* note 3, p. 64.

35. *Id.* at 66.

36. It is important to recognize that some would prefer to designate a trusted friend as their health care representative, rather than a family member. For example, in a survey of 118 homosexual male patients with AIDS in San Francisco, 47 percent stated that they would choose a partner or friend to act as a health care representative. Thirty-two percent stated that they would choose a family member. Robert Steinbrook, Bernard Lo, Jeffrey Moulton, *et al*, "Preferences of Homosexual Men With AIDS for Life-Sustaining Treatment, " *New England Journal of Medicine* 314(7) (Feb. 13, 1986): 457-60. The Commission's legislative proposal is intended to afford wide latitude in the selection of a health care representative.

37. *See* Robert M. Veatch, "An Ethical Framework for Terminal Care Decisions: A New Classification of Patients," *Journal of the American Geriatric Society* 32 (9) (Sept. 1984): 665-69.

38. Robert N. Swidler, "The Health Care Agent: Protecting the Choices and Interests of Patients Who Lack Capacity," *N.Y.L.S.J. Human Rights* VI (Fall 1988): 14 ("Swidler").

39. Bernard Lo, "Caring for Incompetent Patients: Is There a Physician on the Case?," *Law, Medicine & Health Care* 17(3) (Fall 1989): 217.

40. Joel M. Zinberg, "Decisions for the Dying: An Empirical Study of Physicians' Responses to Advance Directives," *Vermont Law Review* 13 (Winter 1989): 458, 483 & n. 151; Swidler, *supra* note 38, p. 10.

41. FLA. STAT. ANN. sec. 765.02 (West 1986); IND. CODE ANN. secs. 16-8-11-12(c) (Burns Supp. 1988); MD. HEALTH-GEN. CODE ANN. sec. 5-611 (1987); N.H. REV. STAT. ANN. sec. 137-H:1 (Supp. 1988); UTAH CODE ANN. sec. 75-2-1102(a) (Supp. 1988). Several other states affirm the patient's right to accept or request treatment in their statutes' legislative findings. ARIZ. REV. STAT. ANN. secs. 36-3201-3210 (1986); IOWA CODE ANN. secs. 144A.1-.11 (1989); TENN. CODE ANN. secs. 32-11-102, 32-11-103(8) (Supp. 1988).

42. Beauchamp & Childress, *supra* note 2, pp. 80-82.

43. David L. Jackson & Stuart J. Youngner, "Patient Autonomy and "Death With Dignity": Some Clinical Caveats," *New England Journal of Medicine* 301 (Aug. 1979): 404-408 ("Jackson & Youngner"); Jay Katz, *supra* note 2.

44. Beauchamp & Childress, *supra* note 2, pp. 83-85; Faden & Beauchamp, *supra* note 2, pp. 287-90; Appelbaum, Lidz & Meisel, *supra* note 2, pp. 81-93.

45. *See, e.g.*, President's Commission, *Making Health Care Decisions*, *supra* note 1, pp. 60-62; The Hastings Center, *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying* (The Hastings Center 1987), pp. 26-27 ("Hastings Center *Guidelines*").

46. President's Commission, *Making Health Care Decisions*, *supra* note 1, pp. 56-57; President's Commission, *Deciding to Forego*, *supra* note 27, pp. 121-22.

47. *See* Jackson & Youngner, *supra* note 43; Bruce L. Miller, "Autonomy & the Refusal of Lifesaving Treatment," *Hastings Center Report* 11 (Aug. 1981): 22-28.

48. Paul S. Appelbaum and Thomas Grisso, "Assessing Patients' Capacities to Consent to Treatment," *New England Journal of Medicine* 319(25) (Dec. 22, 1988): 1635.

49. *See* Katz, *supra* note 2, chapts. 5 and 6; Jackson & Youngner, *supra* note 43.

50. Some commentators state this point more forcefully, claiming that "(t)he search for a single test of competency is a search for a Holy Grail." Loren H. Roth, Alan Meisel & Charles W. Lidz, "Tests for Competency to Consent to Treatment," *American Journal of Psychiatry* 134(3) (Mar. 1977): 283.

51. President's Commission, *Making Health Care Decisions*, *supra* note 1, pp. 60-61.

52. *Id.*, p. 60; Buchanan & Brock, *supra* note 3, pp. 31-37.

53. President's Commission, *Making Health Care Decisions*, *supra* note 1, p. 170.

54. Buchanan & Brock, *supra* note 3, pp. 32-33.

55. *See* Jackson & Youngner, *supra* note 43.

56. Katz, *supra* note 2.

57. President's Commission, *supra* note 1, pp. 173-75; Appelbaum, Lidz & Meisel, *supra* note 2, pp. 90-93.

58. Hastings Center *Guidelines*, *supra* note 45, p. 11; Barbara A. Brown, Steven H. Miles, *et al.*, "The Prevalence and Design of Ethics Committees in Nursing Homes," *Journal of the American Geriatrics Society* 35(11) (Nov. 1987): 1028-33 ("Brown, Miles, *et al.*").

59. Gerald R. Winslow, "From Loyalty to Advocacy: A New Metaphor for Nursing," *Hastings Center Report* 14(3) (June 1984): 32-40.

60. Brown, Miles, *et al.*, *supra* note 58.

61. Hastings Center *Guidelines*; *supra* note 45, p. 30.

62. *Id.*

63. Bernard Lo, "*The Clinical Use of Advance Directives,*" *in Medical Ethics: A Guide for Health Professionals* (John F. Monagle, ed., Aspen 1988), p. 212.

64. *See, e.g*, Buchanan and Brock, *supra* note 3, p. 62.

65. Tom L. Beauchamp and Laurence B. McCullough, *Medical Ethics: The Moral Responsibilities of Physicians* (Prentice-Hall, Inc. 1984), chapt. 5.

66. Edmund D. Pellegrino and David C. Thomasma, "The Conflict Between Autonomy and Beneficence in Medical Ethics: Proposal for a Resolution," *Journal of Contemporary Health Law and Policy* 3 (1987): 23-46. The authors argue that since autonomy is a good (though not the only good) of the patient, the physician's duty to benefit the patient includes the duty to seek to enhance or to restore patient autonomy, and that patient autonomy ought to be viewed as an end of medicine.

67. *See* authorities cited *infra* note 69.

68. *See, e.g., In re Quinlan*, 70 N.J. 10, 355 A.2d 647, *cert. denied sub nom. Garger v. New Jersey*, 429 U.S. 922 (1976); *In re Jobes*, 108 N.J. 394, 529 A.2d 434 (1987); *Gray v. Romeo*, 697 F. Supp. 580 (D.R.I. 1988); *Rasmussen v. Fleming*, 154 Ariz. 207, 741 P.2d 674 (1987); *Conservatorship of Drabick*, 200 Cal App. 3d 185, 245 Cal Rptr. 840 (Ct. App. 1988); President's Commission, *Deciding to Forego*, *supra* note 27, Hastings Center *Guidelines*, *supra* note 45; New York State Task Force, *supra* note 28; American Medical Association Council on Ethical and Judicial Affairs, *Current Opinions* ("AMA Council"); Joint Report of the Council on Scientific Affairs

and Council on Ethical and Judicial Affairs, "Persistent Vegetative State and the Decision to Withdraw or Withhold Life Support", *Journal of the American Medical Association* 263(3) (Jan. 19, 1990): 426-30.

69. While there is general consensus that an incompetent patient who is terminally ill has the right to refuse life-sustaining treatment, *see, e.g., In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985); *John F. Kennedy Memorial Hospital v. Bludworth*, 452 So. 2d 921 (Fla. 1984); *In re Spring*, 380 Mass. 629, 405 N.E.2d 115 (1980); President's Commission, *Deciding to Forego*, *supra* note 27; Hastings Center *Guidelines*, *supra* note 45; AMA Council, *supra* note 68, there does not appear to be widespread agreement on the definition of "terminal illness" ("terminal condition").

70. *Accord* Hastings Center *Guidelines*, *supra* note 45.

71. AMA Council, *supra* note 68; *Warthen v. Toms River Community Memorial Hosp.*, 109 N.J. Super. 18, 488 A.2d 229 (1985); *In re Requena*, 213 N.J. Super. 443, 517 A.2d 869 (App. Div. 1986).

72. Beauchamp and Childress, *supra* note 2, p. 387.

73. Jonsen & Siegler, *supra* note 30, pp. 93-94.

74. *See* Hastings Center *Guidelines*, *supra* note 45, pp. 8, 19-20.

75. *Id.*, pp. 32-33.

76. *In re Jobes*, 108 N.J. 394, 425, 529 A.2d 434, 450 (1987) (citing *In re Requena*, 213 N.J. Super. 443, 517 A.2d 869 (App. Div. 1986)). *Requena* rejected the hospital's reliance on a policy not to participate in the withholding or withdrawal of artificially provided fluids and nutrition where the patient had no notice of the policy prior to her decision to forego treatment. *See also In re Rodas*, No. 86PR139, slip op. (D.Ct., Mesa Cty., Colo, Jan. 22, 1987).

77. *In re Jobes*, 108 N.J. at 425, 529 A.2d at 450.

78. George J. Annas, "Transferring the Ethical Hot Potato," *Hastings Center Report* 17(1) (Feb. 1987): 21.

79. Letter from Forrest A. Brower, Group Vice President, New Jersey Hospital Association, to Daniel F. O'Connell, Esq., Commission Chairman (Dec. 9, 1988); Public hearing testimony of James Cunningham, Executive Director, New Jersey Association of Health Care Facilities (Nov. 29, 1988).

80. *See* Office of Technology Assessment, *Institutional Protocols for Decisions About Life-Sustaining Treatments: Special Report* (U.S. Govt. P.O. 1988), pp. 8-9; Hastings Center *Guidelines*, p. 33.

81. Arthur L. Kellerman & Terence F. Ackerman, "Interhospital Patient Transfer: The Case For Informed Consent," *New England Journal of Medicine* 319(10) (Sept. 8, 1988): 643-47.

82. *See* Stuart E. Lind, "Transferring The Terminally Ill," *New England Journal of Medicine* 311(18) (Nov. 1, 1984): 1181-82; *In re Requena*, 213 N.J. Super. 443, 517 A.2d 869 (1986).

83. *See, e.g.*, Sidney H. Wanzer, S. James Adelstein, *et al.*, "The Physician's Responsibility Toward Hopelessly Ill Patients," *New England Journal of Medicine* 310(15) (Apr. 12, 1984): 956.

84. *Id.*

85. George A. Oakes, "A Prosecutor's View of Treatment Decisions," in *Legal and Ethical Aspects of Treating Critically and Terminally Ill Patients* (A. Edward Doudera & J. Douglas Peters, eds. AUPHA Press 1982), pp. 194-200; George J. Annas and Leonard H. Glantz, "The Right of Elderly Patients to Refuse Life-sustaining Treatment," *The Milbank Quarterly* 64 (Supp. 2) (1986): 95-162.

86. For thorough discussion of health care professionals' perceptions of the law and the role of legal perceptions in medical decisionmaking, *see* Marshall B. Kapp and Bernard Lo, "Legal Perceptions and Medical Decision Making, *The Milbank Quarterly* 64 (Supp. 2) (1986): 163-202 ("Kapp and Lo").

87. Bernard Lo, Glenn Saika, *et al.*, "Do Not Resuscitate Decisions: A Prospective Study at Three Teaching Hospitals," *Archives of Internal Medicine* 145 (1985): 1115-17 (in 4 of 136 cases studied in San Francisco, physicians who disagreed with family members of an incompetent patient about treatment gave oral do not resuscitate orders and intentionally did not document the order in the patient's records).

88. Kapp & Lo, *supra* note 86, pp. 172-73.

89. *In re Farrell*, 108 N.J. 335, 358, 529 A.2d 404, 415 (1987) ("Unfortunately, fears of civil and criminal liability have often forced family members or doctors to seek judicial intervention before they help a patient to effectuate his or her decision to withdraw treatment.").

90. *In re Quinlan*, 70 N.J. 10, 49, 355 A.2d 647, 668, *cert. denied sub nom Garger v. New Jersey*, 429 U.S. 922 (1976).

91. Although the stated terms of immunity provisions differ somewhat among the states, legislation in other states governing advance directives has uniformly included a statutory grant of immunity to health care professionals and health care institutions. *See* the statutes cited *supra* note 23.

92. *N.J.S.A.* 52:14B-1 *et. seq* (West 1968).

93. S. Van McCrary and Jeffrey R. Botkin, "Hospital Policy on Advance Directives: Do Institutions Ask Patients About Living Wills?", *Journal of the American Medical Association* 262(17) (Nov. 3, 1989): 2412-13.

94. *Id.*; David Orentlicher, "Advance Medical Directives", *Journal of the American Medical Association* 263 (17) (May 2, 1990): 2367 (citing a 1988 public opinion survey conducted by the American Medical Association).

Chapter Four: Proposed Advance Directives for Health Care Act With Commentary

(The proposed New Jersey Advance Directives for Health Care Act was approved in final form by the Commission on December 29, 1988.)

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Proposed New Jersey Advance Directives for Health Care Act With Commentary

An act concerning health care decisionmaking for patients lacking decisionmaking capacity and who have executed advance directives for health care.

Be it enacted by the Senate and General Assembly of the State of New Jersey that:

Section 1: Legislative Findings

The Legislature finds and declares that:

A) Competent adults have the fundamental right, in collaboration with their health care providers, to control decisions about their own health care. This State recognizes, in its law and public policy, the personal right of the individual patient to make voluntary, informed choices to accept, to reject, or to choose among alternative courses of medical and surgical treatment.

B) Modern advances in science and medicine have made possible the prolongation of the lives of many seriously ill individuals, without always offering realistic prospect for improvement or cure. For some individuals the possibility of extended life is experienced as meaningful and of benefit. For others, artificial prolongation of life may seem to provide nothing medically necessary or beneficial, serving only to extend suffering and prolong the dying process. This State recognizes that the fundamental right of individual choice extends to decisions to have medical or surgical means or procedures calculated to prolong life provided, withheld, or withdrawn.

C) In order that the right to control decisions about one's own health care should not be lost in the event a patient loses decisionmaking capacity and is no longer able to participate actively in making his or her own health care decisions, this State recognizes the right of competent adults to plan ahead for health care decisions through the execution of advance directives, such as living wills and durable powers of attorney, and to have the wishes expressed therein respected, subject to certain limitations.

D) The right of individuals to forego life-sustaining measures is subject to certain interests of society. The most significant of these societal interests is the preservation of life, understood to embrace both an interest in preserving the life of the particular patient and a related but distinct interest in preserving the sanctity of all human life as an enduring social value. A second, closely related societal interest is the protection of individuals from direct and purposeful self-destruction, motivated by a specific intent to

die. A third interest is the protection of innocent third parties who may be harmed by the patient's decision to forego therapy; this interest may be asserted to prevent the emotional and financial abandonment of the patient's minor children or to protect the paramount concerns of public health or safety. A fourth interest encompasses safeguarding the ethical integrity of the health care professions, individual professionals, and health care institutions, and maintaining public confidence and trust in the integrity and caring role of health care professionals and institutions. Finally, society has an interest in ensuring the soundness of health care decisionmaking, including both protecting vulnerable patients from potential abuse or neglect and facilitating the exercise of informed and voluntary patient choice.

E) In accordance with these state interests, this State expressly rejects on both legal and moral grounds the practice of active euthanasia, as by deliberate lethal injection intended to cause death. No individual shall have the right to, nor shall any physician or other health care professional be authorized to engage in, the practice of active euthanasia.

F) In order to assure respect for patients' previously expressed wishes when the capacity to participate actively in decisionmaking has been lost or impaired; to facilitate and encourage a sound decisionmaking process in which patients, health care representatives, families, physicians, and other health care professionals are active participants; to properly consider patients' interests both in self-determination and in well-being; and to provide necessary and appropriate safeguards concerning the termination of life-sustaining treatment for incompetent patients as the law and public policy of this State, the Legislature hereby enacts the New Jersey Advance Directives for Health Care Act.

Comment

Section 1 identifies the fundamental principles, concerns and objectives which underlie and inform the approach taken in the Act. Of special importance, the Act seeks to achieve an appropriate balance between respect for patients' rights to control decisions about their own health care, in particular the right to forego life-sustaining measures, and other sometimes competing societal interests, in particular society's interests in the preservation of life and in the integrity of the medical profession. The Act gives greater weight to the societal interests identified in section 1(D) than has been typical of case law in this area, including the opinions of the New Jersey Supreme Court.

Section 2: Definitions

All definitions are intended solely for the purposes of this Act. As used in this Act:

A) *"Adult"* means an individual of 18 or more years of age.

B) *"Advance directive for health care"* or *"advance directive"* means a writing executed in accordance with the requirements of this Act. The term "advance directive" encompasses both the designation of a health care representative (known as a "proxy directive" or a "medical durable power of attorney") and a statement of personal wishes regarding health care in the event of loss of decisionmaking capacity (known as an

"instruction directive" or, in popular discourse, as a "living will").

C) *"Attending physician"* means the physician selected by or assigned to the patient who has primary responsibility for the treatment and care of the patient.

D) *"Decisionmaking capacity"* means a patient's ability to understand and appreciate the nature and consequences of health care decisions, including the benefits and risks of each, and alternatives to any proposed health care, and to reach an informed decision. An individual's decisionmaking capacity is evaluated relative to the demands of a particular health care decision.

E) *"Declarant"* means a competent adult who executes an advance directive.

F) *"Do not resuscitate order"* means a physician's written order not to attempt cardiopulmonary resuscitation in the event the patient suffers a cardiac or respiratory arrest.

G) *"Emergency care"* means immediate treatment provided in response to a sudden, acute and unanticipated medical crisis in order to avoid injury, impairment, or death.

H) *"Health care decision"* means a decision to accept or to refuse any treatment, service or procedure used to diagnose, treat or care for a patient's physical or mental condition, including "life-sustaining treatment" as defined in this Act. "Health care decision" also means a decision to accept or to refuse the services of a particular physician, other health care professional or health care institution, including a decision to accept or to refuse a transfer of care.

I) *"Health care institution"* means all institutions, facilities, and agencies licensed, certified, or otherwise authorized by the law of this State to administer health care in the ordinary course of business, including hospitals, nursing homes, residential health care facilities, and home health care agencies, except as further specified below. As used in this Act, "health care institution" also includes all hospice programs operating in this State, but does not include mental health institutions, facilities or agencies, or institutions, facilities or agencies for the developmentally disabled. The term "health care institution" shall not be construed to include "health care professionals" as defined in this Act.

J) *"Health care professional"* means an individual licensed by this State to administer health care in the ordinary course of business or practice of a profession. As used in this Act, the phrase "other health care professionals" refers to health care professionals other than physicians and nurses.

K) *"Health care representative"* means the individual designated by a declarant pursuant to the proxy directive part of an advance directive for the purpose of making health care decisions on the declarant's behalf, or to an individual designated as an alternate health care representative who is acting as the declarant's health care representative in accordance with the terms and order of priority stated in an advance directive.

L) *"Instruction directive"* means a writing which provides instructions and direction

regarding the declarant's wishes for health care in the event of the declarant's decisionmaking incapacity.

M) *"Life-sustaining treatment"* means the use of any medical device or procedure, drugs, surgery or therapy that uses mechanical or other artificial means to sustain, restore or supplant a vital bodily function, and thereby to increase the expected life span of a patient.

N) *"Patient"* means an individual who is under the care of a physician or other health care professional.

O) *"Permanently unconscious"* means a medical condition that has been diagnosed in accordance with currently accepted medical standards and with reasonable medical certainty as total and irreversible loss of consciousness and capacity for interaction with the environment. The term "permanently unconscious" includes without limitation a persistent vegetative state or irreversible coma.

P) *"Physician"* means an individual licensed to practice medicine in this State.

Q) *"State"* means a state, territory, or possession of the United States, the District of Columbia, or the Commonwealth of Puerto Rico.

R) *"Terminal condition"* means the terminal stage of an irreversibly fatal illness, disease or condition. While a determination of a specific "life expectancy" is not required as a precondition for a diagnosis of a "terminal condition," a prognosis of a life expectancy of six months or less, with or without the provision of life-sustaining treatment, based upon reasonable medical certainty, shall be deemed to constitute a terminal condition.

Comment

The comments to section 2 address those definitions of particular importance in the Act, the meaning of which may not be self-evident. Further elaboration and discussion of the implications of defined terms is found in the substantive provisions and accompanying comments in the subsequent sections of the Act.

The Act uses the terms **"advance directive for health care"** and **"advance directive"** (section 2(B)), to refer to a written document executed in accordance with the requirements of the Act. The individual who has executed (who executes) an advance directive is referred to in the Act as the "declarant". A **"declarant"** must be a competent adult of at least 18 years of age. (Sections 2(E) and 2(A)) An advance directive may designate another individual (a **"health care representative"**) to make health care decisions on the declarant's behalf, may contain an **"instruction directive"** (section 2(L)) which states the declarant's personal wishes regarding health care in the event of subsequent decisionmaking capacity, or both. The term **"health care representative"** (section 2(K)), refers to the individual designated by the declarant to make health care decisions on the declarant's behalf, and to an alternate designee serving in the capacity of health care representative.

The Act does *not* use the terms "medical durable power of attorney" or "living will." This represents an effort to provide a comprehensive statutorily recognized means of providing for one's health care in the event of incapacity, through an integrated approach encompassing *both* the designation of a personally-selected health care representative (more commonly known as a "proxy directive" or a "medical durable power of attorney") and the articulation of one's general and specific wishes regarding health care (popularly known as a "living will"). The Act also avoids use of the popular term "living will" because of its ambiguous and possibly confusing references

to both a general concept of foregoing life-sustaining measures and to a specific model document which often is structured only to permit the declarant to direct the foregoing of life-sustaining measures and to do so only in a narrowly defined set of circumstances.

The concept of **"decisionmaking capacity"** (section 2(D)), is at best vaguely defined in existing statutory and common law. The definition adopted in the Act is based upon an understanding of the several interrelated factors ordinarily involved in the decisionmaking process for the typical patient. A patient's decisionmaking capacity may be assessed in terms of three interrelated abilities the patient must possess and exercise in order to reach an informed decision: 1) the ability to understand and to evaluate information relevant to his or her medical condition, including (in lay terms) diagnosis, prognosis, and the risks, benefits and burdens (and associated uncertainties) of the proposed treatment alternatives (including the option of no treatment); 2) the ability to reason and deliberate about available medical information and a course of treatment; and 3) though not expressly stated in the definition, the ability to act upon personal values and objectives in evaluating relevant information, including the risks and benefits of the proposed treatment and its alternatives.

The second sentence of the definition states that, as used in this Act, decisionmaking capacity is primarily a functional and decision-specific concept. The Act rejects inflexible concepts of capacity based upon the patient's advanced age or general mental status, short of extreme circumstances. Patients should not be presumed to lack capacity merely on the basis of fitting into a category, such as being elderly, mentally ill, retarded or disabled. Furthermore, a patient may possess the capacity to make some health care decisions but not others. Thus, decisionmaking capacity may vary with the demands of a particular health care decision, and should be evaluated relative to the demands of that particular decision.

The Act intentionally uses the terms "capacity" and "incapacity" rather than "competence" and "incompetence" to characterize the patient's abilities to make health care decisions. The term competence is most often thought of as a legal concept associated with a threshold determination by a court of a person's capacity to make particular types of decisions, usually business or financial decisions. In the context of health care decisionmaking, the concepts of competence and incompetence are sometimes employed to separate patients into two sharply differentiated groups: Those from whom consent must be obtained (absent, for example, medical emergency) and those who, in blunt terms, can be and often are ignored in the decisionmaking process. The decision-specific approach adopted by the Act rejects the concept of competence as one which separates patients into two sharply differentiated groups; the Act therefore avoids use of the terms "competence" and "incompetence" which ordinarily convey this meaning.

The term **"health care decision"** (section 2(H)) is intended to be defined broadly. "Health care decision" refers to a decision to accept or to refuse any form of treatment, service or procedure used for either the diagnosis or treatment of the patient's physical or mental condition. While the term is specifically defined to include "life-sustaining treatment" (section 2(M)), the definition is much broader and encompasses diagnostic procedures and services, as well as treatment that is not life-sustaining. The Act is intended to afford individuals the right to consent to or to refuse by an advance directive a broad range of health care services, whether diagnostic or therapeutic, necessary to sustain life, to treat non-life-threatening conditions, or to relieve pain or suffering. The second sentence of the definition expressly includes decisions about transfers of care in the meaning of "health care decision", recognizing that an important part of health care is the choice of a health care professional, such as a physician, and of a health care institution.

The term **"life-sustaining treatment"** (section 2(M)) is also intended to be defined broadly. "Life-sustaining treatment" refers to a broad range of medical devices or procedures, drugs, surgery or therapy, where providing such treatment to the patient would continue a vital bodily function and increase the life expectancy of the patient. As used in the Act, the definition of life-sustaining treatment is not intended to include, nor to exclude, artificially provided fluids and nutrition. As discussed more fully in the comments to sections 15 and 16, the Act adopts a decision-specific approach to decisions to forego artificially provided fluids and nutrition which specifically

identifies, in section 16, the circumstances in which the Act permits the withholding or withdrawal of artificially provided fluids and nutrition pursuant to the terms of an advance directive. Thus, with respect to decisions to forego artificially provided fluids and nutrition under this Act, the term "life-sustaining treatment" has no operative significance.

In contrast to some states, the Act does not exclude "comfort care" from the definition of "life-sustaining treatment." Since many measures which make the patient more comfortable are also life-sustaining, such an exclusion can be confusing. The Act seeks to avoid this confusion by allowing that life-sustaining treatment may be withheld or withdrawn pursuant to the Act, even if the treatment to be foregone would also make the patient more comfortable; at the same time sections 15(B) and 16(C) expressly state that the Act does not impair professional obligations to alleviate pain and make the patient comfortable when life-sustaining measures are foregone.

The Act uses the term **"patient"** (section 2(N)) in its ordinary and commonly understood sense, to refer to an individual who is under the care of a physician or other health care professional. In contrast, many states use the term "qualified patient", often defining a "qualified patient" as a patient who has executed an advance directive and who has been determined by one or more physicians to be in a terminal condition. Typically, the central purpose of this approach is to permit an advance directive to be used only to direct the withholding or withdrawal of life-sustaining treatment, and only in circumstances where the patient has been determined to be in a terminal condition. The scope of this Act is not restricted in either of these respects, and avoiding the term "qualified patient" (and not structuring the Act around such a definition) serves to avoid an important potential confusion with the approach taken in other states.

The term **"permanently unconscious"** (section 2(O)) refers to a patient who has *totally* and *irreversibly* lost consciousness and capacity for interaction with the environment. While the definition states that permanent unconsciousness includes a persistent vegetative state and the similar (but not identical) condition of irreversible coma, permanent unconsciousness is not to be taken as a medical or scientific term which labels a specific set of diagnostic criteria. The term "permanently unconscious" is intended to avoid the technical complexities of accurately defining medical conditions in favor of a more common sense understanding of what it means for a patient to have irreversibly lost capacity for a cognitive sapient state. A diagnosis of permanent unconsciousness must be made in accordance with currently accepted medical standards and with reasonable medical certainty.

The term "permanently unconscious" does not include patients who meet neurological criteria for the declaration of death, unless an exemption recognized by law from application of such criteria for declaring death, based upon the personal religious beliefs or moral convictions of the patient, prohibits the declaration of death upon the basis of neurological criteria, or health care providers responsible for the patient's care choose to accommodate such a claim of exemption.

In most cases the bodily functions of a patient in a state of permanent unconsciousness can be maintained with artificial life-support for many years. Thus, with rare exceptions, a permanently unconscious patient will not meet the criteria for a diagnosis of a "terminal condition" (discussed below). The use of the terms "permanent unconsciousness" and "terminal condition" in the substantive provisions of the Act recognizes the current understanding of these terms as referring to distinct medical conditions and avoids unnecessary and unhelpful debate concerning whether the permanently unconscious patient should be regarded as "terminal".

The definition of **"terminal condition"** (section 2(R)) requires a diagnosis that the patient's illness, disease or condition is *irreversible* and *fatal*. The key phrase here is that the patient be diagnosed to be in the "terminal stage" of the illness or disease process. The concept of irreversibility, not that of incurability, expresses the fundamental concern about the dying process. Under this definition a reversible condition is not terminal; an irreversible condition is by definition incurable. (A patient could have an "incurable" but "reversible" condition.) Since there are terminal "conditions" not attributable to disease processes, the term "condition" is used rather than

"illness", as "illness" is ordinarily identified with a disease process.

Diagnosis of a terminal condition does not require a specific prognosis of length of life remaining as a necessary element of such a determination. In contrast to the law of some other states, the Act does not require that the patient's prognosis be "imminent" death, nor does the Act use the phrase "death within a relatively short time", which appears to be a more flexible standard yet conveys a sense of imminence. A requirement that death be imminent or within a short time was considered too restrictive of the patient's right to refuse treatment and to choose a less burdensome dying process.

The Act also rejects use of a fixed and inflexible time period (such as one year) established by statute. The circumstances and inevitable variations in a patient's condition and prognosis make a fixed time period both artificial and unrealistic. It is intended that physicians not be unduly constrained by a fixed time period in the exercise of professional judgment. Nor are physicians compelled to announce that a patient either does or does not have a terminal condition based upon a prognosis of a specific life expectancy fixed by statute. However, the definition of terminal condition does set forth a ***guideline*** for prognosis of life expectancy--six months or less. Patients whose life expectancy is determined, with reasonable medical certainty, to be six months or less are clearly within the meaning of "terminal condition", and should be considered terminal for purposes of the Act. The six month guideline for prognosis of life expectancy was adopted in part to correspond to federal and state law governing reimbursement of health care costs, *e.g.*, under Medicare and hospice regulations. This is intended, however, only as a guideline. Where the physician cannot state with reasonable medical certainty that the patient has a life expectancy of six months or less the patient's condition may, nonetheless, be terminal within the meaning of the definition. By not adopting the requirement that to be "terminally ill" a patient's life expectancy must be determined to be one year or less, the Act would modify existing law under *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985).

The patient's prognosis is to be determined "with or without the provision of life-sustaining treatment." This follows the approach taken in the majority of states, and rejects the position taken in some states that the physician's judgment should be based upon the patient's prognosis "regardless of" (*i.e.*, with) the administration of life-sustaining measures. This does not mean, however, that the patient's prognosis with the provision of life-sustaining treatment should be considered irrelevant to the decisionmaking process.

Section 3: Basic Principles

This section summarizes the key operative provisions of this Act. This section is to be read in the context of the entire Act, and is not intended, and shall not be construed, to substitute for or modify the operation of the other provisions of this Act.

A) A competent adult (the declarant) may execute an advance directive for health care, in accordance with section 4 of this Act. The advance directive may include the designation of a health care representative, in accordance with section 6(B); an instruction directive, in accordance with section 6(C); or both.

B) The declarant may subsequently re-affirm or modify the advance directive, in accordance with section 5(A), or revoke the advance directive, in accordance with section 5(B). Notwithstanding any other provision of this Act, a patient's contemporaneously expressed wish that medically appropriate life-sustaining treatment and/or artificially provided fluids and nutrition necessary to sustain life be provided shall be respected, in accordance with section 11(A)(4).

C) An advance directive becomes operative when it is transmitted to the attending physician or to the health care institution, in accordance with section 7, and when the declarant is determined to lack decisionmaking capacity, in accordance with section 8.

D) Once operative, an advance directive designating a health care representative confers upon the health care representative the legal authority to participate in the decisionmaking process, in accordance with section 11, and to make health care decisions on the patient's behalf, in accordance with section 9 and the other provisions of this Act.

E) In the absence of a designated health care representative, an instruction directive, once operative, shall be respected and implemented in accordance with section 12 and the other provisions of this Act.

F) Life-sustaining treatment and/or artificially provided fluids and nutrition necessary to sustain life may be withheld or withdrawn from a patient pursuant to an advance directive in circumstances specified in sections 15 and 16, respectively. A declarant's directive to withhold or withdraw artificially provided fluids and nutrition must be explicitly stated, in accordance with sections 6 and 16. Decisions to withhold or withdraw life-sustaining treatment and/or artificially provided fluids and nutrition necessary to sustain life shall be reviewed by a qualified institutional or regional reviewing body, or by an appropriate public agency, in the particular circumstances specified by sections 15(A)(4) and 16(A)(3), respectively, and in accordance with the process provided by section 18 or by other law.

G) Health care professionals and institutions, acting in accordance with sections 10 and 13, shall make appropriate affirmative inquiry of patients, family members, and others regarding the existence of advance directives; shall seek to inform and educate their patients concerning advance directives; shall respect a patient's designation of a health care representative and a patient's instruction directive; and shall participate in good faith in the decisionmaking process set forth in section 11.

H) Health care professionals may decline to participate in the withholding or withdrawing of life-sustaining treatment and/or artificially provided fluids and nutrition necessary to sustain life, on the basis of sincerely held personal or professional convictions, in accordance with section 10. In such cases, the health care professional shall facilitate the appropriate, respectful and timely transfer of the patient's care.

I) Private religiously-affiliated health care institutions may adopt institutional policies and practices defining circumstances in which they will decline to participate in the withholding or withdrawing of life-sustaining treatment and/or artificially provided fluids and nutrition necessary to sustain life, in accordance with, and subject to the requirements established by, section 13(E).

J) Individuals and institutions, acting in good faith, and in accordance with the provisions of this Act and any rules and regulations established by the Department of Health pursuant to this Act, to carry out the terms of an advance directive, shall be immune from legal liability and from discipline for unprofessional conduct, in accordance with section 22. Those acting in willful contravention of requirements established by or pursuant to this Act may be subject to legal liability, regulatory action, or proceedings for professional misconduct, in accordance with section 27.

Comment

Section 3 is intended as a summary and roadmap of the most significant operative provisions of the Act. This section should not be read to change in any way the operation of the other provisions of the Act.

Subpart A: Execution and Effectuation of Advance Directives

Section 4: Executing an Advance Directive

A) Who may execute an advance directive

A declarant may execute an advance directive for health care at any time.

B) Means of execution

1) An advance directive shall be signed and dated by or at the direction of the declarant in the presence of two subscribing adult witnesses. The witnesses shall attest that the declarant is of sound mind and free of duress or undue influence. An advance directive may be supplemented by a video or audio tape.

2) Designated health care representatives shall not act as witnesses to the execution of an advance directive.

3) An advance directive may be made self-proved at the time of execution by following the formal requirements stated in *N.J.S.A.* 3B:3-4 for making a testamentary will self-proved.

Comment

Subpart A prescribes the formal requirements for execution, re-affirmation, modification and revocation of an advance directive, as well as the basic nature and content of such documents. This subpart also states when an advance directive becomes legally operative and how this is to be determined. By expressly stating formalities for the legal validity of advance directives and the process to be followed to determine when a patient's advance directive becomes legally operative, the Act resolves uncertainties under existing law (see *In re Conroy*, 98 N.J. 321, 486 A.2d 1209, 1229-30 & n.5 (1985) as to whether advance directives are legally valid and the legal basis for the obligations of health care providers to honor such documents, and also clarifies the existing legal status of durable powers of attorney for health care (see *In re Peter*, 108 N.J. 365, 529 A.2d 419, 426 (1987)).

Section 4 sets forth the minimum requirements for the execution of a valid advance directive. The execution requirements follow closely the requirements for execution of a testamentary will in New Jersey (*N.J.S.A.* 3B:3-1 *et seq.*) and are also very similar to the requirements for execution of advance directives in most other states.

Section 4(A) provides that a declarant, *i.e.*, any competent individual of 18 or more years of age (see sections 2(A) and 2(E)), may execute an advance directive. The Act contemplates that, as is the case under existing law, an adult will be presumed competent unless determined by a court to be incompetent. The advance directive must be signed and dated by the declarant, or by another person directed by the declarant to sign on the declarant's behalf. (Section 4(B)(1))

Section 4(B)(1) requires that two witnesses sign the advance directive, attesting by their signatures that the declarant is of sound mind and free of duress or undue influence. Witnesses are not required to know or attest to the contents of the advance directive. The Act does not require any specific qualifications for those who may serve as witnesses, so long as they are adults. However, recognizing a potential conflict of interest situation, section 4(C)(2) provides that designated health care representatives (including alternate designees) may not serve as witnesses. In this regard, the Act provides greater protection than New Jersey's testamentary wills statute, which places no statutory restrictions on who may serve as a witness (*N.J.S.A.* 3B:3-8). The attending or family physician is not disqualified from serving as a witness, as has been the case in some other states.

Section 4(A) provides that a declarant may execute an advance directive at any time. Consistent with the approach of most other states, the Act does not limit the right or opportunity of individuals to write advance directives to the time of on-set of a serious (life-threatening) condition, nor is the declarant required to re-affirm or re-execute a directive periodically, or following admission to a health care institution. While an individual's periodic and more contemporaneous re-evaluation of the terms of his or her advance directive is advisable, to make this practice a condition of a directive's legal validity would be unduly restrictive of individuals' rights to plan ahead for their health care decisions and would undermine the efficacy of directives as advance planning documents. Similarly, section 6(D) provides that once validly executed, an advance directive is legally valid for an indefinite period of time, subject to the declarant's revocation of the document in accordance with section 5 of this Act.

A declarant may supplement his or her advance directive with an audio or video tape (section 4(B)(1), and may seek greater assurance that an advance directive will not later be challenged on technical grounds of validity by following the procedure established by *N.J.S.A.* 3B:3-4 for making a testamentary will self-proved (section 4(B)(3)). However, neither of these provisions modify or substitute for the formal execution requirements of section 4. Deletion of section 4(B)(3) would clarify any potential confusion regarding the process for self-proving a will, and would be consistent with the intent of the Act.

Section 5: Re-Affirming, Modifying and Revoking an Advance Directive

A) Re-Affirmation and Modification

1) A declarant may re-affirm or modify either a designation of a health care representative, or an instruction directive, or both.

2) Re-affirmation or modification shall be made in accordance with the requirements for execution of an advance directive.

B) Revocation

1) An individual, whether competent or incompetent, may revoke a prior designation

of a health care representative or a prior instruction directive, or both, by the following means:

a) Notification, orally or in writing, to the health care representative, physician, or other health care professional, or other reliable witness; or

b) Destruction or attempted destruction of the document, or other act evidencing an intent to revoke the advance directive.

2) An advance directive shall also be revoked by the declarant's execution of a subsequent advance directive in accordance with section 4 of this Act.

3) Designation of the individual's spouse as health care representative shall be revoked upon divorce or legal separation, unless otherwise specified in the advance directive.

C) Re-affirmation, modification or revocation of an advance directive is effective upon communication to the health care representative, the attending physician, or other health care professional responsible for the patient's care.

Comment

Section 5 sets forth the minimum requirements for re-affirmation or modification of an advance directive, and states the means by which an advance directive may be revoked. Under section 5(A), a declarant may re-affirm or modify a previously executed advance directive by following the same formalities as are required for execution of an advance directive under section 4 (*e.g.*, signing, two witnesses). As noted in comment to section 4, neither re-affirmation nor modification of an advance directive are required, though either may be advisable where it would serve to make the written statement of the declarant's wishes more accurate or more current, and less subject to question on the ground that the statements contained in it were remote in time, not properly informed, or otherwise fail to represent what the patient's current wishes would be.

Section 5(B) states the means by which an advance directive may be revoked, and is intended to freely allow revocation. Similar to most other states, this section specifically identifies several ways in which legally valid revocation can be made, including oral or written notification to an appropriate individual and destruction of the document. Both the provision for oral or written notification (section 5(B)(1)(a)) and for any "other act evidencing an intent to revoke" (section 5(B)(1)(b)), which would include, for example, a physical sign communicating an intent to revoke, are designed to recognize a range of actions as legal means of revocation.

In contrast to the requirements for execution, re-affirmation and modification of an advance directive, section 5(B)(1) provides that an individual need not be competent to revoke an advance directive. This provision contemplates that advance directives will most often be used to instruct the foregoing or limiting of health care, in particular life-sustaining measures. Consequently, a patient's expressed desire to revoke a directive, even when incompetent, may be construed in many cases as a desire to have life-sustaining measures continued, and this wish should be respected. However, in some cases the acts or expressions of a patient with impaired competence may be misinterpreted, or the patient may act out of anger or depression and later change his or her mind. In these circumstances a patient's prior competently expressed wishes, in particular the designation of a health care representative, should not be invalidated. To address this situation the Legislature may wish to consider amending section 5 to allow an incompetent patient to suspend an advance directive (*i.e.*, the designation of a health care

representative, an instruction directive, or both), and subsequently to reinstate that directive by oral or written notification of this intent, provided to the health care representative, physician, nurse or other health care professional.

Sections 5(B)(2) and 5(B)(3) recognize two circumstances in which automatic revocation of a prior directive would occur by operation of law. In order to assure that an individual's most recent written statement of his or her wishes is legally operative, section 5(B)(2) provides that the current execution of an advance directive shall effect the automatic revocation of any previously executed advance directive(s).

Section 5(B)(3) provides for the automatic revocation of the designation of a spouse as the declarant's health care representative where that spouse becomes divorced or legally separated from the declarant. In this event, legal authority as health care representative belongs to any alternate designees, in accordance with their stated priority. If the declarant does not wish the legal authority of a spouse to be automatically revoked upon divorce or legal separation, he or she must state this in the advance directive. The declarant's instruction directive is unaffected by section 5(B)(3).

Section 5(C) recognizes that those responsible for acting upon a change in the patient's advance directive must become aware of this information. Thus, section 5(C) provides that in order to be effective a re-affirmation, modification or revocation must be communicated to the health care representative, to the attending physician, or to another health care professional responsible for the patient's care. Such knowledge need not be communicated directly by the declarant, and may be communicated by another person. The Act does not require that the person conveying knowledge of a re-affirmation, modification or revocation be acting on the declarant's behalf, a requirement in some states with respect to communication of a revocation. Where the declarant's intention is not communicated directly by the declarant, communication is assumed to be in good faith, but the health care representative and the attending physician should make additional inquiry to assure that the declarant's wishes have been properly conveyed.

Sections 5(A)(1) and 5(B)(1) provide that the designation of a health care representative and the writing of an instruction directive may be viewed as severable acts. If an individual who has previously executed an advance directive wishes to change the designated health care representative (to modify or revoke the designation) or to change the contents of an instruction directive (to modify or revoke the instructions), it is not necessary to re-execute the entire document, and the unchanged part remains legally valid. Section 5(B) would, for example, allow an individual to orally revoke an instruction directive while retaining the written legal authority of a health care representative. However, where substantial changes are contemplated (*i.e.*, modification of an advance directive), the document should be re-executed in accordance with section 4.

Section 6: Advance Directives for Health Care

A) An advance directive may include the designation of a health care representative, or an instruction directive, or both.

B) Designation of a health care representative

1) In accordance with the requirements of section 4 of this Act, a declarant may designate one competent adult to act as his or her legally authorized health care representative.

2) Who may be designated as a health care representative

a) Any competent adult, including but not limited to an individual's spouse, adult

child, parent or other family member, friend, religious or spiritual advisor, or other person of the individual's choosing, may be designated as a health care representative.

b) Restrictions

i) A declarant may not designate as a health care representative an operator, administrator or employee of a health care institution where, at the time the advance directive is executed, the declarant is a patient or resident of, or has applied for admission to, such health care institution, unless the operator, administrator or employee is related to the individual by blood, marriage or adoption.

ii) This restriction does not apply to a physician, provided that the physician shall not serve as the patient's attending physician and as the patient's health care representative at the same time.

3) Alternate designees; order of priority

A declarant may designate one or more alternate health care representatives, listed in order of priority. In the event the primary designee is unavailable, unable or unwilling to serve as health care representative, or is disqualified from such service pursuant to this section or other law, the next designated alternate shall serve as health care representative. In the event the primary designee subsequently becomes available and able to serve as health care representative, the primary designee may, insofar as then practicable, serve as health care representative.

4) The designation may direct the health care representative to consult with specified individuals (including alternate designees, family members and friends) in the course of the decisionmaking process.

5) The designation shall state the limitations, if any, to be placed upon the authority of the health care representative.

C) Instruction directives

1) A declarant may execute an instruction directive stating the declarant's general treatment philosophy and objectives; the declarant's specific wishes regarding the provision, withholding or withdrawal of any form of health care, including life-sustaining treatment; or both. An instruction directive may, but need not, be executed contemporaneously with or be attached to the designation of a health care representative.

2) A declarant intending to instruct that artificially provided fluids and nutrition

should be withheld or withdrawn under certain conditions shall so indicate by an explicit statement in the instruction directive.

D) Legal validity

A duly executed advance directive for health care is legally valid in accordance with the provisions of this Act, unless revoked in accordance with section 5.

E) Advance directives: Standard forms

1) Advance directives conforming to the standard forms set forth in Appendix A to this Act shall be recognized as legally valid in form.

2) An advance directive need not conform to one of these standard forms to be legally valid. A declarant may supplement a written advance directive with a video or audio tape.

Comment

Section 6 provides for the nature and basic content of an advance directive. The Act goes well beyond existing legislation in other states in its applicability to a broad range of health care decisions, and in its recognition that patients should be permitted to request, in an advance directive, the continued provision of life-sustaining measures as well as the foregoing of life-sustaining measures. This approach is a significant departure from the laws of most other states, which often provide that instruction directives (living wills) may only be used to direct the foregoing of life-sustaining measures, typically limited to the single condition of terminal illness.

The Act gives priority to the designation of a trusted family member or friend to make decisions on the declarant's behalf as the essential means of achieving the objectives of a sound decisionmaking process respectful of patient wishes and well-being; several provisions of the Act are designed to structure a decisionmaking process in which the health care representative is actively involved on the patient's behalf. This approach is grounded in the fact that a health care representative selected by the patient, who most often will be a trusted and loving family member, will generally be best situated to understand and evaluate the patient's wishes in a flexible and realistic way, duly attentive to the patient's actual and contemporaneous medical circumstances, including changing medical information and possible courses of treatment and care, and to give due weight to these factors in reaching a treatment decision. In contrast, an instruction directive alone is inherently a static and inflexible document. The Act is intended to strongly encourage individuals to designate a health care representative *and* to provide their chosen health care representative with general and specific instructions for their future health care (an integrated directive).

The Act also permits individuals to choose to execute a proxy directive alone, or an instruction directive alone, thereby affording individuals important flexibility in planning ahead for their future health care. (Section 6(A)) Although the Act does not require consultation with or the assistance of others in the process of preparing an advance directive, given the importance of health care decisions at the end of life it is strongly recommended that individuals give careful and thoughtful consideration to the writing of an advance directive, and that they consult with others, such as family members, a physician, or an attorney, in this process. Section 6(D) makes clear that a properly executed advance directive is a legally valid document, unless and until revoked.

Designation of a health care representative. Section 6(B)(2) states the scope and limitations regarding who may be designated as a health care representative. While section 6(B)(2)(a) is intended to afford individuals a broad range

of choice in selecting a health care representative (and any alternate designees), including but not limited to a spouse, adult child, parent, friend, or any other person (provided he or she is an adult and competent), the Act also identifies and seeks to prevent certain potential conflict of interest situations from arising. Thus, section 6(B)(2)(b) places certain restrictions on who may be designated as health care representative. Where the declarant is a patient or resident of a health care institution, or has applied for admission to a health care institution, the declarant may not designate an operator, administrator or employee of that institution as his or her health care representative, unless the person chosen is also a member of the declarant's family. (Section 6(B)(2)(b)(i)) If a health care representative is disqualified from service, health care providers should look to alternate designees to serve as health care representative, in accordance with their stated order of priority in the directive.

The Act permits a physician to serve as the patient's health care representative, but does not permit a physician to serve as both attending physician and as health care representative at the same time. (Section 6(B)(2)(b)(ii)) Therefore, where possible the declarant should discuss with his or her physician which role (attending physician or health care representative) is preferred in advance of designating a physician as health care representative. A physician who has been selected as health care representative should choose one role or the other, either by disqualifying himself from service as health care representative, or by assuming that role and effecting an appropriate transfer of care to another attending physician.

Section 6(B)(3) anticipates that in some circumstances the declarant's first choice as health care representative will be unavailable, unable or unwilling to serve in that capacity. Thus, this section provides that a declarant may designate one or more persons as an alternate health care representative, listing each in order of priority. An alternate designee is authorized to serve as health care representative, in accordance with the stated order of priority in the directive. An alternate designee may also serve as health care representative if the primary designee is disqualified from assuming this role, such as under section 6(B)(2)(b)(i) or section 5(B)(3) (designation of a health care representative revoked by legal separation or divorce), or by operation of other law. If the declarant's primary designee later becomes available and able to serve as health care representative, that individual may serve in that capacity, if it is practicable for him or her to do so.

Section 6(B)(4) is intended to encourage a declarant to direct his or her health care representative to consult with specified individuals in the course of making health care decisions on the declarant's behalf. Section 6(B)(5) permits the declarant to state any desired limitations upon the health care representative's authority.

Instruction directives. Section 6(C) sets forth guidelines for the nature and content of a declarant's statement of personal views and specific instructions for health care. The Act permits the declarant broad discretion to state his or her instructions and directions for health care in a manner suited to the declarant's personal wishes. As stated in section 6(C)(1), an instruction directive may contain a statement of the declarant's general treatment philosophy and objectives, a statement of the declarant's specific instructions regarding particular forms of health care, or both. A declarant may direct the provision of particular forms of health care, including life-sustaining measures, or may direct the withholding or withdrawal of particular forms of health care, including life-sustaining measures; and a declarant may request one form of health care while refusing another.

As discussed in the comment to section 16, the Act recognizes that the withholding or withdrawal of artificially provided fluids and nutrition raises some distinctive problems for public policy. In addition, experience suggests that patients' prior written instructions can be unclear or ambiguous with respect to decisions to forego artificially provided fluids and nutrition. Section 6(C)(2) addresses these important concerns by providing that a request that artificially provided fluids and nutrition be withheld or withdrawn under certain conditions must be indicated explicitly in an instruction directive (such as by an express written statement, or by otherwise completing a form in a manner that clearly instructs that artificially provided fluids and nutrition be withheld or withdrawn). The Act is intended to encourage the practice of writing specific instructions on this question. This section should be read in conjunction with the provisions of section 16.

Section 6(E) provides a mechanism for legal recognition of sample forms for advance directives by attaching such forms as an Appendix to the Act. The New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care (the "Commission") and its Task Force on Public and Professional Education have developed several advance directive forms and are currently developing supporting educational materials. It should be noted that the Act does not require that a declarant use any particular advance directive form; any properly executed document will be recognized as legally valid.

Section 7: When an Advance Directive Becomes Operative

A) An advance directive becomes operative when 1) it is transmitted to the attending physician or to the health care institution, and 2) it is determined pursuant to section 8 of this Act that the patient lacks capacity to make a particular health care decision.

B) Treatment decisions pursuant to an advance directive shall not be made and implemented until there has been an opportunity reasonable under the circumstances to establish, and where appropriate confirm, a reliable diagnosis and prognosis for the patient.

Comment

Section 7 establishes the preconditions to an advance directive becoming legally operative. Under section 7(A), two conditions must be met before an advance directive is operative. First, the advance directive must become known to the attending physician or to the health care institution. Initially, it is the responsibility of the patient, or of another acting on the patient's behalf, to transmit an advance directive to health care providers. The obligations of inquiry imposed upon the attending physician (section 10) and upon the health care institution (section 13) are intended to assure that if the patient has executed an advance directive, it will be transmitted to physicians and health care institutions responsible for the patient's care. However, neither the patient nor others acting for the patient are required to "communicate" the contents of the advance directive to health care providers, as has been required by some other states. Once transmitted, it is the responsibility of health care providers to become familiar with the contents of a patient's advance directive.

Second, before an advance directive becomes operative it must be determined, in accordance with section 8, that the patient lacks capacity to make a particular health care decision on his or her own behalf. If the patient possesses decisionmaking capacity, the patient has the right to make his or her own health care decisions, and there is no reason to look to an advance directive.

When the two preconditions of section 7(A) are met, the legal operation of an advance directive is "triggered", and health care representatives and health care providers should look to an advance directive and to the provisions of this Act to determine their rights and obligations.

Section 7(B) establishes an important precondition to treatment decisionmaking pursuant to an advance directive, and makes explicit what often, but not always, occurs in practice. This section seeks to assure that health care representatives and physicians do not make treatment decisions that are uninformed or hasty, by requiring that there be a reasonable opportunity to clearly understand the patient's diagnosis and prognosis before implementing a treatment decision. Establishing a reliable diagnosis and prognosis may warrant consultation and confirmation by another physician, as is required by the Act in specified cases involving life-sustaining measures under sections 15 and 16. What constitutes "reasonable opportunity" to establish the patient's diagnosis and prognosis will necessarily depend on the circumstances.

Section 8: Determination of Incapacity to Make Health Care Decisions

A) Criteria for determinations of decisionmaking incapacity

For purposes of this Act, a determination that a patient lacks decisionmaking capacity shall be based upon, but need not be limited to, evaluation of the patient's ability to understand and appreciate the nature and consequences of a particular health care decision, including the benefits and risks of, and alternatives to, the proposed health care, and to reach an informed decision.

B) Who may determine incapacity

1) Initial determination by attending physician

The attending physician shall, in the first instance, determine whether the patient lacks capacity to make a particular health care decision. The determination shall be stated in writing, shall include the attending physician's opinion concerning the nature, cause, extent, and probable duration of the patient's incapacity, and shall be made a part of the patient's medical records.

2) Confirmation of incapacity

a) The attending physician's determination of incapacity shall be confirmed by one or more qualified physicians. The opinion of the confirming physician(s) shall be stated in writing and made a part of the patient's medical records in the same manner as that of the attending physician. Confirmation of incapacity is not required where the patient's incapacity is clearly apparent, and the attending physician and the health care representative agree that confirmation is unnecessary.
b) If it is determined that a patient lacks decisionmaking capacity because of a mental or psychological impairment or a developmental disability, and neither the attending physician nor the confirming physician(s) has specialized training or experience in diagnosing mental or psychological conditions or developmental disabilities of the same or similar nature, a determination of incapacity shall be confirmed by one or more physicians with appropriate specialized training or experience. The opinion of the confirming physician(s) shall be stated in writing and made a part of the patient's medical records in the same manner as that of the attending physician.

3) A physician designated by the patient's advance directive as a health care representative shall not make the determination of incapacity.

C) Notice of determination

1) The attending physician shall inform the patient (if the patient has any ability to comprehend that he or she has been determined to lack decisionmaking capacity) and the health care representative a) that the patient has been determined to lack capacity

to make a particular health care decision; b) that each has the right to contest this determination; and c) that each may have recourse to the dispute resolution process established by the health care institution pursuant to section 14 of this Act.

2) Notice to the patient and the health care representative shall be documented in the patient's medical records.

D) Effect of determination

A determination of incapacity under this Act is solely for the purpose of implementing an advance directive in accordance with the provisions of this Act, and shall not be construed as a determination of a patient's incapacity or incompetence for any other purpose.

Comment

Section 8 establishes the process and criteria to be followed for determining whether a patient lacks decisionmaking capacity. Consistent with existing law, unless determined to lack decisionmaking capacity the patient is presumed to have capacity (to be competent), and has the legal authority to make health care decisions on his or her own behalf. As stated in comment to section 7, the purpose of a determination of incapacity is to trigger the operation of an advance directive.

Criteria for determining incapacity. Section 8(A) states the criteria for determining that a patient lacks decisionmaking capacity. This section makes operative the definition of decisionmaking capacity (section 2(D)), stating that a determination of a patient's decisionmaking incapacity shall be based upon an evaluation of the patient's ability to understand and appreciate information regarding the nature and consequences of a particular health care decision, including the benefits and risks of the proposed health care and its alternatives, and to reach an informed decision. The Act recognizes that some patients may appear to properly understand and evaluate relevant information, and to do so in accordance with personal values and objectives, yet the patient's deliberative process may be impaired by hidden fears or denial, or by some other psychological factor or disorder. Other patients may be capable of making a health care decision, but be unable to adequately assimilate particular information or to express a decision due to a developmental disability or impaired ability to communicate. Thus, section 8(A) provides that a determination of incapacity need not be strictly limited to assessment of the patient's abilities to understand and evaluate relevant information, and may and should take other factors into account as well.

The Act contemplates that the question of capacity should be raised, and a more thorough assessment made, where there is substantial evidence of a deficit in any of these abilities. For example, a patient's apparent inability to offer intelligible reasons for a decision, or to indicate the major factors in his or her decision and the weight given to these factors, *i.e.*, weighing of the risks, benefits and burdens of the proposed treatment and its alternatives, is a call to more thorough evaluation of the patient's decisionmaking capacity. Physicians responsible for assessing and determining the patient's decisionmaking capacity should also be alert to the presence of underlying psychological impairments or developmental disabilities. Such apparent impairments of decisionmaking capacity are not, however, in themselves ground for a determination of incapacity. Rather, evidence of psychological impairments or disorders, or of developmental disability, should be taken as a call to further conversation with the patient and a more extensive evaluation of the patient's abilities.

Standards of capacity. While section 8(A) states the criteria to be applied in determining decisionmaking incapacity, it does not provide specific statutory guidance regarding a standard or standards to govern

determinations of decisionmaking incapacity, *i.e.*, what level of abilities the patient must possess and be able to act upon in order to make a particular health care decision. The Act's decision-specific approach recognizes that the level of ability required for the exercise of decisionmaking capacity will vary with the task of making particular health care decisions. The Act also contemplates that decisionmaking capacity will vary with the significance and irreversibility of the consequences of particular treatment choices; when the consequences for patient well-being are serious, *e.g.*, in the case of a patient's decision to forego life-sustaining measures, physicians should be especially circumspect in assessing the patient's capacity to make an informed decision.

Thus, the critical factors are that the decision, including the relative importance the patient assigns to the risks, benefits and burdens of the treatment alternatives, is grounded in the patient's personal values and objectives, and that the decision results from a rational deliberative process that is based upon intelligible (even if not universally shared) reasons. As the complexity of relevant medical information increases and as the potential consequences of a particular health care decision become more serious, the necessary level of abilities needed to make an informed decision will increase as well. Physicians responsible for assessing and determining decisionmaking capacity should be attentive to these concerns and to the decision-specific nature of capacity determinations under the Act. It should not be assumed that a patient who lacks capacity to make one health care decision also lacks capacity to make other health care decisions.

Furthermore, the fact that physicians or other health care professionals may disagree with the patient's decision is not itself ground for a determination of incapacity. The Act rejects a so-called "maximalist" or "outcome-based" approach to decisionmaking capacity which would require that the patient reach the "correct" decision, purportedly determined by objective third party judgment, often thought of in terms of medical judgment. In particular, a patient's decision to reject a burdensome intervention and to accept a shorter life expectancy when confronted with a serious life-threatening condition, or to reject an undesired prolongation of a burdensome dying process, is not in and of itself sufficient evidence of decisionmaking incapacity. The Act also rejects a so-called "minimalist" approach to decisionmaking capacity which would require of the patient only the ability to express a preference for a particular course of health care, without regard to the patient's ability to understand and evaluate relevant information.

Who determines incapacity. The Act provides for an "informal" (non-judicial) process which places responsibility for such determinations with physicians. Under section 8(B)(1), the initial determination of a patient's decisionmaking incapacity is to be made by the attending physician. The attending physician's determination is to be confirmed by at least one additional qualified physician, unless the patient's incapacity is clearly apparent (for example, the patient is permanently unconscious) and the attending physician and the health care representative agree that a confirming opinion is unnecessary. (Section 8(B)(2)) Since proper diagnosis and evaluation of a mental or psychological impairment, or of a developmental disability, which impairs a patient's decisionmaking capacity may require specialized training or experience, the Act makes special provision for such cases, by requiring that if neither the attending nor the confirming physician possesses the relevant expertise, a physician with appropriate expertise be called in to evaluate the patient and to provide a confirming (or disconfirming) opinion of the patient's incapacity. (Section 8(B)(2)(b)) To protect against a potential conflict of interest, section 8(B)(3) prohibits a physician who is designated as the patient's health care representative from making a determination of the patient's incapacity.

The Act's approach to determining decisionmaking capacity is intended to be adaptable to existing medical practices and to the need for flexibility in response to changing medical circumstances, particularly for those patients with impaired capacity whose decisionmaking abilities may change daily, if not more frequently. Where this Act applies, *i.e.*, where the patient has executed an advance directive and decisionmaking capacity is in question, it is not necessary to seek a court determination of the patient's decisionmaking capacity. In placing with physicians responsibility for determining a patient's decisionmaking capacity, the Act is consistent with *In re Farrell*, 108 N.J. 335, 529 A.2d 404, 415 & n. 8 (1987). The Act departs from *Farrell* in requiring only one, not two, non-attending physicians to confirm the patient's incapacity. In the context of the Act, which sets forth a

comprehensive framework for the decisionmaking process, including a number of safeguards to protect patient well-being, the Act's approach is somewhat less burdensome than the requirements of *Farrell*, and provides equal, if not greater, protection for patients.

Notice and documentation. Given the important consequences of a determination of incapacity, it is essential for the patient and health care representative to be promptly notified and for this determination to be properly documented. Section 8(C)(1) requires that upon a determination of incapacity the patient (if the patient is not comatose and has some ability to understand) and health care representative be given prompt notice of this determination by the attending physician. Under section 8(C)(1), both the patient and the health care representative are to be informed that if either disagrees with the determination of incapacity, either may invoke an institutional dispute resolution process (*see* section 14) in an effort to resolve such disagreement. Section 8(C)(1) is intended to set an outside limit upon the time within which notification must be made. The physician may notify the health care representative of the patient's condition at an earlier time, before a formal determination (of record) of incapacity is made, where this would better enable the health care representative to become involved in the patient's care at an early stage.

Sections 8(B)(1) and 8(B)(2) require the attending physician and any additional physicians who evaluate the patient's capacity to document in writing their opinions, including the nature, cause, extent and probable duration of the patient's incapacity, and to enter their evaluations in the patient's medical records. The attending physician should also document the notice of such a determination provided to the patient and health care representative. (Section 8(C)(2))

Effect of determinations of incapacity. Section 8(E) provides that a determination of incapacity to make health care decisions in accordance with section 8 does not mean that the patient lacks capacity, or is incompetent, to make other types of decisions, such as financial decisions. It should be noted that the process for determining patient capacity established by the Act is intended to apply only in the context of advance directives, and is not intended to change existing law in other areas where a different process, such as a formal court determination, may be required.

Subpart B: Rights and Responsibilities of the Parties

Section 9: The Rights and Responsibilities of the Health Care Representative

A) Legal authority

1) A designated health care representative shall have legal authority to make health care decisions on behalf of the patient. The health care representative shall act in good faith and within the bounds of the authority granted by an advance directive and by this Act.

2) If a different individual has been appointed as the patient's legal guardian, the health care representative shall retain legal authority to make health care decisions on the patient's behalf, unless the terms of the legal guardian's court appointment, or other court decree, provide otherwise.

3) The conferral of legal authority on the health care representative is not intended, and shall not be construed, to thereby impose liability upon the health care representative for any portion of the patient's health care costs.

4) An individual designated as a health care representative or as an alternate health care representative may decline to serve in that capacity.

B) Decisionmaking authority

1) The health care representative shall exercise the patient's right to be informed of the patient's medical condition, prognosis and treatment options, and to give informed consent to or refusal of health care.

2) In the exercise of these rights and responsibilities, the health care representative shall seek to make the health care decision the patient would have made had he or she possessed decisionmaking capacity under the circumstances, or, where the patient's wishes cannot adequately be determined, shall make a health care decision in the best interests of the patient.

C) In the exercise of these rights and responsibilities, the health care representative shall act in accordance with the decisionmaking process established by section 11 of this Act.

Comment

Subpart B sets forth the rights and responsibilities of those responsible for the patient's care and the decisionmaking process to be followed when making health care decisions in accordance with an advance directive. The Act adopts the shared decisionmaking model of the physician-patient relationship as developed in the work of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, and applies this model to the situation in which a health care representative participates in the decisionmaking process on the patient's behalf. The Act is intended to structure and facilitate a process in which the physician, health care representative and patient work together with complementary and interactive roles in order to establish greater mutual understanding and an effective basis for active participation in the decisionmaking process by both the health care representative and the patient. While the Act is primarily addressed to the roles of the attending physician, health care representative and patient, other family members and other members of the health care team should also be appropriately involved as collaborative participants in the decisionmaking process. The shared decisionmaking approach is designed to promote a sound decisionmaking process which best advances the patient's right to and interest in both self-determination and well-being with respect to health care decisions.

Section 9 sets forth the authority and core rights and responsibilities of the health care representative. This section should be read cumulatively with the other provisions of the Act; the health care representative also has rights and obligations under other applicable provisions of the Act, including in particular the responsibility to follow the decisionmaking process set forth in section 11, as stated in section 9(C). The authority granted to the health care representative is grounded in the view that most often the individual chosen by the patient (usually a close family member or friend) is best situated to understand and evaluate the patient's values and objectives, and to do so in a flexible and realistic way duly attentive to the patient's actual and contemporaneous medical circumstances, including changing medical information and possible courses of treatment and care.

Legal authority. Section 9(A)(1) provides that the valid designation of a health care representative confers upon that person the legal authority to make health care decisions on the patient's behalf when the patient has been determined, in accordance with section 8, to lack decisionmaking capacity. It is not required that the health care representative be appointed by a court as the patient's legal guardian. Health care providers are to look to the

health care representative as the person with legal authority to make decisions on the patient's behalf, and need not seek further recourse to a guardianship proceeding to confirm the health care representative's legal authority. This is consistent with the practice under existing law pursuant to *In re Peter*, 108 N.J. 365, 529 A.2d 419, 429 (1987).

Section 9(A)(2) anticipates that, in some circumstances, another individual will have been appointed as the patient's legal guardian. In such cases, the health care representative nonetheless has legal authority to make health care decisions on the patient's behalf, unless the court's appointment of a legal guardian, or some other court order, provides that the health care representative does not have this authority.

Section 9(A)(4) recognizes that the responsibilities of serving as health care representative may impose heavy burdens (*e.g.*, psychological and emotional burdens) and that some individuals will wish to decline (and perhaps should decline) this responsibility. Neither the health care representative nor any alternate designee is absolutely bound to assume the role and responsibilities of health care representative; both may decline to serve in that capacity. In such cases, an alternate designee may assume the role of health care representative, in the order of priority stated in the advance directive. (See section 6(B)) A health care representative should not be concerned that assuming these responsibilities will also bring financial obligations for the costs of the patient's care; nor should treatment decisions be unduly influenced by personal responsibility for health care expenses. Thus, section 9(A)(3) provides that designation of a health care representative does not make the health care representative, or any alternate designee, responsible for any of the patient's health care costs, nor may health care providers seek to impose payments on a health care representative by virtue of his or her status as health care representative. (Of course, if the health care representative is a member of the patient's family, as will often be the case, there may be financial responsibilities that derive from this familial relationship.)

Decisionmaking authority. Section 9(B)(1) provides that once the legal role of health care representative is assumed, the health care representative essentially "steps into the shoes" of the patient, and has the same right to make informed health care decisions as the patient would have if able to do so. The health care representative has the right to be informed of the patient's medical condition and prognosis, and of the recommended treatment and its alternatives, and has the right to consent to or to refuse health care on the patient's behalf. (The attending physician has a correlative obligation to seek informed consent from the health care representative, in accordance with section 11(A)(1).) The health care representative has broad authority to make the same kinds of health care decisions the patient would have the right to make on his or her own behalf, such as decisions to accept or to refuse diagnostic and therapeutic measures, including life-sustaining measures, to accept or to reject the care of a particular physician or health care institution, and to accept, reject or request a transfer of care. (See the definition of "health care decision", section 2(H).)

Section 9(B)(2) provides that in the exercise of his or her authority, the health care representative should seek, first and foremost, to make the health care decision the patient would make under the circumstances, if able to do so. In cases in which the direction provided by an advance directive is uncertain or ambiguous as applied to the patient's current medical condition and circumstances, it is intended here, and under section 11, that the health care representative have authority to exercise informed and reasonable judgment to interpret the patient's wishes, and that the health care representative not be rigidly constrained to make an unduly mechanistic interpretation of the terms of the directive. At times, however, it may not be possible to adequately determine what the patient's wishes would be. For example, there may be no instruction directive or other clear evidence of the patient's wishes; or the instruction directive may be ambiguous or otherwise fail to provide clear guidance, perhaps because the patient's medical circumstances have changed radically from those previously contemplated by the advance directive. In such cases, section 9(B)(2) gives the health care representative authority to make a health care decision he or she believes to be in the patient's best interests based upon what is known of the patient's wishes.

As stated in section 9(A)(1), the health care representative is obligated at all times to act in good faith to carry out his or her responsibilities in accordance with the terms and limitations of an advance directive and of the Act. The health care representative's rights and responsibilities in the decisionmaking process are set forth at

greater length in section 11.

Section 10: The Rights and Responsibilities of Physicians and Other Health Care Professionals

In addition to any rights and responsibilities recognized or imposed by or pursuant to the other provisions of this Act, or by other law, physicians, nurses, and other health care professionals shall have the following rights and responsibilities:

A) Physicians

1) The attending physician shall make an affirmative inquiry of the patient, family or others, as appropriate under the circumstances, concerning the existence of an advance directive. The attending physician shall note in the patient's medical records whether or not an advance directive exists, and the name of the patient's health care representative, if any, and shall attach a copy of the advance directive to the patient's medical records. The attending physician shall document in the same manner the re-affirmation, modification, or revocation of an advance directive, if he or she has knowledge of such action.

2) The attending physician shall act in accordance with the decisionmaking process established by section 11 of this Act.

3) **Professional conscience**

A physician may decline to participate in the withholding or withdrawing of life-sustaining treatment and/or artificially provided fluids and nutrition necessary to sustain life, in accordance with his or her sincerely held personal or professional convictions. In such circumstances, the physician shall act in good faith to inform the patient and the health care representative, and the chief of the medical staff or other designated institutional official, of this decision as soon as practicable, and to effect appropriate, respectful and timely transfers of care, and to assure that patients are not abandoned or treated disrespectfully.

4) In the event of transfer of a patient's care, the attending physician shall assure the timely transfer of the patient's medical records, including a copy of the patient's advance directive.

B) Nurses and other health care professionals: Professional conscience

Nurses and other health care professionals may decline to participate in the withholding or withdrawing of life-sustaining treatment and/or artificially provided fluids and nutrition necessary to sustain life, in accordance with their sincerely held personal or professional convictions. In such circumstances, nurses and other health care

professionals shall act in good faith to inform the patient and the health care representative, and the head of the nursing or other professional staff or other designated institutional official, of this decision as soon as practicable, to cooperate in effecting appropriate, respectful and timely transfers of care, and to assure that patients are not abandoned or treated disrespectfully.

C) Nothing in this Act shall be construed to require physicians, nurses or other health care professionals to begin, continue, withhold, or withdraw health care in a manner contrary to law or accepted professional standards.

Comment

Section 10 sets forth certain rights and responsibilities of physicians and other health care professionals. This section should be read cumulatively with the other provisions of the Act, and does not substitute for or modify the rights and responsibilities of physicians and other health care professionals under other provisions of the Act.

Section 10(A) is intended to facilitate implementation of advance directives. This section requires the attending physician to make an affirmative inquiry of the patient, family or others to determine whether the patient has executed an advance directive. The attending physician's role should be complementary to the routine inquiry about advance directives at the time of admission (and subsequently) undertaken in accordance with institutional policies, pursuant to section 13(A). Where intake documents in the admission process indicate that the patient has an advance directive, the attending physician should follow up and verify this information, and should obtain a copy of the advance directive. The timing and nature of the conversation with the patient or family should be appropriate to the circumstances, and not formalistic or insensitive; section 10(A)(1) is designed to permit the attending physician discretion in conducting this conversation.

It is important for all members of the health care team to be made aware of whether or not an advance directive is operative for the patient, and of whether there is a health care representative involved in the patient's care. To facilitate this process, section 10(A)(1) provides that following receipt of an advance directive the attending physician is required to attach a copy of the document to the patient's medical records, and to note in the patient's medical records that there is an advance directive, as well as the name of the health care representative. Ordinarily, notation in the records should also include how to contact the health care representative, or other important identifying information. Section 10(A)(1) also provides that other relevant information, including the absence of an advance directive, or knowledge of a re-affirmation, modification or revocation of the patient's advance directive, should be documented in the patient's medical records by the attending physician. In contrast to some states, which permit the attending physician to record the known terms of an advance directive when the written document is unavailable, the Act does not accord legal significance to an advance directive unless a copy of the document itself is available to those responsible for the patient's care.

Professional conscience. In the practice of their profession, health care professionals, in particular physicians and nurses who are primarily responsible for implementing treatment decisions, should and do have the right to remain true to certain morally or religiously based personal and professional convictions, and to decline or withdraw from participation in a particular course of treatment, or in the care of a particular patient. Sections 10(A)(3) and 10(B) anticipate that at times strongly and sincerely held differences in values and objectives between a health care professional and the patient or family regarding a proposed decision to forego life-sustaining measures may lead to (perhaps intractable) dispute about the proper course of treatment for the patient. In these circumstances, the right to decline or withdraw from the patient's care, for reasons of conscience, honors the personal and professional integrity of the health care professional. Thus, sections 10(A)(3) and 10(B) accord specific statutory recognition, in limited circumstances, to a right of professional conscience for physicians, nurses and other health care professionals, generally recognized (most often for physicians) under common law and codes of professional

responsibility. A claim of professional conscience under the Act should always be based upon "sincerely held personal or professional convictions". This section does not permit physicians, nurses or other health care professionals to withdraw from the care of a patient on grounds of personal distaste or prejudice, or fear of potential legal liability or unfavorable publicity. Section 10 should be read in conjunction with sections 15 and 16, which state the scope and limitations for the conditions in which the Act authorizes the foregoing of life-sustaining measures pursuant to an advance directive.

Sections 10(A)(3) and 10(B) also provide that in cases of intractable dispute, physicians, nurses, and other health care professionals seeking to exercise this right of professional conscience have certain obligations. The health care professional should act in good faith to inform the patient and the health care representative, as well as an appropriate member of the staff (*e.g.*, chief of the medical or nursing staff or other designated official) of this decision as soon as possible. An appropriate and respectful transfer of care must be effected in a timely fashion not harmful to the patient's well-being and interests before a health care professional may withdraw from responsibility for the patient's care. The primary responsibility for effecting an appropriate transfer of care, including timely transfer of the patient's medical records (with the patient's advance directive) where necessary, rests with the attending physician and the health care institution. (Sections 10(A)(3) and 13(C))

These obligations regarding transfers of care are grounded in the Act's fundamental commitment to protecting patient well-being. The Act does not permit patient abandonment under any circumstances. A physician, nurse or other health care professional who seeks to withdraw from the patient's care under this section must continue to care for that patient until a transfer of care is effected. (However, there is no obligation to withhold or withdraw life-sustaining measures during this time.) In those hopefully rare cases in which an appropriate transfer of care cannot be effectuated, the health care professional must continue to care for the patient; if disagreement cannot be resolved at the institutional level, judicial intervention may be necessary.

Section 10(C) makes clear that the Act does not require physicians, nurses and other health care professionals to provide, withhold or withdraw health care for a patient in a manner contrary to law or accepted medical standards.

Section 10 should not be construed to modify or limit existing legal rights of physicians, nurses or other health care professionals to refuse to accept a patient's care or to decline the continued care of a patient under a variety of other circumstances not addressed by the Act.

Section 11: The Decisionmaking Process

A) The health care representative and the attending physician

1) The health care representative and the attending physician, and where appropriate any additional physician(s) responsible for the patient's care, shall discuss the nature and consequences of the patient's medical condition, and the risks, benefits and burdens of the proposed health care and its alternatives. Except as provided by section 11(A)(4) below, the attending physician shall obtain informed consent to or refusal of health care from the health care representative.

2) Discussion of the proposed treatment and its alternatives shall include, as appropriate under the circumstances, the availability, benefits and burdens of rehabilitative treatment, therapy, and services.

3) The decisionmaking process shall allow, as appropriate under the circumstances,

adequate time for the health care representative to understand and deliberate about all relevant information before a treatment decision is implemented.

4) The patient with impaired decisionmaking capacity

a) Following a determination that the patient's decisionmaking capacity is impaired, the health care representative and the attending physician shall, to the extent reasonable, discuss the treatment options with the patient, and seek to involve the patient as a participant in the decisionmaking process. The health care representative and the attending physician shall seek to promote the patient's capacity for effective participation and shall take the patient's expressed wishes into account in the decisionmaking process.

b) Once decisionmaking authority has been conferred upon a health care representative pursuant to an advance directive, if the patient is found to possess adequate decisionmaking capacity with respect to a particular health care decision, the patient shall retain legal authority to make that decision. In such circumstances, the health care representative may continue to participate in the decisionmaking process in an advisory capacity, unless the patient objects.

c) Notwithstanding any other provision of this Act, if a patient with impaired capacity clearly expresses or manifests the contemporaneous wish that medically appropriate life-sustaining treatment and/or artificially provided fluids and nutrition necessary to sustain life be provided, that wish shall take precedence over any contrary decision of the health care representative and any contrary statement in the patient's instruction directive.

B) The health care representative

1) Determining the patient's wishes

In acting to implement a patient's wishes pursuant to an advance directive, the health care representative shall give priority to the patient's instruction directive, and may also consider, as appropriate and necessary, the following forms of evidence of the patient's wishes:

a) Reliable oral or written statements previously made by the patient, including but not limited to statements made to family members, friends, health care professionals or religious leaders;

b) Other reliable sources of information, including the health care representative's personal knowledge of the patient's values, preferences and goals; and

c) The patient's contemporaneous expressions, including non-verbal expressions.

2) Effect of instruction directives

a) An instruction directive shall provide direction to the health care representative, in accordance with its terms.

b) If the instruction directive, in conjunction with other evidence of the patient's wishes, does not provide, in the exercise of reasonable judgment, clear direction as applied to the patient's medical condition and the treatment alternatives, the health care representative shall exercise reasonable discretion, in good faith, to effectuate the terms, intent, and spirit of the instruction directive and other evidence of the patient's wishes.

3) Inadequate evidence of the patient's wishes

Subject to the provisions of this Act, and unless otherwise stated in an advance directive, if the patient's wishes cannot be adequately determined, then the health care representative shall make a health care decision in the patient's best interests.

Comment

Section 11 sets forth the decisionmaking process to be followed by the health care representative and the physician in making health care decisions on the patient's behalf. As stated above, along with sections 9 and 10, this section is designed to facilitate a process of shared decisionmaking among the health care representative, the physician and the patient (wherever reasonable). Decisions to withhold or withdraw life-sustaining measures are subject to the scope and limitations of sections 15 and 16.

Joint responsibilities of the health care representative and physician. Section 11(A) states the core responsibilities of the health care representative and physician in the process of informed consent. The attending physician is obligated to obtain informed consent or refusal from the health care representative before a course of treatment is implemented (unless a recognized exception to the requirement of informed consent applies, such as a medical emergency). Section 11(A)(1) provides that the health care representative and the attending physician (and with respect to particular health care decisions any other physician(s) responsible for the patient's care), shall discuss the nature and consequences of the patient's medical condition, and the risks, benefits and burdens of the proposed health care and its alternatives. Section 11(A)(2) is intended to assure that where appropriate (for example, where the patient has suffered a traumatic and disabling injury) this discussion addresses whether rehabilitative treatment and services would be of potential benefit to the patient, and whether such care and support is available. In many circumstances, it may be appropriate for the health care representative and the attending physician to view the patient's care as involving a continuing process, and to agree upon a treatment plan for the patient which is sufficiently flexible to accommodate changes in clinical circumstances over time, and which is designed to facilitate on-going dialogue, rather than to view treatment decisions as isolated, episodic events. Section 11(A)(3) makes clear that the decisionmaking process should always be sensitive to allowing adequate time for understanding and deliberation before a treatment decision is made.

As provided elsewhere in the Act (*see* sections 1(D) and 8), a determination of decisionmaking incapacity does not mean that a patient may be ignored as someone whose expressed wishes no longer count. The majority of patients who lack full decisionmaking capacity experience intermittent periods of lucidity and mental function (sometimes referred to as "fluctuating capacity"), or are able to exercise the requisite abilities to make some,

perhaps less complex or consequential, decisions, but not others (sometimes referred to as "diminished capacity"). In short, many patients possess impaired decisionmaking capacity. Section 11(A)(4)(a) is designed to maximize the patient's capacity for self-determination and effective participation in the decisionmaking process. This section provides that in these circumstances the health care representative and the attending physician are jointly obligated to involve the patient with impaired capacity as an active participant in the decisionmaking process, to the extent it is reasonable to do so. Often this will mean efforts to talk with the patient about the treatment options; it may also mean at times treating secondary conditions which impair the patient's cognitive abilities, or employing assistive devices or other mechanisms to improve the patient's ability to communicate effectively. The patient's expressed wishes, including for example expressions of pain or discomfort, or apprehension about invasive procedures, should be taken into account in the decisionmaking process, even though the patient lacks capacity to make that treatment decision on his or her own behalf. (Section 11(A)(4)(a)) It is intended that this section be construed broadly to apply to most, if not all, patients who have some level of ability to communicate with others and who are neither permanently unconscious nor severely demented. (The severely demented will at times show responsiveness to pain or discomfort.)

Limitations on the health care representative's authority. Consistent with the decision-specific nature of decisionmaking incapacity adopted by the Act, section 11(A)(4)(b) recognizes that in some cases a patient will in fact have the capacity to make one or more, but not all, health care decisions, even though a health care representative has become involved on the patient's behalf. In these circumstances, the patient's right to self-determination should be respected. Thus, section 11(A)(4)(b) provides that when the patient possesses decisionmaking capacity the patient's legal authority to make that particular health care decision should be recognized.

Section 11(A)(4)(b) may appear to create some uncertainty about whether it is the patient or the health care representative who has the legal authority to give informed consent. It is important to note that the Act is not intended to create a situation of sequential authority which shifts the locus of decisionmaking back and forth between the patient (where the patient has capacity to make a health care decision) and the health care representative (where the patient lacks capacity to make a health care decision). Once the role of the health care representative has been triggered under the Act, the health care representative should continue to be actively involved in the decisionmaking process for all health care decisions, including those particular decisions regarding which the patient possesses decisionmaking capacity and legal authority. If the patient objects to the health care representative's continued participation, this objection should be respected. (A patient's objection to the health care representative's participation in a particular decision does not in itself constitute a revocation of the health care representative's legal authority under the Act.)

Physicians should be aware that under this section, if both the patient and the health care representative agree on the decision to be made, legally valid consent or refusal has been obtained. Thus, it would be advisable in these circumstances to expressly seek consent from both the patient and the health care representative. In the event of disagreement, and in the face of uncertainty about who has the legal authority to give informed consent or refusal, recourse to a dispute resolution mechanism, pursuant to section 14, may be appropriate.

Section 11(A)(4)(c) states an important limitation on the authority of the health care representative and the attending physician to implement a decision to forego life-sustaining measures on the patient's behalf. This section states that the patient's current and clearly expressed wish for continued life must be respected, even if the health care representative would otherwise have reached a decision that (particular) life-sustaining measures should be withheld or withdrawn, and even if the patient's instruction directive states the patient's prior wish that (particular) life-sustaining measures be withheld or withdrawn. However, section 11(A)(4)(c) requires only the provision of medically appropriate treatment; it does not require physicians to provide medically inappropriate treatment to patients. This section is grounded in a commitment to the preservation of life, and to the principle that a patient's contemporaneous wish to continue living should override prior written instructions or the judgments of others. Uncertainties with respect to the meaning of the patient's expressions and behavior should be resolved in

favor of preserving life.

Determining the patient's wishes. Section 11(B) sets forth the basic approach to be followed by the health care representative to implement an advance directive. In particular, this section states the manner in which the health care representative should seek to make a health care decision based upon the patient's previously expressed wishes. Section 11(B) provides that if the patient has executed an integrated advance directive, the health care representative should look first to the instruction directive, and should give the terms of the instruction directive priority. Where the instruction directive provides clear and unambiguous direction for the health care decision to be made, it should be followed in accordance with its terms. (Section 11(B)(2)(a)) However, section 11(B)(1) provides that the health care representative is not rigidly bound by the terms of the instruction directive alone. It is intended that the health care representative have broad discretion to seek out and evaluate other sources of knowledge about the patient's wishes, including but not limited to the patient's contemporaneous expressions and the several other likely reliable types of evidence identified in section 11(B)(1).

Past experience with instruction directives demonstrates that prior written instructions, often written remotely in time from their actual use, may fail to contemplate the patient's current medical circumstances or may otherwise fail to provide clear direction for the health care decision to be made. In these circumstances, the health care representative is granted discretion to evaluate available evidence of the patient's wishes and to seek to reach a decision that he or she reasonably judges to be consistent with the terms, intent and spirit of what is known of the patient's wishes, including in particular the patient's instruction directive. (Section 11(B)(2)(b))

In some cases, such as where the patient has not executed an instruction directive or where medical circumstances have changed radically from those originally contemplated by the instruction directive, it will not be possible to determine the patient's wishes. Section 11(B)(3) provides that in these circumstances the health care representative has the authority (and the responsibility) to exercise reasonable judgment to make a health care decision in the patient's best interests, based upon what is known of the patient's wishes, including the health care representative's personal knowledge of the patient. This authority is grounded in the fact that the patient has designated a trusted family member or friend, and ordinarily wants his or her health care representative to exercise sound judgment to act in the patient's best interests based upon what is known of the patient's wishes. In the exercise of this authority, the health care representative should seek out the participation and counsel of the attending physician, as well as others.

Protecting patient well-being. In some cases the health care representative may misinterpret or misapply the instruction directive or other evidence of the patient's wishes, or may fail to exercise sound and informed judgment. In rare cases the health care representative may find it emotionally difficult or impossible to accept personal responsibility for carrying out the patient's wishes, or may feel that effecting the patient's wishes is contrary to the dictates of personal morality or conscience. There is also the theoretical possibility of the health care representative acting on the basis of improper or selfish motivations, financial or otherwise.

In the first instance the physician-patient-health care representative relationship plays a critical role in safeguarding the patient's interests. It is the responsibility of the attending physician (and other members of the health care team), both legally and ethically, to scrutinize both the decision and the decisionmaker to assure that decisions are made in accordance with sound medical practice and legal and ethical norms, and to safeguard the patient against possible errors in judgment or wrongdoing. Health care providers, especially physicians, should be attentive to these concerns throughout the course of the patient's care. The Act contemplates that in most cases discussions with the patient, health care representative and family will reveal any suspicion of improper judgment, undue influence or other wrongdoing. In the event discussion fails to resolve misunderstandings or disagreements, or suspicion of wrongdoing remains, further inquiry should be handled initially through established institutional procedures; it may be appropriate to seek recourse to an institutional dispute resolution mechanism, pursuant to section 14. In some cases it may be necessary to refer the matter to an appropriate governmental agency, such as

the Ombudsman.

Section 12: Instruction Directives in the Absence of a Designated Health Care Representative

A) If the patient has executed an instruction directive but has not designated a health care representative, or if neither the designated health care representative nor any alternate designee is able or available to serve, an instruction directive shall be legally operative. If the instruction directive provides clear and unambiguous guidance under the circumstances, it shall be honored in accordance with its specific terms by a legally appointed guardian (if any), family members, physicians, other health care professionals, health care institutions, and others acting on the patient's behalf.

B) If the instruction directive is, in the exercise of reasonable judgment, not specific to the patient's medical condition and the treatment alternatives, the attending physician, in consultation with a legally appointed guardian (if any), family members, or others acting on the patient's behalf, shall exercise reasonable judgment to effectuate the wishes of the patient, giving full weight to the terms, intent, and spirit of the instruction directive. Departure from the specific terms and provisions of the instruction directive shall be based upon clearly articulable factors not foreseen or contemplated by the instruction directive, including but not limited to the circumstances of the patient's medical condition.

C) Nothing in this Act is intended, or shall be construed, to impair the legal force and effect of instruction directives executed prior to the effective date of this Act.

Comment

Section 12 sets forth the decisionmaking process to be followed where the patient has executed an instruction directive, but has no health care representative. In such cases, instruction directives should be respected as legally operative documents, in accordance with this section and the other provisions of the Act. In this regard, the Act gives instruction directives greater force and effect than is the case under existing law, which characterizes instruction directives as the "best evidence" of the patient's wishes, *In re Peter*, 108 N.J. 365, 529 A.2d 419, 426 (1987); *see also In re Conroy*, 98 N.J. 321, 486 A.2d 1209, 1229 &n.5 (1985) (a living will is "relevant evidence" of the patient's wishes). As provided by section 12(C), the Act does not retroactively impair the legal validity of instruction directives executed before the Act takes effect. Thus, section 12 applies with equal force to instruction directives executed prior to the effective date of the Act. The interpretation and application of the terms of such documents is to be in accordance with the provisions of the Act.

Section 12(A) states that where an instruction directive provides clear and unambiguous direction for the health care decision to be made, those responsible for the patient's care are obligated to follow the specific terms of the instruction directive. As noted in comment to section 9, the Act also anticipates that an instruction directive may not give specific direction. In particular, a prior written document may not foresee or contemplate certain medical conditions. In these circumstances, section 12(B) authorizes the exercise of reasonable judgment to effectuate the patient's wishes, with particular emphasis to be accorded the terms, intent and spirit of the instruction directive. In order to assure faithful interpretation and implementation of the patient's expressed wishes, a course of treatment which departs from the specific terms of an instruction directive should be based upon relevant and identifiable factors the patient has not foreseen and addressed in his or her instructions, most significantly, the

patient's current medical condition. Those responsible for the patient's care should be able to clearly identify and state those factors, as well as why this provides sufficient reason not to follow the instruction directive. It should be noted in this regard that the Act is fully consistent with a woman's ability to express in her instruction directive a preference for continued treatment in the event of pregnancy. At the same time, section 12(B) recognizes that a later pregnancy may not be contemplated when writing an instruction directive, and provides a mechanism for addressing this situation.

This section does not alter the obligations of health care professionals to involve the patient in the decisionmaking process and to take the patient's expressed wishes into account, in accordance with section 11(A)(4). Nor does this section impair the obligations of health care professionals under section 11(A)(4)(c) to respect the patient's clear and contemporaneous expression or manifestation that life-sustaining measures be provided, even if the instruction directive directs the foregoing of such measures.

It is important to recognize that section 12 does not authorize, nor does it prohibit, the foregoing of life-sustaining measures in the best interests of the patient when an instruction directive fails to provide adequate means to determine what the patient would want under the circumstances. Only the health care representative, in consultation with the attending physician, is given this authority under the Act. Thus, in such cases, in the absence of a health care representative, a decision to forego life-sustaining measures in the patient's best interests will be governed by other law, and families, health care professionals and others should look to existing New Jersey law for guidance.

Section 12 does not specifically identify who has the legal authority to make health care decisions on the patient's behalf when there is no health care representative. It is intended that in such cases existing law and practice will continue to govern this question; often this will mean that decisions are made (as has traditionally been the case) within the physician-patient-family relationship. Since one of the individuals responsible for the patient's care will always be the attending physician, section 12(B) places with the attending physician the lead responsibility for interpreting an unclear or ambiguous instruction directive, and for doing so in light of other evidence of the patient's wishes including the patient's contemporaneous expressions.

Section 13: The Rights and Responsibilities of Health Care Institutions

In addition to any rights and responsibilities recognized or imposed by or pursuant to the other provisions of this Act, or by other law, health care institutions shall have the following rights and responsibilities:

A) Routine inquiry

Health care institutions shall adopt such policies and practices as are necessary to provide for routine inquiry, at the time of admission and at such other times as are appropriate under the circumstances, concerning the existence and location of an advance directive.

B) Education

1) Patients, health care representatives and families

a) Health care institutions shall adopt such policies and practices as are necessary to provide appropriate informational materials concerning advance directives to all

interested patients, families and health care representatives, and to assist patients interested in discussing and executing an advance directive.

b) Health care institutions shall adopt such policies and practices as are necessary to educate patients, health care representatives, and families about the availability, benefits and burdens of rehabilitative treatment, therapy and services, including but not limited to, family and social services, self-help and advocacy services, employment and community living, and use of assistive devices. Health care institutions shall, in consultation with the attending physician, assure that such information is discussed with patients and health care representatives and made a part of the decisionmaking process, as appropriate under the circumstances.

2) Physicians, nurses and other health care professionals

Health care institutions shall adopt such policies and practices as are necessary to inform physicians, nurses and other health care professionals of their rights and responsibilities under this Act, to assure that such rights and responsibilities are understood, and to provide a forum for discussion and consultation regarding the requirements of this Act.

C) Transfers of care

Where transfers of care are necessary, including transfers for the purpose of effectuating the patient's wishes regarding the withholding or withdrawing of life-sustaining treatment and/or artificially provided fluids and nutrition necessary to sustain life, health care institutions shall, in consultation with the attending physician, take all reasonable steps to effect the appropriate, respectful and timely transfer of patients to the care of alternative health care professionals or institutions, as necessary, and shall assure that patients are not abandoned or treated disrespectfully. In such circumstances, health care institutions shall assure the timely transfer of the patient's medical records, including a copy of the patient's advance directive.

D) Dispute resolution

Health care institutions shall establish procedures and practices for dispute resolution, in accordance with section 14 of this Act.

E) Private religiously-affiliated health care institutions: Institutional conscience

1) Private religiously-affiliated health care institutions may develop institutional policies and practices defining circumstances in which they will decline to participate in the withholding or withdrawing of specified life-sustaining treatments and/or artificially provided fluids and nutrition necessary to sustain life. Such policies and practices shall be written, and shall be properly communicated to patients, families

and health care representatives prior to or upon the patient's admission, or as soon after admission as is practicable.

2) If such institutional policies and practices appear to conflict with the legal rights of a patient wishing to forego health care, the health care institution shall attempt to resolve such a conflict, and if mutually satisfactory accommodation cannot be reached, shall take all reasonable steps to effect the appropriate, timely and respectful transfer of the patient to the care of another health care institution appropriate to the patient's needs, and shall assure that the patient is not abandoned or treated disrespectfully.

F) Nothing in this Act shall be construed to require health care institutions to participate in the beginning, continuing, withholding or withdrawing of health care in a manner contrary to law or accepted medical standards.

Comment

Section 13 sets forth the core rights and responsibilities of health care institutions governed by the Act. This section should be read cumulatively with the other provisions of the Act, and does not substitute for or modify the rights and responsibilities of health care institutions under other provisions of the Act. The obligations of health care institutions under this section are intended to apply regardless of whether the Department of Health issues any rules and regulations pursuant to its authority under section 20. (Of course, health care institutions would be obligated to comply with any rules and regulations the Department of Health does issue.)

Institutional policies. Section 13(A) is intended to assure that patients' advance directives become known to health care providers. This section requires health care institutions to establish institutional policies and practices designed to make routine inquiry of patients, families or others to determine whether the patient has executed an advance directive, and if so, how the document may be located. Routine inquiry should focus upon the admission process, making this information part of a patient's intake documentation, and thereby assuring that the attending physician and other health care professionals are properly informed. Institutional policy and practice should also be sufficiently flexible to accommodate the needs and interests of patients and families so as not to impose pro forma questioning at an inappropriate time (for example, upon an emergency admission). Institutions should also assure that subsequent conversation with patients and families takes place when necessary, particularly where this inquiry has not occurred previously at the time of admission. The attending physician's correlative obligation of inquiry under section 10(A)(1) should be incorporated into the development of institutional policy and practice. Though not required by section 13, institutions should consider including as part of their policies a mechanism for review of advance directives to assure proper execution and legal validity of the documents.

Section 13(B) sets forth several educational responsibilities of health care institutions. Section 13(B)(1)(a) recognizes that if advance directives are to be widely and effectively used as a method of advance planning, active steps must be taken to inform and educate patients and families. This section places some of these educational responsibilities with health care institutions. As a corollary to the physician's obligations under section 11(A)(1), section 13(B)(1)(b) establishes an institutional responsibility to provide information, education and support to patients, health care representatives and families about rehabilitative treatment, therapy and services, where appropriate to the patient's care. It is intended that in fulfilling their educational responsibilities health care institutions have broad discretion to develop policies and practices appropriate to their own institutional needs and concerns. It should be noted that section 13(B) does not require health care institutions to give legal advice to patients, families, physicians or others.

The Commission and its Task Force on Public and Professional Education plan to develop recommended

guidelines for institutional policies and practices designed to assist health care institutions in carrying out these responsibilities.

Section 13(D) makes clear that all health care institutions governed by the Act are required to establish an institutional dispute resolution mechanism available to patients, families, physicians, nurses and others, in accordance with section 14. While not required by the Act, developing an institutional policy to establish and implement a dispute resolution mechanism may be advisable.

Transfers of care. Section 13(C) states an institution's responsibilities in the event it is necessary to transfer a patient's care, either to another health care professional or to another health care institution. As part of its responsibility to provide quality compassionate care for all patients, the health care institution should, in consultation with the attending physician, cooperate in and facilitate a transfer of care requested or authorized by the health care representative, including when the transfer is for the purpose of carrying out the patient's wishes to forego life-sustaining measures. Any decision to transfer should give priority to patient well-being and should be timely and sensitive to the patient's needs. In many cases this will mean transfer to another physician or institution who shares more closely the patient's treatment objectives and is prepared to honor the patient's wishes. Under the Act, health care institutions share with the attending physician responsibility for assuring appropriate transfers of care, and also for assuring that the process includes prompt transfer of the patient's medical records, with a copy of the patient's advance directive. Ultimate responsibility for assuring that the transfer process is respectful of patients' wishes and interests rests with the health care institution. In no event does the Act permit patient abandonment. If efforts to resolve disagreements prove unsuccessful and an appropriate transfer of care cannot be accomplished with the consent of the health care representative, the institution must continue to care for the patient, and has the option of seeking court intervention.

Institutional conscience. Section 13(E) provides for a limited right of institutional conscience which in many respects parallels the individual right of professional conscience provided in section 10. This right of institutional conscience applies only to private religiously-affiliated health care institutions.

This section recognizes that some health care institutions do hold strong formal commitments to a particular philosophy of care, or to particular principles, and that such formal commitments can forcefully shape the character of an institution. As a general matter, the Act acknowledges that those institutions grounded in certain religious traditions are the most likely candidates to embody an institutional philosophy of care taking a particular position with respect to the foregoing of life-sustaining measures. Religiously-affiliated institutions have most often been most active in formulating policies or codes of ethics to govern the provision of care. However, the scope of section 13(E) rests ultimately not on a conclusion about which health care institutions have "consciences" nor on conclusions of constitutional law, but on the prudential judgment that, given the reality that effectuating transfers of care in controversial cases has often been difficult for patients and families, and the concern that private institutions might invoke claims of conscience to avoid potentially troublesome situations, over-extending legal recognition of institutional conscience might risk unduly decreasing the number of institutional settings in which patients and families can properly expect their rights and wishes to prevail. While section 13(E) recognizes a right of "institutional conscience", its exercise and benefits are primarily intended to honor the identity of philosophy of care and professional commitments shared, both individually and collectively, by those who constitute and exemplify that health care institution.

Thus, section 13(E)(1) provides that private religiously-affiliated health care institutions may adopt policies and practices stating the circumstances in which the institution (more precisely, its health care professionals) does not intend to comply with a patient's wishes that life-sustaining treatment and/or artificially provided fluids and nutrition be withheld or withdrawn. A statement of policy grounded in institutional conscience should be based upon sincerely held religious and moral beliefs reflected in the institution's charter, policies or practices, and shared by those responsible for the delivery of health care at that institution in a way which embodies a particular institutional philosophy of care.

In order to protect patient rights and to avoid potentially charged conflict and burdensome litigation, section 13(E)(1) requires that patients, families and health care representatives be given proper notice of the institution's policies and practices, generally before or upon admission and acceptance of care. A private religiously-affiliated health care institution wishing to adopt such policies must do so in writing. In cases of conflict between a patient's wishes and institutional policy, an institution may not rely upon its policy if it has not made proper efforts to put the policy in writing and to give notice to the patient, family, and health care representative.

Where institutional policy appears to conflict with a patient's wishes that life-sustaining measures be withheld or withdrawn, section 13(E)(2) provides that the institution's first responsibility is to seek to resolve this conflict, initially by facilitating further discussion, and perhaps by recourse to the institution's dispute resolution mechanism. If a mutually agreeable approach to the patient's care cannot be found, the institution is responsible for making reasonable efforts to effect a timely and respectful transfer of the patient's care to another institution. Efforts to transfer care should endeavor to place the patient in a health care institution appropriate to the patient's needs, *i.e.*, an institution which has not adopted a formal policy in conflict with the patient's wishes to forego treatment and which has a philosophy of care more compatible with the patient's wishes. Private religiously-affiliated institutions choosing to exercise this right of institutional conscience may wish to maintain a list of possible transfer institutions which have not adopted policies similar to their own.

In the event suitable transfer (with the consent of the health care representative) cannot be effectuated, judicial review may be appropriate. As with other provisions of the Act, in no event does this section permit patient abandonment. The institution is obligated to continue to care for the patient, pending any further action to resolve the conflict, though it is not obligated during this time to comply with the patient's wishes in violation of its stated policies and practices. (Section 13(E)(2))

Similarly to section 10(C), which applies to physicians, nurses and other health care professionals, section 13(F) makes clear that the Act does not require health care institutions to provide, withhold or withdraw health care for a patient in a manner contrary to law or accepted medical standards.

Section 14: Dispute Resolution

A) In the event of disagreement among the patient, health care representative, and attending physician concerning the patient's decisionmaking capacity or the appropriate interpretation and application of the terms of an advance directive to the patient's course of treatment, the parties shall seek to resolve such disagreement by resort to procedures and practices established within the health care institution, including but not limited to consultation with an institutional ethics committee, or with a person or persons designated by the health care institution for this purpose.

B) Health care professionals involved in the patient's care, other than the attending physician, and administrators of a health care institution may also invoke the dispute resolution process established by the health care institution to seek to resolve disagreement concerning the patient's decisionmaking capacity or the appropriate interpretation and application of the terms of an advance directive.

C) If disagreement cannot be reconciled through an institutional dispute resolution process, resolution in a court of appropriate jurisdiction may be sought.

Comment

Section 14 provides for an institutional dispute resolution mechanism to be established by the health care institution. The purpose of this section is to make available to patients, family members, physicians and others an internal and easily accessible process for seeking to resolve misunderstandings and disagreements without the necessity for more formal and burdensome resort to the courts. As stated in section 14(C), institutional review is to precede, but not necessarily to supplant, judicial review. Where disagreements cannot be resolved, court review may be appropriate.

Section 14(A) specifically contemplates two types of potential disagreements which may arise in the course of the patient's care--those concerning the patient's decisionmaking capacity and those concerning the interpretation and application of an advance directive (including clarification and confirmation of the patient's medical condition, where necessary). Where the patient, health care representative or attending physician disagree on either of these questions, section 14(A) provides that such disagreements are to be brought to an institutional dispute resolution process, established by the health care institution. While section 14 expressly contemplates that disagreements may arise regarding the patient's decisionmaking capacity or the patient's course of treatment, nothing in this section is intended to discourage those responsible for the patient's care from seeking assistance in resolving disagreements on other matters. Section 14(B) provides that the dispute resolution process may also be invoked by other health care professionals involved in the patient's care, and by administrators of the facility.

Although health care institutions are required (here and by section 13(D)) to establish a dispute resolution mechanism to serve the purposes stated in this section, the precise nature of this process is left to the institution to develop, in accordance with institutional needs and concerns. The process might involve consultation with an institutional ethics committee or with a single individual (such as an "ethics consultant"). It is important to note that an ethics committee established for the purposes of dispute resolution under this section is not necessarily subject to the requirements of section 18, which apply to institutional or regional reviewing bodies, such as ethics committees, engaged in prospective case consultation.

Subpart C: Scope and Limitations Regarding Life-Sustaining Measures

Section 15: Decisions to Forego Life-Sustaining Treatment

A) Consistent with the terms of an advance directive and the provisions of this Act, life-sustaining treatment, other than artificially provided fluids and nutrition necessary to sustain life, may be withheld or withdrawn from a patient in the following circumstances:

1) When the life-sustaining treatment is experimental and not a proven therapy, or is likely to be ineffective or futile in prolonging life, or is likely merely to prolong an imminent dying process; or

2) When the patient is permanently unconscious, as determined by the attending physician and confirmed by a second qualified physician; or

3) When the patient is in a terminal condition, as determined by the attending physician and confirmed by a second qualified physician; or

4) In the event none of the above circumstances applies, when the patient has a serious irreversible illness or condition, and the likely risks and burdens associated with the medical intervention to be withheld or withdrawn may reasonably be judged

to outweigh the likely benefits to the patient from such intervention, and imposition of the medical intervention on an unwilling patient would be inhumane. In such cases, prior to implementing a decision to withhold or withdraw life-sustaining treatment, the attending physician shall seek prompt consultation with a qualified institutional or regional reviewing body in accordance with section 18 of this Act, or shall promptly seek approval of a public agency recognized by law for this purpose.

B) Nothing in this section is intended, or shall be construed, to impair the obligations of physicians, nurses and other health care professionals to provide for the care and comfort of the patient and to alleviate pain, in accordance with accepted medical and nursing standards.

C) Nothing in this section is intended, or shall be construed, to abridge any Constitutionally-protected right to refuse treatment, based upon the free exercise of religion or the right of privacy, under either the United States Constitution or the Constitution of the State of New Jersey.

Comment

Subpart C governs the foregoing of life-sustaining measures. The Act takes a situation-specific approach to the circumstances in which life-sustaining measures may be withheld or withdrawn pursuant to a patient's advance directive. Sections 15 and 16 provide important conditions and limitations for the withholding or withdrawal of life-sustaining treatment and/or artificially provided fluids and nutrition, respectively, including specific procedures to be followed before decisions to forego life-sustaining measures may be implemented. Section 15 governs the foregoing of life-sustaining treatment, as defined in section 2(M); decisions to forego artificially provided fluids and nutrition are governed by section 16. The Act's approach is grounded in careful consideration of the appropriate role of societal interests as sources of limitation upon the duty of health care providers and of society to comply with patients' expressed wishes to forego life-sustaining measures. In giving greater weight to societal interests with respect to the foregoing of artificially provided fluids and nutrition, the Act departs from existing case law in New Jersey and virtually all other states, which has made little or no distinction between the foregoing of artificially provided fluids and nutrition and other life-sustaining measures, in accordance with the patient's wishes. In contrast, statutory law in some other states takes a different and more restrictive approach to the foregoing of artificially provided fluids and nutrition pursuant to an advance directive than is taken to other forms of life-sustaining measures.

Section 15(A) identifies the four categories of medical circumstances in which the Act authorizes the withholding or withdrawal of life-sustaining treatment, pursuant to the terms of the patient's advance directive. This section codifies widespread societal consensus regarding the circumstances in which a patient's expressed wishes to forego life-sustaining treatment should be respected. The Act's approach is substantially (though not necessarily completely) in accord with the views of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, the Hastings Center, and numerous court decisions across the country, including the decisions of the New Jersey Supreme Court. The Act rejects the approach taken in the statutes of many other states which have limited the patient's right to refuse life-sustaining treatment pursuant to an advance directive to the medical circumstance in which the patient is in a terminal condition. This approach is overly restrictive of patients' rights and contrary to widely held societal values.

Ineffective, futile or experimental treatments. Section 15(A)(1) provides that when life-sustaining treatment is likely to be ineffective or futile, or is likely to merely prolong an imminent dying process, a patient's expressed wishes to forego such treatment should be honored. This section codifies, in the context of advance directives, widely shared societal judgments that a patient should not be required to accept ineffective, futile and possibly intrusive

and burdensome treatment contrary to his or her expressed wishes. This section also provides, consistently with widely shared values, that a patient should not be compelled to accept experimental treatment of unproven therapeutic value contrary to his or her expressed wishes. In the circumstances contemplated by section 15(A)(1), a confirming diagnosis of the patient's medical condition is not required prior to implementing the patient's wishes to forego life-sustaining treatment.

Permanent unconsciousness. Section 15(A)(2) provides that when the patient is permanently unconscious and the provision of life-sustaining treatment serves only to maintain bodily functions in the absence of any realistic medical prospect for return to a cognitive sapient state, the patient's expressed wishes to forego such treatment should be honored. In this regard, section 15(A)(2) follows existing New Jersey law under *Quinlan*, *Peter* and *Jobes*. However, this section would alter existing law in one important respect. Section 15(A)(2) provides that where the patient has an advance directive, the attending physician's diagnosis and prognosis that the patient is permanently unconscious must be confirmed by a second qualified physician; most often this will mean a neurologist. In contrast, current law requires confirmation of the patient's condition by a prognosis committee, *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, *cert. denied sub nom. Garger v. New Jersey*, 429 U.S. 922 (1976), or by two independent physicians where no prognosis committee is available. *In re Peter*, 108 N.J. 365, 529 A.2d 419, 429 (1987). The requirement of only one confirming medical opinion is responsive to concerns that the Supreme Court guidelines in this regard may be overly burdensome in practice, and too often result in unreasonable delays in respecting patient wishes. The Act seeks to establish a workable procedure for confirming the accuracy of a diagnosis while at the same time providing meaningful safeguards for patients through the shared decisionmaking process set forth in other provisions of the Act. While this section would not require confirmation of the patient's condition by a prognosis committee, resort to a prognosis committee is certainly appropriate where one is available. The Act places no limitations upon the number of physicians who may examine the patient and give their medical opinion.

Terminal condition. Section 15(A)(3) provides that when the patient is in a terminal condition, as defined in section 2(R), the patient's expressed wishes to forego life-sustaining treatment should be honored. This section is consistent with existing New Jersey law under *Conroy*, though as discussed in comment to section 2(R), the Act's definition of "terminal condition" departs slightly from *Conroy's* definition of "terminal illness". Similarly to section 15(A)(2), the requirement in section 15(A)(3) that the patient's condition be confirmed by one nonattending physician is intended to assure practicable and accurate evaluation of the patient's diagnosis and prognosis without making respect for patient wishes unduly burdensome. Consultation with additional physicians to determine the patient's medical condition is always appropriate.

Other life-threatening illness or condition. Section 15(A)(4) provides for a fourth category of patients with respect to whom the foregoing of life-sustaining treatment is authorized by the Act. This section applies only in cases in which the patient does not meet the criteria of sections 15(A)(1) through 15(A)(3), *i.e.*, when the patient is not imminently dying, not permanently unconscious, and not in a terminal condition. Section 15(A)(4) addresses foregoing of life-sustaining treatment, pursuant to an advance directive, when the patient has a serious and *irreversible* (but not terminal) condition, and the likely risks and burdens of providing the treatment in question may reasonably be judged to outweigh its likely benefits and imposing this intervention on the patient contrary to his or her wishes would be inhumane.

Like the other provisions of section 15(A), section 15(A)(4) is grounded in shared societal consensus regarding the circumstances in which a patient's expressed wishes to forego life-sustaining treatment should be honored. However, this fourth circumstance presents a more morally problematic situation; one in which societal interests favoring continued provision of treatment may carry greater weight. Therefore, additional safeguards are warranted before a decision to forego life-sustaining treatment is implemented, and section 15(A)(4) provides that prior to implementing a decision to withhold or withdraw life-sustaining treatment for a patient in this circumstance, another level of review should take place.

Section 15(A)(4) provides that an institutional or regional reviewing body (such as an institutional ethics committee), or an appropriate public agency (such as the Ombudsman or a court), must be consulted before a

decision to forego life-sustaining treatment can be implemented. Thus, the Act would establish for the first time (here and in section 16(A)(3)), a mandatory prospective case consultation role (in limited circumstances) for an ethics committee or like body. This process must be initiated promptly by the attending physician. The process to be followed by an institutional or regional reviewing body engaged in prospective case consultation pursuant to section 15(A)(4) is set forth in section 18.

This process of local review is intended to provide appropriate protection for patients in a potentially morally problematic circumstance while being less burdensome, intrusive and time consuming than other review processes, such as the Office of the Ombudsman for the Institutionalized Elderly or the courts. Where this process of local review is implemented by nursing homes or other institutions within the Ombudsman's jurisdiction, the Act provides that in the limited circumstances described in section 15(A)(4), institutional or regional review is a legally recognized alternative to Ombudsman review.

It should be noted that section 15(A)(4) states that a reviewing body such as an ethics committee is to be "qualified". As discussed in comment to section 18, the Act anticipates that legal standards for ethics committees engaged in prospective case consultation will be developed as part of the Commission's continuing work. In the Commission's view, a number of existing ethics committees in New Jersey substantially meet these standards already, and are qualified to perform this function in the circumstances of section 15(A)(4). Deletion of the term "qualified" would serve to make clear that existing ethics committees are authorized by the Act to perform this function until legal standards for such committees are in place.

Palliative care. In most cases, patients who refuse life-sustaining treatment desire a dignified and less burdensome dying process, and do not intend to refuse palliative and nursing care. In addition, health care providers have strongly held professional obligations to provide palliative measures to relieve patient suffering. In recognition of these concerns and of some existing confusion regarding the provision of palliative care when life-sustaining treatment is terminated, section 15(B) makes clear that the withholding or withdrawal of a particular life-sustaining treatment under the Act does not mean the cessation of all treatment and care for the patient. Physicians, nurses and other health care professionals should continue to alleviate pain and to take other steps to care for and comfort the patient, in accordance with accepted medical and nursing standards, unless such measures are contrary to the patient's clearly expressed wishes. Continued comfort care should ideally be a part of the patient's treatment plan, agreed upon among the attending physician, health care representative and patient.

Effect on other laws. Section 15(C) provides that the Act is not intended to alter or impair patients' constitutional rights to refuse treatment, under the United States Constitution and the Constitution of the State of New Jersey. However, to the extent any provisions of this section are inconsistent with the existing common law rights of patients to forego life-sustaining treatment pursuant to an advance directive, *this Act controls*. It is especially important to note here that the Act applies only when the patient has executed an advance directive, and does not limit patient rights under existing law in other circumstances. Section 15(C) should be especially relevant to the courts, which should, to the extent reasonable, construe it in a manner consonant with constitutional protections of patients' rights to refuse treatment, based upon the free exercise of religion or the right of privacy.

Section 16: Decisions to Forego Artificially Provided Fluids and Nutrition

A) Consistent with the explicit terms of an advance directive and the provisions of this Act, artificially provided fluids and nutrition necessary to sustain life may be withheld or withdrawn from a patient in the following circumstances:

1) When the artificial provision of fluids and nutrition is likely to be ineffective or futile in prolonging life, or is likely merely to prolong an imminent dying process; or

2) When the patient is permanently unconscious, as determined by the attending physician and confirmed by a second qualified physician; or

3) When the patient is in a terminal condition, as determined by the attending physician and confirmed by a second qualified physician, and the likely risks and burdens associated with the least burdensome treatment modality likely to be effective may reasonably be judged to outweigh the likely benefits to the patient from such intervention, and imposition of the intervention on an unwilling patient would be inhumane. In such cases, prior to implementing a decision to withhold or withdraw artificially provided fluids and nutrition, the attending physician shall seek prompt consultation with a qualified institutional or regional reviewing body in accordance with section 18 of this Act, or shall promptly seek approval of a public agency recognized by law for this purpose.

B) This Act does not provide authorization for the health care representative, or any other individual acting pursuant to this Act, to direct or implement the withholding or withdrawal of artificially provided fluids and nutrition necessary to sustain life in the absence of explicit instructions to that effect in the patient's advance directive.

C) Nothing in this section is intended, or shall be construed, to impair the obligations of physicians, nurses and other health care professionals to provide for the care and comfort of the patient and to alleviate pain, in accordance with accepted medical and nursing standards.

D) Nothing in this section is intended, or shall be construed, to abridge any Constitutionally-protected right to refuse treatment, based upon the free exercise of religion or the right of privacy, under either the United States Constitution or the Constitution of the State of New Jersey.

Comment

Section 16 provides important conditions and limitations for decisions to forego artificially provided fluids and nutrition necessary to sustain life. Section 16 is based upon the view that the withholding or withdrawal of life-sustaining fluids and nutrition (such as by nasogastric tube, gastrostomy tube, jejunostomy tube, or intravenous infusion) from patients who lack decisionmaking capacity or are otherwise vulnerable raises important and distinctive problems for social policy that justify protective measures, beyond those applicable in section 15 to the foregoing of other life-sustaining measures. Such protective measures include both substantive and procedural safeguards intended to protect against abuse of patients and to protect important societal values, including in particular respect for and protection of human life, and the preservation of public confidence in the caring role of health care professionals.

Explicit statement of patient wishes. Section 16(A) states that a decision to forego artificially provided fluids and nutrition pursuant to an advance directive is to be based upon an explicit statement in the patient's advance directive instructing the withholding or withdrawal of artificially provided fluids and nutrition. (See also section 6(C)(2).) The requirement of specificity here is responsive to special public policy concerns regarding the foregoing of artificially provided fluids and nutrition, and is designed to assure that such decisions are based upon clear evidence of the patient's wishes and are not subject to uncertainty or ambiguity.

This approach is further emphasized by section 16(B), which provides that absent such an explicit instruction, the Act does not authorize the health care representative, the attending physician, or any other individual responsible for the patient's care to direct or implement the withholding or withdrawal of artificially provided fluids and nutrition necessary to sustain life. It is important to note, however, that the Act does not prohibit, nor does it make unlawful, a decision to forego artificially provided fluids and nutrition for patients who have advance directives but have not written explicit instructions on this question; and the Act does not require that artificially provided fluids and nutrition always be provided in such cases. In some cases, for example where the patient is imminently dying or is suffering a prolonged and burdensome dying process, it may be appropriate to infer a patient's wishes that artificially provided fluids and nutrition be withheld or withdrawn from other more general language in the patient's advance directive and other evidence of the patient's wishes.

While the Act itself provides no authority for this decision, and thus no *statutory* immunity would be conferred for implementing this decision, in the absence of an explicit instruction those responsible for the patient's care should look to other existing law to determine the legal basis for a decision to forego artificially provided fluids and nutrition. Existing New Jersey law makes no distinction between artificially provided fluids and nutrition and other life-sustaining measures, and does not require that a patient's wishes to forego artificially provided fluids and nutrition be explicitly stated. Under existing law those who follow in good faith the procedures established by the New Jersey Supreme Court would be immune from liability.

Medical circumstances. Section 16 takes a situation-specific approach to decisions to forego artificially provided fluids and nutrition which is in many respects parallel, but not identical, to the provisions of section 15 for decisions to forego life-sustaining treatment. Section 16(A) identifies the three categories of medical circumstances in which the Act authorizes the withholding or withdrawal of artificially provided fluids and nutrition in accordance with the explicit terms of the patient's advance directive and other provisions of the Act.

Section 16(A)(1) provides that artificially provided fluids and nutrition may be withheld or withdrawn when such measures are likely to be ineffective or futile, or are likely to merely prolong an imminent dying process. The rationale and approach here, both substantively and procedurally, is the same as that taken in the parallel provisions of section 15(A)(1).

Section 16(A)(2) provides that when the patient is permanently unconscious, as determined by the attending physician and confirmed by a second qualified physician (*e.g.*, a neurologist), and the provision of artificially provided fluids and nutrition serves only to maintain bodily functions in the absence of any realistic medical prospect for return to a cognitive sapient state, the patient's expressed wishes to forego such measures should be honored. The rationale and approach here, both substantively and procedurally, is the same as that taken in the parallel provisions of section 15(A)(2).

Section 16(A)(3) provides for a third category of patients with respect to whom the foregoing of artificially provided fluids and nutrition is permitted by the Act. This section applies only in cases in which the patient does not meet the criteria of sections 16(A)(1) and 16(A)(2), *i.e.*, when the patient is neither imminently dying nor permanently unconscious. Section 16(A)(3) recognizes that the foregoing of potentially beneficial artificially provided fluids and nutrition for a patient who is not imminently dying and may live for more than a short period, and who is not permanently unconscious, raises distinctive concerns, and therefore imposes both substantive and procedural safeguards under these circumstances.

Under this section, a patient must be diagnosed as having a terminal condition, as defined in the Act, by the attending physician and one confirming physician. In addition, it must be determined, in the exercise of reasonable judgment, that continued provision of the *least burdensome* and medically appropriate modality for artificial provision of fluids and nutrition would impose greater risks and burdens on the patient than benefits, and that continued imposition of the intervention contrary to the patient's expressed wishes would be inhumane. A key element of the decisionmaking process here is an evaluation of the relative benefits, risks and burdens for the patient

of the alternative and medically appropriate treatment modalities. For example, a gastrostomy tube generally is experienced by patients as less intrusive and irritating and presents lesser risks of infection over time than a nasogastric tube, yet a gastrostomy tube requires a surgical procedure, with attendant risks of bleeding and infection. The range of medically appropriate alternatives often will depend upon the patient's medical condition, in particular the functional status of the gastrointestinal system.

Section 16(A)(3) also provides that prior to implementing a decision to forego artificially provided fluids and nutrition in these circumstances another level of review should take place. An institutional or regional reviewing body (such as an institutional ethics committee), or an appropriate public agency (such as the Ombudsman or a court) must be consulted before a decision to forego artificially provided fluids and nutrition can be implemented. Thus, like section 15(A)(4), this section establishes, in limited circumstances, a mandatory prospective case consultation role for an ethics committee or like body. The attending physician is responsible for promptly informing the reviewing body of the contemplated decision and requesting consultation. The process to be followed by an institutional or regional reviewing body engaged in prospective case consultation pursuant to section 16(A)(3) is set forth in section 18. (As noted in comment to section 15(A)(4), deletion of the term "qualified" here would serve to make clear that existing ethics committees are authorized by the Act to perform this function until legal standards for such committees are in place.)

Palliative care. Similarly to section 15(B), section 16(C) makes clear that the withholding or withdrawal of artificially provided fluids and nutrition under the Act does not mean the cessation of all treatment and care for the patient. Physicians, nurses and other health care professionals should continue to alleviate pain and to take other steps to care for and comfort the patient, in accordance with accepted medical and nursing standards, unless such measures are contrary to the patient's expressed wishes. Continued comfort care should ideally be a part of the patient's treatment plan, agreed upon among the attending physician, the health care representative and the patient.

Some health care professionals consider artificially provided fluids and nutrition to be "basic care" or "comfort care" to be provided to patients in all but very limited circumstances. The Act rejects this approach, and section 16(C) should not be construed to authorize continued provision of artificially provided fluids and nutrition contrary to the patient's wishes on these grounds. In the event of a sincere conflict of values, the Act recognizes a right of professional conscience and of institutional conscience (for private religiously-affiliated health care institutions); a transfer of care would be appropriate in cases of irresolvable disagreement.

Effect on other laws. Similarly to section 15(C), section 16(D) provides that the Act is not intended to alter or impair patients' constitutional rights to refuse treatment, including artificially provided fluids and nutrition, under the United States Constitution and the Constitution of the State of New Jersey. To the extent any provisions of this section are inconsistent with the existing common law rights of patients to forego artificially provided fluids and nutrition pursuant to an advance directive, *this Act controls*. However, as noted above, the Act's requirement of explicitness should not be construed to prohibit the foregoing of artificially provided fluids and nutrition under existing common law. Again, it is especially important to note here that the Act applies only when the patient has executed an advance directive, and is not intended to limit patient rights under existing law in other circumstances. Section 16(D) should be especially relevant to the courts, which should, to the extent reasonable, construe it in a manner consonant with constitutional protections of patients' rights to refuse treatment, based upon the free exercise of religion or the right of privacy.

Section 17: Do Not Resuscitate Orders

A) Consistent with the terms of an advance directive and the provisions of this Act, the attending physician may issue a do not resuscitate order.

B) Nothing in this Act is intended, or shall be construed, to impair any existing legal

authority to issue a do not resuscitate order where the patient has not executed an advance directive.

C) A do not resuscitate order must be entered in writing in the patient's medical records prior to implementation of the order.

Comment

Section 17 provides guidelines for the issuance of do not resuscitate orders pursuant to the terms of an advance directive. Under section 17(A) the attending physician may issue an order that cardiopulmonary resuscitation not be attempted if the patient suffers a cardiac or respiratory arrest (a DNR order) if such an order is consistent with the terms of an advance directive and the provisions of the Act. In order to be legally effective the DNR order must be put in writing in the patient's medical chart and records before it is implemented. This assures proper notice to health care professionals responsible for the patient's care, as well as the accountability of physicians for issuance of DNR orders.

Section 17(B) makes clear that the requirements established by the Act regarding issuance of DNR orders are applicable only within the context of the Act, *i.e.*, only where the patient has executed an advance directive. The Act does not alter or impair any existing legal authority of physicians to enter DNR orders, nor does it affect the manner in which they are issued, in cases where the patient has no advance directive.

Section 18: Institutional and Regional Reviewing Bodies

A) Advisory role

1) An institutional or regional reviewing body which engages in prospective case consultation pursuant to sections 15(A)(4) and 16(A)(3) shall advise the attending physician, patient and health care representative whether it believes that the withholding or withdrawal of the medical intervention under consideration would be in conformity with the requirements of this Act, including without limitation a) whether such action would be within the scope of the patient's advance directive; and b) whether it may reasonably be judged that the likely risks and burdens associated with the medical intervention to be withheld or withdrawn outweigh its likely benefits, and whether it may reasonably be judged that imposition of the medical intervention on an unwilling patient would be inhumane. The attending physician, patient and health care representative shall also be advised of any other course of diagnosis or treatment recommended for consideration.

2) The advice of the institutional or regional reviewing body shall be documented in the patient's medical records.

B) Following advice: immunity

1) A health care representative who follows and implements in good faith the advice of an institutional or regional reviewing body acting in accordance with section 18(A) of this Act shall not be subject to criminal or civil liability for such actions.

2) A physician, nurse or other health care professional who follows and implements in good faith, and in accordance with accepted professional standards, the advice of an institutional or regional reviewing body acting in accordance with section 18(A) of this Act shall not be subject to criminal or civil liability or to discipline for unprofessional conduct for such actions.

C) Advice not legally binding

The advice of an institutional or regional reviewing body acting in accordance with section 18(A) of this Act is not legally binding. A health care representative, physician, nurse, or other health care professional who believes the advice should not be followed may choose to:

1) Pursue an alternative course of treatment for the patient. In such cases, no immunity is conferred upon such actions by this Act, and such individuals are subject to existing norms of civil and criminal law and professional conduct; or

2) Seek review by a public agency recognized by law for this purpose; or

3) Seek review by a court of appropriate jurisdiction.

D) Nothing in this section shall preclude transfer of the patient to another appropriate health care professional or health care institution. In such cases the health care institution responsible for the patient's care shall assure that the health care professional or health care institution to which the patient is transferred is properly informed of the advice given by the institutional or regional reviewing body.

E) Accreditation

An institutional or regional reviewing body acting in accordance with section 18(A) of this Act shall conform to standards established by law and shall be subject to periodic accreditation and review under procedures established by law.

Comment

Section 18 provides the process to be followed when a prospective case consultation is called for under sections 15(A)(4) or 16(A)(3). Under the Act, section 18 applies only in the circumstances specified in sections 15(A)(4) and 16(A)(3). The reviewing body may be institutional, such as an institutional ethics committee, or regionally based. The Act is intended to permit, and indeed to encourage, health care institutions to consider participation in an ethics committee on an inter-institutional or regional basis. This may be especially important for some nursing homes and for home health agencies.

Nature of committee review. In the specified circumstances, the Act gives such committees a mandatory review function, but does not give the committee final decisionmaking authority. While section 18(A)(1) provides that the committee is to render its advice, as stated in section 18(C) this advice is not binding. Decisionmaking authority rests with the health care representative in collaboration with the attending physician. Where there is no health care

representative, the locus of decisionmaking authority will be determined under other law, and not by the Act, but generally will rest within the physician-patient-family relationship. (*See* the comment to section 12.)

Section 18(A)(1) states the standard of review to be applied by the committee. The committee should determine whether it finds the proposed withholding or withdrawal of a particular medical intervention to be within the scope of (consistent with) the terms of the patient's advance directive and in conformity with the requirements of the Act, including in particular whether the proposal to forego life-sustaining measures meets the substantive standards of sections 15(A)(4) and 16(A)(3), respectively. Thus, the key question presented is whether the committee finds, in light of all the relevant factors-- most importantly the terms of the patient's advance directive and the patient's current medical condition--that the proposed decision to withhold or withdraw the medical intervention is based upon a reasoned weighing of risks, burdens and benefits for the patient under the circumstances. The central issue for the committee is whether the decision to forego life-sustaining measures falls within a range of reasonable and permissible decisions under the circumstances of the case. The committee is not called upon to determine whether it believes the withholding or withdrawal of the medical intervention is "right" or "wrong", and the committee should not construe its role in this manner.

Upon completion of its deliberations, the committee shall advise the attending physician, the patient and the health care representative as to whether it believes the proposed decision to forego treatment is permissible under the Act. The committee may also recommend an alternative course of diagnosis or treatment for the patient. (Section 18(A)(1)) The committee's recommendations are to be documented (entered in writing) in the patient's medical records, pursuant to section 18(A)(2).

Legal consequences. While the Act states that the prospective case consultation role of an institutional or regional reviewing body is advisory, and does not give the committee decisionmaking authority, consultation with the committee would be mandatory and would therefore have specific legal consequences, thereby giving the committee's recommendations more than purely "advisory" status. Sections 18(B) and 18(C) state the legal consequences of the committee's advice.

Section 18(B) recognizes that those responsible for the patient's care who properly follow a legally required process of review should be accorded legal protection for following the committee's advice. Thus, this section provides that a health care representative, physician, nurse or other health care professional who acts in good faith to follow the committee's advice would have immunity from legal liability. Physicians, nurses and other health care professionals would also be immunized against professional disciplinary action.

However, as provided in section 18(C), the committee's advice is not binding, and those who choose not to follow the committee's recommendation(s) may pursue other courses of action, including acting on the previously proposed treatment decision, or seeking review by the Ombudsman or by a court. In this case, no immunity is conferred by the Act for such actions, and existing legal norms would apply. Those who do not follow the committee's recommendation(s) are *not* thereby subject to liability by virtue of having chosen to pursue a different course of action.

Transfers of care. One possible consequence of the committee's recommendations is that a transfer of care will be sought by those who strongly disagree with those recommendations. For example, where the committee's advice does not support the decision proposed by the health care representative, or where the advice is contrary to the personal or professional convictions of a member of the health care team, such as the attending physician, transfer of care to another health care professional or institution may be requested. Section 18(D) makes clear that those responsible for the patient's care retain this option. (Of course, the committee could also recommend a transfer of care.) However, the committee's consultation and recommendations are not nullified by a transfer of care and remain a part of the patient's medical record. In the event a transfer of care is effectuated, the health care institution is responsible for assuring that the committee's recommendations are properly communicated to the health care professional or health care institution assuming responsibility for the patient's care, including transfer of the

written statement of the committee's recommendations entered in the patient's medical records. Those responsible for the patient's care are free to seek another consultation with a committee of the transferee institution.

Accreditation. Section 18(E) provides that standards for the establishment and operation of committees engaged in prospective case consultation pursuant to the Act are to be established by law, as is a process for the periodic accreditation and review of committees engaged in this function. These standards and procedures are not provided by the Act itself. The Commission and its Task Force on Institutional Ethics Committees are currently developing recommendations for a statutory approach to establish standards and procedures to govern, among other things, the prospective case consultation role for committees set forth in the Act. It should be recognized, however, that under section 18(E) these standards need not be derived from statutory law, and could, for example, be established by regulation or by judicial decision.

As noted in comment to sections 15(A)(4) and 16(A)(3), it is expected that a number of existing ethics committees in New Jersey health care institutions substantially meet these standards already, and will need to make only minor adjustments with respect to their membership and operation. Other institutions would be required to create a new institutional entity, or to participate in an inter-institutional or regionally based committee. In the absence of standards recognized by law, it would nonetheless be consistent with the Act's intent to require prospective case consultation by ethics committees which now exist in New Jersey, or which may be established in the future, in the limited circumstances contemplated by the Act. The absence at this time of legal standards for prospective case consultation should not discourage health care institutions from using existing ethics committees, or from establishing or participating in committees, to provide the prospective case consultation required by the Act.

Nothing in the Act should be construed to prevent or discourage health care representatives, patients, physicians, or others from seeking the advice and support of an ethics committee in a variety of other circumstances beyond those set forth in sections 15(A)(4) and 16(A)(3).

Subpart D: Implementation and Legal Consequences

Section 19: Health Care Institutions Governed by This Act; Inapplicability to Providers of Emergency Care

A) Health care institutions subject to this Act

1) The provisions of this Act apply to all health care institutions as defined in section 2(I) of this Act.

2) Nothing in this Act is intended, or shall be construed, to alter, amend or revoke the rights and responsibilities under existing law of health care institutions not governed by the provisions of this Act.

3) Nothing in this Act is intended, or shall be construed, to preclude mental health institutions, facilities or agencies, or institutions, facilities or agencies for the developmentally disabled, from respecting an advance directive for health care executed by a patient or resident pursuant to this Act.

B) Providers of emergency care; exemption

The provisions of this Act shall not be construed to require emergency personnel,

including paid or volunteer fire fighters; paramedics; members of an ambulance team, rescue squad, or mobile intensive care unit; or emergency room personnel of a licensed health care institution, to withhold or withdraw emergency care in circumstances which do not afford reasonable opportunity for careful review and evaluation of an advance directive without endangering the life of the patient.

Comment

Subpart D provides for important aspects of the implementation and legal consequences of the Act.

Section 19 states the scope of application of this Act to health care institutions, and provides a qualified exemption from the requirements of the Act for providers of emergency care. The Act applies to most, but not all, health care institutions in the State of New Jersey. Section 19(A) incorporates by reference the definition of "health care institution" in section 2(I), and provides that the Act applies to all institutions, facilities and agencies licensed, certified or otherwise authorized to provide health care in this State, including hospitals, nursing homes, residential health care facilities, and home health care agencies, and to all hospice programs operating in the State of New Jersey. This section (and the definition) should be construed broadly to assure respect for patients' advance directives in the various health care settings in this State and to provide appropriate protections to health care providers who honor advance directives in conformity with the provisions of the Act.

The Act does not apply to state-administered mental health institutions, facilities or agencies, or to those state institutions, facilities and agencies devoted to care of the developmentally disabled. (See definition of "health care institution", section 2(I)) While the Act would not effect any changes in the rights and obligations of those institutions, facilities or agencies under existing law, nothing in the Act would prohibit such institutions, facilities or agencies from respecting an advance directive that has been properly executed by one of its patients or residents. (Section 19(A)(3)) The exclusion of state-administered facilities provided by section 19(A)(3) was originally based upon the view that decisions to forego life-sustaining measures in such facilities may pose some special questions and concerns warranting special attention. However, those prior concerns are no longer considered sufficient to warrant this exclusion, and an amendment to include state-administered facilities within the coverage of the Act on the same basis as other health care institutions is encouraged.

Section 19(B) provides a qualified exemption from the provisions of the Act for emergency care providers. Emergency care providers, such as fire fighters, paramedics, and members of an ambulance team, are not obligated to seek to evaluate complex information in emergency circumstances where the patient's life may be endangered and should continue to act upon their professional commitments to preserve life. However, where the patient's wishes are clearly understood in advance of a medical crisis requiring immediate intervention, emergency care providers should act in good faith to carry out a patient's wishes that life-sustaining treatment not be provided. For example, where, pursuant to a patient's advance directive there is a physician's order not to resuscitate which has been properly communicated to emergency personnel, this order should be respected. Where doubt exists, emergency care providers should err in favor of preserving life.

Section 20: Implementation of Advance Directives

In accordance with the "Administrative Procedure Act," *N.J.S.A.* 52:14B-1 *et seq.*, the State Department of Health may establish rules and regulations necessary to oversee and assure compliance with this Act. Such rules and regulations may require health care institutions to adopt policies and practices designed to

A) make routine inquiry, at the time of admission and at such other times as are

appropriate under the circumstances, concerning the existence and location of an advance directive;

B) provide appropriate informational materials concerning advance directives to all interested patients, families and health care representatives, and to assist patients interested in discussing and executing an advance directive;
C) educate patients, health care representatives, and families about the availability, benefits and burdens of rehabilitative treatment, therapy and services, as appropriate;

D) inform physicians, nurses, and other health care professionals of their rights and responsibilities under this Act, to assure that such rights and responsibilities are understood, and to provide a forum for discussion and consultation regarding the requirements of this Act; and

E) otherwise comply with the provisions of this Act.

Comment

Section 20 authorizes, but does not require, the Department of Health to promulgate rules and regulations to oversee and assure compliance with the Act. Section 20 directs, but does not limit, the exercise of regulatory authority to enforcement of the obligations of health care institutions to facilitate implementation of advance directives. Thus, the regulatory provisions authorized by sections 20(A) through 20(D) parallel the obligations of health care institutions set forth in sections 13(A) and 13(B) of the Act. Section 20(E) provides for a generalized authority in the Department of Health to establish rules and regulations as may be necessary to oversee and enforce compliance of health care institutions with any and all other obligations established by the Act. In the exercise of its authority under this section the Department of Health is required to follow the "Administrative Procedure Act", *N.J.S.A.* 52:14B-1, *et seq.* The Legislature may wish to consider mandating that the Department of Health formally promulgate such rules and regulations in order to more strongly assure implementation of advance directives. Such a legislative determination would be consistent with the purposes of the Act.

Section 21: Reporting and Monitoring

A) In accordance with the "Administrative Procedure Act," *N.J.S.A.* 52:14B-1 *et seq.*, the State Department of Health shall establish such rules, regulations, policies 8and practices as may be necessary to collect annual reports from health care institutions, and to gather such additional data as is reasonably necessary, to oversee and evaluate the implementation of this Act. The Department of Health shall seek to minimize the burdens of record-keeping imposed by such rules, regulations, policies and practices, and shall seek to assure the appropriate confidentiality of patient records.

B) The State Department of Health and the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care shall jointly evaluate the implementation of this Act and report to the State Legislature, including recommendations for any changes deemed necessary, after a period of not more than five years from the effective date of this Act.

Comment

Given the somewhat complex and innovative features of the Act and some of the concerns that have been expressed regarding aspects of its implementation, section 21 requires the collection of data necessary to evaluate the Act's effectiveness in achieving its intended objectives and provides a mechanism for proposing any necessary changes. The Department of Health is directed to collect reports, on an annual basis, from health care institutions regarding their experience with the implementation of the Act. The collection of data should accord particular attention to the extent to which advance directives are being honored by health care providers, to the way in which the decisionmaking process is working, and to identification of particular concerns, including protection against possible abuse. While minimizing unnecessary paperwork, this process should provide an empirically sound basis for recognizing and correcting any difficulties.

Section 21(B) provides that evaluation of the effectiveness of the Act shall be undertaken jointly by the Department of Health and the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care. These bodies are directed to report their conclusions to the New Jersey State Legislature, including recommendations for any changes that may be necessary to better achieve the objectives of the Act. The initial report is to be made to the Legislature within not more than five years from the effective date of the Act. In the event serious difficulties arise, an earlier report would be possible.

The requirement that the initial report be made to the Legislature within five years of the effective date of the Act has no automatic effect upon the continued validity of the Act; the Act does not contain a formal "sunset" provision.

Section 22: Immunities

A) A health care representative acting in good faith and in accordance with the provisions of this Act to carry out the terms of an advance directive shall not be subject to criminal or civil liability for such actions.

B) A health care professional or health care institution acting in good faith and in accordance with the provisions of this Act, any rules and regulations established by the Department of Health pursuant to this Act, and accepted professional standards, to carry out the terms of an advance directive shall not be subject to criminal or civil liability or to discipline for unprofessional conduct.

Comment

Section 22 provides a good faith immunity for health care representatives and health care providers who act in accordance with the provisions of the Act (and in the case of health care providers any applicable rules and regulations) to carry out the terms of an advance directive. Under section 22(A) health care representatives who implement the terms of an advance directive in good faith and who do so in accordance with their responsibilities under the Act (in particular sections 9 and 11) shall be immune from criminal and civil liability. This section is intended to make clear to health care representatives that good faith actions to carry out their responsibilities pursuant to an advance directive are insulated from potential liability.

Section 22(B) extends to physicians, nurses, hospitals, nursing homes and other health care professionals and institutions governed by the Act, and applies to criminal or civil liability and to discipline for unprofessional conduct. This section does not provide a blanket immunity and does not absolve from liability or from professional discipline those whose actions are contrary to accepted professional standards or the requirements of the Act. This section is intended to make clear to health care providers that non-negligent actions undertaken in compliance with

the Act and applicable regulations to implement an advance directive are insulated from potential liability. Physicians and other health care providers should be confident that they may exercise sound professional judgment in seeking to follow the terms of an advance directive in accordance with the Act. This statutory grant of immunity is intended to calm existing concerns of unfounded and burdensome entanglements in legal proceedings, and to obviate any perceived need to seek advance approvals from courts prior to implementing a treatment decision pursuant to an advance directive and the requirements of the Act.

While this section provides immunities for good faith behavior, section 27 imposes penalties for willful failure to comply with advance directives or with the Act.

Section 23: Presumptions

The absence of an advance directive shall create no presumption with respect to a patient's wishes regarding the provision, withholding or withdrawing of any form of health care. This Act does not apply to persons who have not executed an advance directive.

Comment

Section 23 recognizes that an advance directive is a mechanism for expressing in written form one's wishes for health care in the event of subsequent decisionmaking incapacity. Those responsible for the patient's care should make no presumptions about the patient's wishes merely because those wishes are not stated in writing. The rights and responsibilities established by the Act are designed to establish and foster a decisionmaking process to be followed where the patient has executed an advance directive. As noted elsewhere, if the patient has not executed an advance directive, the Act simply does not apply. In such cases health care decisions should be made in accordance with other existing law.

Section 24: Effect on Insurance

The execution of an advance directive pursuant to this Act shall not in any manner affect, impair or modify the terms of, or rights or obligations created under, any existing policy of health insurance, life insurance or annuity, or governmental benefits program. No health care practitioner or other health care provider, and no health service plan, insurer, or governmental authority, shall deny coverage or exclude from the benefits of service any individual because that individual has executed or has not executed an advance directive. The execution (or non-execution) of an advance directive shall not be made a condition of coverage under any policy of health insurance, life insurance or annuity, or governmental benefits program.

Comment

Section 24 provides that neither an individual's choice regarding whether or not to execute an advance directive, nor the nature and content of that choice (as expressed in the selection of a health care representative and/or in an instruction directive), shall be a legally valid ground for the denial, impairment or modification of rights or obligations under the terms of existing policies of health insurance, life insurance or annuity, or any governmental benefits programs. Section 24 also prohibits health care practitioners, health service plans, insurers, and governmental authorities from employing an individual's execution or non-execution of an advance directive

as a basis for the denial of coverage or for exclusion from the benefits of service. Providers of health insurance, life insurance or annuity, and governmental health benefits programs may not make an individual's decision to execute or not to execute an advance directive a condition of coverage under any such policies or programs. (Section 27(B)(4) makes such coercive practices a crime.)

This section (along with section 27(B)(4)) is intended to protect the rights of individuals to control decisions about their own health care against potentially coercive practices, by precluding insurers or care providers from cutting off benefits or services or conditioning their cost or availability (such as through changes in premiums) upon the exercise or non-exercise of this right.

Section 25: Recognition of Advance Directives Executed in Other States or Countries

An advance directive executed under the laws of another state in compliance with the laws of that state or the State of New Jersey is validly executed for purposes of this Act. An advance directive executed under the laws of a foreign country in compliance with the laws of that country or the State of New Jersey, and not contrary to the public policy of this State, is validly executed for purposes of this Act.

Comment

Section 25 provides that an advance directive executed under the laws of another state or of a foreign country which meets the *execution* requirements of that state or country, or of the state of New Jersey (for example, signed and dated by a competent adult, with two witnesses), shall be treated as a validly executed advance directive by health care providers, family and others. Section 25 recognizes that in our mobile society there are likely to be New Jersey residents who have moved here from elsewhere as well as residents of other states or countries who are receiving health care in this State, and that such patients' rights to have an advance directive honored should not depend upon technicalities of law which may differ from state to state. Section 25 is intended to require the honoring of advance directives that may not be in strict compliance with the procedural requirements of the laws of another state or the state of New Jersey, or a foreign country, but which are in substantial compliance with the law of either state, or with the law of a foreign country.

At the same time, this section recognizes that the substantive law of other states and countries may differ in important respects from the substantive provisions of the Act. In order to protect this state's interest in the integrity of its public policy, section 25 would deny legal recognition of terms of an advance directive that rely upon rights or seek to impose obligations that are contrary to the public policy of New Jersey. For example, if an advance directive requests active euthanasia, as by lethal injection, such a request would not be honored. Decisionmaking in accordance with the contents of an advance directive executed under the law of another state or country is to be in accordance with both the procedural and substantive provisions of the Act.

Section 26: Effect on Other Laws

A) Homicide and suicide

The withholding or withdrawing of life-sustaining treatment pursuant to section 15 of this Act or of artificially provided fluids and nutrition necessary to sustain life pursuant to section 16 of this Act, when performed in good faith, and in accordance with the terms of an advance directive and the provisions of this Act, shall not constitute homicide, suicide, assisted suicide, or active euthanasia.

B) "Powers of Attorney," *N.J.S.A.* 46:2B

1) To the extent any of the provisions of this Act are inconsistent with *N.J.S.A. 46:2B* concerning the designation of a health care representative, the provisions of this Act shall have priority.

2) Durable powers of attorney for health care executed pursuant to *N.J.S.A. 46:2B* prior to the effective date of this Act shall have the same legal force and effect as if they had been executed in accordance with the provisions of this Act.

C) "Ombudsman for the Institutionalized Elderly," *N.J.S.A.* 52:27G-1, *et seq.*

The Office of the Ombudsman for the Institutionalized Elderly shall adopt policies and practices necessary to comply with the requirements of this Act, and shall make a written statement of its obligations under this Act available to the public.

D) "Public Guardian for Elderly Adults," *N.J.S.A.* 52:27G-20, *et seq.*

The Office of the Public Guardian for Elderly Adults shall adopt policies and practices necessary to comply with the requirements of this Act, and shall make a written statement of its obligations under this Act available to the public.

E) Emancipated Minors

Nothing in this Act is intended, or shall be construed, to impair the rights of emancipated minors under existing law.

Comment

Section 26 states the impact of this Act upon several other laws which are or may be affected by the Act. Section 26(A) provides that respecting a patient's wishes, as expressed in an advance directive, to reject a prolonged and burdensome dying process and to accept an earlier death is legally permissible and is not an unlawful taking of life, *i.e.*, such action does not constitute homicide. That a patient wishes to forego life-sustaining measures in the circumstances specified in sections 15 and 16 does not mean that the patient's wishes are motivated by a specific intent to die, *i.e.*, that the patient intends to commit suicide. Consequently, respecting the patient's wishes does not implicate a health care representative or health care provider in the assisting of suicide; *N.J.S.A.* 2C:11-6, which makes aiding suicide a crime, does not apply to the withholding or withdrawal of life-sustaining measures in conformity with the Act. Section 26(A) follows the approach of the vast majority of statutes of other states and the uniform holdings of courts in New Jersey and elsewhere.

Section 26(A) also provides that the termination of life-sustaining measures pursuant to the Act does not constitute "active euthanasia." As stated in section 1(E), the Act rejects as a matter of public policy the practice of "active euthanasia" (sometimes referred to as "mercy killing"), *i.e.*, the intentional causing of the patient's death, such as by deliberate lethal injection. Patients have no right to request a lethal injection, nor is any physician or health care provider obligated or authorized to engage in the practice of active euthanasia. In contrast, the withholding or withdrawal of life-sustaining measures pursuant to the Act may be characterized as "passive euthanasia". Although the term "euthanasia" is often used in ethical discourse, with the exception of distinguishing

and rejecting active euthanasia, the Act generally avoids use of the term "euthanasia", on the ground that it is frequently ambiguous and subject to misunderstanding, and increasingly has been used by some in a politically and morally controversial manner which mischaracterizes and confuses the issues. It is important to emphasize here that the right of patients recognized by the Act is properly construed and characterized as a right to decide, including the right to refuse unwanted medical interventions, not as a so-called "right to die". The withholding or withdrawal of life-sustaining measures in accordance with the terms of a patient's advance directive and the provisions of the Act is both legally and morally permissible.

Section 26(B) provides that the Act creates the preferred, but not the exclusive, method for the designation of a legally authorized health care representative. Under *In re Peter*, 108 N.J. 365, 529 A.2d 419 (1987), the New Jersey Powers of Attorney law may be used to give an individual a durable power of attorney to make health care decisions (a durable power of attorney for health care). That ruling is not affected by the Act, and nothing in the Act is intended to invalidate designation of a health care representative made under the Powers of Attorney law. (Section 26(B)(1)) However, the Act establishes more comprehensive requirements for such a designation and should be followed for this purpose. Section 26(B)(2) provides that durable powers of attorney for health care executed pursuant to the provisions of the Powers of Attorney law and prior to the effective date of the Act shall continue to be recognized as legally valid documents with the same legal force and effect as if they had been executed pursuant to this Act. The rights and responsibilities of health care representatives and of health care providers are to be governed by the Act, without regard to the time or manner of the designation of a health care representative (assuming the document is validly executed).

Section 26(C) provides that the Office of the Ombudsman is bound by the requirements of the Act and is obligated to adopt policies and practices necessary to carry out its obligations under the Act. Sections 15(A)(4) and 16(A)(3) expressly provide that in specified circumstances a local review process meeting standards established by law would be a legally recognized alternative to Ombudsman review for cases within the Ombudsman's jurisdiction; in those cases there would be no requirement of Ombudsman review. In other respects, the Act accords broad discretion to the Ombudsman to determine the specific nature of the policies and practices it adopts. It is recommended, though not required by the Act, that since the risks of actual abuse are minimal in cases involving advance directives, the Ombudsman establish a process of expedited review for cases involving advance directives. This process should include looking to local mechanisms, such as ethics committees, to carry out routine prospective review functions. As ethics committees become better established in the nursing home setting, the Ombudsman should rely upon such committees to assure that the elements of sound decisionmaking are in place and to provide on-site expedited review of cases involving advance directives. It would be consistent with the Act's intent for the Legislature to seek to assure greater public input and accountability by requiring the Ombudsman to adopt regulations setting forth its obligations under the Act. Whether or not policies and practices (or regulations) are formally adopted, section 26(B) requires the Ombudsman to adopt a written statement of its obligations under the Act and to make this statement available to the public.

Section 26(D) provides that the Office of the Public Guardian for Elderly Adults (the "Public Guardian") is bound by the requirements of the Act and is obligated to adopt policies and practices necessary to carry out its obligations under the Act. Although the cases in which the Public Guardian becomes involved on behalf of a patient with an advance directive likely will be rare, in some cases the Public Guardian will be legally appointed to act on the patient's behalf. The Legislature may wish to require that the Public Guardian adopt regulations setting forth its obligations under the Act in such cases. Whether or not policies and practices (or regulations) are formally adopted, section 26(C) requires the Public Guardian to adopt a written statement of its obligations under the Act and to make this statement available to the public.

Section 26(E) addresses the effect of the Act upon the rights and responsibilities of emancipated minors. The Act states that adults, *i.e.*, individuals 18 years of age or older, may execute advance directives, and that adults may serve as health care representatives. Adults are generally presumed to be competent to make health care decisions (as well as to make other types of decisions) absent a determination of incompetency. In contrast,

under common law minors (those under the age of majority, ordinarily defined as the age of 18) have not been presumed competent to make health care decisions on their own behalf. Certain exceptions to this rule, both in statute and common law, have evolved, and emancipated minors have been widely recognized in some circumstances as having the legal authority to consent to (or refuse) health care (as well as to make other types of decisions). Section 26(E) is intended to preserve the rights of emancipated minors under existing law, and to allow the competence of emancipated minors to execute an advance directive, or to serve as a health care representative on behalf of a family member or friend, to be determined on an individual basis.

Section 27: Penalties

A) Willful failure to follow this Act

1) Willful failure by a health care professional to act in accordance with practices and procedures established by this Act shall constitute professional misconduct.

2) Willful failure by a health care institution to act in accordance with practices and procedures established by this Act shall be subject to a fine of not more than $1000.00 per instance. Penalties for violations of this Act shall be recovered in a summary civil proceeding, brought in the name of the State in the Superior Court pursuant to the Penalty Enforcement Law (*N.J.S.A.* 2A:58-1 *et seq.*).

B) The following acts constitute crimes:

1) To willfully conceal, cancel, deface, obliterate or withhold personal knowledge of an advance directive or a modification or revocation thereof, without the declarant's consent, is a crime of the [_____] degree.

2) To falsify or forge an advance directive or a modification or revocation thereof of another individual is a crime of the [_____] degree.

3) To coerce or fraudulently induce the execution of an advance directive or a modification or revocation thereof is a crime of the [_____] degree.

4) To require or prohibit the execution of an advance directive or a modification or revocation thereof as a condition of coverage under any policy of health insurance, life insurance or annuity, or governmental benefits program, or as a condition of the provision of health care is a crime of the [_____] degree.

C) The sanctions provided in this section shall not be construed to repeal any sanctions applicable under other law.

Comment

Section 27(A) provides for enforcement of the Act and of patients' rights to have their advance directives respected by establishing penalties for the willful failure of health care professionals and health care institutions to follow the Act. Under section 27(A)(1), physicians, nurses and other health care professionals who willfully fail to act in accordance with the practices and procedures established by the Act (including for example, willful refusal to recognize an advance directive, to consult an institutional or regional reviewing body, or to transfer a patient in

accordance with the requirements of the Act), will be deemed to have committed an act of professional misconduct and are subject to discipline by the appropriate authority (such as the Board of Medical Examiners). Under section 27(A)(2), willful failure on the part of a health care institution to follow the Act is punishable by fine, recoverable in a summary civil proceeding that may be brought in the name of the State, for example by the Department of Health.

Section 27(B) provides criminal penalties for actions clearly designed to undermine an individual's wishes as expressed in an advance directive, or by the modification or revocation of an advance directive. The prohibitions of section 27(B) apply to all persons, including but not limited to health care representatives, physicians, health care providers, family members, and others. The penalties established by section 27(B) are intended to apply regardless of the eventual result of the unlawful actions. Thus, to be criminally sanctioned the conduct need not result in the unauthorized withholding or withdrawal of life-sustaining measures, thereby hastening death; nor need it result in the continuation of treatment and the unauthorized prolongation of a burdensome dying process.

Section 27(B)(4) provides sanctions for violations of section 24 of the Act, by making it a criminal offense to require or prohibit the execution, modification or revocation of an advance directive as a condition of providing insurance coverage, or to condition the provision of health care upon the execution, modification or revocation of an advance directive.

The appropriate severity of crime and penalty for each of the acts specified in this section is to be determined by the Legislature. The Legislature may wish to consider imposing a more severe penalty for prohibited actions in subparagraphs 27(B)(1) through (3) which result in the involuntary earlier death of a patient.

Section 28: Severability

If any provision of this Act or its application to any individual or circumstance is held invalid, the invalidity shall not affect other provisions or applications of this Act which can be given effect without the invalid provision
or application, and to this end the provisions of this Act are severable.

Comment

Section 28 states that should a particular provision of the Act be held invalid, the other provisions that can be given effect without the invalid provision will continue to have legal force and effect. The invalidity of one provision will not invalidate the entire Advance Directives For Health Care Act. Section 28 follows widely used language enacted by a number of state legislatures and approved by the Uniform Law Commissioners in the Uniform Rights of the Terminally Ill Act (1985).

Section 29: Short Title

This Act may be cited as the New Jersey Advance Directives for Health Care Act.

EFFECTIVE DATE: This Act shall take effect 180 days from its enactment.

Part Three

Appendix

Proposed New Jersey Advance Directives for Health Care Act

Approved in principle, December 14, 1988
Approved in final form, December 29, 1988

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Proposed New Jersey Advance Directives for Health Care Act

An act concerning health care decisionmaking for patients lacking decisionmaking capacity and who have executed advance directives for health care.

Be it enacted by the Senate and General Assembly of the State of New Jersey that:

Section 1: Legislative Findings

The Legislature finds and declares that:

A) Competent adults have the fundamental right, in collaboration with their health care providers, to control decisions about their own health care. This State recognizes, in its law and public policy, the personal right of the individual patient to make voluntary, informed choices to accept, to reject, or to choose among alternative courses of medical and surgical treatment.

B) Modern advances in science and medicine have made possible the prolongation of the lives of many seriously ill individuals, without always offering realistic prospect for improvement or cure. For some individuals the possibility of extended life is experienced as meaningful and of benefit. For others, artificial prolongation of life may seem to provide nothing medically necessary or beneficial, serving only to extend suffering and prolong the dying process. This State recognizes that the fundamental right of individual choice extends to decisions to have medical or surgical means or procedures calculated to prolong life provided, withheld, or withdrawn.

C) In order that the right to control decisions about one's own health care should not be lost in the event a patient loses decisionmaking capacity and is no longer able to participate actively in making his or her own health care decisions, this State recognizes the right of competent adults to plan ahead for health care decisions through the execution of advance directives, such as living wills and durable powers of attorney, and to have the wishes expressed therein respected, subject to certain limitations.

D) The right of individuals to forego life-sustaining measures is subject to certain interests of society. The most significant of these societal interests is the preservation of life, understood to embrace both an interest in preserving the life of the particular patient and a related but distinct interest in preserving the sanctity of all human life as an enduring social value. A second, closely related societal interest is the protection of individuals from direct and purposeful self-destruction, motivated by a specific intent to die. A third interest is the protection of innocent third parties who may be harmed by the patient's decision to forego therapy; this interest may be asserted to prevent the emotional and financial abandonment of the patient's minor children or to protect the paramount

concerns of public health or safety. A fourth interest encompasses safeguarding the ethical integrity of the health care professions, individual professionals, and health care institutions, and maintaining public confidence and trust in the integrity and caring role of health care professionals and institutions. Finally, society has an interest in ensuring the soundness of health care decisionmaking, including both protecting vulnerable patients from potential abuse or neglect and facilitating the exercise of informed and voluntary patient choice.

E) In accordance with these state interests, this State expressly rejects on both legal and moral grounds the practice of active euthanasia, as by deliberate lethal injection intended to cause death. No individual shall have the right to, nor shall any physician or other health care professional be authorized to engage in, the practice of active euthanasia.

F) In order to assure respect for patients' previously expressed wishes when the capacity to participate actively in decisionmaking has been lost or impaired; to facilitate and encourage a sound decisionmaking process in which patients, health care representatives, families, physicians, and other health care professionals are active participants; to properly consider patients' interests both in self-determination and in well-being; and to provide necessary and appropriate safeguards concerning the termination of life-sustaining treatment for incompetent patients as the law and public policy of this State, the Legislature hereby enacts the New Jersey Advance Directives for Health Care Act.

Section 2: Definitions

All definitions are intended solely for the purposes of this Act. As used in this Act:

A) "Adult" means an individual of 18 or more years of age.

B) "Advance directive for health care" or "advance directive" means a writing executed in accordance with the requirements of this Act. The term "advance directive" encompasses both the designation of a health care representative (known as a "proxy directive" or a "medical durable power of attorney") and a statement of personal wishes regarding health care in the event of loss of decisionmaking capacity (known as an "instruction directive" or, in popular discourse, as a "living will").

C) "Attending physician" means the physician selected by or assigned to the patient who has primary responsibility for the treatment and care of the patient.

D) "Decisionmaking capacity" means a patient's ability to understand and appreciate the nature and consequences of health care decisions, including the benefits and risks of each, and alternatives to any proposed health care, and to reach an informed decision. An individual's decisionmaking capacity is evaluated relative to the demands of a particular health care decision.

E) "Declarant" means a competent adult who executes an advance directive.

F) "Do not resuscitate order" means a physician's written order not to attempt cardiopulmonary resuscitation in the event the patient suffers a cardiac or respiratory arrest.

G) "Emergency care" means immediate treatment provided in response to a sudden, acute and unanticipated medical crisis in order to avoid injury, impairment, or death.

H) "Health care decision" means a decision to accept or to refuse any treatment, service or procedure used to diagnose, treat or care for a patient's physical or mental condition, including "life-sustaining treatment" as defined in this Act. "Health care decision" also means a decision to accept or to refuse the services of a particular physician, other health care professional or health care institution, including a decision to accept or to refuse a transfer of care.

I) "Health care institution" means all institutions, facilities, and agencies licensed, certified, or otherwise authorized by the law of this State to administer health care in the ordinary course of business, including hospitals, nursing homes, residential health care facilities, and home health care agencies, except as further specified below. As used in this Act, "health care institution" also includes all hospice programs operating in this State, but does not include mental health institutions, facilities or agencies, or institutions, facilities or agencies for the developmentally disabled. The term "health care institution" shall not be construed to include "health care professionals" as defined in this Act.

J) "Health care professional" means an individual licensed by this State to administer health care in the ordinary course of business or practice of a profession. As used in this Act, the phrase "other health care professionals" refers to health care professionals other than physicians and nurses.

K) "Health care representative" means the individual designated by a declarant pursuant to the proxy directive part of an advance directive for the purpose of making health care decisions on the declarant's behalf, or to an individual designated as an alternate health care representative who is acting as the declarant's health care representative in accordance with the terms and order of priority stated in an advance directive.

L) "Instruction directive" means a writing which provides instructions and direction regarding the declarant's wishes for health care in the event of the declarant's decisionmaking incapacity.

M) "Life-sustaining treatment" means the use of any medical device or procedure, drugs, surgery or therapy that uses mechanical or other artificial means to sustain, restore or supplant a vital bodily function, and thereby to increase the expected life span of a patient.

N) "Patient" means an individual who is under the care of a physician or other health care professional.

O) "Permanently unconscious" means a medical condition that has been diagnosed in accordance with currently accepted medical standards and with reasonable medical certainty as total and irreversible loss of consciousness and capacity for interaction with the environment. The term "permanently unconscious" includes without limitation a persistent vegetative state or irreversible coma.

P) "Physician" means an individual licensed to practice medicine in this State.

Q) "State" means a state, territory, or possession of the United States, the District of Columbia, or the Commonwealth of Puerto Rico.

R) "Terminal condition" means the terminal stage of an irreversibly fatal illness, disease or condition. While a determination of a specific "life expectancy" is not required as a precondition for a diagnosis of a "terminal condition," a prognosis of a life expectancy of six months or less, with or without the provision of life-sustaining treatment, based upon reasonable medical certainty, shall be deemed to constitute a terminal condition.

Section 3: Basic Principles

This section summarizes the key operative provisions of this Act. This section is to be read in the context of the entire Act, and is not intended, and shall not be construed, to substitute for or modify the operation of the other provisions of this Act.

A) A competent adult (the declarant) may execute an advance directive for health care, in accordance with section 4 of this Act. The advance directive may include the designation of a health care representative, in accordance with section 6(B); an instruction directive, in accordance with section 6(C); or both.

B) The declarant may subsequently re-affirm or modify the advance directive, in accordance with section 5(A), or revoke the advance directive, in accordance with section 5(B). Notwithstanding any other provision of this Act, a patient's contemporaneously expressed wish that medically appropriate life-sustaining treatment and/or artificially provided fluids and nutrition necessary to sustain life be provided shall be respected, in accordance with section 11(A)(4).

C) An advance directive becomes operative when it is transmitted to the attending physician or to the health care institution, in accordance with section 7, and when the declarant is determined to lack decisionmaking capacity, in accordance with section 8.

D) Once operative, an advance directive designating a health care representative confers upon the health care representative the legal authority to participate in the decisionmaking process, in accordance with section 11, and to make health care decisions on the patient's behalf, in accordance with section 9 and the other provisions of this Act.

E) In the absence of a designated health care representative, an instruction directive, once operative, shall be respected and implemented in accordance with section 12 and the other provisions of this Act.

F) Life-sustaining treatment and/or artificially provided fluids and nutrition necessary to sustain life may be withheld or withdrawn from a patient pursuant to an advance directive in circumstances specified in sections 15 and 16, respectively. A declarant's directive to withhold or withdraw artificially provided fluids and nutrition must be explicitly stated, in accordance with sections 6 and 16. Decisions to withhold or withdraw life-sustaining treatment and/or artificially provided fluids and nutrition necessary to sustain life shall be reviewed by a qualified institutional or regional reviewing body, or by an appropriate public agency, in the particular circumstances specified by sections 15(A)(4) and 16(A)(3), respectively, and in accordance with the process provided by section 18 or by other law.

G) Health care professionals and institutions, acting in accordance with sections 10 and 13, shall make appropriate affirmative inquiry of patients, family members, and others regarding the existence of advance directives; shall seek to inform and educate their patients concerning advance directives; shall respect a patient's designation of a health care representative and a patient's instruction directive; and shall participate in good faith in the decisionmaking process set forth in section 11.

H) Health care professionals may decline to participate in the withholding or withdrawing of life-sustaining treatment and/or artificially provided fluids and nutrition necessary to sustain life, on the basis of sincerely held personal or professional convictions, in accordance with section 10. In such cases, the health care professional shall facilitate the appropriate, respectful and timely transfer of the patient's care.

I) Private religiously-affiliated health care institutions may adopt institutional policies and practices defining circumstances in which they will decline to participate in the withholding or withdrawing of life-sustaining treatment and/or artificially provided fluids and nutrition necessary to sustain life, in accordance with, and subject to the requirements established by, section 13(E).

J) Individuals and institutions, acting in good faith, and in accordance with the provisions of this Act and any rules and regulations established by the Department of Health pursuant to this Act, to carry out the terms of an advance directive, shall be immune from legal liability and from discipline for unprofessional conduct, in accordance with section 22. Those acting in willful contravention of requirements

established by or pursuant to this Act may be subject to legal liability, regulatory action, or proceedings for professional misconduct, in accordance with section 27.

Subpart A: Execution and Effectuation of Advance Directives

Section 4: Executing an Advance Directive

A) Who may execute an advance directive

A declarant may execute an advance directive for health care at any time.

B) Means of execution

1) An advance directive shall be signed and dated by or at the direction of the declarant in the presence of two subscribing adult witnesses. The witnesses shall attest that the declarant is of sound mind and free of duress or undue influence. An advance directive may be supplemented by a video or audio tape.

2) Designated health care representatives shall not act as witnesses to the execution of an advance directive.

3) An advance directive may be made self-proved at the time of execution by following the formal requirements stated in *N.J.S.A.* 3B:3-4 for making a testamentary will self-proved.

Section 5: Re-Affirming, Modifying and Revoking an Advance Directive

A) Re-Affirmation and Modification

1) A declarant may re-affirm or modify either a designation of a health care representative, or an instruction directive, or both.

2) Re-affirmation or modification shall be made in accordance with the requirements for execution of an advance directive.

B) Revocation

1) An individual, whether competent or incompetent, may revoke a prior designation of a health care representative or a prior instruction directive, or both, by the following means:

a) Notification, orally or in writing, to the health care representative, physician, or other health care professional, or other reliable witness; or

b) Destruction or attempted destruction of the document, or other act evidencing an intent to revoke the advance directive.

2) An advance directive shall also be revoked by the declarant's execution of a subsequent advance directive in accordance with section 4 of this Act.

3) Designation of the individual's spouse as health care representative shall be revoked upon divorce or legal separation, unless otherwise specified in the advance directive.

C) Re-affirmation, modification or revocation of an advance directive is effective upon communication to the health care representative, the attending physician, or other health care professional responsible for the patient's care.

Section 6: Advance Directives for Health Care

A) An advance directive may include the designation of a health care representative, or an instruction directive, or both.

B) Designation of a health care representative

1) In accordance with the requirements of section 4 of this Act, a declarant may designate one competent adult to act as his or her legally authorized health care representative.

2) Who may be designated as a health care representative

a) Any competent adult, including but not limited to an individual's spouse, adult child, parent or other family member, friend, religious or spiritual advisor, or other person of the individual's choosing, may be designated as a health care representative.

b) Restrictions

i) A declarant may not designate as a health care representative an operator, administrator or employee of a health care institution where, at the time the advance directive is executed, the declarant is a patient or resident of, or has applied for admission to, such health care institution, unless the operator, administrator or employee is related to the individual by blood, marriage or adoption.

ii) This restriction does not apply to a physician, provided that the physician shall not serve as the patient's attending physician and as the patient's health care representative at the same time.

3) Alternate designees; order of priority

A declarant may designate one or more alternate health care representatives, listed in order of priority. In the event the primary designee is unavailable, unable or unwilling to serve as health care representative, or is disqualified from such service pursuant to this section or other law, the next designated alternate shall serve as health care representative. In the event the primary designee subsequently becomes available and able to serve as health care representative, the primary designee may, insofar as then practicable, serve as health care representative.

4) The designation may direct the health care representative to consult with specified individuals (including alternate designees, family members and friends) in the course of the decisionmaking process.

5) The designation shall state the limitations, if any, to be placed upon the authority of the health care representative.

C) Instruction directives

1) A declarant may execute an instruction directive stating the declarant's general treatment philosophy and objectives; the declarant's specific wishes regarding the provision, withholding or withdrawal of any form of health care, including life-sustaining treatment; or both. An instruction directive may, but need not, be executed contemporaneously with or be attached to the designation of a health care representative.

2) A declarant intending to instruct that artificially provided fluids and nutrition should be withheld or withdrawn under certain conditions shall so indicate by an explicit statement in the instruction directive.

D) Legal validity

A duly executed advance directive for health care is legally valid in accordance with the provisions of this Act, unless revoked in accordance with section 5.

E) Advance directives: Standard forms

1) Advance directives conforming to the standard forms set forth in Appendix A to this Act shall be recognized as legally valid in form.[1]

2) An advance directive need not conform to one of these standard forms to be legally valid. A declarant
may supplement a written advance directive with a video or audio tape.

Section 7: When an Advance Directive Becomes Operative

A) An advance directive becomes operative when 1) it is transmitted to the attending physician or to the health care institution; and 2) it is determined pursuant to section 8 of this Act that the patient lacks capacity to make a particular health care decision.

B) Treatment decisions pursuant to an advance directive shall not be made and implemented until there has been an opportunity reasonable under the circumstances to establish, and where appropriate confirm, a reliable diagnosis and prognosis for the patient.

Section 8: Determination of Incapacity to Make Health Care Decisions

A) Criteria for determinations of decisionmaking incapacity

For purposes of this Act, a determination that a patient lacks decisionmaking capacity shall be based upon, but need not be limited to, evaluation of the patient's ability to understand and appreciate the nature and consequences of a particular health care decision, including the benefits and risks of, and alternatives to, the proposed health care, and to reach an informed decision.

B) Who may determine incapacity

1) Initial determination by attending physician

The attending physician shall, in the first instance, determine whether the patient lacks capacity to make a particular health care decision. The determination shall be stated in writing, shall include the attending physician's opinion concerning the nature, cause, extent, and probable duration of the patient's incapacity, and shall be made a part of the patient's medical records.

2) Confirmation of incapacity

a) The attending physician's determination of incapacity shall be confirmed by one or more qualified physicians. The opinion of the confirming physician(s) shall be stated in writing and made a part of the patient's medical records in the same manner as that of the attending physician. Confirmation of incapacity is not required where the patient's incapacity is clearly apparent, and the attending physician and the health care representative agree that confirmation is unnecessary.

b) If it is determined that a patient lacks decisionmaking capacity because of a mental or psychological impairment or a developmental disability, and neither the attending physician nor the confirming physician(s) has specialized training or experience in diagnosing mental or psychological conditions or developmental

disabilities of the same or similar nature, a determination of incapacity shall be confirmed by one or more physicians with appropriate specialized training or experience. The opinion of the confirming physician(s) shall be stated in writing and made a part of the patient's medical records in the same manner as that of the attending physician.

3) A physician designated by the patient's advance directive as a health care representative shall not make the determination of incapacity.

C) Notice of determination

1) The attending physician shall inform the patient (if the patient has any ability to comprehend that he or she has been determined to lack decisionmaking capacity) and the health care representative a) that the patient has been determined to lack capacity to make a particular health care decision; b) that each has the right to contest this determination; and c) that each may have recourse to the dispute resolution process established by the health care institution pursuant to section 14 of this Act.

2) Notice to the patient and the health care representative shall be documented in the patient's medical records.

D) Effect of determination

A determination of incapacity under this Act is solely for the purpose of implementing an advance directive in accordance with the provisions of this Act, and shall not be construed as a determination of a patient's incapacity or incompetence for any other purpose.

Subpart B: Rights and Responsibilities of the Parties

Section 9: The Rights and Responsibilities of the Health Care Representative

A) Legal authority

1) A designated health care representative shall have legal authority to make health care decisions on behalf of the patient. The health care representative shall act in good faith and within the bounds of the authority granted by an advance directive and by this Act.

2) If a different individual has been appointed as the patient's legal guardian, the health care representative shall retain legal authority to make health care decisions on the patient's behalf, unless the terms of the legal guardian's court appointment, or other court decree, provide otherwise.

3) The conferral of legal authority on the health care representative is not intended, and shall not be construed, to thereby impose liability upon the health care representative for any portion of the patient's health care costs.
4) An individual designated as a health care representative or as an alternate health care representative may decline to serve in that capacity.

B) Decisionmaking authority

1) The health care representative shall exercise the patient's right to be informed of the patient's medical condition, prognosis and treatment options, and to give informed consent to or refusal of health care.

2) In the exercise of these rights and responsibilities, the health care representative shall seek to make the health care decision the patient would have made had he or she possessed decisionmaking capacity under the circumstances, or, where the patient's wishes cannot adequately be determined, shall make a health care decision in the best interests of the patient.

C) In the exercise of these rights and responsibilities, the health care representative shall act in accordance with the decisionmaking process established by section 11 of this Act.

Section 10: The Rights and Responsibilities of Physicians and Other Health Care Professionals

In addition to any rights and responsibilities recognized or imposed by or pursuant to the other provisions of this Act, or by other law, physicians, nurses, and other health care professionals shall have the following rights and responsibilities:

A) Physicians

1) The attending physician shall make an affirmative inquiry of the patient, family or others, as appropriate under the circumstances, concerning the existence of an advance directive. The attending physician shall note in the patient's medical records whether or not an advance directive exists, and the name of the patient's health care representative, if any, and shall attach a copy of the advance directive to the patient's medical records. The attending physician shall document in the same manner the re-affirmation, modification, or revocation of an advance directive, if he or she has knowledge of such action.

2) The attending physician shall act in accordance with the decisionmaking process established by section 11 of this Act.

3) Professional conscience

A physician may decline to participate in the withholding or withdrawing of life-sustaining treatment and/or artificially provided fluids and nutrition necessary to sustain life, in accordance with his or her sincerely held personal or professional convictions. In such circumstances, the physician shall act in good faith to inform the patient and the health care representative, and the chief of the medical staff or other designated institutional official, of this decision as soon as practicable, and to effect appropriate, respectful and timely transfers of care, and to assure that patients are not abandoned or treated disrespectfully.

4) In the event of transfer of a patient's care, the attending physician shall assure the timely transfer of the patient's medical records, including a copy of the patient's advance directive.

B) Nurses and other health care professionals: Professional conscience

Nurses and other health care professionals may decline to participate in the withholding or withdrawing of life-sustaining treatment and/or artificially provided fluids and nutrition necessary to sustain life, in accordance with their sincerely held personal or professional convictions. In such circumstances, nurses and other health care professionals shall act in good faith to inform the patient and the health care representative, and the head of the nursing or other professional staff or other designated institutional official, of this decision as soon as practicable, to cooperate in effecting appropriate, respectful and timely transfers of care, and to assure that patients are not abandoned or treated disrespectfully.

C) Nothing in this Act shall be construed to require physicians, nurses or other health care professionals to begin, continue, withhold, or withdraw health care in a manner contrary to law or accepted professional standards.

Section 11: The Decisionmaking Process

A) The health care representative and the attending physician

1) The health care representative and the attending physician, and where appropriate any additional physician(s) responsible for the patient's care, shall discuss the nature and consequences of the patient's medical condition, and the risks, benefits and burdens of the proposed health care and its alternatives. Except as provided by section 11(A)(4) below, the attending physician shall obtain informed consent to or refusal of health care from the health care representative.

2) Discussion of the proposed treatment and its alternatives shall include, as appropriate under the circumstances, the availability, benefits and burdens of rehabilitative treatment, therapy, and services.

3) The decisionmaking process shall allow, as appropriate under the circumstances, adequate time for the health care representative to understand and deliberate about all relevant information before a treatment decision is implemented.

4) The patient with impaired decisionmaking capacity

a) Following a determination that the patient's decisionmaking capacity is impaired, the health care representative and the attending physician shall, to the extent reasonable, discuss the treatment options with the patient, and seek to involve the patient as a participant in the decisionmaking process. The health care representative and the attending physician shall seek to promote the patient's capacity for effective participation and shall take the patient's expressed wishes into account in the decisionmaking process.

b) Once decisionmaking authority has been conferred upon a health care representative pursuant to an advance directive, if the patient is found to possess adequate decisionmaking capacity with respect to a particular health care decision, the patient shall retain legal authority to make that decision. In such circumstances, the health care representative may continue to participate in the decisionmaking process in an advisory capacity, unless the patient objects.

c) Notwithstanding any other provision of this Act, if a patient with impaired capacity clearly expresses or manifests the contemporaneous wish that medically appropriate life-sustaining treatment and/or artificially provided fluids and nutrition necessary to sustain life be provided, that wish shall take precedence over any contrary decision of the health care representative and any contrary statement in the patient's instruction directive.

B) The health care representative

1) Determining the patient's wishes

In acting to implement a patient's wishes pursuant to an advance directive, the health care representative shall give priority to the patient's instruction directive, and may also consider, as appropriate and necessary, the following forms of evidence of the patient's wishes:

a) Reliable oral or written statements previously made by the patient, including but not limited to statements made to family members, friends, health care professionals or religious leaders;

b) Other reliable sources of information, including the health care representative's personal knowledge of the patient's values, preferences and goals; and

c) The patient's contemporaneous expressions, including non-verbal expressions.

2) Effect of instruction directives

a) An instruction directive shall provide direction to the health care representative, in accordance with its terms.

b) If the instruction directive, in conjunction with other evidence of the patient's wishes, does not provide, in the exercise of reasonable judgment, clear direction as applied to the patient's medical condition and the treatment alternatives, the health care representative shall exercise reasonable discretion, in good faith, to effectuate the terms, intent, and spirit of the instruction directive and other evidence of the patient's wishes.

3) Inadequate evidence of the patient's wishes

Subject to the provisions of this Act, and unless otherwise stated in an advance directive, if the patient's wishes cannot be adequately determined, then the health care representative shall make a health care decision in the patient's best interests.

Section 12: Instruction Directives in the Absence of a Designated Health Care Representative

A) If the patient has executed an instruction directive but has not designated a health care representative, or if neither the designated health care representative nor any alternate designee is able or available to serve, an instruction directive shall be legally operative. If the instruction directive provides clear and unambiguous guidance under the circumstances, it shall be honored in accordance with its specific terms by a legally appointed guardian (if any), family members, physicians, other health care professionals, health care institutions, and others acting on the patient's behalf.

B) If the instruction directive is, in the exercise of reasonable judgment, not specific to the patient's medical condition and the treatment alternatives, the attending physician, in consultation with a legally appointed guardian (if any), family members, or others acting on the patient's behalf, shall exercise reasonable judgment to effectuate the wishes of the patient, giving full weight to the terms, intent, and spirit of the instruction directive. Departure from the specific terms and provisions of the instruction directive shall be based upon clearly articulable factors not foreseen or contemplated by the instruction directive, including but not limited to the circumstances of the patient's medical condition.

C) Nothing in this Act is intended, or shall be construed, to impair the legal force and effect of instruction directives executed prior to the effective date of this Act.

Section 13: The Rights and Responsibilities of Health Care Institutions

In addition to any rights and responsibilities recognized or imposed by or pursuant to the other provisions of this Act, or by other law, health care institutions shall have the following rights and responsibilities:

A) Routine inquiry

Health care institutions shall adopt such policies and practices as are necessary to provide for routine inquiry, at the time of admission and at such other times as are appropriate under the circumstances, concerning the existence and location of an advance directive.[1]

B) Education

1) Patients, health care representatives and families

a) Health care institutions shall adopt such policies and practices as are necessary to provide appropriate informational materials concerning advance directives to all interested patients, families and health care representatives, and to assist patients interested in discussing and executing an advance directive.[1]

b) Health care institutions shall adopt such policies and practices as are necessary to educate patients, health care representatives, and families about the availability, benefits and burdens of rehabilitative treatment, therapy and services, including but not limited to, family and social services, self-help and advocacy services, employment and community living, and use of assistive devices. Health care institutions shall, in consultation with the attending physician, assure that such information is discussed with patients and health care representatives and made a part of the decisionmaking process, as appropriate under the circumstances.

2) Physicians, nurses and other health care professionals

Health care institutions shall adopt such policies and practices as are necessary to inform physicians, nurses and other health care professionals of their rights and responsibilities under this Act, to assure that such rights and responsibilities are understood, and to provide a forum for discussion and consultation regarding the requirements of this Act.[1]

C) Transfers of care

Where transfers of care are necessary, including transfers for the purpose of effectuating the patient's wishes regarding the withholding or withdrawing of life-sustaining treatment and/or artificially provided fluids and nutrition necessary to sustain life, health care

institutions shall, in consultation with the attending physician, take all reasonable steps to effect the appropriate, respectful and timely transfer of patients to the care of alternative health care professionals or institutions, as necessary, and shall assure that patients are not abandoned or treated disrespectfully. In such circumstances, health care institutions shall assure the timely transfer of the patient's medical records, including a copy of the patient's advance directive.

D) Dispute resolution

Health care institutions shall establish procedures and practices for dispute resolution, in accordance with section 14 of this Act.

E) Private religiously-affiliated health care institutions: Institutional conscience

1) Private religiously-affiliated health care institutions may develop institutional policies and practices defining circumstances in which they will decline to participate in the withholding or withdrawing of specified life-sustaining treatments and/or artificially provided fluids and nutrition necessary to sustain life. Such policies and practices shall be written, and shall be properly communicated to patients, families and health care representatives prior to or upon the patient's admission, or as soon after admission as is practicable.

2) If such institutional policies and practices appear to conflict with the legal rights of a patient wishing to forego health care, the health care institution shall attempt to resolve such a conflict, and if mutually satisfactory accommodation cannot be reached, shall take all reasonable steps to effect the appropriate, timely and respectful transfer of the patient to the care of another health care institution appropriate to the patient's needs, and shall assure that the patient is not abandoned or treated disrespectfully.

F) Nothing in this Act shall be construed to require health care institutions to participate in the beginning, continuing, withholding or withdrawing of health care in a manner contrary to law or accepted medical standards.

Section 14: Dispute Resolution

A) In the event of disagreement among the patient, health care representative, and attending physician concerning the patient's decisionmaking capacity or the appropriate interpretation and application of the terms of an advance directive to the patient's course of treatment, the parties shall seek to resolve such disagreement by resort to procedures and practices established within the health care institution, including but not limited to consultation with an institutional ethics committee, or with a person or persons designated by the health care institution for this purpose.

B) Health care professionals involved in the patient's care, other than the attending physician, and administrators of a health care institution may also invoke the dispute resolution process established by the health care institution to seek to resolve disagreement concerning the patient's decisionmaking capacity or the appropriate interpretation and application of the terms of an advance directive.

C) If disagreement cannot be reconciled through an institutional dispute resolution process, resolution in a court of appropriate jurisdiction may be sought.

Subpart C: Scope and Limitations Regarding Life-Sustaining Measures

Section 15: Decisions to Forego Life-Sustaining Treatment

A) Consistent with the terms of an advance directive and the provisions of this Act, life-sustaining treatment, other than artificially provided fluids and nutrition necessary to sustain life, may be withheld or withdrawn from a patient in the following circumstances:

1) When the life-sustaining treatment is experimental and not a proven therapy, or is likely to be ineffective or futile in prolonging life, or is likely merely to prolong an imminent dying process; or

2) When the patient is permanently unconscious, as determined by the attending physician and confirmed by a second qualified physician; or

3) When the patient is in a terminal condition, as determined by the attending physician and confirmed by a second qualified physician; or

4) In the event none of the above circumstances applies, when the patient has a serious irreversible illness or condition, and the likely risks and burdens associated with the medical intervention to be withheld or withdrawn may reasonably be judged to outweigh the likely benefits to the patient from such intervention, and imposition of the medical intervention on an unwilling patient would be inhumane. In such cases, prior to implementing a decision to withhold or withdraw life-sustaining treatment, the attending physician shall seek prompt consultation with a qualified institutional or regional reviewing body in accordance with section 18 of this Act, or shall promptly seek approval of a public agency recognized by law for this purpose.

B) Nothing in this section is intended, or shall be construed, to impair the obligations of physicians, nurses and other health care professionals to provide for the care and comfort of the patient and to alleviate pain, in accordance with accepted medical and nursing standards.

C) Nothing in this section is intended, or shall be construed, to abridge any Constitutionally-protected right to refuse treatment, based upon the free exercise of religion or the right of privacy, under either the United States Constitution or the Constitution of the State of New Jersey.

Section 16: Decisions to Forego Artificially Provided Fluids and Nutrition

A) Consistent with the explicit terms of an advance directive and the provisions of this Act, artificially provided fluids and nutrition necessary to sustain life may be withheld or withdrawn from a patient in the following circumstances:

1) When the artificial provision of fluids and nutrition is likely to be ineffective or futile in prolonging life, or is likely merely to prolong an imminent dying process; or

2) When the patient is permanently unconscious, as determined by the attending physician and confirmed by a second qualified physician; or

3) When the patient is in a terminal condition, as determined by the attending physician and confirmed by a second qualified physician, and the likely risks and burdens associated with the least burdensome treatment modality likely to be effective may reasonably be judged to outweigh the likely benefits to the patient from such intervention, and imposition of the intervention on an unwilling patient would be inhumane. In such cases, prior to implementing a decision to withhold or withdraw artificially provided fluids and nutrition, the attending physician shall seek prompt consultation with a qualified institutional or regional reviewing body in accordance with section 18 of this Act, or shall promptly seek approval of a public agency recognized by law for this purpose.

B) This Act does not provide authorization for the health care representative, or any other individual acting pursuant to this Act, to direct or implement the withholding or withdrawal of artificially provided fluids and nutrition necessary to sustain life in the absence of explicit instructions to that effect in the patient's advance directive.

C) Nothing in this section is intended, or shall be construed, to impair the obligations of physicians, nurses and other health care professionals to provide for the care and comfort of the patient and to alleviate pain, in accordance with accepted medical and nursing standards.

D) Nothing in this section is intended, or shall be construed, to abridge any Constitutionally-protected right to refuse treatment, based upon the free exercise of religion or the right of privacy, under either the United States Constitution or the Constitution of the State of New Jersey.

Section 17: Do Not Resuscitate Orders

A) Consistent with the terms of an advance directive and the provisions of this Act, the attending physician may issue a do not resuscitate order.

B) Nothing in this Act is intended, or shall be construed, to impair any existing legal authority to issue a do not
resuscitate order where the patient has not executed an advance directive.

C) A do not resuscitate order must be entered in writing in the patient's medical records prior to implementation of the order.

Section 18: Institutional and Regional Reviewing Bodies

A) Advisory role

1) An institutional or regional reviewing body which engages in prospective case consultation pursuant to sections 15(A)(4) and 16(A)(3) shall advise the attending physician, patient and health care representative whether it believes that the withholding or withdrawal of the medical intervention under consideration would be in conformity with the requirements of this Act, including without limitation a) whether such action would be within the scope of the patient's advance directive; and b) whether it may reasonably be judged that the likely risks and burdens associated with the medical intervention to be withheld or withdrawn outweigh its likely benefits, and whether it may reasonably be judged that imposition of the medical intervention on an unwilling patient would be inhumane. The attending physician, patient and health care representative shall also be advised of any other course of diagnosis or treatment recommended for consideration.

2) The advice of the institutional or regional reviewing body shall be documented in the patient's medical records.

B) Following advice: immunity

1) A health care representative who follows and implements in good faith the advice of an institutional or regional reviewing body acting in accordance with section 18(A) of this Act shall not be subject to criminal or civil liability for such actions.

2) A physician, nurse or other health care professional who follows and implements in good faith, and in accordance with accepted professional standards, the advice of an institutional or regional reviewing body acting in accordance with section 18(A) of this Act shall not be subject to criminal or civil liability or to discipline for unprofessional conduct for such actions.

C) Advice not legally binding

The advice of an institutional or regional reviewing body acting in accordance with section 18(A) of this Act is not legally binding. A health care representative, physician, nurse, or other health care professional who believes the advice should not be followed may choose to:

1) Pursue an alternative course of treatment for the patient. In such cases, no immunity is conferred upon such actions by this Act, and such individuals are subject to existing norms of civil and criminal law and professional conduct; or

2) Seek review by a public agency recognized by law for this purpose; or

3) Seek review by a court of appropriate jurisdiction.

D) Nothing in this section shall preclude transfer of the patient to another appropriate health care professional or health care institution. In such cases the health care institution responsible for the patient's care shall assure that the health care professional or health care institution to which the patient is transferred is properly informed of the advice given by the institutional or regional reviewing body.

E) Accreditation

An institutional or regional reviewing body acting in accordance with section 18(A) of this Act shall conform to standards established by law and shall be subject to periodic accreditation and review under procedures established by law.[2]

Subpart D: Implementation and Legal Consequences

Section 19: Health Care Institutions Governed by This Act; Inapplicability to Providers of Emergency Care

A) Health care institutions subject to this Act

1) The provisions of this Act apply to all health care institutions as defined in section 2(I) of this Act.

2) Nothing in this Act is intended, or shall be construed, to alter, amend or revoke the rights and responsibilities under existing law of health care institutions not governed by the provisions of this Act.

3) Nothing in this Act is intended, or shall be construed, to preclude mental health institutions, facilities or agencies, or institutions, facilities or agencies for the developmentally disabled, from respecting an advance directive for health care executed by a patient or resident pursuant to this Act.

B) Providers of emergency care; exemption

The provisions of this Act shall not be construed to require emergency personnel, including paid or volunteer fire fighters; paramedics; members of an ambulance team, rescue squad, or mobile intensive care unit; or emergency room personnel of a licensed health care institution, to withhold or withdraw emergency care in circumstances which do not afford reasonable opportunity for careful review and evaluation of an advance directive without endangering the life of the patient.

Section 20: Implementation of Advance Directives

In accordance with the "Administrative Procedure Act," *N.J.S.A.* 52:14B-1 *et seq.*, the State Department of Health may establish rules and regulations necessary to oversee and assure compliance with this Act. Such rules and regulations may require health care institutions to adopt policies and practices designed to

A) make routine inquiry, at the time of admission and at such other times as are appropriate under the circumstances, concerning the existence and location of an advance directive;

B) provide appropriate informational materials concerning advance directives to all interested patients, families and health care representatives, and to assist patients interested in discussing and executing an advance directive;

C) educate patients, health care representatives, and families about the availability, benefits and burdens of rehabilitative treatment, therapy and services, as appropriate;

D) inform physicians, nurses, and other health care professionals of their rights and responsibilities under this Act, to assure that such rights and responsibilities are understood, and to provide a forum for discussion and consultation regarding the requirements of this Act; and

E) otherwise comply with the provisions of this Act.

Section 21: Reporting and Monitoring

A) In accordance with the "Administrative Procedure Act," *N.J.S.A.* 52:14B-1 *et seq.*, the State Department of Health shall establish such rules, regulations, policies and practices as may be necessary to collect annual reports from health care institutions, and to gather such additional data as is reasonably necessary, to oversee and evaluate the implementation of this Act. The Department of Health shall seek to minimize the burdens of record-keeping imposed by such rules, regulations, policies

and practices, and shall seek to assure the appropriate confidentiality of patient records.

B) The State Department of Health and the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care shall jointly evaluate the implementation of this Act and report to the State Legislature, including recommendations for any changes deemed necessary, after a period of not more than five years from the effective date of this Act.

Section 22: Immunities

A) A health care representative acting in good faith and in accordance with the provisions of this Act to carry out the terms of an advance directive shall not be subject to criminal or civil liability for such actions.

B) A health care professional or health care institution acting in good faith and in accordance with the provisions of this Act, any rules and regulations established by the Department of Health pursuant to this Act, and accepted professional standards, to carry out the terms of an advance directive shall not be subject to criminal or civil liability or to discipline for unprofessional conduct.

Section 23: Presumptions

The absence of an advance directive shall create no presumption with respect to a patient's wishes regarding the provision, withholding or withdrawing of any form of health care. This Act does not apply to persons who have not executed an advance directive.

Section 24: Effect on Insurance

The execution of an advance directive pursuant to this Act shall not in any manner affect, impair or modify the terms of, or rights or obligations created under, any existing policy of health insurance, life insurance or annuity, or governmental benefits program. No health care practitioner or other health care provider, and no health service plan, insurer, or governmental authority, shall deny coverage or exclude from the benefits of service any individual because that individual has executed or has not executed an advance directive. The execution (or non-execution) of an advance directive shall not be made a condition of coverage under any policy of health insurance, life insurance or annuity, or governmental benefits program.

Section 25: Recognition of Advance Directives Executed in Other States or Countries

An advance directive executed under the laws of another state in compliance with the laws of that state or the State of New Jersey is validly executed for purposes of this Act. An advance directive executed under the laws of a foreign country in compliance with the laws of that country or the State of New Jersey, and not contrary to the public policy of this State, is validly executed for purposes of this Act.

Section 26: Effect on Other Laws

A) Homicide and suicide

The withholding or withdrawing of life-sustaining treatment pursuant to section 15 of this Act or of artificially provided fluids and nutrition necessary to sustain life pursuant to section 16 of this Act, when performed in good faith, and in accordance with the terms of an advance directive and the provisions of this Act, shall not constitute homicide, suicide, assisted suicide, or active euthanasia.

B) "Powers of Attorney," *N.J.S.A.* 46:2B

1) To the extent any of the provisions of this Act are inconsistent with *N.J.S.A.* 46:2B concerning the designation of a health care representative, the provisions of this Act shall have priority.

2) Durable powers of attorney for health care executed pursuant to *N.J.S.A.* 46:2B prior to the effective date
of this Act shall have the same legal force and effect as if they had been executed in accordance with the provisions of this Act.

C) "Ombudsman for the Institutionalized Elderly," *N.J.S.A.* 52:27G-1, *et seq.*

The Office of the Ombudsman for the Institutionalized Elderly shall adopt policies and practices necessary to comply with the requirements of this Act, and shall make a written statement of its obligations under this Act available to the public.

D) "Public Guardian for Elderly Adults," *N.J.S.A.* 52:27G-20, *et seq.*

The Office of the Public Guardian for Elderly Adults shall adopt policies and practices necessary to comply with the requirements of this Act, and shall make a written statement of its obligations under this Act available to the public.

E) Emancipated Minors

Nothing in this Act is intended, or shall be construed, to impair the rights of emancipated minors under existing law.

Section 27: Penalties

A) Willful failure to follow this Act

1) Willful failure by a health care professional to act in accordance with practices and procedures established by this Act shall constitute professional misconduct.

2) Willful failure by a health care institution to act in accordance with practices and procedures established by this Act shall be subject to a fine of not more than $1000.00 per instance. Penalties for violations of this Act shall be recovered in a summary civil proceeding, brought in the name of the State in the Superior Court pursuant to the Penalty Enforcement Law (*N.J.S.A.* 2A:58-1 *et seq.*).

B) The following acts constitute crimes:[3]

1) To willfully conceal, cancel, deface, obliterate or withhold personal knowledge of an advance directive or a modification or revocation thereof, without the declarant's consent, is a crime of the [_____] degree.

2) To falsify or forge an advance directive or a modification or revocation thereof of another individual is a crime of the [_____] degree.

3) To coerce or fraudulently induce the execution of an advance directive or a modification or revocation thereof is a crime of the [_____] degree.

4) To require or prohibit the execution of an advance directive or a modification or revocation thereof as a condition of coverage under any policy of health insurance, life insurance or annuity, or governmental benefits program, or as a condition of the provision of health care is a crime of the [_____] degree.

C) The sanctions provided in this section shall not be construed to repeal any sanctions applicable under other law.

Section 28: Severability

If any provision of this Act or its application to any individual or circumstance is held invalid, the invalidity shall not affect other provisions or applications of this Act which

can be given effect without the invalid provision or application, and to this end the provisions of this Act are severable.

Section 29: Short Title

This Act may be cited as the New Jersey Advance Directives for Health Care Act.

EFFECTIVE DATE: This Act shall take effect 180 days from its enactment.

Notes

1. The Task Force on Public and Professional Education of the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care shall develop:

1) Standard forms for advance directives (Section 6(E)), to be attached as an Appendix to this Act;

2) Recommended guidelines for institutional policies and practices regarding routine inquiry (Section 13(A));

3) Recommended guidelines for institutional policies and practices regarding education of patients, families and health care representatives (Section 13(B)(1)); and

4) Recommended guidelines for institutional policies and practices regarding professional education (Section 13(B)(2)).

2. The New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care and its Task Force on Institutional Ethics Committees shall develop a statutory proposal setting forth standards and procedures for accreditation of institutional and regional reviewing bodies (Section 18(E)).

3. The appropriate severity of crime and penalty for each of the acts identified in this section is a matter for legislative determination on which the Commission possesses no special expertise.

DURABLE POWER OF ATTORNEY FOR HEALTH CARE

(Designation of Health Care Representative)

I understand that as a competent adult, I have the right to make decisions about my health care. There may come a time when I am unable, due to physical or mental incapacity, to make my own health care decisions. In these circumstances, those caring for me will need direction and they will turn to someone who knows my values and health care wishes. By writing this durable power of attorney for health care I appoint a health care representative with the legal authority to make health care decisions on my behalf and to consult with my physician and others. I direct that this document become part of my permanent medical records.

A) I,_____, hereby designate_____,
of_____
_____,
(home address and telephone number of health care representative)

as my health care representative to make any and all health care decisions for me, including decisions to accept or to refuse any treatment, service or procedure used to diagnose or treat my physical or mental condition and decisions to provide, withhold or withdraw life-sustaining measures. I direct my representative to make decisions on my behalf in accordance with my wishes as stated in this document, or as otherwise known to him or her. In the event my wishes are not clear, my representative is authorized to make decisions in my best interests, based on what is known of my wishes.

This durable power of attorney for health care shall take effect in the event I become unable to make my own health care decisions, as determined by the physician who has primary responsibility for my care, and any necessary confirming determinations.

B) If the person I have designated above is unable, unwilling or unavailable to act as my health care representative, I hereby designate the following person(s) to act as my health care representative, in the order of priority stated:

1. *name*_____
   *address*_____
   *city*_____ *state*_____
   *telephone*_____

2. *name*_____
   *address*_____
   *city*_____ *state*_____
   *telephone*_____

C) Specific Directions: **Please initial the statement below which best expresses your wishes.**

____My health care representative is authorized to direct that artificially provided fluids and nutrition, such as by feeding tube or intravenous infusion, be withheld or withdrawn.

____My health care representative does not have this authority, and I direct that artificially provided fluids and nutrition be provided to preserve my life, to the extent medically appropriate.

(If you have any additional specific instructions concerning your care you may use the space below or attach an additional statement.)

_____
_____
_____
_____

D) The original or a copy of this document has been given to my health care representative and to the following:

*1. name*_____
*address*_____
*city*_____ *state*_____ *telephone*_____

*2. name*_____
*address*_____
*city*_____ *state*_____ *telephone*_____

E) By writing this durable power of attorney for health care, I inform those who may become entrusted with my care of my health care wishes and intend to ease the burdens of decisionmaking which this responsibility may impose. I have discussed the terms of this designation with my health care representative and he or she has willingly agreed to accept the responsibility for acting on my behalf in accordance with my wishes as expressed in this document. I understand the purpose and effect of this document and sign it knowingly, voluntarily and after careful deliberation.

Signed this ____ day of _____, 19___.

*signature*_____
*address*_____
*city*_____ *state*_____

F) I declare that the person who signed this document, or asked another to sign this document on his or her behalf, did so in my presence, that he or she is personally known to me, and that he or she appears to be of sound mind and free of duress or undue influence. I am 18 years of age or older, and am not designated by this or any other document as the person's health care representative, nor as an alternate health care representative.

1. *witness*_____
*address*_____
*city*_____ *state*_____
*signature*_____ *date*_____

2. *witness*_____
*address*_____
*city*_____ *state*_____
*signature*_____ *date*_____

New Jersey Commission on Legal and Ethical Problems
in the Delivery of Health Care
(The New Jersey Bioethics Commission)
May 1990

ADVANCE DIRECTIVE FOR HEALTH CARE

[Combined Durable Power of Attorney for Health Care and Instruction Directive]

I understand that as a competent adult I have the right to make decisions about my health care. There may come a time when I am unable, due to physical or mental incapacity, to make my own health care decisions. In these circumstances, those caring for me will need direction concerning my care and will turn to someone who knows my values and health care wishes. I understand that those responsible for my care will seek to make health care decisions in my best interests, based upon what they know of my wishes. In order to provide the guidance and authority needed to make decisions on my behalf:

I,_____hereby declare and make known my instructions and wishes for my future health care. This advance directive for health care shall take effect in the event I become unable to make my own health care decisions, as determined by the physician who has primary responsibility for my care, and any necessary confirming determinations. I direct that this document become part of my permanent medical records.

In completing Part One of this directive, you will designate an individual you trust to act as your legally recognized health care representative to make health care decisions for you in the event you are unable to make decisions for yourself.

In completing Part Two of this directive, you will provide instructions concerning your health care preferences and wishes to your health care representative and others who will be entrusted with responsibility for your care, such as your physician, family members and friends.

Part One: Designation of a Health Care Representative

A) I hereby designate:

*name*_____
*address*_____
*city*_____*state*_____ *telephone*_____

as my health care representative to make any and all health care decisions for me, including decisions to accept or to refuse any treatment, service or procedure used to diagnose or treat my physical or mental condition, and decisions to provide, withhold or withdraw life-sustaining measures. I direct my representative to make decisions on my behalf in accordance with my wishes as stated in this document, or as otherwise known to him or her. In the event my wishes are not clear, or a situation arises I did not anticipate, my health care representative is authorized to make decisions in my best interests, based upon what is known of my wishes.

I have discussed the terms of this designation with my health care representative and he or she has willingly agreed to accept the responsibility for acting on my behalf.

next page please

(B) If the person I have designated above is unable, unwilling or unavailable to act as my health care representative, I hereby designate the following person(s) to act as my health care representative, in the order of priority stated:

1. *name*_____
   *address*_____
   *city*_____ *state*_____
   *telephone*_____

2. *name*_____
   *address*_____
   *city*_____ *state*_____
   *telephone*_____

Part Two: Instruction Directive

In Part Two, you are asked to provide instructions concerning your future health care. This will require making important and perhaps difficult choices. Before completing your directive, you should discuss these matters with your health care representative, doctor, family members or others who may become responsible for your care.

In Section C, *you may state the circumstances in which various forms of medical treatment, including life-sustaining measures, should be provided, withheld or discontinued. If the options and choices below do not fully express your wishes, you should use* Section E, *and/or attach a statement to this document which would provide those responsible for your care with additional information you think would help them in making decisions about your medical treatment.*

Please familiarize yourself with all sections of Part Two before completing your directive.

C) To inform those responsible for my care of my specific wishes, I make the following statement of personal views regarding my health care:

Initial one of the following two statements with which you agree:

1.____ I direct that all medically appropriate measures be provided to sustain my life, regardless of my physical or mental condition.

2.____ There are circumstances in which I would not want my life to be prolonged by further medical treatment. In these circumstances, life-sustaining measures should not be initiated and if they have been, they should be discontinued. I recognize that this is likely to hasten my death. In the following, I specify the circumstances in which I would choose to forego life-sustaining measures.

If you have initialed statement 2, also initial each of the following statements with which you agree:

a.____ I realize that there may come a time when I am diagnosed as having an incurable and irreversible illness, disease, or condition. If this occurs, and my attending physician and at least one additional physician who has personally examined me determine that my condition is terminal, I direct that life-sustaining measures which would serve only to artificially prolong my dying be withheld or discontinued. I also direct that I be given all medically appropriate care necessary to make me comfortable and to relieve pain.

In the space provided, write in the bracketed phrase with which you agree:

To me, terminal condition means that my physicians have determined that:

_____.

[I will die within a few days] [I will die within a few weeks]
[I have a life expectancy of approximately_____or less *(enter 6 months, or 1 year)*]

b.____ If there should come a time when I become permanently unconscious, and it is determined by my attending physician and at least one additional physician with appropriate expertise who has personally examined me, that I have totally and irreversibly lost consciousness and my capacity for interaction with other people and my surroundings, I direct that life-sustaining measures be withheld or discontinued. I understand that I will not experience pain or discomfort in this condition, and I direct that I be given all medically appropriate care necessary to provide for my personal hygiene and dignity.

c.___ I realize that there may come a time when I am diagnosed as having an incurable and irreversible illness, disease, or condition which may not be terminal. My condition may cause me to experience severe and progressive physical or mental deterioration and/or a permanent loss of capacities and faculties I value highly. If, in the course of my medical care, the burdens of continued life with treatment become greater than the benefits I experience, I direct that life-sustaining measures be withheld or discontinued. I also direct that I be given all medically appropriate care necessary to make me comfortable and to relieve pain.

(Paragraph c. covers a wide range of possible situations in which you may have experienced partial or complete loss of certain mental and physical capacities you value highly. In the space provided below, you may want to specify in more detail the conditions in which you would choose to forego life-sustaining measures. You might include a description of the faculties or capacities, which, if irretrievably lost, would lead you to accept death rather than continue living. You may want to express any special concerns you have about particular medical conditions or treatments, or any other considerations which would provide further guidance to those who may become responsible for your care. Please use the space provided. If necessary, you may attach a separate statement to this document or use Section E to provide additional instructions.)

Examples of conditions which I find unacceptable are:

_____
_____
_____
_____

D) Specific Instructions: Artificially Provided Fluids and Nutrition; Cardiopulmonary Resuscitation (CPR). *In this section, you are asked to indicate your treatment preferences as they pertain to two specific types of life-sustaining measures.*

In the space provided, write in the bracketed phrase with which you agree:

1. In the circumstances initialed above in Section C, I direct that artificially provided fluids and nutrition, such as by feeding tube or intravenous infusion, _____.
[be withheld or withdrawn and that I be allowed to die] [be provided to the extent medically appropriate]

2. In the circumstances initialed above in Section C, if I should suffer a cardiac arrest, I direct that cardiopulmonary resuscitation (CPR) _____.
[not be provided and that I be allowed to die]
[be provided to preserve my life, unless medically inappropriate or futile]

3. If neither of the above statements adequately expresses your wishes concerning artificially provided fluids and nutrition or CPR, please explain your wishes below.

_____
_____
_____

E) Additional Instructions: *(You should provide any additional information about your health care preferences which is important to you and which may help those concerned with your care to implement your wishes. You may wish to direct your health care representative, family members, or your health care providers to consult with others, or you may wish to direct that your care be provided by a particular physician, hospital, nursing home, or at home. If you are or believe you may become pregnant, you may wish to state specific instructions. If you need more space than is provided here you may attach an additional statement to this directive.)*

_____
_____
_____
_____
_____

F) Brain Death: *(The State of New Jersey recognizes the irreversible cessation of all functions of the entire brain, including the brain stem (also known as whole brain death), as a legal standard for the declaration of death. However, individuals who cannot accept this standard because of their personal religious beliefs or moral convictions may request that it not be applied in determining their death.)*

Initial the following statement only if it applies to you:

____ To declare my death on the basis of the whole brain death standard would violate my personal religious beliefs or moral convictions. I therefore wish my death to be declared solely on the basis of the traditional criteria of irreversible cessation of cardio-respiratory (heart and lung) function.

G) **After Death: Anatomical Gifts** *(It is now possible to transplant human organs and tissue in order to save and improve the lives of others. Organs, tissues and other body parts are also used for therapy, medical research and education. This section allows you to indicate your desire to make an anatomical gift and if so, to provide instructions for any limitations or special uses.)*

Initial the statements which express your wishes

1. _____ I wish to make the following anatomical gift to take effect upon my death:

   A. ____ any needed organs or body parts
   B. ____ only the following organs or parts
   _____,

for the purposes of transplantation, therapy, medical research or education, or

   C. _____ my body for anatomical study, if needed.
   D._____ special limitations, if any:
   _____.

If you wish to provide additional instructions, such as indicating your preference that your organs be given to a specific person or institution, or be used for a specific purpose, please do so in the space provided below.

_____
_____
_____

2. ____ I do not wish to make an anatomical gift upon my death.

Part Three: Signature and Witnesses

H) The original or a copy of this document has been given to the following people *(NOTE: If you have chosen to designate a health care representative, it is important that you provide him or her with a copy of your directive.)*:

1. *name*_____
   *address*_____
   city _____*state*_____*telephone*_____

2. *name*_____
   *address*_____
   city _____*state*_____*telephone*_____

I) By writing this advance directive, I inform those who may become entrusted with my health care of my wishes and intend to ease the burdens of decisionmaking which this responsibility may impose. I have discussed the terms of this designation with my health care representative and he or she has willingly agreed to accept the responsibility for acting on my behalf in accordance with this directive. I understand the purpose and effect of this document and sign it knowingly, voluntarily and after careful deliberation.

Signed this _____day of_____, 19____.

*signature*_____
*address*_____
*city*_____*state*_____

J) I declare that the person who signed this document, or asked another to sign this document on his or her behalf, did so in my presence, that he or she is personally known to me, and that he or she appears to be of sound mind and free of duress or undue influence. I am 18 years of age or older, and am not designated by this or any other document as the person's health care representative, nor as an alternate health care representative.

1. *witness*_____
   *address*_____
   *city*_____*state*_____
   *signature*_____
   *date*_____

2. *witness*_____
   *address*_____
   *city*_____*state*_____
   *signature*_____
   *date*_____

New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care (The New Jersey Bioethics Commission) May 1990

INSTRUCTION DIRECTIVE

I understand that as a competent adult I have the right to make decisions about my health care. There may come a time when I am unable, due to physical or mental incapacity, to make my own health care decisions. In these circumstances, those caring for me will need direction concerning my care and they will require information about my values and health care wishes. In order to provide the guidance and authority needed to make decisions on my behalf:

A) I,_____, hereby declare and make known to my family, physician, and others, my instructions and wishes for my future health care. I direct that all health care decisions, including decisions to accept or refuse any treatment, service or procedure used to diagnose, treat or care for my physical or mental condition and decisions to provide, withhold or withdraw life-sustaining measures, be made in accordance with my wishes as expressed in this document. This instruction directive shall take effect in the event I become unable to make my own health care decisions, as determined by the physician who has primary responsibility for my care, and any necessary confirming determinations as may be required by law. I direct that this document become part of my permanent medical records.

Part One: Statement of Wishes Concerning My Future Health Care

In this document, you are asked to provide instructions concerning your future health care. This will require making important and perhaps difficult choices. Before completing your directive, you should discuss these matters with your doctor, family members or others who may become responsible for your care.

In Section B, *you may state the circumstances in which various forms of medical treatment, including life-sustaining measures, should be provided, withheld or discontinued. If the options and choices below do not fully express your wishes, you should use* Section D, *and/or attach a statement to this document which would provide those responsible for your care with additional information you think would help them in making decisions about your medical treatment.*

Please familiarize yourself with all sections before completing your directive.

B) To inform those responsible for my care of my specific wishes, I make the following statement of personal views regarding my health care:

Initial one of the following two statements with which you agree:

1.____ I direct that all medically appropriate measures be provided to sustain my life, regardless of my physical or mental condition.

2.____ There are circumstances in which I would not want my life to be prolonged by further medical treatment. In these circumstances, life-sustaining measures should not be initiated and if they have been, they should be discontinued. I recognize that this is likely to hasten my death. In the following, I specify the circumstances in which I would choose to forego life-sustaining measures.

next page please

If you have initialed statement 2, also initial each of the following statements with which you agree:

a.____ I realize that there may come a time when I am diagnosed as having an incurable and irreversible illness disease, or condition. If this occurs, and my attending physician and at least one additional physician who has personally examined me determine that my condition is terminal, I direct that life-sustaining measures which would serve only to artificially prolong my dying be withheld or discontinued. I also direct that I be given all medically appropriate care necessary to make me comfortable and to relieve pain.

In the space provided, write in the bracketed phrase with which you agree:

To me, terminal condition means that my physicians have determined that:

_____.

[I will die within a few days] [I will die within a few weeks]
[I have a life expectancy of approximately_____or less *(enter 6 months, or 1 year)*]

b.____ If there should come a time when I become permanently unconscious, and it is determined by my attending physician and at least one additional physician with appropriate expertise who has personally examined me, that I have totally and irreversibly lost consciousness and my capacity for interaction with other people and my surroundings, I direct that life-sustaining measures be withheld or discontinued. I understand that I will not experience pain or discomfort in this condition, and I direct that I be given all medically appropriate care necessary to provide for my personal hygiene and dignity.

c.___ I realize that there may come a time when I am diagnosed as having an incurable and irreversible illness, disease, or condition which may not be terminal. My condition may cause me to experience severe and progressive physical or mental deterioration and/or a permanent loss of capacities and faculties I value highly. If, in the course of my medical care, the burdens of continued life with treatment become greater than the benefits I experience, I direct that life-sustaining measures be withheld or discontinued. I also direct that I be given all medically appropriate care necessary to make me comfortable and to relieve pain.

(Paragraph **c.** *covers a wide range of possible situations in which you may have experienced partial or complete loss of certain mental and physical capacities you value highly. In the space provided below, you may want to specify in more detail the conditions in which you would choose to forego life-sustaining measures. You may include a description of the faculties or capacities, which, if irretrievably lost, would lead you to accept death rather than continue living. You may want to express any special concerns you have about particular medical conditions or treatments, or any other considerations which would provide further guidance to those who may become responsible for your care. Please use the space provided and, if necessary, you may attach a separate statement to this document or use* **Section D** *to provide additional instructions.)*

Examples of conditions which I find unacceptable are:

_____
_____
_____
_____
_____
_____

C) Specific Instructions: Artificially Provided Fluids and Nutrition; Cardiopulmonary Resuscitation (CPR). *In this section, you are asked to indicate your treatment preferences as they pertain to two specific types of life-sustaining measures.*

In the space provided, write in the bracketed phrase with which you agree:

1. In the circumstances initialed above in Section B, I direct that artificially provided fluids and nutrition, such as by feeding tube or intravenous infusion,_____.
[be withheld or withdrawn and that I be allowed to die] [be provided to the extent medically appropriate]

2. In the circumstances initialed above in Section B, if I should suffer a cardiac arrest, I direct that cardiopulmonary resuscitation(CPR)_____.
[not be provided and that I be allowed to die]
[be provided to preserve my life, unless medically inappropriate or futile]

3. If neither of the above statements adequately expresses your wishes concerning artificially provided fluids and nutrition or CPR, please explain your wishes below.

_____
_____
_____

D) Additional Instructions: *(You should provide any additional information about your health care preferences which is important to you and which may help those concerned with your care to implement your wishes. You may wish to direct family members or your health care providers to consult with others, or you may wish to direct that your care be provided by a particular physician, hospital, nursing home, or at home. If you are or believe you may become pregnant, you may wish to state specific instructions. If you need more space than is provided here you may attach an additional statement to this directive.)*

_____
_____
_____
_____
_____
_____

E) Brain Death: *(The State of New Jersey recognizes the irreversible cessation of all functions of the entire brain, including the brain stem (also known as whole brain death), as a legal standard for the declaration of death. However, individuals who cannot accept this standard because of their personal religious beliefs or moral convictions may request that it not be applied in determining their death.)*

Initial the following statement only if it applies to you:

____ To declare my death on the basis of the whole brain death standard would violate my personal religious beliefs or moral convictions. I therefore wish my death to be declared solely on the basis of the traditional criteria of irreversible cessation of cardio-respiratory (heart and lung) function.

F) After Death: Anatomical Gifts *(It is now possible to transplant human organs and tissue in order to save and improve the lives of others. Organs, tissues and other body parts are also used for therapy, medical research and education. This section allows you to indicate your desire to make an anatomical gift and if so, to provide instructions for any limitations or special uses.)*

Initial the statements which express your wishes

1. _____ I wish to make the following anatomical gift to take effect upon my death:

A. ____ any needed organs or body parts
B. ____ only the following organs or parts
_____,

for the purposes of transplantation, therapy, medical research or education, or

C. _____ my body for anatomical study, if needed.
D._____ special limitations, if any:

_____.

If you wish to provide additional instructions, such as indicating your preference that your organs be given to a specific person or institution, or be used for a specific purpose, please do so in the space provided below.

_____
_____
_____

2. ____ I do not wish to make an anatomical gift upon my death.

Part Two: Signature and Witnesses

G) The original or a copy of this document has been given to the following people *(NOTE: If you have a family member, friend or family physician who will be responsible for your care, it is important that you provide at least one of these persons with a copy of your directive.)*

1. *name*_____
*address*_____
city _____*state*_____*telephone*_____

2. *name*_____
*address*_____
city _____*state*_____*telephone*_____

H) By writing this instruction directive, I inform those who may become entrusted with my health care of my wishes and intend to ease the burdens of decisionmaking which this responsibility may impose. I understand the purpose and effect of this document and sign it knowingly, voluntarily and after careful deliberation.

Signed this _____day of_____, 19____.

*signature*_____
*address*_____
*city*_____*state*_____

I) I declare that the person who signed this document, or asked another to sign this document on his or her behalf, did so in my presence, that he or she is personally known to me, and that he or she appears to be of sound mind and free of duress or undue influence. I am 18 years of age or older, and am not designated by this or any other document as the person's health care representative, nor as an alternate health care representative.

1. *witness*_____
   *address*_____
   *city*_____ *state*_____
   *signature*_____
   *date*_____

2. *witness*_____
   *address*_____
   *city*_____ *state*_____
   *signature*_____
   *date*_____

New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care (The New Jersey Bioethics Commission) May 1990

Do Not Resuscitate Orders

Policy Statement
Approved December 29, 1988

Cardiopulmonary resuscitation (CPR), as used in this report, refers to treatment administered by health care professionals for cardiac or respiratory arrest. If administered properly and in timely fashion, CPR may restore functioning in a significant number of cases. Because of this life-saving potential, and because the need for CPR typically occurs in emergency circumstances requiring quick decisions and rapid response, standing orders in most health care institutions equipped to perform CPR require its administration in the absence of a specific order to the contrary.

Such contrary orders, known as "Do Not Resuscitate" orders or "DNRs", have been the subject of widespread discussion over the past decade or more. It is now widely agreed that CPR may be foregone, on the basis of a previously ordered DNR, in a number of circumstances. Among the justifications for DNR orders are respect for patient wishes (based on a prior informed decision by a competent patient or on an advance directive), and medical futility (usually based on the very limited prospects for a successful resuscitation in certain medical circumstances, perhaps combined with a judgment regarding the burdens of this invasive technique in particular circumstances). Recently published research has provided a firmer statistical basis for judgments regarding medical futility in different medical circumstances, and has stimulated debate on the meaning and implications of "futility" as an indication for DNRs.

DNRs have been the subject of an extensive medical, ethical, and legal literature; of a variety of guidelines; of court cases; and, most recently, of legislation. The Joint Committee on Accreditation of Health Care Organizations now requires institutions to develop standards for DNRs as part of its accreditation requirements. More dramatically, following a series of critical investigations of DNR practices in New York, the New York Task Force on Life and the Law recommended, and the New York State Legislature enacted, with the Governor's approval, comprehensive legislation establishing a legal framework for DNR orders in New York State. This legislation has been the subject of some controversy during its implementation phase; it is perhaps still too early to evaluate how successful a model it will provide for legislative action in other jurisdictions.

While recognizing that there is, as yet, little or no statutory or case law directly addressing DNR practice in New Jersey, the Bioethics Commission has little doubt that DNR orders can now be issued by New Jersey physicians, consistent with accepted medical standards, in appropriate circumstances. The Commission has not yet had the opportunity to study the topic of DNRs in depth, and is thus not prepared at this time to recommend comprehensive guidelines

or statutory requirements to govern all DNR practice. The Commission has, however, addressed DNRs in the specific context of its proposed advance directives legislation. The Commission there recognizes that cardiopulmonary resuscitation, like other potentially life-sustaining treatments, may be foregone, and a Do Not Resuscitate order issued and respected, pursuant to a patient's advance directive. The legislation proposed by the Commission also provides that "a Do Not Resuscitate order must be entered in writing in the patient's medical records prior to implementation of the order."

While the proposed legislation is limited to the context of advance directives, the Commission believes that the underlying policy of requiring DNRs to be written and charted by the responsible physician in advance of implementation is wise and prudent policy more generally, and urges health care institutions and health care professionals to act accordingly. The Bioethics Commission plans to address the issue of DNR orders on a more comprehensive basis in the course of its future work.

Foregoing of Artificially Provided Fluids and Nutrition

Policy Statement
Approved December 29, 1988

The question of withdrawing or withholding artificially provided fluids and nutrition from seriously ill patients who are unable or unwilling to ingest food and water on their own is perhaps the most emotionally charged, politically controversial, and morally portentous issue that has come before the Commission. On the one hand, the various methods of tube-feeding involve placement and continuing supervision by medical (and sometimes surgical) personnel, can involve risks of injury and side effects, and may constitute disturbing and uncomfortable intrusions on the patient during the dying process.* The courts have generally viewed tube feeding as a medical procedure and have included tube feedings with the other medical procedures that may be refused by a competent adult patient or, in a variety of circumstances, on behalf of an incompetent patient. Thus, the existing case law, including the current law of New Jersey, makes little or no distinction between withdrawal of artificially provided fluids and nutrition and other medical procedures, in accordance with accepted principles of patient autonomy, at least in the cases and circumstances thus far presented to the courts.

On the other hand, many within the society view the provision of food and water to the sick and vulnerable as special and distinctive, requiring analysis in its own terms and not as part of a larger category involving mechanical respirators, kidney dialysis machines, artificial hearts, or other esoteric, high technology interventions. On this view, feeding the hungry and relieving the thirsty are the essence of humane and compassionate care, and their provision to those in need the potent symbol of our civilization's commitment to the value and sanctity of life. The universality of need for food and water and the inevitability of death following their withdrawal, on this understanding, serve to distinguish the provision of fluids and nutrition from other medical technologies, and to create a unique and powerful symbolism. In addition, serious concerns have been raised that societal legitimation of withdrawing fluids and nutrition may open the door to neglect of the elderly and vulnerable, particularly in a time of great concern for containing the costs of health care. Some have argued that acceptance of the arguments supporting withdrawal or withholding of fluids and nutrition may or will lead to (undesirable) legal or social acceptance of active euthanasia.

In the view of the Commission, there are powerful and important arguments on both sides of this painful debate. This society has staked much on its commitment to the principles of autonomy and self-determination, and has learned difficult lessons about the limits of our abilities to truly help those who do not wish our collective assistance, those who truly prefer "the right

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* A description of the technological procedures involved in tube-feeding, drawn from the work of the federal Office of Technology Assessment, follows this document.

to be left alone" (or with caring families), free of the heavy hand of the State. But we have also learned how seemingly civilized societies can shunt the powerless and vulnerable to the margins of society, subject to abandonment, abuse, and sometimes worse. The correct balance can be hard to find, and the Commission does not feel that the path is best illuminated by abstract slogans or global generalizations. The varieties of human responses and clinical situations are simply too diverse and multifaceted to allow for simple answers, at least at this stage of the debate. While individual Commissioners undoubtedly weigh these factors differently, as might be expected, and some would prefer a more absolute stance in one direction or the other,* the Commission as a whole believes that a more nuanced and situation-specific approach provides the soundest and most prudent basis for law and social policy at this time.

The meaning of this "situation-specific approach" is illustrated by the Commission's analysis of a series of "paradigm" cases:

(1) The case for respecting individual self-determination is at its strongest when the individual concerned is awake and aware, has made an informed choice in light of existing medical realities and personal goals, and will experience the consequences of the choice (or the refusal of others to respect that choice). The demand for respect is heightened still further when the individual is irreversibly dying, and the scope of available choice is limited to a modicum of control over the indignities of the dying process. The image of a dying patient, attached to tubes against his or her will and tied down by physical restraints to prevent him (or her) from forcefully pulling out the tubes, dramatically calls forth the real and symbolic commitments to patient choice that are widely and properly shared throughout this State and Nation.

Our society's commitment to patient choice demands respect and legal protection. This alone would be sufficient to justify rejection of legislative proposals requiring artificial provision of fluids and nutrition without regard to the wishes of competent patient. Recognition of the competent patient's right to choose in such circumstances does not pose serious dangers of any precipitous slide down the slippery slope toward abandonment or maltreatment of the most vulnerable and powerless.

(2) It is increasingly evident that large numbers of persons foresee and contemplate the possibility of losing decisionmaking capacity at or near the end of life, and wish to make advance provisions for their care in the event their medical condition precludes them from doing so themselves. For some, and perhaps for many, the specter of having their dying process extended by artificial feeding, without the prospect of recovery or relief of other symptoms, is abhorrent. The basis for such preferences may be purely self-directed, as with a desire to "die naturally" or to avoid futile and burdensome interventions or the prolongation of unnecessary physical suffering. It may be due to concerns for others, including avoidance of prolonged emotional suffering or catastrophic financial consequences for loved ones. It may result from an individual's concern for the wise shepherding of communal resources. The Commission shares the conviction, so often recognized

* See the separate Commissioner statements in this Appendix.

in court decisions and in the scholarly and policy literature, that it is meaningful and appropriate to speak of extending respect for autonomy to apply to such situations--a conviction at the heart of the Commission's support for legislative recognition of advance directives for health care. However, the Commission also believes that as patient choice becomes less specific and more remote in time and circumstance, and as safeguards against possible misunderstandings or abuse or neglect are less assured, there must be a balancing of legitimate societal concerns against the claims of asserted autonomy.

What, then, are the relevant factors in this balancing?

(a) The specificity and clarity with which the patient's wishes are expressed. This is important in at least two respects: first, it provides greater assurance that a given decision truly reflects the patient's autonomous desires; and second, it provides a barrier against potential abuse of this or other patients.

(b) The patient's medical situation and prospects. As noted by the *Quinlan* court, social acceptance of and agreement with a particular choice does have some moral and legal significance. It appears that legal, professional, and societal support for respecting a patient's choice to refuse artificially provided fluids and nutrition is strongest when tube-feeding serves only to prolong the dying process of an irreversibly dying patient or to sustain biological existence in the nether-world of permanent coma or a persistent vegetative state. These medical conditions represent the areas of greatest social and moral consensus; holding to them provides a useful barrier against potentially dangerous extensions to institutionalized and other especially vulnerable populations.

(c) Timing and certainty of diagnosis and prognosis. The patient's diagnosis and prognosis must be established with reasonable medical certainty. Sufficient time must be allowed for establishment and, where necessary, confirmation of the patient's status, and for a sound decisionmaking process, before steps with irrevocable consequences are undertaken.

(d) The burdens, risks, and indignities associated with the particular technology, or with its absence. Technological interventions intended to prolong life may in fact prolong the dying process, introduce unnecessary suffering and side-effects, and rob the patient of the opportunity to spend his or her final days in relative peace. Inappropriately managed withdrawals of fluids and nutrition can result in unnecessary suffering, as well as in an earlier death. Professional and caring nursing techniques can do much to assure a patient's comfort through the dying process. Judgments regarding technological interventions should be based on the facts and circumstances of individual situations, not on stereotypes or rhetorical slogans.

The evaluation of these factors in particular factual circumstances is not free from controversy, but such nuanced efforts can help to "flesh out" their meaning in a way that abstract pronouncements at a high level of generality cannot. The Commission believes that the following principles should guide the establishment of policy in this area:

1. Attempts to define or characterize the artificial provision, by tube, of fluids and nutrition as entirely outside the scope of "medical treatments", without regard to

the facts and circumstances of such provision, are neither legally nor ethically justified.

2. Attempts to compel the initiation and continuation of artificial provision, by tube, of fluids and nutrition, or to prohibit the withholding or withdrawal of artificially provided fluids and nutrition, without regard to the facts and circumstances of the individual case, are neither legally nor ethically justified.

3. The withholding or withdrawal of life-sustaining fluids and nutrition from incompetent or otherwise vulnerable patients raises important and distinctive problems for social policy that justify protective measures, beyond those normally applicable to the withdrawal of other medical treatments. Such protective measures include both substantive and procedural safeguards intended to protect both against abuse of individual patients and dangers to important social values, including respect for the sanctity of life, the prohibition against taking of innocent life, and the preservation of public confidence in the caring role of medical and other health care professionals.

As applied to particular cases, the Commission believes the following conclusions are justified:

1) When the patient is suffering from an incurably terminal condition and the artificial provision of fluids and nutrition serves only to prolong the dying process while imposing what the patient reasonably believes to be unacceptable risks, discomfort, or indignity, the contemporaneous wishes of the competent patient, or clear and convincing evidence of the patient's competent, previously expressed wishes (as by an explicit statement in an advance directive) regarding the withholding or withdrawal of artificially provided fluids and nutrition, should be honored.

2) When the patient is reliably diagnosed as permanently unconscious (i.e., under present medical terminology, in an irreversible coma or persistent vegetative state), and the artificial provision of fluids and nutrition serves only to maintain bodily functions in the absence of any realistic medical prospect for a return to a cognitive or sentient existence, clear and convincing evidence of the patient's competent, previously expressed wishes (as by an explicit statement in an advance directive) regarding the withholding or withdrawal of artificially provided fluids and nutrition, should be honored.

The Commission has sought to embody this analysis in its statutory proposal for advance directives for health care. The Commission's proposal includes a section specifically addressing the withholding or withdrawing of artificially provided fluids and nutrition, in the particular context of an advance directive. This section requires a clear and explicit expression of intent

by the declarant, distinguishes among different medical situations, and mandates special review in the more problematic cases. The full text of this provision is reproduced below:

Section 16: Decisions to Forego Artificially Provided Fluids and Nutrition

A) Consistent with the explicit terms of an advance directive and the provisions of this Act, artificially provided fluids and nutrition necessary to sustain life may be withheld or withdrawn from a patient in the following circumstances:

1) When the artificial provision of fluids and nutrition is likely to be ineffective or futile in prolonging life, or is likely merely to prolong an imminent dying process; or

2) When the patient is permanently unconscious, as determined by the attending physician and confirmed by a second qualified physician; or

3) When the patient is in a terminal condition, as determined by the attending physician and confirmed by a second qualified physician, and the likely risks and burdens associated with the least burdensome treatment modality likely to be effective may reasonably be judged to outweigh the likely benefits to the patient from such intervention, and imposition of the intervention on an unwilling patient would be inhumane. In such cases, prior to implementing a decision to withhold or withdraw artificially provided fluids and nutrition, the attending physician shall seek prompt consultation with a qualified institutional or regional reviewing body in accordance with section 18 of this Act, or shall promptly seek approval of a public agency recognized by law for this purpose.

B) This Act does not provide authorization for the health care representative, or any other individual acting pursuant to this Act, to direct or implement the withholding or withdrawal of artificially provided fluids and nutrition necessary to prolong life in the absence of explicit instructions to that effect in the patient's advance directive.

C) Nothing in this section is intended, or shall be construed, to impair the obligations of physicians, nurses and other health care professionals to provide for the care and comfort of the patient and to alleviate pain, in accordance with accepted medical and nursing standards.

D) Nothing in this section is intended, or shall be construed, to abridge any Constitutionally-protected right to refuse treatment, based upon the free exercise of religion or the right of privacy, under either the United States Constitution or the Constitution of the State of New Jersey.

The Commission has not yet fully considered the circumstances in which artificially provided fluids and nutrition may be withheld or withdrawn from an incompetent patient in the absence of an advance directive, or when an advance directive does not provide clear and explicit guidance on this question. The Commission has committed itself to giving priority to these issues in the next phase of its work. Pending the completion of that process, the Commission does not intend that its proposed Advance Directives for Health Care Act be construed to limit any patient rights conferred by existing law, and believes that existing law should continue to govern in circumstances not covered by this proposed legislation.

Tube Feeding Techniques: Placement, Indications for Use, and Associated Risks

Nasogastric tubes may be placed by a physician, another health care professional, the patient, or a trained family member. The position of the tube must be tested before each feeding, because the tube can be mistakenly placed in the patient's lungs; if food or fluids are put in the tube while it is in the patient's lungs, severe respiratory distress will occur, potentially causing death. Other risks of nasogastric tube feeding include irritation of the nose, throat, and esophagus, and aspiration, a condition caused by regurgitation of the stomach contents into the lungs.

Nasoenteral tubes are usually placed by the physician or a specially trained nurse and must be tested every few days by a trained health care professional or by X-ray. These tubes are recommended for short-term use in patients for whom regurgitation and aspiration are likely or whose stomach or upper intestinal functions are impaired.

Potential problems include the difficulty of passing the tube through the pylorus (the small opening at the lower end of the stomach) and laceration of the pylorus or other parts of the gastrointestinal tract if the tube is removed too rapidly. In addition, feeding into the duodenum and jejunum tends to cause diarrhea.

Pharyngostomy and esophagostomy tubes must be surgically placed by a physician. Esophagostomy tubes are seldom used now. Pharyngostomy tubes are recommended for long-term use because they do not irritate the nose and throat like nasogastric and nasoenteral tubes. Potential problems include aspiration, scarring of the insertion site, and swallowing difficulty.

Gastrostomy tubes are placed by one of two methods. Surgical placement, that is always by a physician, is done with a local, spinal, or general anesthetic. A new method, percutaneous endoscopic placement, does not require surgery or general anesthetic. Gastrostomy tubes are recommended for long-term use and when swallowing is impaired as a result of obstruction or neurological disease.

Potential problems include aspiration, skin irritation around the tube site, and displacement of the tube into the abdominal cavity. In addition, the small balloon that is sometimes used to hold the gastrostomy tube in place can obstruct the pylorus and interfere with gastric emptying.

Jejunostomy tubes are surgically placed. These tubes are recommended for long-term use when there is a problem with gastric emptying or regurgitation. Potential risks include skin irritation around the tube site, clogging, displacement of the tube, and diarrhea.

SOURCE: *Adapted from Oley Foundation, "Nutritional Support and Hydration for Critically and Terminally Ill Elderly," prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, November 1985.*

This description of tube feeding techniques is reproduced from the Office of Technology Assessment, *Life-Sustaining Technologies and the Elderly* (U.S. Govt. P.O. 1987), p. 282.

Additional View on Fluids and Nutrition

December 29, 1988

The following Commissioners wish the Report to reflect that they hold that life-prolonging medical treatment includes artificially or technologically supplied nutrition and hydration in keeping with the opinions of, among others: The American Medical Association; The American College of Physicians; The American Academy of Neurology; The American Geriatrics Society; The Medical Society of New Jersey; The New Jersey Board of Medical Examiners; The New Jersey Chapter of The American College of Physicians; The New Jersey Geriatrics Society; The New Jersey State Nurses' Association; The New Jersey Dieticians Associations; The New Jersey Hospice Organization; The Supreme Court of New Jersey; The New Jersey Bar Association; The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research; The Hastings Center and the New York State Task Force on Life and the Law. We have concluded that it is wisest and most plausible to understand these methods as medical interventions that may be foregone in some cases.

Senator Gabriel M. Ambrosio
Paul W. Armstrong
Sr. Jane Frances Brady
Diana Czerepuszko
Joseph Fennelly
Robert Fischer
Noreen Haveron
Mary K. Lindner
Patricia Murphy
Michael Nevins
William I. Strasser
Mary S. Strong

ADDITIONAL STATEMENT OF VIEWS
by Rabbi Shmuel Blech

In light of the enormous complexities of the issues deliberated by the Commission and in recognition of the potentially far-reaching implications that any decisions regarding life and death must engender, I wish to incorporate the following statement to more fully reflect my personal views on these issues.

The Commission has struggled long and arduously in an attempt to reconcile the irreconcilable. All of us accept both individual autonomy and the preservation of human life as basic and fundamental moral values. Unfortunately, there are times when the two come into conflict with one another, and it is impossible to preserve one without sacrificing the other. This report, whose conclusions reflect a substantial consensus among the Commissioners, represents a sincere effort to delineate circumstances in which society should accord full respect to the autonomy of each of its members, even at the cost of permitting an earlier death.

In my view, the sanctity of life, as expressed in the collective historical and sociological traditions of civilized man, cannot be subject to compromise--regardless of consequence. It is too precious and germane to the essence of the human experience to allow for it--even when in collision with the rights of an individual, and certainly not in the context of subjective, third-party determinations based on so-called "quality-of-life" considerations. Non-moribund, and certainly non-terminal, patients, acting perhaps on occasion even against the expert medical advice of their own physician, cannot morally act to discontinue their lives without the awesome specter of consensual suicide looming in the background, symbolic of an ominous new ethic, yet undefined. Any dilution of societal respect for the sanctity of human life, even in the course of upholding the supremacy of personal liberty in any one of its many guises, carries with it the danger of further compromise of that principle. This concern, in my view, is all the more cogent in light of the Commission's willingness to permit individuals to choose the withholding of non-burdensome life sustaining measures even in non-terminal situations. This will become all that much more worrisome and problematic when attempts are made to broaden the application of these imprecise concepts for a future continuum in as yet unchartered waters.

Unavoidable at the same time is a subtle message that a youth and health-conscious society is at present sending out to its most vulnerable citizens--the aged, infirm, handicapped, retarded--that burden is the most pronounced component in the value of life formulation. Safeguards built into the proposed legislation cannot fully mitigate the impact of that message--particularly to those who, by definition, are and must see themselves as being an ongoing burden. The net effect of this mentality, both on those who carry "the burden" and those "carried", must yet remain a painful and frightful mystery in its inherent unpredictability.

Insofar as the internal integrity of the moral system to which I subscribe is concerned, the dilemma with which the Commission has grappled admits of a radically different solution. Judaism enshrines preservation of life as a paramount value, to which virtually all others are rendered subservient. The exceptions to this principle are narrow and rather well-defined.

The quandary that I face is of an entirely different nature: to what extent should such views be urged upon a legislative body charged with promulgating legal norms for a pluralistic society?

Acceptance of pluralism perforce entails civil recognition of autonomy in many areas of human conduct, to a degree not necessarily espoused by particular constituent sectors of the society. Nevertheless, most concede that untrammelled liberty can rapidly degenerate into anarchy, and that, at least in some circumstances, unrestrained expression of personal autonomy may unconscionably compromise public interests. The manifold dilemmas confronting us beg for a comprehensive conceptual approach rather than an intuited situational response. The latter carries with it a clear danger of eroding the unique value inherent in every human life. In the absence of a well formulated and carefully structured socio-moral theory, restraint is to be commended.

I recognize and accept the voices of concern articulated by many of our colleagues and agree with much that they say in their separate statements. I cannot in good conscience condone, as they cannot, any weakening of full protection for the sacred nature of life. The handwriting is on the wall--the precipitous angle of the slope is clearly in place. I have, nevertheless, chosen to support the legislative initiative and report generated by the Commission--not because it adopts the precise ideals dear to me, but because people of integrity and diverse opinions have wrestled at great length, to achieve a compromise resolution. This effort has exacted some intellectual, philosophical and ideological price from each of us. The work as a whole, in respectfully presenting both majority and minority thinking, does encompass the full range of views which this wrenching issue has generated. At the very minimum, the proposal allows for the expression of one's religious and/or personal moral ethic--an ingredient crucial to all of us.

I hope this gesture of support will encourage caution and sensitivity in dealing with the legitimate issues raised by those voices of concern.

Rabbi Shmuel Blech

A Rationale for Abstaining From Full Acceptance of Proposal
December 29, 1988

We acknowledge the considerable time and effort expended in preparing this proposed Advance Directives for Health Care Act and we recognize the efforts made to respond and adapt to concerns raised during the deliberations. However, there remain several ethical and moral issues we must address. We are most concerned with the introduction of a new cause of death brought about by the removal of life-sustaining treatment or fluids and nutrition from non-dying patients.

A terminally ill patient has the duty to care for his own health and to seek necessary medical care from others, but this principle does not mean that all possible remedies must be used in all circumstances. He is not required to use "heroic or extraordinary" means; that is, means which offer no reasonable hope of benefit or which involve excessive hardship. The Act unwisely extends that principle to those individuals who are not terminally ill.

We reject the notion that the provision of fluids and nutrition is a medical treatment. Although the Act does not so state, some Commissioners propound that view. We note that the laws of 19 states exclude the provision of fluids and nutrition from life-sustaining procedures that can be refused to an incompetent patient through a living will.[1] Fluids and nutrition, being basic to human life, are aspects of normal care. A basic point that must be kept in mind is that the discontinuance of fluids and nutrition does not simply allow the person to die from existing pathology, but may initiate a new cause of death --- starvation or dehydration. Too often, lurking behind the decision to withdraw fluids and nutrition is the assumption that the quality of life has so deteriorated that the patient would be better off dead. Where the Act allows discontinuance of fluids and nutrition or life-sustaining treatment from the permanently unconscious patient, it follows this assumption, because such a patient is not dying or even necessarily suffering from a specific illness. Human life, however, is a basic good and the foundation of other goods, notably personal dignity and human rights. All reasonable efforts should be made to sustain life, and thus there should be a presumption in favor of providing fluids and nutrition to the unconscious, non-dying patient unless or until the benefits of fluids and nutrition are clearly outweighed by a definite danger or burden to the patient, or are totally useless. Of and by itself, coma, permanent or not, does not justify direct termination of the patient's life. It must be emphasized that the judgement made here is not that the person's life is useless or excessively burdensome; rather, the judgment made is that the means used to preserve life is useless or excessively burdensome.

Thus, our position is that the withdrawal or withholding of life-sustaining treatment or artificially provided fluids and nutrition should be limited to terminal cases arising from irreversible pathology from which death is imminent.

Since the report's discussion of fluids and nutrition provides the basis for much of what we have commented on, we offer several observations. In the report the point is made that social support for respecting a patient's choice to refuse fluids and nutrition is strongest when tube feeding serves only to sustain "biological existence in the nether-world of permanent coma or a

persistent vegetative state." This language prejudges the issue in our view. Medical science knows very little about patients who are apparently permanently comatose or in a persistent vegetative state. For example, in the Jobes case eminent neurologists were at odds over the diagnosis. Moreover, there are documented cases where a permanently comatose patient has revived to live a normal life.

We support the provisions of the Act which allow a patient with impaired capacity who clearly expresses or manifests the contemporaneous wish that medically appropriate life-sustaining treatment be provided, to have that wish take precedence over the contrary decision of the health care representative and the patient's instruction directive. This is a mandate to the health care representative and health care professional that they must abide by the known wishes of the patient that life-sustaining treatment be provided. We are pleased it was amended to include the provision of fluids and nutrition.

We also support the provisions of the Act which protect the professional conscience and the conscience of religiously-affiliated health care institutions. We do not accept, however, the identical provision in each section which compels the professional or religious institution to transfer the patient. We think the approach which would more adequately and completely protect their consciences would be to place this burden on the family or health care representative. It could be stipulated that the professional or institution must refrain from impeding the transfer in any way.

We regret that the institutional conscience provision does not include non-religiously affiliated hospitals. This omission ignores the fact that the moral values (e.g. Hippocratic oath, respect for life) on which professional conscience is based also may shape the institutional conscience. We submit there is ample legal authority for applying institutional conscience to non-religiously affiliated hospitals. the Commission's proposed legislation on determination of death recognizes not only a religious exemption but also one grounded in personal moral convictions. Our Supreme Court in Jobes left open the possibility that an institution's policy not to participate in the withdrawal or withholding of artificial feeding, if communicated in advance to the patient, would be upheld. Throughout the report is the notion that a patient's choice is paramount. What is neglected is the equally valid principle that a hospital should not be compelled to violate its moral and ethical principles. If a non-religiously affiliated health care institution notifies a patient that its policy prohibits the withdrawal or withholding of life-sustaining treatment and artificially provided fluids and nutrition, such a policy should be honored so that the institution can be faithful to its code of ethics.

Missing from the Act is a specific statutory protection for the unborn child of a pregnant woman who may be subject to the withdrawal or withholding of life-sustaining treatment or artificially supplied fluids and nutrition. We are not totally satisfied with the report's suggestion that such protection can be inferred from the Act. See sections 1(C) and section 12(B). The Life-Prolonging Procedure Act of Florida expressly states that an advance directive "shall have no effect during the course of the pregnancy." We believe that our act should include a specific provision that life-sustaining treatment and artificially provided fluids and nutrition should not be withdrawn from a pregnant woman if continued treatment may benefit her unborn child. Inclusion of such a provision is not banned by any of the United States Supreme Court's decisions which removed most legal restrictions on abortion. At least 12 other states have similar provisions.[2]

We adhere to the moral principle that it is possible to kill innocent persons by acts of omission, as well as acts of commission. Whenever the failure to provide appropriate medical treatment or adequate food and fluids carries out a proposal, adopted by choice, to end life, such an action is an act of killing by omission. In short, it is passive euthanasia. The Act purports to reject "active euthanasia" but fails to define it or to explain whether this word is meant to include euthanasia by omission, thus reducing the efficacy of its disclaimer that it does not authorize euthanasia. We would define euthanasia as "an act or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated." We recommend the formulation which Florida placed in its Life-Prolonging Procedure Act. Section 11 of the Florida law provides: "Nothing in this Act shall be construed to condone, authorize, or approve mercy killing or euthanasia, or to permit any affirmative or deliberate act or omission to end life other than to permit the natural process of dying."

Our viewpoint is not unique. As an example, in 1987 over 100 theologians, ethicists and physicians of varying faiths and backgrounds joined in a statement regarding the feeding and hydrating of permanently unconscious and other vulnerable persons.[3] They also perceive that the issue is not the unfettered right to control one's medical care but rather the exercise of that right within ethical limits. Life-sustaining treatment, as well as fluids and nutrition, are necessary for the preservation of life. Law and morality should recognize a strong presumption in favor of them. Decisions to forego these means of upholding life should be examined carefully to be certain that such determinations are not guided by a discriminatory attitude regarding the value of the lives of persons with disabilities or by an intention of deliberately hastening the death of such persons. Above all, public policy in this area must be based on a positive attitude toward disabled and terminally ill patients, who have a right to live with dignity and with reasonable care until the moment of death.

Respectfully submitted,

Rev. Robert Harahan
The Honorable Richard Kamin
Rita M. Martin

Notes

1. Bopp, "Nutrition and Hydration for Patients: The Constitutional Aspects," Issues in Law & Medicine, Vol. 4, No. 1 (1988), at p. 9, n. 67.

2. Handbook of Living Will Laws, Society for the Right to Die, (1987), at p. 31ff.

3. May et al., "Feeding and Hydrating the Permanently Unconscious and Other Vulnerable Persons," Issues in Law & Medicine, Vol. 3, No. 3 (1987), at p. 203ff.

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

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

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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, incapacited 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 circumstanes 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-6j.

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, 1986, 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.

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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 reinstituted. 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 countervailing 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 Colyer, 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.

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Introduction to Part Four

The expanding power of medicine and technology has raised complex issues at the intersection of law, medicine and ethics, creating moral dilemmas which regularly confront patients, families, physicians, and others involved in the health care process. Traditionally, most health care decisions have been made within the privacy of the physician-patient-family relationship. In recent years, public concern about the uses of medical technology and the potential abuse of vulnerable patients has led to the widely held belief that in certain circumstances some form of prospective review is warranted. On numerous occasions the courts have served this reviewing function. Increasingly, the health care community and policymakers have looked to the development of alternative mechanisms, such as some form of review by an institutional ethics committee or a state agency. Such alternatives hold the promise of less cumbersome and more timely review than the court system, while offering a sound basis for public confidence in the process.

While decisions about the uses and abuses of medical technology implicate fundamental societal values, allocation of the responsibility for making such decisions bespeaks fundamental beliefs about the proper roles of patients, families, physicians, institutional committees, courts and government agencies in health care decisionmaking. Part Four of the report discusses the Commission's studies of several important areas in which committees, courts, and state agencies have become involved in health care decisionmaking in New Jersey.

Chapter One of Part Four discusses the Commission's study to date of the role of the Office of the Ombudsman for the Institutionalized Elderly (the "Ombudsman") in decisions to forego life-sustaining measures for the institutionalized elderly in New Jersey. For many institutionalized elderly patients, advanced age and serious illness is accompanied by diminished physical and mental capacities, the absence of surviving family members, and inadequate financial resources. These factors, along with endemic characteristics of some long-term care facilities, can contribute to the social isolation of patients and to limited access to medical resources and support services. These concerns are especially important when decisions to withhold or withdraw life-sustaining measures from incompetent elderly nursing home patients are contemplated. In *In re Conroy,*[1] the New Jersey Supreme Court responded to these concerns by creating a role for the Ombudsman in reviewing decisions about life-sustaining measures for incompetent elderly nursing home residents.

Mandated to address issues still in need of resolution in the aftermath of *Conroy*, and responsive to concerns within the health care community regarding the scope and implementation of the Ombudsman's role in reviewing such decisions, the Commission undertook the study of the Ombudsman's participation in the health care decisionmaking process. The Office's role with respect to decisions to forego life-sustaining measures for elderly nursing home residents has been

a central and continuing focus of the Commission's deliberations. Chapter One also chronicles the Commission's involvement, as a member of the New Jersey health care community, in the development of public policy regarding the role of the Ombudsman.

In the course of its deliberations in the area of death and dying, the Commission invited the participation and testimony of the Office of the Public Guardian for Elderly Adults (the "Public Guardian"). Chapter Two of this Part briefly summarizes the role of the Public Guardian, with particular focus upon medical guardianship services provided by that Office. As noted elsewhere in the report, the Commission plans in its future work to address issues surrounding decisionmaking for incompetent patients who have not previously expressed their wishes in an advance directive, with special attention to those patients who also do not have a family member or friend acting on their behalf -- situations in which the Public Guardian may be called upon to represent the patient's interests. The Commission plans to study further the role and concerns of the Public Guardian in the area of health care decisionmaking and hopes to work cooperatively with the Public Guardian in this effort.

Chapters Three and Four provide a preliminary examination of two issues: the New Jersey implementation of "Baby Doe" procedures, and sterilization of persons incapable of consenting to the procedure. Both areas involve decisionmaking for incompetent and vulnerable patients, and both the government and the courts have created substantive and procedural guidelines for decisionmaking in these cases. Decisions to forego life-sustaining measures for disabled infants with life-threatening conditions have been the subject of both federal and state legislation and regulation. Chapter Three provides an overview of this complex area, focusing upon the Child Abuse Amendments of 1984, which expanded the definition of medical neglect to situations involving the withholding of medically indicated treatment from disabled infants with life-threatening conditions, and examines the implementation of the federal law and regulations in New Jersey. In contrast, the New Jersey Supreme Court's decision in *In re Grady* (discussed in Chapter Four) fashioned standards to protect both the rights and best interests of incompetent persons facing nonconsensual sterilization, and held that such decisions should be made only by a court.

Chapter One:
The Office of the Ombudsman for the Institutionalized Elderly

Based upon national trends, by the year 2000, citizens 60 years of age and older will make up almost 20% of New Jersey's population.[2] Many will be residents of facilities providing long-term care for the elderly. The circumstances of advancing age can often lead to the isolation of the institutionalized elderly, limiting access to the full range of resources which have been created to provide them with needed care and comfort. These factors can result in an institutionalized elderly person's increased exposure to potential neglect and abuse.[3]

The quality of care received by the elderly in long-term care institutions has been a source of continuing concern to policymakers, the health care community and the public for many years. Revelations in the mid 1970's disclosed the existence of facilities that failed to provide residents with clean and healthy surroundings, adequate nutrition, basic care and other necessities. These findings prompted a number of legislative and executive inquiries, at both the national and state levels. The facts uncovered in these inquiries ushered in a new era of government oversight of health care facilities for the elderly. In 1974 the New Jersey State Legislature created the New Jersey Nursing Home Study Commission, charged with a mandate to study conditions in nursing homes throughout the state and to develop recommendations to address and correct identified problems. One of the recommendations presented in the Interim Report of that Commission was the establishment of a state ombudsman for elderly residents of nursing homes.[4] It was in this historical context that the Office of the Ombudsman for the Institutionalized Elderly (the "Ombudsman" or the "Office") was created by the New Jersey Legislature in 1977.[5]

The original mandate of the Office was to investigate complaints about inadequate conditions which existed in some long-term care facilities and to work to improve the quality of patient care in long-term care facilities. Since its creation, the Ombudsman's role has expanded beyond this original mandate, as a result of both statutory action and judicial decision, to include a role in overseeing life-sustaining treatment decisions for incompetent, elderly nursing home residents. A brief survey of the development of the Office provides a background for understanding the Ombudsman's role in health care decisionmaking and the Commission's policy recommendations.

The Ombudsman's Basic Responsibilities

The legislation that established the Ombudsman's Office recognized that, due to a variety of circumstances, the elderly require special assistance in securing and exercising their basic civil and human rights. The enabling legislation charged the Ombudsman with the responsibility of "promoting, advocating and insuring, as a whole and in particular cases, the adequacy of the care received, and the quality of life experienced, by elderly patients, residents and clients of facilities

within this State".[6] The 1977 statute established a significant role for the Ombudsman in monitoring the quality of services provided for residents and clients of long-term care facilities.[7]

In order to fulfill these objectives the Ombudsman is given authority to receive, investigate and respond to complaints concerning particular facilities. The Office is furnished with considerable investigative powers, including the right to hold private or public hearings; to make necessary inquiries; to enter without notice and inspect the premises of a facility or governmental agency, as well as any records or files relevant to its investigation; and to issue subpoenas for sworn testimony or documentary evidence.[8] If in the course of an investigation conditions are found which endanger the health or safety of residents or clients, the Ombudsman is authorized to try to resolve the problem through direct negotiations. Should negotiated resolution fail or prove inappropriate, the Ombudsman may report the findings to the proper government agency for further action.[9] Among the Office's resources is the authority to recruit and train volunteers, to serve as patient companions and advocates, assisting to extend the services of the Office to facilities caring for the elderly in all regions of the State.[10] A substantial volunteer program has been initiated by the Office.

While for administrative purposes the Ombudsman is located in the Department of Community Affairs ("DCA"), the DCA exercises no supervision or control over the Office. Rather, the Ombudsman is directly accountable to and serves at the pleasure of the Governor, who makes the appointment with the advice and consent of the Senate. As a consequence, New Jersey's Ombudsman has considerable independence in conducting its inquiries, reinforcing and strengthening its investigatory role.[11]

In September of 1983 the Legislature added to the responsibilities of the Office by passing the "Mandatory Adult Abuse Reporting Act," amending the original statute. These amendments specifically extend the Office's authority to the protection of vulnerable patients against "abuse or exploitation." "Abuse" is defined as the "willful infliction of physical pain, injury or mental anguish; unreasonable confinement; or the willful deprivation of services which are necessary to maintain a person's physical or mental health."[12] The Act requires health care professionals who suspect the "abuse or exploitation" of institutionalized elderly patients to report the information to the Ombudsman for investigation.

In accordance with the provisions of the 1983 amendments, the Ombudsman is required to investigate a reported complaint and to transmit a report of the results of the inquiry to the proper governmental agency for possible action. The significance of the Act lies in the serious nature of the harms to which the Ombudsman was now asked to attend, and the sanctions and penalties which could be imposed on individuals who fail to report suspected abuses. The mandatory reporting requirement of the statute was apparently intended to ensure that the Ombudsman would be notified in appropriate cases and would have an opportunity to conduct an appropriate investigation. According to the Office, "the effect of the law has been to greatly increase the number of reported cases of abuse and exploitation".[13]

As discussed below, it was this statutory language to which the New Jersey Supreme Court looked in *Conroy* in creating a role for the Ombudsman in reviewing decisions to withhold or withdraw life-sustaining measures for incompetent, elderly nursing home patients.

The Ombudsman and the Courts: Involving the Ombudsman in Life-Sustaining Treatment Decisions*

As noted above, neither the Ombudsman's enabling legislation nor the 1983 amendments specifically define a role for the Ombudsman in reviewing or investigating proposed decisions to withhold or withdraw life-sustaining measures. The Ombudsman's Office focused its efforts principally on receiving and investigating complaints ranging from personal abuse and neglect (such as improper use of restraints or sexual assault), poor dietary programs, dangerous physical environment, fraud and other abuses of patient and/or family rights. The Ombudsman's role in reviewing decisions to forego life-sustaining measures was created by the New Jersey Supreme Court in *Conroy*[14] (1985). By statute, the Ombudsman's jurisdiction is limited to institutionalized residents of long-term care facilities who are 60 years of age or older.[15]

In *Conroy*, the Court was presented with a request to withdraw a nasogastric feeding tube from an 84 year old nursing home resident who was suffering from serious and permanent mental and physical impairments, and was incompetent to make her own treatment decisions. The patient was expected to die within approximately one year, even with the provision of life-sustaining treatment. Noting the absence of statutory guidance for decisionmaking in this area, the Court established guidelines for decisionmaking for patients who, like Claire Conroy, are elderly, chronically ill, and institutionalized, and who are aware, conscious and able to interact with their environment to a limited extent, but whose functioning is severely and permanently impaired with a relatively short life-expectancy. In developing guidelines for decisionmaking the Court was especially concerned to protect the interests of vulnerable, elderly, incompetent, institutionalized nursing home patients.

At the outset, the Court rejected the decisionmaking procedure it had provided in *Quinlan* for hospitalized PVS patients, "namely, the concurrence of the guardian, family, attending physician and hospital prognosis committee." This procedure was seen as "not entirely appropriate for patients such as Claire Conroy" in light of "significant differences in the patients, the health care providers and the institutional structures of hospitals and nursing homes."[16] The Court enumerated and discussed a number of the factors which, in its view, distinguish the hospital and nursing home settings.

First, the Court noted that nursing home residents tend to be elderly persons suffering from chronic and severe disabilities and mental impairments who require assistance with daily living. The elderly nursing home patient's death may not infrequently be viewed as consistent with advanced age and general infirmity. Second, the Court found that often nursing home

* For a more detailed analysis of existing law and the role of the Ombudsman in life-sustaining treatment decisions, *see* the discussion of the general legal context in Part Three of the report.

residents are without any family and suffer from severe social isolation. The Court felt that the involvement of caring family members, whose participation was an integral part of the decisionmaking process in *Quinlan*, "may not be a realistic possibility for many nursing home residents." Third, physicians were seen to play a much more limited role in nursing homes and to be less familiar with the personalities and preferences of their patients. And finally, the Court concluded that nursing homes represent the most troubled component of the health care system which "in any event, [generally do not] have "ethics" or "prognosis" committees to review the attending doctor's assessment of a patient's prognosis."[17]

With this background in mind, the Court turned to the 1983 amendments to the Ombudsman statute, which directs the Ombudsman to protect elderly institutionalized patients against "abuse." These amendments define "abuse", in relevant part, as the willful infliction of physical pain, injury or mental anguish, unreasonable confinement, or *the willful deprivation of services which are necessary to maintain a person's physical and mental health.*"[18] Relying upon this statutory authority, the Court crafted a prospective reviewing role for the Ombudsman prior to implementation of a decision to withhold or withdraw life-sustaining treatment from an incompetent nursing home resident 60 years of age or older.

Specifically, *Conroy* provides that any person, such as a family member, guardian, attending physician, or the nursing home administrator, who believes that a decision to forego life-sustaining treatment for a patient would effectuate the patient's wishes or best interests, or conversely, who reasonably believes that such a decision would be an abuse of that patient, should notify the Ombudsman's Office of the proposed decision. The Ombudsman is directed to treat every notification of a proposal to forego life-sustaining treatment as a possible "abuse" and to undertake an investigation. In addition to information provided by the attending physician and nurses concerning the patient's medical condition, two independent physicians, unaffiliated with the nursing home or the attending physician, must be appointed by the Ombudsman to confirm the patient's medical condition and prognosis. If these physicians confirm the patient's medical condition and prognosis, the guardian may decide to withhold or withdraw the life-sustaining treatment, with the concurrence of the Ombudsman. In cases in which a decision on behalf of a terminally ill patient is based in whole or in part on evaluation of the patient's best interest, the concurrence of the patient's family, if any, is also required.[19] When this procedure is followed in good faith, participants in the process receive immunity from civil and criminal liability.

Two years later, in the *Peter*[20] case, the Court further refined the role of the Ombudsman. In *Peter*, the patient was diagnosed as being in a persistent vegetative state, with no hope of recovery but not expected to die in the near future. Ms. Peter had specifically designated a close friend as a surrogate decisionmaker with durable power of attorney. Finding that "elderly nursing home patients in the persistent vegetative state are threatened by the same conditions that put Claire Conroy at risk,"[21] and finding further that because Ms. Peter was in a nursing home there was no prognosis committee[22], the Court again required that the Ombudsman be given the opportunity to investigate and to prevent any possible mistreatment. Accordingly, the procedure mandated in *Peter* requires that the Ombudsman be notified of any decision to forego life-

sustaining treatment from elderly, nursing home patients in a persistent vegetative state. The Ombudsman is given responsibility for securing two independent medical opinions to provide information and confirmation regarding the matters which had been referred to the "prognosis" committee in *Quinlan*, specifically, that the patient is comatose with no reasonable possibility of recovery to a cognitive, sapient state.

Under *Peter*, the Ombudsman is also required to consult with health care providers (and the treating physician, if there is one) to ascertain whether the patient has designated a family member or close friend to act as surrogate decisionmaker, or in the absence of such a designation, to determine whether there is a close and caring family member willing and able to act on the patient's behalf. In either case, the Ombudsman should defer any decisions concerning life-support to such a designated surrogate (a health care representative) or family member. In the absence of a close and caring family member or a designated surrogate, a guardian must be appointed to represent the patient's interests.[23] As under *Conroy*, participants who act in good faith to follow these procedures receive immunity from legal liability.

In the wake of *Conroy* and *Peter*, as well as the other opinions of the New Jersey Supreme Court, *Farrell* [24] and *Jobes* [25] (which, together with *Peter*, comprise the 1987 "trilogy" of termination-of-treatment decisions), there exists considerable debate and concern regarding both the intended and appropriate role for the Ombudsman in life-sustaining treatment decisions. Some interpret existing law to support, if not mandate, a broad role for the Ombudsman, with substantial involvement in all contemplated decisions to forego life-sustaining treatment for elderly, incompetent, institutionalized patients; others see the Court's emphasis on the role of family members and the importance of respecting the integrity of the physician-patient-family relationship as a source of legal (and ethical) limitation upon the Ombudsman's involvement in such decisions. While the Ombudsman's Office has taken the former position, the latter view is most forcefully stated by numerous members and representatives of New Jersey's health care and legal communities and others interested in creating a properly protective but not excessively cumbersome environment for health care decisionmaking for New Jersey's institutionalized elderly. While the Commission has not sought to take a definitive position on the "correct" interpretation of existing law, the Commission's work reflects a strong commitment to the integrity of the physician-patient-family relationship, and to the search for less cumbersome and less intrusive mechanisms for appropriate review of decisions to forego life-sustaining measures than has been characteristic of court intervention and New Jersey's experience with the Office of the Ombudsman.

Implementing the Procedures: The Ombudsman Controversy

Approximately one year after the Court's trilogy of termination-of-treatment decisions, the Ombudsman's interpretation of the Office's legal mandate and proper role was set forth in an August 30, 1988 letter from Acting Ombudsman Rodriguez to all long-term care facilities within the jurisdiction of the Office.* The letter stated the Ombudsman's view that, pursuant to

*This letter is reproduced in full in the Appendix to this Part of the report.

the "Mandatory Reporting of Adult Abuse Law" (the 1983 amendments) and the New Jersey Supreme Court's decisions in *Conroy* and *Peter*, "*every* proposal to forego life-sustaining medical diagnosis or treatment for any psychiatric hospital or nursing home patient age 60 and over who has not been currently and legally determined able to make such decisions on his/her own is a possible case of patient abuse."[26]

All such contemplated decisions are said to be subject to a mandatory reporting requirement applicable to "each medical director, physician, administrator, social worker, nurse, aide and other caregiving facility staff." "Upon receipt of a report of such potential abuse, the Ombudsman's Office must investigate." The letter provides a lengthy list of "all kinds of possible situations" where treatment decisions are said to constitute "possible abuse" and to be subject to the mandatory reporting requirement, including "Do-Not-Resuscitate" orders and orders not to transfer care to a hospital ("Do-Not-Hospitalize" orders), withholding or withdrawing of cardiopulmonary resuscitation, antibiotics, hemodialysis, artificial feeding systems, oxygen or mechanical ventilation, foregoing urinalysis or blood work, and decisions not to perform an amputation.[27]

The letter goes on to state that "there are exactly and only *two* kinds of exceptional cases in which it is merely optional, not mandatory, to notify the Ombudsman of a proposal to withhold or withdraw life-sustaining medical treatment or diagnosis." The first circumstance is where the patient is "currently verified" to be competent and making an informed refusal of the treatment or diagnostic procedure.[28] Pursuant to this approach, the patient would be presumed *incompetent*, unless determined by two independent physicians to be competent and giving informed refusal, the procedure set forth by the New Jersey Supreme Court in In re *Farrell*[29] (the so-called "*Farrell* Test").*

The second circumstance is where the treatment or diagnostic procedure is "medically futile" in one of two "highly restrictive senses," *i.e.*, where it is "counter-productive [and] would actually accelerate the patient's death," or where it "would not relieve (or, in the case of diagnosis, determine the etiology of) the patient's organic symptoms which the treatment is designed to alleviate."[30]

The broad scope of the reporting requirement and of the Ombudsman's role set forth in the August 30 letter is further emphasized by the letter's insistence that these rules apply "regardless of whether such a proposal comes from a relative, a guardian, a close friend, a physician, an attorney-in-fact under a written Power of Attorney, a "responsible party," or anyone else, including the patient," and regardless of whether the patient has an advance directive, or has provided other written or oral directions regarding life-sustaining measures.[31] The letter concludes by stating that "(p)atients' families, per se, no matter how devoted and caring, have *no known legal authority* to forego life-sustaining medical treatment or diagnosis on a patient's behalf. A family member's initiating or consenting to a "Do Not Hospitalize" order

* *See* the discussion of existing law in Part Three of the report. Contrary to the interpretation in the August 30 letter, *Farrell* maintains the traditional presumption of competence.

or a "Do Not Resuscitate" order, for instance, does not make those orders legal."[32]

The Response of the Health Care Community

The August 30 letter sparked intense controversy throughout the health care community. The Governor, various government agencies and the Commission itself received numerous letters and communications expressing concern about the Ombudsman's understanding of his role and the consequences of the Ombudsman's directives for patients, their families and professionals seeking to provide quality compassionate care for the incompetent institutionalized elderly. Responses to the August 30 letter raised issues which have been a source of continuing concern to the Commission throughout its study of decisions to forego life-sustaining measures. The following summary of these responses illustrates the serious and strongly felt concerns among members of the health care community, families and members of the legal profession.

At bottom, many contend that the Ombudsman overstepped his legal mandate and interfered with the rights of patients and families, in collaboration with health care professionals, to determine the course of their own treatment.[33] The August 30 letter, it is argued, rests on a mistaken understanding, or too "stringent" a reading, of the relevant Court decisions.[34] Critics of the Ombudsman's approach have noted that the New Jersey Supreme Court has stressed respect for and deference to the privacy of the physician-patient-family relationship, a central theme of the Court decisions ignored by the Ombudsman.[35] Furthermore, members of the health care community contend that by presuming potential "abuse" in such a broad class of cases in which a decision to forego life-sustaining measures is contemplated, and by insisting on mandatory notification and investigation of such decisions, the Ombudsman has created an atmosphere of suspicion and distrust.[36] This atmosphere is demeaning to patients, families and health care professionals, and threatens to interfere with the sound exercise of professional judgment.[37]

Implementation of the Ombudsman's investigating and reviewing responsibilities raised serious concerns as well. Reportedly, in some cases the Ombudsman's investigation of a proposed decision has caused unnecessary delays and expense, compounding an already difficult situation for patient, family and professionals.[38] Furthermore, health care professionals have reported a widespread perception that in order to "escape" the Ombudsman review process, it may be preferable to discharge patients to the home, or to transfer them to a hospital (the Ombudsman has no jurisdiction in hospitals). This motive to transfer care, which in some cases may be "'inappropriate hospitalization' that just runs up costs," further threatens the quality of patient care.[39] Thus, practical problems encountered when the Ombudsman has undertaken an investigation and become involved in a case have raised further questions regarding the efficacy of Ombudsman involvement and the priority use of the Office's resources.

Former Ombudsman Rodriguez responded to these concerns by insisting that the Office was only applying, not interpreting, the law.[40] In his view the August 30 letter was a recitation of its interpretation of existing case law meant to clarify and not to change the law. It was not intended to extend the authority of the Office or to modify existing regulatory procedures.[41] The Office asserted that the Court decisions required that, with the two exceptions noted above, all

proposed decisions to withhold or withdraw life-sustaining treatments (as listed in the letter) be treated as having the potential for abuse and that the Ombudsman be notified and investigate such decisions. The same procedure was required regardless of whether the patient had an advance directive, or whether the proposal to forego life-sustaining measures was made by a close relative or a complete stranger.[42] The Ombudsman acknowledged that these facts would be relevant in determining a patient's intent, but did not absolve anyone from the responsibility to notify the Office, nor did they alter the Ombudsman's responsibility to investigate. While noting that additional expenses were incurred along with occasional delays, the Office claimed that this additional cost was negligible when compared to the potential harm of a hasty, mistaken or improper decision.[43] *

A Proposed Regulatory Response

In March of 1989, "in order to clarify confusion about the use of life-sustaining treatments for nursing home residents" and to "clearly define those situations in which the Ombudsman for the Institutionalized Elderly must be notified," the Department of Health developed a set of regulations.[44] The draft regulations, which addressed a number of important issues, were submitted for review to the Health Care Administration Board (the "HCAB"). The HCAB heard testimony and reviewed the proposal at its April 13, 1989 meeting. With respect to the role of the Ombudsman, in the Commission's view the Department of Health's approach represented "a good faith attempt to respond to existing concerns and confusion in the long-term care community and to provide a framework for improvements in...sometimes counter-productive relationships between the Ombudsman and many health professionals, patients, and families." However, the Commission, joining with other members of New Jersey's health care community, opposed the release of the Department's proposed regulations on the ground, among others, that "the actions necessary to respond to the current controversy are the proper prerogative of the State Legislature, not of a necessarily more limited administrative or regulatory process."[45] At its meeting on April 13, 1989, the HCAB voted not to release the regulations, stating that in its view a statutory solution was preferable to regulatory action.[46]

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* Amidst the furor created by the August 30 letter, some pursued a formal legal response. In December of 1988, the New Jersey Hospital Association in conjunction with the Medical Center at Princeton brought a lawsuit challenging the August 30 letter on the ground, among others, that it was not issued pursuant to the New Jersey Administrative Procedure Act, and therefore constituted an unlawful rule-making. *The New Jersey Hospital Association and the Medical Center at Princeton, et. al v. Hector M. Rodriguez, as Ombudsman*, No. L88-6457. Joining in the lawsuit were The Medical Society of New Jersey, The New Jersey State Nurses Association and the New Jersey Association of Non-Profit Homes for the Aging. As a practical matter, the lawsuit resolved the controversy surrounding the August 30 letter itself. On April 13, 1989, in settlement of the lawsuit, the Ombudsman withdrew the letter. Soon thereafter, the Office submitted formal proposed regulations for public review and comment, in accordance with the Administrative Procedure Act. The proposed regulations, discussed more fully below, were published in the New Jersey Register on June 5, 1989. On May 5, 1989, Ombudsman Rodriguez resigned.

The Commission's Response: Reviewing Life-Sustaining Treatment Decisions, the Role of the Ombudsman, and Institutional Ethics Committees

In fashioning its policy recommendations concerning the role of the Ombudsman, the Commission chose to address the immediate and pressing issues highlighted by the controversy within the context of a broader search for ideas and proposals which would provide long-term guidance to the public, professionals, government officials and policymakers. In order to provide this guidance the Commission placed questions concerning the role of the Ombudsman on the agenda of both the full Commission and its Task Force on Institutional Ethics Committees. In the course of these deliberations, the Commission developed a series of responses summarized in the remainder of this chapter. The Commission's formal recommendations are found in a policy statement, approved by the Commission on December 29, 1988, and the Commission's comments on the Ombudsman's proposed regulations, submitted pursuant to the regulatory process on September 5, 1989.*

Throughout its work, the Commission has stressed the fundamental themes of respecting patient wishes and promoting patient well-being; respecting the integrity of the physician-patient-family relationship without undue and cumbersome intrusion; protecting vulnerable patients against abuse through recourse to appropriate review mechanisms; and the structuring of a sound decisionmaking process sensitive to these sometimes competing values and concerns. The involvement of a state agency in reviewing treatment decisions at the end of life raises as well fundamental issues of the proper role of government authority, and of the scope and limitations of government intervention as a protective mechanism for incompetent, elderly institutionalized patients. All of these themes are at work in the Commission's study of the Ombudsman's role in life-sustaining treatment decisions for the institutionalized elderly. The Commission's recommendations to date represent a partial response to some of the special concerns presented by the nursing home setting and the unique role of New Jersey's Ombudsman in this area.

The Commission recognizes that society has a legitimate and important interest in safeguarding seriously ill and vulnerable patients against the foregoing of treatment based upon mistaken diagnosis or prognosis, misunderstanding of the patient's wishes, or improper judgment of the patient's best interests. At the same time, patients should be protected against the continued provision of medical treatment that serves merely to prolong an inevitable dying process and its attendant suffering, and the imposition of unwanted and burdensome interventions, contrary to the patient's wishes and best interests. As stated by the New Jersey Supreme Court in *Conroy*, "(t)o err either way -- to keep a person alive under circumstances under which he would rather have been allowed to die, or to allow that person to die when he would have chosen to cling to life -- would be deeply unfortunate."[47]

Of particular concern to the Commission has been formulation of a decisionmaking process, including where appropriate recourse to a reviewing mechanism, that is balanced, timely and sensitive to the medical, ethical and personal dimensions of end-of-life decisions. As

* Both documents are reproduced in full in the Appendix to Part Four.

evidenced by the outcry of the health care community, for a dying patient, insensitive intrusion, or a lengthy delay in the review and implementation of a treatment decision, can cause serious harm and be an "abuse" of the patient and his or her family. As summarized in the Commission's policy statement:

> Given the possibility of errors with serious consequences in either direction, the Commission believes that the hallmarks of an appropriate process of decisionmaking and review must be balance, proportionality, timeliness, and sensitivity to the medical, moral and emotive dimensions -- and the inescapable ambiguities -- of such decisions. Any approach that is directed solely to preventing one form of error (*e.g.*, inappropriate foregoing of treatment) without regard to these other dimensions runs the risk -- or perhaps more realistically, incurs the certainty -- of encouraging or forcing errors in the opposite direction. The challenge ... is to develop a set of substantive principles and procedural protections that will be properly sensitive to both sets of risks and concerns and will not themselves impose costs and barriers that defeat the very purpose for their existence.

Accordingly, the Commission recommends that any procedural or regulatory scheme devised by the Ombudsman or other public agency should develop a process of review that insures timely decisionmaking without unnecessary delays; is sensitive to the feelings and needs of those involved in the decisionmaking process; targets the Office's investigative and other resources to cases with identifiable indicia of potential abuse or special vulnerability; allows for expedited review in cases in which risk is minimal or non-existent; avoids cumbersome, time-consuming, expensive or intrusive procedures; and aims at fostering a complementary and cooperative relationship with institutional or regional ethics committees.

The Commission strongly recommends that the Ombudsman develop a systematic and clear process that reflects these concerns and which facilitates timely implementation and resolution without presuming abuse in every case. To achieve these goals, the Office should set forth factors (indicia of abuse) designed to identify those cases in which Ombudsman review is most needed, such as those situations involving patients without prior written directives and lack of an involved advocate for a vulnerable patient, evidence of indifference or ill-motive by those acting on the patient's behalf, or irreconcilable disagreements among family members or health care professionals. The Ombudsman could then focus its investigative resources on those cases in which risk of error is greatest. The Commission also recommends that in its review of a proposed treatment decision, the Office give significant weight and deference to a patient's advance directive setting forth a patient's wishes concerning medical treatment, and that any review of a patient's advance directive be expedited.

The Commission believes that local ethics committees, either institutionally or regionally based, can and should play an increasingly central role in prospectively reviewing treatment decisions. A local review process which is closer to the clinical setting and more easily accessible can effectively assure that the elements of sound decisionmaking are in place. Such committees can provide expedited review in cases posing minimal risks of abuse and can identify particular cases in which further review by the Ombudsman is warranted. Ethics committees are

already well-established in hospitals, and have an increasing presence in the nursing home setting. The Commission recommends that "(a)s such committees become better established in [nursing homes and other long-term care facilities]...the Ombudsman should rely on such committees for routine prospective review functions." At the same time, the Ombudsman "should retain authority to participate in individual case reviews on an audit or spot-check basis," and should continue to engage in prospective review where there is no effective ethics committee in place, where cases are referred to the Ombudsman for further review, and where specific cases posing special risks of abuse warrant Ombudsman involvement. The Commission also believes that the Ombudsman's Office should have a supervisory or audit role to assure that individual ethics committees in nursing homes are functioning properly and effectively.

While the Commission recommends that the Ombudsman formally recognize the role of ethics committees, as outlined above, through the exercise of its regulatory authority, the Commission believes that legislative action may be needed to legally empower local and regional ethics committees to perform prospective case review. The Commission has taken a first step in this direction in its proposed "New Jersey Advance Directives for Health Care Act." Specifically, sections 15(A)(4) and 16(A)(3) of the proposed legislation provide that in specified circumstances a local review process meeting standards established by law would be a legally recognized alternative to Ombudsman review for cases within the Ombudsman's jurisdiction.*

More significantly in this context, over the past year, the Commission, through its Task Force on Institutional Ethics Committees, has made substantial progress in the development of a more comprehensive approach to a prospective case consultation role for institutional and regional ethics committees. Both the Commission and the Task Force recommend that all hospitals and nursing homes in New Jersey establish committees (termed in the proposal "bioethics consultation committees") suited to this prospective reviewing function. Further development of the appropriate legal framework within which such committees should function, including the precise relationship between such committees and the role of the Ombudsman in reviewing life-sustaining treatment decisions, are issues foremost on the Commission and Task Force agenda.**

The Ombudsman's Proposed Regulations: The Commission's Response

On June 5, 1989, the Ombudsman published in the New Jersey Register and made available for public comment a proposal to revise the Office's existing administrative rules. The proposed regulations are designed to "give an interpretation of the law requiring certain reporting to the Office" and to cover when and how both required and optional reports are to be made to the Office, as well as how such reports are to be handled.

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*See "Proposed New Jersey Advance Directives for Health Care Act: With Commentary," secs. 15(A)(4) and 16(A)(3), Part Three, Chapter Four.

**A complete discussion of the work of the Commission and its Task Force on Institutional Ethics Committees concerning a prospective case consultation role for institutional and regional ethics committees may be found in Part Five of the report. *See also* the discussion of the existing legal context in Part Three.

On September 5, 1989, the Commission provided its comments on the proposed regulations, one of close to 40 sets of comments considered by the Office in its revision of the proposed regulations.* The Commission's comments iterate its commitment to the general approach described above. Thus, the Commission's comments stress, among other points, the importance of a timely and sensitive review process designed to respect patient rights and to protect patient well-being; and of establishing and making public a system of priorities for the Ombudsman's involvement in life-sustaining treatment decisions, including expedited review of cases posing minimal risks of actual abuse, such as cases in which a decision to forego life-sustaining treatment is contemplated pursuant to the terms of a patient's advance directive, or cases in which close and caring family members are acting on the patient's behalf and family and health care professionals concur that life-sustaining treatment should be withheld or withdrawn. Deference to local review processes and a cooperative relationship with ethics committees engaged in prospective case review is strongly encouraged. In the Commission's view, the Ombudsman's proposed regulations should go significantly further in achieving these important objectives.

Also of particular importance, the Commission's comments seek to address, in small measure, the atmosphere of suspicion and distrust engendered by the term and language of "patient abuse." While recognizing that this language is statutorily based, the Commission, like many in the health care community, finds the language of "patient abuse" to be generally ill-suited to many or most situations in which patients, family members, health care representatives, and physicians contemplate a decision to forego life-sustaining treatment. In the Commission's view, the proposed regulations should, following the Court in *Conroy*, formally recognize that the withholding or withdrawal of life-sustaining treatment, pursuant to the patient's wishes or where such treatment does not benefit the patient, and in accordance with applicable law and regulation, is not to be construed as a "willful deprivation of services," or as an instance of "abuse."

Conclusion

In the aftermath of the formal withdrawal of the August 30 letter and the change in leadership in the Ombudsman's Office, the intensity of the controversy within the health care community has abated. The current Ombudsman has been working cooperatively with the health care community to address continuing concerns and to further develop the Office's proposed regulations. The revised regulations were published in the New Jersey Register on April 2, 1990; yet no formal change in the Office's regulations has been adopted. Consequently, while the atmosphere and attitude within the health care community has improved, little formal change in existing legal requirements has been achieved. Health care professionals, patients, and families continue somewhat uneasily to try to find their way in a situation characterized by uncertainty regarding their legal rights and obligations.[48] The Commission remains concerned about the possible "chilling effect" of the present situation on the exercise of both good medical judgment and respect for patient and family rights, interests and prerogatives. The Commission

* The proposed regulations and the Commission's response are reproduced in the Appendix to this Part.

strongly believes that the absence of clear and appropriate guidelines can only impede the development of a working environment of trust which gives all participants in the decisionmaking process the confidence to exercise their best judgment in fulfilling their professional, legal and ethical obligations.

The Commission also believes that changes it has recommended in existing regulations, its legislative initiatives on advance directives, and its continuing examination of a prospective case consultation role for ethics committees will help to provide necessary protections for the incompetent institutionalized elderly, while simultaneously framing a more well-defined and manageable role for the Ombudsman in the decisionmaking process. As stated in the Commission's policy statement:

> To the degree legislative action is required to refine the definition of abuse, to empower local or regional ethics committees to perform prospective case review in appropriate fashion, and to enable the Ombudsman both to audit the committee review process and to rely on that process in a broad class of individual cases, thereby enabling the Ombudsman's Office to focus on the cases most requiring its attention, the Commission believes such legislative action is warranted and should take place.

The Commission plans to continue these initiatives through its Task Force on Institutional Ethics Committees and to devote substantial attention to further development of recommendations for a legislative approach designed to provide a clear legal mandate for ethics committees. In conjunction with these efforts, the Commission looks forward to continuing to work with the health care community and the Ombudsman to refine and implement a more balanced and effective legal and ethical environment to confront these difficult decisions in a manner respectful of the rights and protective of the well-being of all elderly, institutionalized citizens.

Notes

1. 98 N.J. 321, 486 A.2d 1209 (1985).

2. "Report of the Governor's Advisory Council on Elderly Abuse" (May 15, 1986). The Council was established by Executive Order 103 on May 28, 1985, and was chaired by Commissioner of Community Affairs Leonard S. Coleman, Jr. It was charged with the responsibility to develop a comprehensive strategy to prevent elderly abuse in New Jersey.

3. *Id.*, pp. iii-iv.

4. "Interim Report of the New Jersey Nursing Home Study Commission" (March 1976).

5. *N.J.S.A* 52:27G-1 *et seq.* (West 1977; amended 1983). ("An Act concerning the health, safety, welfare, civil and human rights of elderly persons, establishing the Office of the Ombudsman for the Institutionalized Elderly, and making an appropriation"). Prior to the statutory creation of an independent Office of the Ombudsman, a federally funded position of ombudsman for nursing home patients existed as a "one man" office in the Division of Aging within the Department of Community Affairs.

6. *N.J.S.A.* 52:27G-6 (West 1977).

7. *N.J.S.A.* 52:27G-7.1. This was an act to "amend and supplement" the statute establishing the Office of the Ombudsman.

8. *N.J.S.A.* 52:27G-8 (West 1977).

9. *N.J.S.A.* 52:27G-7 (West 1977).

10. *N.J.S.A.* 52:27G-10 (West 1977).

11. This is in contrast to the typical role of the Ombudsman's Office in other states. Abraham Monk, Leonard W. Kaye and Howard Litwin, *Resolving Grievances in the Nursing Home: A Study of the Ombudsman Program* (Columbia University Press 1984): 89.

12. *N.J.S.A.* 52:27G-2(a) (West 1983).

13. Jack D'Ambrosio, "Office of the Ombudsman for the Institutionalized Elderly," *The New Jersey Lawyer* (Winter 1985): 46.

To facilitate reporting, the Office established an "800" telephone number and required nursing homes to display it and other information about the services of the Office in prominent locations in the facility. *N.J.S.A.* 52:27G-11 (West 1977). A brochure distributed by the Office of the Ombudsman provides the public and professionals with information on the various services offered by the Office.

14. 98 N.J. 321, 486 A.2d 1209 (1985).

15. *N.J.S.A.* 52:27G *et seq.* (West 1977).

16. 98 N.J. at 375, 486 A.2d at 1237.

17. *Id.* at 375-76, 486 A.2d at 1237-38.

18. *N.J.S.A.* 52:27G-2(a) (West 1983) (emphasis added).

19. 98 N.J. at 383-84, 486 A.2d at 1241-42.

20. *In re Peter*, 108 N.J. 365, 529 A.2d 419 (1987).

21. *Id.* at 383, 529 A.2d at 428.

22. *Id.*

23. *Id.* at 383-84, 529 A.2d at 429.

24. *In re Farrell*, 108 N.J. 335, 529 A.2d 404 (1987).

25. *In re Jobes*, 108 N.J. 394, 529 A.2d 434 (1987).

26. Letter from Hector Rodriguez, Acting Ombudsman, to all long-term care facilities within the jurisdiction of the Office (Aug. 30, 1988), p. 1 (the "August 30 letter").

27. *Id.*, pp. 1-2.

28. *Id.* (emphasis in original).

29. 108 N.J. at 335, 529 A. 2d at 415.

30. August 30 letter, *supra* note 26, pp. 2-3.

31. *Id.*, p. 1.

32. *Id.*, p. 3 (emphasis in original).

33. Letter from the Jewish Home and Rehabilitation Center, Westfield, N.J., to Commission on Legal and Ethical Problems in the Delivery of Health Care (Oct. 6, 1988); Letter from Giles Scofield, Staff Attorney, Citizens Concerned for Dying, to Commission on Legal and Ethical Problems in the Delivery of Health Care (Oct. 3, 1988).

34. *See* Legal opinion prepared at the request of Senator Gabriel M. Ambrosio by the Legislative Counsel, Office of Legislative Services (Nov. 14, 1988), p.6. The opinion letter was prepared by Anita M. Saynisch, the Associate Counsel. The letter states in relevant part:

> Although the ombudsman's position set forth in his letter of August 30, 1988, may be arguable under current law, his position is less justifiable when read in the light of the overriding principle that the decision to withhold or withdraw treatment should be left free from judicial and other bureaucratic interference.
>
> The court throughout the "right-to-die" cases has stressed the importance of family in these decisions. In *Peter* the court summarized its view:
>
> > We emphasize that in this and every case, the ultimate decision is not for the Court. The decision is primarily that of the patient, competent or incompetent, and the patient's family or guardian and physician. 108 *N.J.* at 385 (see also *The Matter of Kathleen Farrell*, 108 *N.J.* at 358-59).
>
> In summary, the positions taken by the Ombudsman in his letter of August 30, 1988, in large part, are arguable ones in the light of the powers bestowed on the office pursuant to statute and the statute's interpretation in the New Jersey Supreme Court decision of *In re Peter*.

35. David M. Price & Paul W. Armstrong, "New Jersey's Granny Doe Squad: Arguments about Mechanisms for Protection of Vulnerable Patients," *Law, Medicine & Health Care* 178 (3) (Fall 1988): 259.

36. Letter from New Jersey State Nurses Association to Governor Thomas H. Kean (Oct. 3, 1988) (copy to the Commission).

37. Diane M. Gianelli, "N.J. MDs upset with patient 'abuse' law," *American Medical News* (Nov. 4, 1988), p. 27 ("Gianelli").

38. Letter from the American Geriatrics Society to Acting Ombudsman Rodriguez (Dec. 19, 1988) (copy to the Commission and others). The Court in *Conroy*, 98 N.J. at 384, 486 A.2d at 1242, held that the Ombudsman should use his statutory authority to hire the two consulting physicians necessary to confirm a diagnosis of terminal illness. The Court indicated that "the physicians may be compensated by the patient's estate, the guardian, the family, or the nursing home." In the event these sources cannot provide sufficient funds the guardian is to seek reimbursement from the Ombudsman or "possibly" Medicare. The same rule applies where there is a contemplated decision to forego life-sustaining treatment for a PVS patient.

39. Gianelli, *supra* note 37.

40. Kathleen Bird, "Ombudsman Letter Creates Legal Furor," *The New Jersey Law Journal* (Nov. 3, 1988).

41. Kathleen Bird, "Ombudsman in Center of a New Storm," *The New Jersey Law Journal* (Feb. 2, 1989), p. 17.

42. *Id.*; Gianelli, *supra* note 37, pp. 29-30.

43. Gianelli, *supra* note 37.

44. Press release from Dr. Molly Coye, State Commissioner of Health (March 16, 1989). The proposal was entitled "Guidelines on Withholding or Withdrawal of Life-Sustaining Treatment For Residents In Long-Term Care Facilities." In addition to seeking to address the Ombudsman procedures, the proposal recommended the use of medical directives for health care to insure that a patient's wishes concerning life-sustaining treatment were on record and available for review by caregivers and, if necessary, the Ombudsman. The proposal included two recommended forms and a detailed description of four sets of procedural requirements for implementing a patient's expressed wishes, tailored to different kinds of situations determined by patient condition and prognosis.

45. "Joint Statement to the Health Care Administration Board" (April 13, 1989). The statement outlined the objections of the signers to the Department of Health proposal. Co-signers of the statement were: The New Jersey Bioethics Commission; The New Jersey Hospital Association; The New Jersey Association of Non-Profit Homes for the Aging; The New Jersey Hospice Organization; The Home Health Assembly of New Jersey; The New Jersey Geriatric Society; The Chairman and Vice-Chairman of the Committee on Biomedical Ethics, the Medical Society of New Jersey; The Citizens' Committee on Biomedical Ethics; and The Executive Committee of the Meadow Lakes Forum.

46. Letter to Governor Thomas Kean from Thomas J. Foley, Chairman of the Health Care Administration Board (May 12, 1989). The letter stated the HCAB's support for S-3320 (now S-1211 in the 1990 legislative session), the proposed New Jersey Advance Directives for Health Care Act.

47. 98 N.J. at 343, 486 A.2d at 1220.

48. Michael Weinstein, "Controversy in N.J. Over Medical Care of the Dying Elderly," *American College of Physicians Observer* 9 (5) (May 1989).

Chapter Two: The Office of The Public Guardian For Elderly Adults

Cognizant of both the growth of the elderly population in New Jersey and of the needs of the elderly for financial, residential, medical and other kinds of assistance, in 1985 the New Jersey Legislature created the Office of the Public Guardian for Elderly Adults (the "Office" or the "Public Guardian"). The purpose of the Office is to provide guardianships for senior citizens over the age of 60 who have been adjudicated incompetent and who have no willing or appropriate family members or friends to care for them or to make certain important types of decisions on their behalf.[1]

Description of the Office

Judicial proceedings seeking the appointment of the Office are brought by institutions or persons that believe a senior citizen is in need of the services provided by the Public Guardian. Examples of petitioners include hospitals, creditors, county welfare agencies, and other public and private agencies.[2] In addition, a court can appoint the Office to serve as guardian when it finds a family member to be an inappropriate surrogate. Following judicial granting of a petition, the Office ordinarily becomes responsible for managing the ward's well-being and assets.

The Office is assisted by its Advisory Council which consists of a panel of medical and legal specialists with expertise in, among other areas, psychiatry, gerontology, and accounting, who render opinions "as needed." The Office may also obtain the services of any other experts it deems necessary in a specific situation. The Office has a full-time staff of 22 attorneys, accountants, caseworkers and clerical staff who coordinate and manage the guardianship process.[3]

General Services

The initial responsibility of the Public Guardian involves placing the ward in the least restrictive environment, dependent upon his or her health and financial status. If hospitalized at the time the Public Guardian is appointed to the case, the patient's physician plays a role in determining the appropriate health care setting. As a practical matter, since most senior citizens require some health care but cannot afford the cost of necessary medical treatment at home for an extended length of time, boarding or nursing home placements frequently provide viable residential alternatives.[4]

Subsequent to placement, the Office generally provides full guardianship services, including the management of financial resources, property and medical decisionmaking. For some persons, however, the Public Guardian may assume only a portion of the full complement of services. For instance, the Office might act as a property guardian or guardian over the

person alone, or might be called on to serve in a temporary capacity. In some cases, the Public Guardian is appointed for a single purpose, such as medical decisionmaking. The Office may also provide a combination, but not all, of these services.[5]

The Office maintains continual contact with its wards. Those who live at home or in group living situations such as boarding homes are visited by caseworkers weekly; bimonthly visits are made to individuals placed in nursing homes. During visits, the caseworker is responsible to meet both with the client to discuss and evaluate concerns or problems, and with health care professionals to review records. From time to time, visits with the patient's physician to keep informed of changes in the patient's health and health care needs may be advised.[6]

From the inception of the Office until December 1989, the Public Guardian has worked with approximately 300 New Jersey residents.[7]

Medical Services

Medical decisionmaking concerning routine medical care as well as emergency procedures is one of the significant services provided by the Public Guardian. The Office's responsibility for medical decisionmaking may arise pursuant to a general guardianship or a special medical guardianship. Decisions regarding medical treatment for wards are made by the Public Guardian with the attending physician and caseworker. The Office seeks to involve the patient and any willing family members or friends in the decisionmaking process as well.

In addition to its medical decisionmaking functions on behalf of the clients for whom the Office maintains general guardianships, the Public Guardian can also be appointed to serve temporarily or permanently as a special medical guardian for a patient who lacks the ability to provide informed consent to a specific requisite (usually emergency) medical procedure. Before agreeing to treatment, the Public Guardian is given information concerning the patient's diagnosis, alternatives and risks. The Public Guardian consults with the attending physician and may call upon its Advisory Council to help reach a decision.[8] In some cases, the Public Guardian has served as a special medical guardian for only one specific medical decision. Frequently, however, even such limited involvement becomes permanent due to subsequent interventions, medical complications, or additional problems that develop with an aging and debilitated population.

The number of special medical guardianship cases has been steadily increasing. Between January 1987 and December of 1989, the Office handled approximately 125 special medical guardianships. In calendar 1989 the Office had over 1,000 inquiries.[9]

Though the Office of the Public Guardian has been involved in many issues of medical decisionmaking, only a small number of cases have involved decisions to continue or terminate life-sustaining measures. The practice of the Public Guardian is to obtain information concerning the patient's diagnosis and prognosis from the attending physician and nurses, as well as from two other physicians unaffiliated with the facility or treating physician. The Office also gathers any evidence of the patient's treatment preferences. In a few cases, the wards have written some

form of advance directive.[10] With respect to terminally ill patients, the Office has followed the *Conroy*[11] guidelines for decisions to forego life-sustaining treatment. In those cases in which the Office of the Ombudsman has jurisdiction, the Ombudsman would be involved in reviewing the decision, pursuant to the *Conroy* and *Peter*[12] decisions. The Public Guardian ordinarily notifies the court of any decision to continue or discontinue life-sustaining measures for a patient.[13]

The Public Guardian has noted that in some cases when a ward is transferred from a residential facility to a hospital, medical records do not follow the patient to the hospital. Without the records, the hospital and physicians are unaware of the appointment of the Public Guardian and may proceed to make medical decisions without the concurrence of the Office or family members.[14] The Office believes it is making progress toward achieving cooperation between residential facilities and hospitals.[15] As awareness of the Office and its functions increases, further cooperation can be anticipated.

Conclusion

The Public Guardian serves a valuable function in protecting the rights and interests of New Jersey's elderly, institutionalized population. The Office has experienced a steady increase in the number of cases in which it has been appointed to serve as either general guardian or as special medical guardian, likely due to a growing awareness within the health care community of the Office's role and responsibilities.[16] Given the dramatic increase in the number of elderly New Jersey citizens, cases presenting issues of the termination of life-sustaining measures can be expected to increase in the future.

As discussed in Part Five of this report, the Commission plans through its Task Force on Protecting Vulnerable Patients to make the study of health care decisionmaking for patients who lack decisionmaking capacity and are without a close family member or friend acting on their behalf a top priority in its future work. The Commission hopes to learn from the experiences and insights of the Public Guardian and to work cooperatively with that Office in these efforts.

Notes

1. *N.J.S.A.* 52:27G-20 *et seq.* (West 1985). Like the Ombudsman for the Institutionalized Elderly, the Public Guardian, created in the executive branch, was allocated to the Department of Community Affairs but deemed to be independent of the Department's control or supervision. *Id.* at 52:27G-23.

2. *See* Office of the Public Guardian for Elderly Adults, Report of Accountability 1988-89 ("Report of Accountability").

3. *See* Office of the Public Guardian's Report to the New Jersey Bioethics Commission, attached to letter from Marie S. Muhler, Public Guardian for Elderly Adults, to Daniel F. O'Connell, Chairman, The New Jersey Bioethics Commission (Oct. 12, 1988), at 2 ("Public Guardian's Report").

4. *Id.* at 3; Report of Accountability.

5. *N.J.S.A.* 52:27G-29 (West 1985).

6. Public Guardian's Report at 3.

7. Telephone conversations between Adrienne Asch, Associate in Social Science and Policy, New Jersey Bioethics Commission, and Marie S. Muhler, Public Guardian for Elderly Adults (Dec. 7 & 28, 1989).

8. Public Guardian's Report at 4.

9. Telephone conversation between Janice Chiantese, Director of Government Relations, New Jersey Bioethics Commission, and Alyce Rosner, Director of Communications, Public Guardian for Elderly Adults (Feb. 28, 1990).

10. *See supra* note 7.

11. 98 N.J. 321, 486 A.2d 1209 (1985).

12. 108 N.J. 365, 529 A.2d 419 (1987).

13. Public Guardian's Report at 4-5.

14. *Id.* at 5.

15. *See supra* note 10.

16. *Id.*

Chapter Three
The Implementation of "Baby Doe" Regulations in New Jersey

Biotechnological advances over the past several decades have allowed many infants born with a wide variety of disabilities to receive medical treatment designed to prolong, improve and save their lives.[1] The positive consequences of administering such techniques cannot be overstated; for instance, while infants born at 28 weeks of gestation were once considered "nonviable fetuses," they can now be treated successfully.[2] At the same time, the possibilities of treatment for newborns with serious disabilities have raised questions of ethical, medical and legal dimensions, including, among others, whether all newborns ought to receive life-sustaining measures and, if not, in what circumstances such treatment may be foregone.

This issue has been the subject of a number of studies conducted over almost two decades. In 1973, a report by two physicians who worked at the special-care nursery of a university hospital revealed that 14 percent of infant deaths at the facility were directly related to the withholding of care. Although the rationale of imminent and unavoidable death underlay some of the decisions to withhold treatment, in other cases the motivation was the probability of lifetime disability for the newborn.[3]

Although related studies and surveys disclosed equivalent results,[4] the question of withholding of medical care for newborns with serious impairments did not attract national attention until 1982, in the well-publicized case popularly known as "Baby Doe." This case, together with that of "Baby Jane Doe," prompted a series of federal regulations (ultimately invalidated by judicial order), followed by an amendment to the federal Child Abuse Act, additional federal regulations, and implementation of this law in each State.

The Baby Doe Cases: Background

Baby Doe was born in Bloomington, Indiana with Down syndrome[5] and a surgically correctable gastrointestinal malformation known as esophageal atresia. (Additional details of his medical condition were not released.)[6] Although intravenous feeding of food and water would have maintained him for a period of time, surgery was necessary both to prevent pneumonia caused by stomach acids reaching the lungs and to provide normal feeding abilities.[7]

The parents were advised by physicians that they could consent either to the major surgery, which would have given their son a 50 percent chance of survival (although nothing could be done to correct his mental retardation resulting from Down's syndrome), or to let "nature take its course," in which case the infant could contract pneumonia and die.[8] The parents decided to forego the operation. Again, no information was released about the considerations that entered into their determination.[9]

The hospital brought an action in state court to override the parents' refusal to consent to corrective surgery. The denial of relief by the trial court was affirmed by the Indiana appellate courts; the state's Supreme Court declined to override the lower court decision not to intervene in the parents' decision.[10] Baby Doe died six days after birth, while an appeal was pending to the United States Supreme Court.[11] The situation of Baby Doe reached newspaper headlines across the country[12] and aroused awareness of and commentary about[13] the issue. Public attention became even further ignited the following year in the New York case of Baby Jane Doe.

In the "Baby Jane Doe" case the medical condition and prognosis of the hospitalized infant were disputed. According to a judicial account, she suffered from multiple birth impairments, including myelomeningocele (also called "spina bifida"),[14] which caused impairments to her rectal, bladder and sensory functions; microcephaly[15]; hydrocephalus[16]; "weak face"[17]; malformed brain stem; spasticity of the upper extremity of her body; and a thumb within her fist. The court account stated that the risk to the baby of severe mental retardation prohibiting her from interacting with her environment or other people was extremely high as a result of having the dual conditions of microcephaly and hydrocephalus. Corrective surgical procedures were unlikely to improve many of her handicaps, including the mental retardation.[18]

Other accounts of Baby Jane Doe questioned the extent of her medical condition. In contrast to the prognosis reported by the court, one physician, a professor of surgery and a national expert on spina bifida, predicted that had Baby Jane Doe received surgery she might have achieved intelligence in the normal range and might have been ambulatory with the aid of braces.[19]

Baby Jane Doe's pediatric neurosurgeon advised performing an operation to correct the spina bifida and hydrocephalus conditions and thereby prolong her life. Her parents, after consulting with physicians, nurses, religious advisors, a social worker and family members, decided that the medical procedure should not be performed; instead, the newborn would be fed nutritiously, administered antibiotics, and her exposed spinal sac would be dressed.[20]

The parents' judgment resulted in the commencement of a legal proceeding brought by an attorney unrelated to Baby Jane Doe or her family, seeking both the appointment of a guardian *ad litem* for the newborn and an order directing the hospital to perform the surgery. The New York Court of Appeals denied relief, finding that the petitioner had no direct interest or relationship to any party and that the New York State Department of Social Services had not been contacted.[21]

The Initial Federal Regulatory Response

In response to the first Baby Doe case, the Department of Health and Human Services ("HHS") began issuing regulations pursuant to section 504 of the Rehabilitation Act of 1973.[22] The initial regulation, called the "Interim Final Rule," was designed to satisfy the emergent needs of a disabled infant denied food or medical care in a program or facility receiving federal financial assistance on the discriminatory basis of his or her impairment. The rule required

timely reporting of alleged violations, prompt investigations and immediate enforcement action if needed.[23] On April 14, 1983 the Interim Final Rule was invalidated in the case of *American Academy of Pediatrics et al. v. Heckler*[24] upon the finding by the federal district court that the regulation was an arbitrary and capricious action by HHS which failed to consider a number of factors relevant to the application of section 504 to the medical care of newborns[25] and which did not meet requisite standards of the Administrative Procedure Act.[26] Subsequent regulations revising details of the first rule followed.[27] The last regulation in the series, called the "Final Rule," was challenged by the American Hospital Association, the American Medical Association and others.

In the plurality opinion of *Bowen v. American Hospital Association et al*[28], the United States Supreme Court held, *inter alia*, that the regulations were not founded upon evidence of discrimination and were not within the authority conferred on the Secretary of HHS by section 504 to prevent discrimination. As a result of *Bowen*, the Final Rules issued by HHS applying section 504 to the situation of withholding of medical care from disabled newborns were permanently enjoined.

The Child Abuse Amendments and Federal Regulations

While litigants were contesting the application of section 504 to the treatment of newborns with disabilities, several organizations were lobbying Congress for legislation specifically designed to deal with the situation of the withholding of medical care from infants who, despite benefitting from treatment, would have lifelong disabilities. After numerous documents were received and testimony heard by the congressional Subcommittee on Family and Human Services,[29] Congress decided to enact legislation. In October 1984 (more than one and a half years before the Supreme Court rendered its opinion in *Bowen*), Congress amended the Child Abuse Prevention and Treatment and Adoption Reform Law ("Child Abuse Amendments").[30] Among other modifications, the amendments provided that in order for a State to receive federal funding under the Act it must, within one year (*i.e.*, by October 9, 1985), provide procedures and/or programs within its child protective services system designed to respond to reports of medical neglect, including reports of the withholding of medically indicated treatment from disabled infants with life-threatening conditions.[31] Essential to the procedures and/or programs are three requirements:

> 1) coordination and consultation with individuals within health care facilities; (2) prompt notification by such individuals of cases of suspected medical neglect, including reports of withholding of medically indicated treatment from disabled infants with life-threatening conditions; and (3) authority pursuant to state law for the child protective service system of the state to pursue any legal remedies, including instituting legal proceedings needed to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions.[32]

The term "withholding of medically indicated treatment" is defined in the Child Abuse Amendments as:

> the failure to respond to the infant's life-threatening conditions by providing

> treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's or physicians' reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions; except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician's or physicians' reasonable medical judgment, (A) the infant is chronically and irreversibly comatose; (B) the provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or (iii) otherwise be futile in terms of the survival of the infant; or (C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.[33]

The Amendments further authorize additional grants to the states to develop, establish, operate or implement the required procedures or programs; to offer information, education or training programs for personnel and parents involved with the welfare of disabled infants; and to establish programs to obtain necessary support services.[34] Finally, the statute requires the Secretary of HHS to provide training and technical assistance programs in order to help states develop, establish, operate or implement procedures or programs and to establish and operate clearinghouses to provide current and complete information concerning medical treatment procedures as well as community resources providing services and treatment for disabled infants.[35]

The Secretary of HHS filed regulations designed to implement the Child Abuse Amendments which became effective in October 1985,[36] as well as interpretive guidelines suggesting non-binding definitions of several statutory terms and phrases[37] and interim model guidelines for the establishment of infant care review committees ("ICRCs") by health care providers.[38] The Regulations clarify some generalities of the statute. For instance, the regulations define the following terms, *inter alia*:[39] "medical neglect" is "the failure to provide adequate medical care,"[40] [including, but not limited to] "the withholding of medically indicated treatment from disabled infants with life-threatening conditions"[41] and "reasonable medical judgment" is defined as "a medical judgment [made] by a reasonably prudent physician, knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved."[42] Another example of a clarification made in the regulations is a specification that issues of medical treatment for infants less than one year old are to be considered under the standards of the statutory definition of "withholding of medically indicated treatment," whereas such issues for infants over one year are to be considered under the more general standards of "medical neglect" unless the infant over one year has been hospitalized since birth, was born extremely prematurely or has long term disabilities.[43]

Other significant points set forth in the Regulations include (1) prompt contact (and annual updates) by each state child protective service agency ("Agency") to each health care facility to obtain the name, title and telephone number of the person whose responsibility it is to coordinate, consult with and notify the Agency of known or suspected cases of medical neglect;[44] and (2) the requisite development of state procedures consistent with state law to obtain access

to medical records and/or other relevant information and to obtain a court order for an independent medical examination of the infant when needed to ensure an appropriate investigation of a medical neglect report.[45]

On the same date that the Secretary of HHS approved the Regulations, she also approved model guidelines (required by the Child Abuse Amendments)[46] for the provision of ICRCs by health care providers. The stated purpose of such committees would be to "educat[e] hospital personnel and families of disabled infants with life-threatening conditions, recommend institutional policies and guidelines concerning the withholding of medically indicated treatment (including appropriate nutrition, hydration, and medication) from such infants, and offer counsel and review in cases involving disabled infants with life-threatening conditions."[47] The Model Guidelines for the ICRCs outline[48] and analyze[49] membership and administration of ICRCs, educational activities, policy development, and counsel and record review of cases.[50]

New Jersey Implementation

The Division of Youth and Family Services ("DYFS") is the child protective services agency in the State of New Jersey. Subsequent to the passage of the federal law and regulations, DYFS became the state arm charged with the responsibility of implementing the Child Abuse Amendments.* Within DYFS, the Institutional Abuse Investigation Unit ("IAIU") became responsible to inquire into allegations of the withholding of medically indicated treatment.[51] The IAIU established a process for dealing with alleged "Baby Doe" cases whereby it annually contacts each health care facility in the State to obtain the name, title and telephone number of the individual(s) designated by the facility to coordinate procedures concerning the withholding of medically indicated treatment from seriously ill newborns with life-threatening conditions. Further, since August 1985 the IAIU has been distributing to each acute care facility a copy of a form entitled Procedures for the Investigation of Baby Doe Cases in New Jersey ("Procedures Memorandum"). The Procedures Memorandum lists DYFS reporting requirements, policies and procedures both for investigating medical neglect cases, including those involving disabled infants with life-threatening conditions, and for pursuing judicial intervention to protect the interests of newborns in appropriate cases.[52] Recently, DYFS commenced the process of transforming the currently uncodified procedures it employs in child abuse cases (including those involving the claimed withholding of medically indicated treatment for newborns) into proposed regulations.

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*In addition to these procedures and in consonance with the spirit of the Child Abuse Amendments, the legislature of the State of New Jersey enacted the Newborn Law on February 25, 1987, as an addition to the Health and Vital Statistics Law of New Jersey. The statute provides in relevant part:

> The governing body of a health care facility licensed in this state...which provides health care services to newborn children shall adopt policies and procedures which ensure that newborn children, including newborn handicapped children, receive a level of nourishment and medical care consistent with accepted medical standards.
>
> If a federal statute or regulation requires that the State submit its regulations and policy to the federal government for approval in order to qualify for federal funding, then the State Department of Health shall so comply. *N.J.S.A.* 26: 2H-12.6 (West 1987).

The Procedures Memorandum first specifies that a person in the medical facility with knowledge of the alleged instance of abuse is to report that information to the IAIU. It then states the requisite steps to be taken following a report of medical neglect. Initially, an IAIU supervisor or investigator and a pediatric consultant employed by DYFS are to be contacted. The pediatric consultant is directed to talk to the facility coordinator, review the condition of the infant, and, if indicated, make an appointment to initiate an on-site investigation. Further, if indicated, the investigative team (defined as the IAIU investigator and pediatric consultant) are to speak to the child's physician, the chairperson of the ICRC, or another designated person with knowledge of the situation.

The next step in the investigative process involves collection of data. Pursuant to statute,[53] the IAIU investigator requests the relevant medical records and proceedings of the ICRC (if applicable) and attempts to obtain information concerning the sequence of events leading up to the referral. After reviewing the records, the pediatric consultant should, if appropriate, examine the child and determine whether, on the basis of available information, the decision to withhold treatment is reasonable. The Procedures Memorandum provides that assistance in these efforts may be furnished by other pediatricians from the New Jersey Chapter of the American Academy of Pediatrics.

The final steps in the procedure involve the process for concluding an investigation. The Procedures Memorandum provides that if DYFS determines that it need no longer be involved in the investigation, a report terminating the investigation shall be prepared and signed by the IAIU investigator, the pediatric consultant and the Institutional Abuse Supervisor. The report must then be sent to the hospital administrator and a limited number of other appropriate parties. Suggested recipients include the New Jersey Department of Health and the Chairman of the Board of Directors of the medical facility involved.

If DYFS determines that intervention is required to protect the infant's interests, the investigator is to confer with the Deputy Attorney General to prepare for judicial action. An "Institutional Abuse Report" must be written containing the same requisites as one prepared when DYFS determines that its involvement is unnecessary. The Procedures Memorandum provides that all reports shall be forwarded within 30 days to the same recipients noted above.

In sum, the DYFS procedures provide a detailed response to the requirements for state implementation posed by the Child Abuse Amendments and the federal regulations. Both federal and state schemes attempt to ensure treatment for those infants whose best interests would be served by the administration of medical care while simultaneously permitting the termination of treatment for newborns whose best interests would so dictate. Nonetheless, some steps may be warranted to further protect the interests of seriously impaired newborns.

Suggestions For Future Action

An examination of the memorandum sent to health care facilities in the state reveals that the general procedures satisfy the requirements delineated in the federal statute.[54] However, in

order to ensure that no instance raising the spectre of abuse slips through the schemes, some further clarifications may be in order.

The Definition of Health Care Facilities

The federal and state laws and procedures focus on the provision of services to newborns within health care facilities. The Child Abuse Amendments require state child protective service systems to coordinate programs for notification of instances of medical neglect with individuals within appropriate health care facilities.[55] The Newborn Law requires the governing bodies of licensed health care facilities providing services to newborns to adopt policies and procedures ensuring a medically acceptable level of nourishment and medical care for infants housed within.[56] Similarly, the DYFS policies and procedures are sent to health care facilities.[57] Consequently, births performed at home or in the private offices of physicians would not fall within the purview of the laws. Perhaps it would be advisable for DYFS to establish a policy whereby all physicians, nurses, midwives or others who assist in childbirth would be provided with information concerning the operative procedures in alleged "Baby Doe" cases.

Clarification of DYFS Procedures Memorandum

Mindful that DYFS intends to clarify through regulations the procedures it employs in, *inter alia*, alleged "Baby Doe" cases, the Commission suggests that the following clarifications be incorporated into the procedures.

First, the memorandum does not offer guidance as to when an on-site investigation or discussions with other medical personnel may be "indicated" after an initial report has been made. Nor is there any elucidation of who is intended by the phrase "another designated person having knowledge of the infant's situation" as someone for the investigative team to contact before reviewing the medical records. By whom, and according to what procedure, is such an individual designated? Is a designation required? Does it include, for instance, a nurse?

Second, according to the Procedures Memorandum, if DYFS decides to intervene in a particular case, it has 30 days to submit an Institutional Abuse Report, after which preparation for court intervention with the Deputy Attorney General is initiated. However, as a practical matter, withholding of medically indicated treatment for a 30 day period could, in some cases, result in imminent death.[58] In the absence of any presumption in favor of treatment, it might be useful to include in the Procedures Memorandum an additional clause to the effect that under emergent circumstances, the IAIU investigator shall promptly confer with the Deputy Attorney General to initiate judicial intervention without the necessity of a written Institutional Abuse Report.

Indeed, actions taken by DYFS in an alleged "Baby Doe" case referred in 1986 demonstrate the agency's recognition that under certain emergent circumstances, written protocol must give way in order to provide appropriate protection for newborns. The report of that case[59], materials about which were furnished to the Commission[60], explained that the case was referred to DYFS as an emergency within the first few hours of the infant's life. It indicates that several of the steps listed in the Procedures Memorandum were not followed and that the sequence of

actions taken was not in the order outlined therein. However, due to the very serious condition of the infant, a decision to dispense with the formalities of some of these steps in order to attempt to save the life of the child (assuming that was the basis of the conclusion regarding how to proceed) may have been entirely appropriate. Furthermore, the description of the action taken by the state suggests that the system in place was capable of responding to the situation in a timely fashion and of expediting specific procedures when necessary.[61]

The Role of Infant Care Review Committees

In its guidelines following the passage of the Child Abuse Amendments, the HHS recommended the establishment of ICRCs to set educational and policy initiatives, provide procedures in cases of alleged neglect of disabled newborns, report results and offer counsel. These suggestions have been well heeded in New Jersey where ICRCs function in a number of large hospitals and where plans for regional ICRCs are being developed to serve smaller health care facilities.*

Because of the potentially powerful role of ICRCs in the process of making decisions about the withdrawal of life-sustaining treatment for severely impaired newborns, and because the work of ICRCs may impact upon the functions of DYFS in this area, the Commission believes that further study of the role of ICRCs is warranted.

Conclusion

Many comprehensive steps have been taken by both the federal and state governments over the past seven years to deal constructively with medical treatment of imperiled newborns. The evidence collected thus far indicates that the measures taken have in large part successfully responded to and deterred instances of medical neglect of imperiled newborns. More detailed conclusions await further exploration of the functioning of ICRCs (both as currently established and as plans for alternative models develop). Additionally, the Commission hopes to have the opportunity, pursuant to the Administrative Procedure Act, to comment on the proposed regulations of DYFS when they are promulgated.

* Indeed, in September 1987 and January 1988, DYFS organized four informational conferences attended by hospital teams of physicians, nurses and social workers in which a range of issues were discussed, including the background to the "Baby Doe" cases, the functioning of the procedures established in New Jersey, and the development of ICRCs. DYFS plans to hold an additional seminar addressed to the issue of ICRCs in the coming year.

Notes

1. *See* The Hasting Center Research Project on the Care of Imperiled Newborns, Imperiled Newborns, *Hastings Center Report*, (Dec. 1987): 7-9 ("Hastings Report"). The Report also discusses the more limited measures taken after World War II. *Id.* at 7.

2. *Id.*

3. Raymond Duff & A.G.M. Campbell, "Moral and Ethical Dilemmas in the Special Care Nursery," *New England Journal of Medicine*, Vol. 289 (1973): 890-94.

4. *See, e.g.*, Shaw, Randolph & Manard, "Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons," *Pediatrics*, Vol. 60 (No. 4, Part 2, Supp. 1977): 588 (finding that 85% of pediatric surgeons and 65% of pediatricians would acquiesce in a decision by parents not to treat an infant born with Down syndrome and a congenital heart disease); I. David Todres, Diane Krane, Mary C. Howell and Daniel C. Shannon, "Pediatricians' Attitudes Affecting Decisionmaking in Defective Newborns," *Pediatrics* Vol. 60 (No. 2, Aug. 1977): 197 (finding that 51% of responding pediatricians would not recommend surgery for an infant born with Down syndrome and intestinal blockage); "Treating the Defective Newborn: A Survey of Physicians' Attitudes," *Hastings Center Report*, Vol. 6 (Apr. 1976): 2 (finding that fifty percent of obstetricians and pediatricians asked their opinions in cases in which infants were born with Down syndrome and a life-threatening but surgically correctable intestinal obstruction favored doing "everything humanly possible" or giving "care, but nothing heroic" while the other half advocated "withhold[ing] all treatment including surgery" or "end[ing] the suffering quickly").

5. Down Syndrome is a chromosomal disorder also called "trisomy 21" in which the nuclei of the cells in a person's body contain 47 rather than 46 chromosomes. One who has this condition manifests certain physical, mental and developmental disabilities, *see In re Grady*, 85 N.J. 235, 240 n.1, 426 A.2d 467, 469 n.1 (1981), including mental retardation in various degrees. *In re Grady*, 170 N.J. Super. 98, 103, 405 A.2d 851, 843-54, *vacated*, 85 N.J. 235, 426 A.2d 467 (1981).

6. *See* Fred Barbash & Cristine Russell, "The Demise of "Infant Doe": Permitted Death Gives New Life to an Old Debate," *Washington Post* (Apr. 17, 1982): A10, col. 1 ("Barbash & Russell").

7. *Id.* at col. 2.

8. *Id.* at col. 1.

9. *Id.*

10. *Id.* at col. 2.

11. *In re Infant Doe*, No. GU 8204-004A (Monroe County Cir. Ct., April 12, 1982), *mandamus denied, sub nom. State ex rel. Infant Doe v. Baker*, No. 482 S 140 (Ind. Sup. Ct., May 27, 1982), *cert. denied sub nom. Infant Doe v. Bloomington Hospital*, 464 U.S. 961 (1983).

12. *See, e.g.*, Barbash & Russell, *supra* note 7, p. A1, col 4; "Baby Dies as Lawyers Pressed Plea on Feeding," *New York Times* (Apr. 16, 1982): A14, col 6.

13. *See, e.g.*, Editorial, "Private Death," *New York Times* (Apr. 27, 1982): A22; Richard A. McCormick & Laurence H. Tribe, "Infant Doe: Where to Draw the Line," *Washington Post* (July 27, 1982): A15; George Will, "The Killing Will Not Stop," *Washington Post* (Apr. 22, 1982): A29, col. 3.

14. This condition is characterized by exposure of the spinal cord and its membranes. *See United States v. University Hospital, State University of New York at Stony Brook*, 729 F.2d 144, 146 (2d Cir. 1984).

15. Characteristic of this medical problem is an abnormally small head. *Id.*

16. "Hydrocephalus" is the medical terminology for accumulation of fluid in the cranial vault. *Id.*

17. This condition prohibited Baby Jane Doe from closing her eyelids or fully sucking with her tongue. *Id.*

18. *Id.*

19. *See* Douglas Biklen, "Framed: Print Journalism's Treatment of Disability Issues," in *Images of the Disabled, Disabling Images* (A. Gartner and T. Joe eds. 1987): 85.

20. *See United States v. University Hospital, State University of New York at Stony Brook*, 729 F.2d 144, 146 (2d Cir. 1984).

21. *Id.* at 146-47. The Court of Appeals affirmed on other grounds the decision of the Appellate Division of the New York Supreme Court which addressed the substantive merits of the case and found that the parents were acting in the best interests of their daughter. In so finding, the appellate court reversed the trial court's order to perform surgery.

22. Rehabilitation Act of 1973, section 504 (codified as amended at 29 U.S.C. section 794 (Supp. 1988)). In addition to providing the statutory groundwork for the regulations, section 504 was cited as authority in a second litigation that followed from the parental decision regarding treatment for Baby Jane Doe for the position that the hospital was required to allow HHS access to her medical records. In *United States v. University Hospital, State University of New York at Stony Brook*, 729 F.2d 144 (2d Cir. 1984), the Second Circuit Court of Appeals specifically found that HHS did not have authority to conduct an investigation and to compel production of the infant's medical records, and more generally held that the application by HHS of section 504 to the situation of medically impaired newborns exceeded the statutory authority conferred by Congress. *Id.* at 154-61.

23. 48 Fed. Reg. 9,630, 9,631 (1983).

24. 561 F. Supp. 395 (D.D.C. 1983).

25. Among the factors enumerated by the Court which HHS failed to examine were: the harmful effects of a 24 hour "hotline" upon ongoing treatment of newborns; the level of care or the appropriateness of termination of medical and constitutional inquiries; the consequences of forced removal of a baby from a hospital in the face of refusal by a parent to permit medical care; the effects of termination of federal financial aid to non-complying health care facilities; the risks of malpractice claims against physicians and hospitals; parental preferences; and means of financially supporting extensive care and allocating scarce medical resources among patients. 561 F. Supp. at 399-400.

26. The Court found that pursuant to the Administrative Procedure Act, 5 U.S.C. sections 553(b) and 553(d) (1977), HHS failed to issue the Interim Final Rule in accordance with the public notice rule or the requirement of a 30 day delay of the effective date of the regulation. 561 F. Supp. at 400-01.

27. On July 5, 1983, HHS issued another proposed rule revising details of the notice required to be posted under the Interim Final Rule and adding the requirement that written administrative procedures be maintained to ensure that state agencies use their authority "to prevent instances of medical neglect of handicapped infants." 40 Fed. Reg. 30,846, 30,851 (1983). On January 12, 1984, HHS published its "final rules on procedures and guidelines relating to nondiscrimination on the basis of handicap in connection with health care for handicapped infants 49 Fed. Reg. 1622 (1984) ("Final Rules"). Among other items, the Final Rules recommended the establishment of Infant Care Review Committees in hospitals, 45 C.F.R. section 84.55(a) (1984), and modified the notice requirement,

necessitating only that notice be posted at locations within the sight of health care personnel providing services to infants. 45 C.F.R. section 84.55(b)(2) (1984).

28. 476 U.S. 610 (1986).

29. *See* 1984 U.S. Code Cong. & Admin. News. 2918, 2922-28.

30. Section 101 *et seq.*, 42 U.S.C. section 5101 *et seq.* (Supp. 1988). This legislation has been referred to as the "compromise amendment" which resulted from extensive negotiations between senators and representatives of medical, disability and right-to-life organizations.

31. Child Abuse Prevention and Treatment and Adoption Program, Section 122, 42 U.S.C. section 5103 (b) (2) (K) (Supp. 1988) "CAPTAP".

32. *Id.*

33. CAPTAP, section 121(2), (3), 42 U.S.C. section 5102(3) (Supp. 1988).

34. CAPTAP, section 123(a) (2), 42 U.S.C. section 5103(c) (1) (Supp. 1988). Examples of support services listed in the statute include social and health services, financial assistance for families, and services needed to facilitate adoptive placements. *Id.*

35. CAPTAP, section 123(a) (2), 42 U.S.C. Section 5103(c) (2) (A) (Supp. 1988).

36. 45 C.F.R. section 1340 (1985).

37. 45 C.F.R. section 1340 app.

38. *Id.*

39. Definitions provided in the regulations that have been omitted here are those that were taken directly from the statute and have been elaborated upon above.

40. This is further defined in the context of the definitions of "child abuse and neglect" in section 3 of the Act and section 1340.2(d) of the Regulations. CAPTAP, section 121(1), 42 U.S.C. section 5102(1) (Supp. 1988) defines "child abuse and neglect" as "the physical or mental injury, sexual abuse or exploitation, negligent treatment, or maltreatment of a child under the age of eighteen, or the age specified by the child protection law of the State in question, by a person...who is responsible for the child's welfare under circumstances which indicate that the child's health or welfare is harmed or threatened thereby..."

41. 45 C.F.R. section 1340.15(b).

42. *Id.*

43. *Id.*

44. *Id.* at section 1340.15(c).

45. *Id.*

46. CAPTAP, section 124(b)(1), 42 U.S.C.A. section 5103 notes (West & Supp. 1988).

47. Model Guidelines for Health Care Providers to Establish Infant Care Review Committees, 45 C.F.R. section 1340 app. (1985).

48. *Id.*

49. *Id.*

50. *Id.*

51. *See* Inter-Office Communication of DYFS from William Waldman, Director, DYFS, to E. John Walzer, Esq., Office of Legal and Regulatory Liaison (Aug. 10, 1988) ("Newborns: Child Abuse and Neglect") ("Inter-Office Communication").

52. *See* Support Operations Manual, Institutional Abuse and Neglect Volume, Institutional Medical Neglect of Disabled Infants with Life-Threatening Conditions Section, at 1.

53. *N.J.S.A.* 9:6-8.40 (West 1977).

54. Specific criticisms were launched against the Procedures Memorandum in a report issued in September 1989 by the United States Commission on Civil Rights entitled *Medical Discrimination Against Children with Disabilities*. This report, however, has been challenged by many individuals and groups. *See, e.g.*, letter from Donald W. Shiff, M.D., president, American Academy of Pediatrics, to William B. Allen, Commission on Civil Rights (May 1, 1989), *reprinted in* United States Commission on Civil Rights, *Medical Discrimination Against Children with Disabilities*, app. 4 at 205 (Sept. 1989) ("The AAP regrets the process and the substance of the Commission report...."). The Bioethics Commission has not had an opportunity to review the report and takes no position on its contents.

55. *See* CAPTAP, Section 122, 42 U.S.C. Section 5103(b)(2)(K) (Supp. 1984).

56. *See* Act Concerning the Care of Newborn Children, *N.J.S.A.* 26:2H-12.6 (West 1987).

57. *See* Support Operations Manual, Man. III, Vol. E, Section 1000, at 1.

58. An example of this is Baby Doe, who died six days after birth.

59. Due to the confidentialities involved (protected by federal and state law), the scope of Commission review of the case has been limited to a summary report prepared by DYFS.

60. The initial information provided to the Commission suggested that there had been three reported incidents. *See* Inter-Office communication of DYFS from William Waldman, Director, DYFS, to E. John Walzer, Esq., Office of Legal and Regulatory Liaison (Aug. 10, 1988) (Newborns: Child Abuse and Neglect"). However, further factfinding by DYFS disclosed that one of the three cases occurred prior to 1985, and the second did not involve a newborn. *See* letter from Raymond Wolfinger, Esq., Office of Legal and Regulatory Liaison, to Alan J. Weisbard, Executive Director, New Jersey Bioethics Commission (Jan. 31, 1989).

61. *See* Letter and attached summary from Susan Manion, Statewide Supervisor, Institutional Abuse Investigation Unit, to Alan J. Weisbard, Executive Director, New Jersey Bioethics Commission (Dec. 8, 1988).

Chapter Four: The "Grady" Procedures

Sterilization of women is a medical procedure, the intended result of which is the permanent prevention of pregnancy[1]. When performed on a woman who consents to the procedure with knowledge and understanding of its nature and consequences, it is a legally acceptable means of contraception. Indeed, a number of courts, including the New Jersey Supreme Court, have found that the right to choose sterilization is incident to the constitutional right to privacy and constitutes a fundamental right.[2] However, performance of sterilizations on women incapable of providing informed consent raises important ethical and constitutional questions, and carries as baggage a history in which those making the decisions have often failed to give priority to the interests of the woman undergoing the procedure.

The *Grady* Case

In the 1981 case of *In re Grady*,[3] the Supreme Court of New Jersey addressed the conditions pursuant to which a guardian may be appointed for the purpose of authorizing a sterilization procedure on an incompetent woman whose limited mental capacity impaired her ability to choose whether or not to undergo the procedure. Before reaching the ultimate question, the Court's analysis addressed several foundational issues, including the legal status of sterilization as to persons who are capable of consenting to the operation and those who are not, the applicability of specific state statutes, and the jurisdictional basis for hearing and determining the application.

Lee Ann Grady was a 19 year old noninstitutionalized woman with Down syndrome.[4] She had been living at home with her parents and younger brother and sister throughout her life and had attended special classes in the public school for many years.[5] At the time of the judicial proceedings, her functional ability was described as being in the range of mental retardation classified as "severe," characterized by retarded speech, language and motor developments.[6]

Realizing that their daughter was approaching the age of 20 when she would be required to leave her special class in the public school, the Gradys decided to place Lee Ann in a sheltered work group and ultimately in a group home for retarded adults. In the words of the court, Lee Ann had "no significant understanding of sexual relationships or marriage. If she became pregnant, she would neither understand her condition nor be able to make decisions about it. Her lack of awareness could lead to severe health problems. It is uncontradicted that she would not be able to care for a baby alone. Indeed, she will probably need lifetime support to care for her own needs."[7] Seeking "dependable and continuous contraception"[8] and acting on the advice of their doctor, the Gradys sought to have Lee Ann sterilized at a hospital. Following the denial of their request, the Gradys petitioned the Superior Court, Chancery Division, for an order appointing a guardian with authority to consent to a sterilization procedure on behalf of Lee Ann.

The Chancery Court appointed a guardian *ad litem* to represent Lee Ann's interests in the proceedings. The court also allowed as intervenors the Public Advocate to represent the public interest[9] and the Attorney General based upon a potential challenge to the constitutionality of a related state statute.[10] In addition to considering the wide variety of evidence, the judge met privately with Lee Ann to gain a first hand impression of her circumstances.

The trial court established a five prong test for courts to employ in deciding such applications. The court found that a judicial body must authorize parental consent to a sterilization procedure on an incompetent woman when the following criteria are satisfied: (1) there is clear and convincing evidence that the woman is incompetent, *i.e.*, incapable of understanding the nature of the sexual function, reproduction, sterilization, or the judicial proceedings dealing with the issue; (2) the incompetency is likely to be permanent; (3) the woman is presumably not infertile or incapable of reproduction; (4) all procedural safeguards have been satisfied, including the appointment of a guardian *ad litem* with full opportunity to present proof and cross-examine witnesses; and (5) the petitioners demonstrate their genuine good faith and primary concern for the best interests of the incompetent.[11] Under the particular circumstances in *Grady*, the court determined that its five part test had been satisfied and granted the petition.

A notice of appeal was filed by the Public Advocate and the Attorney General on several grounds, including the alleged omission by the Chancery Court of certain findings of fact and the failure of that court both to apply provisions of two state statutes and to consider several additional standards in the substantive guidelines.[12]

The Right to Sterilization

The New Jersey Supreme Court began its legal discussion by addressing the basis of the right to be sterilized. The Court found that the right to obtain a voluntary sterilization is grounded in both the federal constitutional right of privacy (pursuant to which the rights to procreation, contraception and abortion have been recognized as fundamental) and the right of privacy protected by the New Jersey Constitution. Furthermore, the court held that the constitutional right to voluntary sterilization also derived from its rationale in the case of *In re Quinlan*:[13]

> A decision to be sterilized is also a part of an individual's personal right to control her own body and life. The state's interest in procreation cannot be greater than its interest in preserving life. If one can decide to forgo artificial life-preservation and thereby sacrifice life, then one can certainly decide to forgo reproductive capacity and thereby relinquish the ability to procreate. Therefore, the right to be sterilized is included in the privacy rights protected by the federal Constitution.[14]

The next question the Court faced was whether the right was applicable to a person whose mental capacity prevented her from making a meaningful choice, and if so, who the appropriate decisionmaker would be. Quoting *Quinlan*, the Court found that "[i]f the decision...is a valuable incident of her right of privacy, as we believe it to be, then it should not be discarded solely on the basis that her condition prevents her conscious exercise of the choice."[15] The Court held that

although parents (and perhaps other relatives or friends in different circumstances) have standing to assert the interests of the incompetent person, in this type of case the ultimate decision must be made by the court.[16] This determination, a departure from the Court's prior and subsequent strong support for family decisionmaking, was based on the Court's recognition of the history of abuse of sterilizations performed on incompetent persons.

In some detail, the Court articulated instances of such historical exploitation.[17] The Court referred to the "eugenics" movement, which advocated the physical and mental improvement of the human race by ensuring that individuals possessing certain traits considered undesirable by society be rendered incapable of reproduction,[18] and to the 1925 case of ***Buck v. Bell***,[19] perhaps the most frequently cited illustration of the beliefs of the time. In *Buck*, the United States Supreme Court, in an opinion written by Justice Oliver Wendell Holmes, upheld a statute that authorized the compulsory sterilization of a legally incompetent woman, stating that "[t]hree generations of imbeciles are enough."[20]

Although the *Grady* Court recognized the philosophical trend discrediting state-mandated eugenic sterilizations, it noted that the practice has not seen its demise; as of 1981 (the year in which *Grady* was written), a number of states had not abandoned compulsory sterilization laws. In order to prevent any kind of continuing abuse and to protect the best interests of incompetent women, the court held that the right of an incompetent woman to obtain a sterilization must be determined by the court.[21]

The next issue addressed by the New Jersey Supreme Court involved the controlling standards for decisionmaking. The Court considered and dismissed the claims put forth by the Public Advocate and the Attorney General that the standards to be applied were governed by two statutes in New Jersey that address the issue of the sterilization of women unable to consent. One, known as the "Bill of Rights for the Mentally Retarded,"[22] applies to patients in treatment at public institutions; the second, a section of the Developmentally Disabled Rights Act ("DDRA"),[23] deals with persons receiving services for the developmentally disabled at any public or private facility in the state. Both statutes prohibit the performance of sterilizations on adjudicated incompetent persons in the absence of a judicial hearing to ascertain the necessity of the procedure. After a lengthy discussion of the history and content of these laws, the *Grady* Court concluded that they did not govern Lee Ann's situation since the hospital was not an institution within the meaning of the Bill of Rights for the Mentally Retarded, nor was Lee Ann a resident or outpatient admitted to a state or private facility for the developmentally disabled under the DDRA.[24]

Having found inapplicable the two statutes arguably controlling decisions concerning the sterilization of mentally incompetent persons, the question remained whether the legislature intended to limit judicial authorization of sterilizations to the situations delineated in the statutes. As a public policy matter, the Court responded in the negative. Against the weight of contrary judicial decisions in other states,[25] the Court held that the decision whether or not a sterilization procedure should be authorized on behalf of a mentally impaired person was within the inherent *parens patriae* jurisdiction of the state courts.[26]

The "Grady" Procedures

Following its determination that a court must be satisfied that sterilization is in the best interests of a mentally impaired person,[27] the New Jersey Supreme Court set forth the procedural and substantive safeguards requisite to a decision of whether or not to grant such an application. In determining the significance of a number of factors, the Court looked for guidance to the case of *In re Hayes*,[28] decided approximately one year earlier by the Washington Supreme Court. The petitioner in *Hayes* was the mother of a 16 year old incompetent minor. She sought to be appointed guardian over her daughter and to obtain authorization to consent to a sterilization procedure on her daughter's behalf. Although under the particular factual circumstances the *Hayes* court concluded that the petition could not be granted, the court developed three procedural and eight substantive standards to guide trial courts in ruling upon such petitions.[29]

The New Jersey Supreme Court expanded and elaborated upon the guidelines established in *Hayes* and in the trial court opinion in *Grady*. The procedural requirements set forth in the high court's decision included: 1) the appointment as soon as possible by the Chancery Court of an independent guardian *ad litem* to meet with the incompetent, present proof, cross-examine witnesses at the hearing, and represent zealously the interests of the incompetent; 2) the receipt by the Chancery Court of independent medical and psychological evaluations by qualified professionals, and, in the discretion of the hearing judge, the appointment of his or her own experts to assist in determining the best interests of the incompetent; and 3) the scheduling by the trial judge of a personal meeting with the individual to assess, in the opinion of the judge, the competency of the impaired woman and her feelings about both the judicial proceedings and the prospect of sterilization. Presence at the hearing by the incompetent woman was found to be unnecessary if in the determination of the hearing judge her presence would not be useful in protecting her rights.[30]

The Court also delineated substantive standards that must be considered before a trial court could authorize a sterilization procedure. First, the judge must find, by clear and convincing evidence, that the individual, presently and in the foreseeable future, is incompetent to make such a decision. Next, the proponent of sterilization must satisfactorily prove, by clear and convincing evidence, that the best interests of the incompetent person dictate the performance of a sterilization procedure. In applying this test, the Court outlined nine factors that, at a minimum, should be examined by a trial judge:

1. The possibility of pregnancy. Fertility is presumed if the medical evidence indicates normal development of sexual organs and the proof does not otherwise raise doubts about fertility.
2. The possibility of trauma or psychological damage if the incompetent woman becomes pregnant or gives birth, or from a sterilization operation.
3. The likelihood of sexual activity.
4. The inability of the incompetent person to understand reproduction or contraception and the likely permanence of that inability.
5. The feasibility and medical advisability of less drastic means of contraception both at the present time and under foreseeable future circumstances.

6. The advisability of sterilization at the time of the application rather than in the future.
7. The present and future ability of the incompetent person to care for a child.
8. Evidence that scientific or medical advances may occur within the foreseeable future which will make possible either improvement of the individual's condition or alternative and less drastic sterilization procedures.
9. A demonstration that the proponents of sterilization are seeking it in good faith and that their primary concern is for the best interests of the incompetent person rather than their own or the public's convenience.[31]

In articulating these substantive standards, the *Grady* Court rejected the position that the *necessity* of sterilization should be proven by the moving party with respect to two factors: (1) the likelihood that the mentally retarded woman will give birth to genetically defective children or her incapacity in the present and foreseeable future to care for such children; and (2) the woman's fertility and the likelihood of sexual activity or pregnancy on her part, and the availability of feasible, less drastic means of contraception.[32] The *Grady* majority stated that a standard of necessity would be a serious infringement on individuals' fundamental rights, perhaps preventing sterilization of a woman whose best interests would dictate undergoing the procedure or imposing sterilization on someone whose best interests would not be served by it.[33]

The New Jersey Supreme Court concluded that under the circumstances of the *Grady* case, the procedural requisites had been satisfied and clear and convincing evidence in the record supported the finding that Lee Ann Grady did not and would not in the foreseeable future have the capacity to make a decision with respect to sterilization. However, the Court found that the trial judge had not applied all of the relevant factors in determining the best interests of the incompetent woman, nor had it applied the clear and convincing standard to its decision concerning Lee Ann's best interests.[34] Therefore, the case was remanded to the Chancery Court to determine, by clear and convincing evidence, whether, in accordance with the factors set forth in the opinion of the higher court, sterilization would be in the best interests of Lee Ann.[35]

Developments Since *Grady*

The standards articulated by the New Jersey Supreme Court in *Grady* have been well-received and influential in other jurisdictions. Although there have been some differences of approach on such relatively technical legal issues as the burden of proof with respect to the fertility of the incompetent woman,[36] the need for proof of medical necessity,[37] or the relevance of religious beliefs,[38] most judicial decisions have adopted the *Grady* factors in whole[39] or part,[40] and virtually all cite *Grady* favorably in reviewing relevant decisions.[41] This widespread judicial acceptance and application of the factors enunciated in *Grady* suggests that the basic reasoning and approach of the decision is sound.

The Commission has engaged in preliminary factfinding research to determine the number of petitions for nonconsensual sterilization that have been filed in New Jersey pursuant to state statutes or the *Grady* decision since 1981. No officially reported judicial decisions were located. With respect to unreported decisions, it was discovered that there is no central depository in the

state for the filing of all unreported cases, and no indexing system to provide ready access. However, a number of county chancery courts do maintain records of local cases. A sampling of available documents in two counties, Morris (where *Grady* originated) and Sussex, discloses only one petition for sterilization of a noninstitutionalized person brought since the *Grady* case. Further, conversations with the superintendents or medical directors of most of the state institutions for the developmentally disabled suggest that no additional petitions have been filed on behalf of patients since 1981.[42]

The relation between the *Grady* standards and the virtual absence of petitions for sterilization of incompetent persons filed in the aftermath of the opinion is unclear. It may be useful to continue to monitor whether the existing schemes, set forth in the Bill of Rights for the Mentally Retarded and in the DDRA as well as in *Grady*, strike the appropriate balance between protecting mentally impaired persons from abusive sterilizations and ensuring them their constitutional right to obtain such a procedure when it would serve their best interests.

Conclusion

The standards set forth in *Grady*, read together with the related sections of the Bill of Rights for the Mentally Retarded and the DDRA, provide a carefully drafted and widely accepted scheme designed to ensure protection of the rights of persons incapable of consenting to the performance of sterilization procedures. Although the case shares with the legislation a primary concern for the best interests of incompetent individuals on whose behalf applications for sterilization are brought, the two have been implemented in different ways. Nonetheless, as a practical matter, there are no significant distinctions suggesting the need to bring the two schemes into closer conformity with one another.

Several scholarly commentators have suggested as an alternative approach to decisionmaking the establishment of committees to review and approve or disapprove of sterilization procedures.[43] The commentators recommend multidisciplinary committees, including physicians, attorneys, lay people, and representatives of the particular ethnic, religious or philosophical groups to which the people on behalf of whom the petitions are brought belong.[44] The rationale given to the employment of such committees is both the insurance of protection from judicial interests that could conceivably conflict with those of the patient,[45] and providing the best assurance that the interests of the mentally impaired person are being effectuated by combining diverse expertise and perspectives in the decisionmaking process. The significance of committees in this context, and their relationship with the more familiar institutional ethics committees, may be worthy of further scrutiny.

Notes

1. Research has been conducted over the past number of years in order to determine the reversibility of female sterilization procedures. Several statistical studies conducted from 1979 to 1984 found a success rate of 67.7 percent, *i.e.*, of all the medical procedures performed to reverse sterilizations, 67.7 percent of the women became pregnant. The percentage of live births was 54.4. *See* Alvin M. Siegler, Jaroslav Hulka and Alik Peretz, "Reversibility of Female Sterilization," *Fertility & Sterility*, Vol. 43 (April 1985): 502-03. The studies cautioned, however, that the relatively high rates of success should not give the impression that sterilization is a reversible technique. Unaccounted for in the research were a number of factors, including the time period from sterilization to reversal, the site of the reversal procedure, the length of the reconstructed tube, and the age of the patient. *Id.* at 501-04. The medical literature suggests that the goal of reversibility of 95 percent of female sterilizations is unrealistic for the near future. *Id.* at 507. Further, the procedure involves a major and expensive operation. *Id.* Consequently, at the present time, sterilization must be characterized as a procedure to permanently prevent pregnancy.

2. *See In re Valerie N.*, 40 Cal. 3d 143, 219 Cal. Rptr. 387, 707 P.2d 760, (1985); *In re A.W.*, 637 P.2d 366, 369 (Colo. 1981); *In re Moe*, 385 Mass. 555, 432 N.E.2d 712, 719 (1982); *In re Grady*, 85 N.J. 235, 249-50, 426 A.2d 467, 473 (1981); *In re Eberhardy*, 102 Wis. 2d 539, 307 N.W.2d 881, 891-92 (1981).

3. 85 N.J. 235, 426 A.2d 467 (1981).

4. Down Syndrome is a chromosomal disorder (also called "trisomy 21") in which the nuclei of the cells in an affected person's body contain 47 rather than 46 chromosomes. Certain physical, mental and developmental disabilities are characteristic of this condition, 85 N.J. 235, 240 n.1, 426 A.2d 467, 469 n.1 (1981), including mental retardation in various degrees. *In re Grady*, 170 N.J. Super. 98, 405 A.2d 851, 853-54 (N.J. Super. Ct. Ch. Div. 1979), *vacated*, 85 N.J. 235, 426 A.2d 467 (1981).

5. 85 N.J. at 240-42, 426 A.2d at 469-70.

6. 170 N.J. Super. 98, 102, 405 A.2d 851, 855 (N.J. Super. Ct. Ch. Div. 1979), *vacated*, 85 N.J. 235, 426 A.2d 467 (1981).

7. 85 N.J. at 242, 426 A.2d at 470.

8. *Id.*

9. Originally, the Public Advocate appeared as *Amicus Curiae*. The Superior Court permitted him to change his status to a representative of the public interest pursuant to N.J.S.A. 52: 27E-1 *et seq.* (West 1974). *See* Brief for Appellee at 6, *In the Matter of Lee Ann Grady*, 85 N.J. 235, 426 A.2d 467 (1981) ("Kahn Brief"); Brief for Appellant at 3, *In the Matter of Lee Ann Grady*, 85 N.J. 235, 426 A.2d 467 (1981) ("Public Advocate Brief").

10. Kahn Brief at 7; Public Advocate Brief at 3.

11. 170 N.J. Super at 125-26, 405 A.2d at 851.

12. *See* Public Advocate Brief; Brief for Attorney General, App., *In the Matter of Lee Ann Grady*, 85 N.J. 235, 426 A.2d 467 (1981).

13. 70 N.J. 10, 355 A.2d 647, *cert. denied sub nom. Garger v. New Jersey*, 429 U.S. 922 (1976).

14. 85 N.J. at 247-50, 426 A.2d at 473-74.

15. *Id.* at 250, 426 A.2d at 474 (quoting *In re Quinlan*, 70 N.J. 10, 41, 355 A.2d 647, 664, *cert. denied sub nom. Garger v. New Jersey*, 429 U.S. 922 (1976)).

16. 85 N.J. at 251, 426 A.2d at 475.

17. *Id.* at 246-47, 426 A.2d at 472-73.

18. The term "eugenics" was coined by Sir Francis Galton during the social Darwinist climate of the mid to late 19th century; the concept flourished in the United States during the 1920's. *See* Robert L. Burgdorff, Jr. & Marsha Pearce Burgdorff, "The Wicked Witch is Almost Dead: Buck v. Bell and the Sterilization of Handicapped Persons," *Temple Law Quarterly*, Vol. 50 (1977): 997.

19. 274 U.S. 200 (1927).

20. *Id.* at 208.

21. 85 N.J. at 252, 426 A.2d at 475.

22. N.J.S.A. 30: 4-23 *et seq.* (West 1965). In 1987, some of the statutory sections were repealed; however, Section 30: 4-24.2(d) which lists the rights of patients including the right not to be subjected to sterilization except under particularly delineated circumstances remained intact.

23. N.J.S.A. 30: 6D-5(a)(4) (West 1977).

24. 85 N.J. at 253-58, 426 A.2d at 476-79.

25. The court cited the following cases holding to the contrary: *Sparkman v. McFarlin*, 552 F.2d 172 (7th Cir. 1977), *rev'd sub nom. Stump v. Sparkman*, 435 U.S. 349 (1978); *Wade v. Bethesda Hosp.*, 337 F. Supp. 671 (S.D. Ohio 1971); *Guardianship of Tulley*, 83 Cal. App. 3d 698, 146 Cal. Rptr. 266 (1978), *cert. denied*, 440 U.S. 967 (1979); *Guardianship of Kemp*, 43 Cal. App. 3d 758, 118 Cal. Rptr. 64 (1974); *In re S.C.E.*, 378 A.2d 144 (Del. Ch. 1977); *A.L. v. G.R.H.*, 163 Ind. App. 636, 325 N.E.2d 501 (1975), *cert. denied*, 425 U.S. 936 (1976); *Holmes v. Powers*, 439 S.W.2d 579 (Ky. Ct. App. 1968); *In re M.K.R.*, 515 S.W.2d 467 (Mo. 1974); *Application of A.D.*, 90 Misc. 2d 236, 394 N.Y.S.2d 139 (Surr. Ct. 1977), *aff'd on other grounds*, 64 A.D.2d 898, 408 N.Y.S.2d 104 (1978); *Frazier v. Levi*, 440 S.W.2d 393 (Tex. Civ. App. 1969).

26. 85 N.J. at 258-62, 426 A.2d at 479-80.

27. The Court noted that unlike other types of cases concerning decisionmaking on behalf of incompetent people, with respect to the issue of sterilization, parental interests might diverge from the interests of the child. *Id.* at 264, 426 A.2d at 482.

28. 92 Wash. 2d 228, 608 P.2d 635 (1980).

29. 608 P.2d at 641.

30. 85 N.J. at 264-65, 426 A.2d at 482.

31. *Id.* at 265-67, 426 A.2d at 482-83.

32. Public Advocate Brief at 41.

33. 85 N.J. at 262-63, 426 A.2d at 481. Justice Handler wrote a concurrence to the opinion of the Supreme Court, the main thrust of which focused on the failure of the majority to adopt the terminology of a necessity standard. He believed that the stringent factors set forth by the majority, particularly the elements of the likelihood of sexual activity and pregnancy and the absence of other feasible and less drastic means of contraception, implicitly included the necessity standard "as an integral, albeit nonexclusive, part of the calculus of concerns..." *Id.* at 274, 426 A.2d at 487 (Handler, J., concurring). He expressed the opinion that in consonance with the spirit of the Developmentally Disabled Rights Act and the "Bill of Rights for the Mentally Retarded," both of which establish

a necessity standard, *id.* at 275, 246 A.2d at 487-88, "with respect to one incapable of choice, necessity must remain an extremely important, if not an indispensable predicate, for the judicial determination of best interests and the interposition of irreversible judicial choice in such a profoundly personal area as sterilization." *Id.* at 274-75, 426 A.2d at 487.

34. Specifically, the Court found: (1) although a presumption of fertility may be made when there is no suggestion of infertility or abnormal development of sexual organs, the trial court did not make a finding about the extent of the possibility of pregnancy for Lee Ann nor its significance in determining the best interests of the incompetent; (2) there was a lack of evidence as to the trauma or psychological damage that Lee Ann could incur by pregnancy or childbirth; (3) the record presented conflicting evidence on the issue of the likelihood of Lee Ann's future sexual activity; (4) the record was unclear on the question of purposes of contraception as well as Lee Ann's future potential to take care of her sexual needs and make her own decisions concerning contraception; (5) there was no finding of fact regarding whether less drastic means of contraception might be in Lee Ann's best interests; (6) the trial court did not make a determination as to the present advisability of a sterilization procedure as compared to a future operation; (7) the possibility of future marriage and childcare with the aid of a spouse had not been considered by the trial court; (8) the lower court did not make a finding on the basis of scientific and medical evidence concerning the possibility of a cure or treatment of Down Syndrome or for less drastic sterilization procedures; and (9) the trial court did adequately find the proponents of Lee Ann's sterilization sought the procedure in good faith, concerned about her best interests. *Id.* at 260-72, 426 A.2d at 484-86.

35. *Id.* at 272, 426 A.2d at 486.

36. *See In re Debra B.*, 495 A.2d 781, 783 (Me. 1985).

37. *See Conservatorship of Valerie N.*, 40 Cal. 3d 143, 219 Cal. Rptr. 387, 707 P.2d 760, 778 (1985); *In re A.W.*, 637 P.2d 366, 375-76 (Colo. 1981); *Wentzel v. Montgomery General Hospital, Inc.*, 447 A.2d 1244, 1254 (Md. 1982), *cert. denied*, 459 U.S. 1147 (1983); *In re Moe*, 385 Mass. 555, 432 N.E.2d 712, 722 (1982).

38. *In re Moe*, 385 Mass. 555, 432 N.E.2d at 723.

39. *See In re Nilsson*, 122 Misc. 2d 458, 471 N.Y.S.2d 439 (Sup. Ct. Livingston Co. 1983); *In re Terwilliger*, 304 Pa. Super. 553, 450 A.2d 1376 (1982).

40. *See, e.g., In re C.D.M.*, 627 P.2d 607 (Alaska 1981); *In re Moe*, 385 Mass. 555, 432 N.E.2d 713 (1982); *In re Truesdell*, 63 N.C. App. 258, 304 S.E.2d 793 (1983), *mod.*, 313 N.C. 421, 329 S.E.2d 630 (1985).

41. *See, e.g., In re Valerie N.*, 40 Cal. 3d 143, 219 Cal. Rptr. 387, 707 P.2d 760 (1985) (construing state statute); *Wentzel v. Montgomery General Hosp.*, 447 A.2d 1244 (Md. 1982), *cert. denied*, 459 U.S. 1147, (1983). *See also* Note, The Incompetent Developmentally Disabled Person's Right of Self-Determination: Right-to-Die, Sterilization and Institutionalization," *American Journal of Law & Medicine*, Vol. 15 (1989): 352-59.

42. Staff have spoken with superintendents or medical directors of seven out of ten state facilities for the developmentally disabled.

43. *See, e.g.*, Barbara A. Burnett, "Voluntary Sterilization for Persons with Mental Disabilities: The Need for Legislation," *Syracuse Law Review*, Vol. 32 (1981): 944, 948 ("Burnett"); Stephen L. Isaacs, "Reproductive Rights 1983: An International Survey," *Columbia Human Rights Law Review*, Vol. 14 (1982-83): 338-39; Gloria S. Neuwirth, Phyllis A. Heisler and Kenneth S. Goldrich, "Capacity, Competence, Consent: Voluntary Sterilization of the Mentally Retarded," *Columbia Human Rights Law Review*, Vol. 6 (1974-75): 465, 470 ("Neuwirth").

44. *See* Burnett, *supra* note 43, at 944, 948; Neuwirth, *supra* note 43, at 470.

45. *See* Neuwirth, *supra* note 43, at 470.

Part Four

Appendix

THOMAS H. KEAN
GOVERNOR

STATE OF NEW JERSEY
OFFICE OF THE OMBUDSMAN
FOR THE INSTITUTIONALIZED ELDERLY

CN 808 TRENTON, NEW JERSEY 08625-0808
(609) 292-8016

Hector M. Rodriguez
Acting OMBUDSMAN

August 30, 1988

_____
_____
_____
_____

RE: Decisions to Withdraw or Withhold Life-Sustaining Medical Diagnosis or Treatment From Patients Age 60 and Over

Dear _____:

As you may know, since 1985 the New Jersey Supreme Court has interpreted the Mandatory Reporting of Adult Abuse Law (N.J.S.A. 52:27G-7.1) to mean that every proposal to forego life-sustaining medical diagnosis or treatment for any psychiatric hospital or nursing home patient age 60 and over who has not been currently and legally determined able to make such decisions on his/her own is a possible case of patient abuse.

This law applies regardless of whether such proposal comes from a relative, a guardian, a close friend, a physician, an attorney-in-fact under a written Power of Attorney, a "responsible party," or anyone else, including the patient. The law applies regardless of whether the patient has a "Living Will" or other written or oral instructions or indications of his/her intentions regarding such diagnosis or treatment.

This abuse law covers all kinds of possible situations, including, without limitation:

- issuing and/or following oral or written "Do Not Resuscitate" orders;
- issuing and/or following oral or written "Do Not Hospitalize" orders;
- withdrawing or withholding cardiopulmonary resuscitation;
- withdrawing or withholding antibiotics;
- withdrawing or withholding hemodialysis;
- withdrawing or withholding artificial feeding systems like nasogastric, gastrostomy, jejunostomy, intravenous or clysis therapy for malnutrition or dehydration;

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- withdrawing or withholding oxygen or mechanical ventilation;
- foregoing urinalysis or blood work in the face of infection of unknown etiology; and
- foregoing amputations.

The law requires that each medical director, physician, administrator, social worker, nurse, aide and other caregiving facility staff learning of such proposal to forego life-sustaining treatment immediately report same to the Ombudsman's Office. [See also the Long-Term Care Manual at 27.3(c)]. The Supreme Court also requires that the facility itself preserve the patient's health pending the outcome of the Ombudsman's investigation.

To comply with New Jersey's law, to protect your patients and to ensure that none of your staff become liable for the possible fines, professional censure and other serious penalties, you should provide a copy of this letter to each of your Medical Director, Director of Nurses and Social Work Supervisor. You may well wish to conduct periodic in-service training (with which the Ombudsman's Office may be able to assist) and otherwise ensure continuing compliance with these rules.

Upon receipt of a report of such potential abuse, the Ombudsman's Office must investigate. The basic purpose of this investigation is to determine whether the legal guidelines for withholding or withdrawing life-sustaining treatment or diagnosis are satisfied.

It is impossible in this letter to describe in detail the legal guidelines which the Ombudsman applies or the procedures used in the investigation phase. However, the applicable rules require the Ombudsman to obtain both the expert opinions of independent, consulting physicians and all available evidence of what the patient's attitude might have been were the patient able to himself/herself make the decision.

Finally, there are exactly and only two kinds of exceptional cases in which it is merely optional, not mandatory, to notify the Ombudsman of a proposal to withhold or withdraw life-sustaining medical treatment or diagnosis:

1) Where the patient (a) has been currently verified [using the special procedures established by the New Jersey Supreme Court in The Matter of Kathleen Farrell, 108 N.J. 335 (1987)] to have the present legal capacity to understand and decide the issue for himself or herself, and (b) after receiving a complete explanation of his/her condition, prognosis, treatment/diagnostic alternatives and the consequences of having and of foregoing same, freely and without any coercion, decides himself/herself to forego the treatment or diagnostic procedure.

Since giving unwanted treatment to a patient who, having the legal capacity to do so, refuses same may itself be an abuse, facilities are cautioned to establish a method for ensuring that all potentially competent patients who refuse life-sustaining treatment or diagnosis are given the Farrell test.

2) Where the treatment or diagnostic procedure in question is "medically futile" in one of the following, highly restrictive senses:

(a) where administering the proposed treatment or diagnostic procedure is counter-productive because it would actually accelerate the patient's death; or

(b) where administering the proposed treatment would not relieve (or, in the case of diagnosis, determine the etiology of) the patient's organic symptoms which the treatment is designed to alleviate.

For a severely demented and dehydrated patient, then, an artificial feeding system (if it can be tolerated by the patient) is not "medically futile." The reason is that, while nutritional support will not relieve the dementia, that is not the kind of symptomatic relief which this therapy is meant to relieve. Thus, if the provision of, e.g., an intravenous line, would overcome the dehydration, then it would not be medically futile.

Patients' families, per se, no matter how devoted and caring, have no known legal authority to forego life-sustaining medical treatment or diagnosis on a patient's behalf. A family member's initiating or consenting to a "Do Not Hospitalize" order or a "Do Not Resuscitate" order, for instance, does not make those orders legal.

I trust that this explanation of the applicable legal rules assists you and your facility's staff. Should you have any questions, kindly contact the Ombudsman's Office.

Very truly yours,

Hector M. Rodriguez
Acting Ombudsman

sas/5063G

Office Of The Ombudsman

Policy Statement
Approved December 29, 1988

Pending the receipt of a response to requests for information from the Office of the Ombudsman, the Bioethics Commission has sought, consistent with its legislative mandate, to examine "existing practices and procedures for decision making, such as ...*Conroy* procedures, and a determination of how well they work and where change is needed." (P.L. 1985, ch. 363, Section 6 (b)). This examination is based on testimony offered by government officials, professional associations, advocacy groups, individual health care professionals, patients, and family members at the Commission's public hearings and meetings; on written submissions to the Commission by individuals and groups; and, not least, on the accumulated experience and expertise of the individuals appointed to this Commission.

While the Commission has sought to inform itself on the existing state of New Jersey statutory law touching on the Ombudsman's functions, has reviewed all the relevant decisions of the New Jersey Supreme Court, and has received oral or written presentations on these cases by Commission members, staff, and outside scholars, the Commission has not sought to render any final collective opinion on the correctness or appropriateness of the Ombudsman's interpretation of his Office's role under existing law. Clearly, there are significant differences of view among the legally trained members of the Commission (and among other members of the legal profession knowledgeable in this area) on this question, ranging from the Ombudsman's insistence that his is the sole correct interpretation of the decisional law; to the belief that the Ombudsman's position is an arguable interpretation of the Court's holdings, but by no means the only permissible interpretation; to the position that the Ombudsman's interpretation is contrary to the spirit, and perhaps, in some respects, to the letter of the New Jersey Supreme Court's opinions concerning these issues. Given these powerful differences of view among knowledgeable lawyers and legal scholars, and the disinclination of the Commission's many non-lawyer members to become embroiled in a professional dispute outside the sphere of their own professional competence, the Commission has chosen to focus its examination of the Ombudsman's "existing practices and procedures" on "how well they work" in a *practical sense*, and on "where change is needed."

Thus, the Commission's inquiry is *not* principally directed to whether the Ombudsman is functioning in conformity with existing law, but rather focuses on how well the current system (based on the Ombudsman's interpretation of existing statutory and decisional law) is working, and whether changes in that system, including the possibility of changes that may require statutory modifications to existing law and practice, would improve the system's operation.

Based on the evidence now before it, the Commission believes that several such changes should be considered.

The Commission begins its analysis with existing statements of policy by the Ombudsman's Office. Although such public written statements of official policy and practice have not been numerous, the Ombudsman did set forth a written "explanation of the applicable legal rules" in a widely circulated letter/memorandum to nursing home administrators dated August 30, 1988.

In the course of this memorandum, which has attracted considerable public and professional response, the Ombudsman states his view of the New Jersey Supreme Court's interpretation of the Mandatory Reporting of Adult Abuse Law as follows:

> every proposal to forego life-sustaining medical diagnosis or treatment for any psychiatric hospital or nursing home patient age 60 and over who has not been currently and legally determined able to make such decisions on his/her own is a possible case of patient abuse. (Emphasis in original.)

The memorandum goes on to provide that:

> The law requires that each medical director, physician, administrator, social worker, nurse, aide and other caregiving facility staff learning of such proposal to forego life-sustaining treatment immediately report same to the Ombudsman's Office. (Emphasis in original.)

The memorandum appears to indicate that failure by any of the aforementioned personnel to report any of a broad class of "possible situations"* as "a possible case of patient abuse" may result in liability for "possible fines, professional censure and other serious penalties." The law applies, in the Ombudsman's view, "regardless of whether such proposal comes from a relative, a guardian, a close friend, a physician, an attorney-in-fact under a written power of attorney, a

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* The memorandum interprets the abuse law to "[cover] all kinds of possible situations, including, without limitation:

- "issuing and/or following oral or written "Do Not Resuscitate" orders;
  "issuing and/or following oral or written "Do Not Hospitalize" orders;
- "withdrawing or withholding cardiopulmonary resuscitation;
- "withdrawing or withholding antibiotics;
- "withdrawing or withholding hemodialysis;
- "withdrawing or withholding artificial feeding systems like nasogastric, gastrostomy, jejunostomy, intravenous or clysis therapy for malnutrition or dehydration;
- "withdrawing or withholding oxygen or mechanical ventilation;
- "foregoing urinalysis or blood work in the face of infection of unknown etiology; and
- "foregoing amputations."

The memorandum subsequently notes and describes "two kinds of exceptional cases in which it is merely optional, not mandatory, to notify the Ombudsman."

'responsible party', or any one else, including the patient", and "regardless of whether the patient has a 'Living Will' or other written or oral instructions or indications of his/her intentions regarding such diagnosis or treatment". The memorandum also states the Ombudsman's view that "(p)atients' families, per se, no matter how devoted and caring, have no known legal authority to forego life-sustaining medical treatment on a patient's behalf." (Emphasis in original.)

The Commission recognizes that the Ombudsman has taken the position that these propositions are consistent with, and indeed compelled by, the existing statutory and decisional law of New Jersey, and does not here seek to pass judgment on the validity of that position. That said, many Commissioners are of the view that the language of "patient abuse," and the potentially intrusive and adversarial nature of inquiries conducted under that rubric, are generally ill-suited to many or most situations in which physicians, close family members, and sometimes the patient (either contemporaneously or through a previously executed living will or advance directive) consider the withholding or withdrawal of medical technologies in accordance with the patient's present or previously-expressed wishes.* While the possibility of improperly motivated actions contrary to the patient's wishes or interests cannot and should not be ruled out *a priori*, and procedures to assure the soundness of the decisionmaking process and the protection of vulnerable patients should be provided, the Commission does not believe that such procedures should be founded on a generalized presumption of bad faith or potential abuse on the part of family members or health care professionals. Rather, the Commission is impressed with the wisdom and balance of the New Jersey Supreme Court's statement in the *Farrell* case (108 N.J. 335, 529 A.2d 404, 414 (1987)):

> Our common human experience teaches us that family members and close friends care most and best for a patient. They offer love and support and concern, and have the best interests of the patient at heart. The importance of the family in medical treatment decisions is axiomatic.

The Court continues by noting that "[t]he law has traditionally respected the private realm of family life which the state cannot enter," and concludes "that this tradition of respect for and confidence in the family should ground our approach to the treatment of the sick."(*Id.*)**

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* On this view, the language of potential abuse, and associated mandatory reporting requirements, should be reserved for cases involving a particularized factual showing to justify suspicions of abuse -- as in traditional cases of physical or sexual abuse -- or a special basis for concern about the vulnerability of the patient.

** See also the New Jersey Supreme Court's parallel discussion in *Jobes*, 108 N.J. 394, 529 A.2d 434, 445 (1987):

> Almost invariably the patient's family has an intimate understanding of the patient's medical attitudes and general world view and therefore is in the best position to know the motives and considerations that would control the patient's medical decisions. ... Family members are best qualified to make substituted judgments for incompetent patients not only because of their peculiar grasp of the patient's approach to life, but also because of their special bonds with him or her.

It is instructive to contrast the Court's attitude toward the family role in medical decisionmaking with its discussion, in the very same case, of an alternative to the family. Consider the following, slightly expurgated quotations from the *Farrell* decision (529 A.2d at 415):

> Likewise, _____ review of a competent patient's refusal of life-sustaining medical treatment is generally not appropriate. Only unusual circumstances, such as a conflict among the physicians, or among the family members, or between the physicians and the family or other health care professionals, would necessitate _____ intervention. ... No matter how expedited, _____ intervention in this complex and sensitive area may take too long. Thus, it could infringe the very rights we want to protect. The mere prospect of a cumbersome, intrusive, and expensive _____ proceeding during such an emotional and upsetting period in the lives of a patient and his or her loved ones would undoubtedly deter many persons from deciding to discontinue treatment. And even if the patient or the family were willing to submit to such a proceeding, it is likely that the patient's rights would nevertheless be frustrated by _____ deliberation. Too many patients have died before their right to reject treatment was vindicated.

In the actual *Farrell* opinion, the blanks were filled in with references to courts and judicial proceedings. One may fairly wonder whether the Court intended, or anticipated, that the role it eschewed for the judiciary would be substituted for by a bureaucratic mechanism seemingly subject to the same ills decried by the Court. The Commission believes that an appropriate and effective review process must be designed to perform its necessary protective function without incurring these unacceptable costs.

The Commission's concern with the existing process reflects its recognition that errors, and with them, serious irreversible consequences, may flow from any of several directions, and not simply from one. There is indeed a legitimate and important societal concern that appropriate treatments may be withheld or withdrawn from seriously ill patients, based on mistaken medical judgments of diagnosis or prognosis, on mistaken understandings of the patient's wishes, or on mistaken assessments of where the patient's best interests truly lie.* Sensible protections must be provided against such possible errors. Yet at the same time, there is also a well-founded basis for concern regarding inappropriate over-treatment, the provision of medical interventions that serve merely to prolong an inevitable dying process and its attendant suffering, or that impose unwanted and burdensome interventions, contrary to the wishes or

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* The Court notes these darker possibilities in its *Jobes* opinion (529 A.2d at 447), and makes provisions to address some of them:

> There will, of course, be some unfortunate situations in which family members will not act to protect a patient. We anticipate that such cases will be exceptional. Whenever a health-care professional becomes uncertain about whether family members are properly protecting a patient's interests, termination of life-sustaining treatment should not occur without the appointment of a guardian.

interests of the patient, as understood by those best positioned to speak for the patient.

Given the possibility of errors with serious consequences in either direction, the Commission believes that the hallmarks of an appropriate process of decisionmaking and review must be balance, proportionality, timeliness, and sensitivity to the medical, moral and emotive dimensions -- and the inescapable ambiguities -- of such decisions. Any approach that is directed solely to preventing one form of error (e.g., inappropriate foregoing of treatment) without regard to these other dimensions runs the risk -- or perhaps more realistically, incurs the certainty -- of encouraging or forcing errors in the opposite direction. The challenge -- and the Commission recognizes the challenge is difficult to meet -- is to develop a set of substantive principles and procedural protections that will be properly sensitive to both sets of risks and concerns and will not themselves impose costs and barriers that defeat the very purpose for their existence.

With these considerations in mind, the Commission concludes that any appropriate process for review, including the existing system of Ombudsman review, must establish and make public a system of priorities for the use of its investigatory resources, taking into account the risks of actual abuse and the urgency of the case or class of cases. Such a system of priorities should include the identification of specific indicia of abuse, potential abuse, or special vulnerability, such as irresolvable disagreements among family members or health care professionals; lack of an involved advocate for a vulnerable patient or evidence of indifference or ill motive by a surrogate; or particular classes of interventions posing special risks, as prerequisites for full prospective review. The system should also provide an expedited review process (if any prospective review is indicated) for classes of cases posing minimal risks of actual abuse, such as advance directive cases or cases involving close and caring families with no disagreements among family members or health care professionals. If legislative action is indeed necessary for such priorities to be established within the Ombudsman's Office, the Commission believes such action is warranted and should take place, in order to strengthen the Office's ability to focus its attention on those situations that most require such attention.

At a deeper and more structural level, the Commission believes that routine review functions, designed to assure the soundness of basic decisionmaking processes, should be performed in a fashion that is not "cumbersome, intrusive and expensive," that is sensitive to the "emotional and upsetting period in the lives of a patient and his or her loved ones," that would not unnecessarily and inappropriately "deter many persons from deciding to discontinue treatment," and that would not frustrate patients' rights through passage of time inherent in a bureaucratic process. The Commission believes that local ethics committees, based in a particular health care institution or regionally established, can and should play a central role in this initial review process. Such ethics committees are already well-established in acute care settings, and are playing an increasing role in nursing homes and other settings. As such committees become better established in areas subject to the Ombudsman's current jurisdiction, the Commission believes the Office of the Ombudsman should rely on such committees for routine prospective review functions. The Ombudsman's Office should retain a supervisory and audit role, to assure that individual ethics committees are functioning properly and effectively, and should retain authority to participate in individual case reviews on an audit or spot-check

basis. The Ombudsman should also retain authority to perform prospective case reviews when there is no effective ethics committee in place, when the ethics committee process identifies cases requiring further review, and in specified classes of cases posing special risks of abuse. Once again, to the degree legislative action is required to refine the definition of abuse, to empower local or regional ethics committees to perform prospective case review in appropriate fashion, and to enable the Ombudsman both to audit the committee review process and to rely on that process in a broad class of individual cases, thereby enabling the Ombudsman's Office to focus on the cases most requiring its attention, the Commission believes such legislative action is warranted and should take place.

Finally, the Commission believes that consideration should be given to the creation of an independent advisory or oversight panel to assist the Ombudsman in formulating priorities and fostering the development and continuing function of an effective network of institutional and regional ethics committees.

In the next phase of its work, the Bioethics Commission and its Task Force on Institutional Ethics Committees will continue, in collaboration with the Office of the Ombudsman and others, to refine these suggestions, looking toward specific recommendations to the Office of the Ombudsman, the State Legislature, the Governor, and the New Jersey public.

(CITE 21 N.J.R. 1510) NEW JERSEY REGISTER, MONDAY, JUNE 5, 1989

(a)

OFFICE OF THE OMBUDSMAN FOR THE INSTITUTIONALIZED ELDERLY

Ombudsman Practice and Procedure
Public Notice Requirements

Proposed Repeal and New Rules: N.J.A.C. 5:100

Authorized By: Hector M. Rodriguez, Ombudsman for the Institutionalized Elderly.
Authority: N.J.S.A. 52:27G-1 et seq.
Proposal Number: PRN 1989-264.

Submit comments by July 5, 1989 to:
Steele R. Chadwell, General Counsel
Office of the Ombudsman for the Institutionalized Elderly
28 West State Street, Room 305
CN 808
Trenton, New Jersey 08625-0808

The agency proposal follows:

Summary

On January 27, 1983, the Legislature charged the Office of the Ombudsman for the Institutionalized Elderly (the "Office") with the responsibility of administering N.J.S.A. 52:27G-7.1 et seq. That statute basically requires persons employed as health care providers in facilities within the Office's jurisdiction to report abuse and exploitation of elderly patients, residents and clients of such facilities to the Office.

In 1985 and again in 1987, the New Jersey Supreme Court interpreted N.J.S.A 52:27G-7.1 et seq. to establish an audit role for the Office regarding decisions to forego life-sustaining treatment for institutionalized patients, residents and clients age 60 and older. In response to numerous inquiries during the ensuing years, the Office has used a variety of public information media to advise persons about its role and about the obligation to make related reports to the Office. One of these informational methods was sending annual, descriptive letters to nursing home administrators.

The most recent such letter was dated August 30, 1988. Like the similar letters sent in 1986 and 1987, the 1988 letter was authorized by law (N.J.S.A. 52:27G-9g, 11b, 11c and 11d), but was not meant itself, as a letter, to be binding or authoritative. Only a properly promulgated administrative rule can have the force of law.

Accordingly, to give an interpretation (not merely a description) of the law requiring certain reporting to the Office, the following comprehensively revised administrative rules are being proposed to replace those now in effect. The proposed new rules also more comprehensively describe the Office's interaction with the public in matters besides abuse and exploitation.

The new rules clarify when and how required reports must be made to the Office, in accordance with statute. They also clarify the receipt, handling and disposition by the Office of optional reports and complaints, whether about abuse or exploitation or otherwise about the health, safety and welfare, the human or civil rights of elderly patients, residents and clients.

Social Impact

The persons benefiting from the Office's advocacy function are the approximately 100,000 patients, residents and clients, aged 60 and older, of approximately 800 different health care facilities throughout New Jersey. These include, but are not limited to, nursing homes, psychiatric hospitals, residential health care facilities, and adult medical day care programs. These facilities are licensed by the New Jersey Department of Health, the New Jersey Department of Human Services and/or the New Jersey Department of Community Affairs. Some are public institutions; more are private.

The State of New Jersey has recognized that institutionalized elderly persons are peculiarly vulnerable, have special needs and problems and are generally isolated from other, non-institutionalized members of the community. The Office was created in response to such needs and problems, as an advocate for the State's institutionalized elderly patients, residents and clients. The Legislature declared as the public policy of the State that the Office secure, preserve and promote the health, safety and welfare of the State's institutionalized elderly and to ensure that its institutionalized elderly are able to enjoy the same civil and human rights guaranteed to all New Jerseyans.

The proposed new rules will assist the institutionalized elderly and others concerned with their welfare by facilitating access to and comprehension of the Office's legal advocacy mandate. The revised rules therefore elucidate means of contacting the Office, its investigauve procedures and methods of taking action, and its availability for community service.

These new rules will assist the institutionalized elderly and others concerned for their welfare, particularly regarding the directives of the New Jersey Supreme Court. These directives are interpretations of the Office's advocacy mandate, in the area of withdrawing and withholding necessary life-sustaining medical treatment. The rules will also specify for caregivers (who are employed by facilities to provide health-related services) and physicians and facility administrators their statutory reporting responsibilities imposed by law.

The proposed new rules are based on the Office's expertise and experience. Without being unduly burdensome, they eliminate some uncertainties about the Office's protective role for the institutionalized elderly and better specify how the Office functions.

The new rules place no new requirements upon the elderly themselves, their caregivers, physicians or facility administrators. Because the rules provide specific guidance in a difficult area, while at the same time providing comprehensive protection for New Jersey's institutionalized elderly, the rules should assist and benefit all those affected.

Economic Impact

The proposed new rules simply clarify what is already expressly provided by statute or court decision. Therefore, the rules themseives will not have an economic impact on affected parties.

There is no tax, fee, charge or other economic cost to the institutionalized elderly who are benefited by the Office's protective and advocacy role described and structured by these rules. Those who report or complain to the Office about any condition affecting the institutionalized elderly incur no cost if they use the Office's toll free "hotline" telephone number available within the 609 and 201 telephone area codes. Any cost of reporting or complaining to the Office is either voluntarily incurred—if the report or complaint is optional—or mandatorily incurred if the report is required under N.J.S.A. 52:27G-7.1 and 7.2. At most, any such economic cost would be that of a letter and postage and/or of telephone toll charges. Any costs are likely to be minimal.

Any costs of the procedures described in the rules already exist as a result of N.J.S.A. 52:27G-1 et seq. and the requirements imposed by the New Jersey Supreme Court. In fact, because they clarify the reporting responsibility already interpreted by the New Jersey Supreme Court under the mandatory abuse and exploitation reporting statute (N.J.S.A. 52:27G-7.1 and 7.2), the new rules could reduce the economic costs associated with unnecessary over-reporting to the Office.

The extent—if any—to which the aggregate minimal costs of reporting as mandated by law increase as a result of these rules' reducing uncertainty about reporting obligations cannot be reliably foreseen. One would expect that any such possible increase in reporting (and, hence, in the minimal associated direct costs) would be offset by a decline in the unnecessary over-reporting of cases to the Office.

Regulatory Flexibility Statement

Making complaints to the Office regarding violations of rights or about the care of elderly insututionalized patients, residents or clients is generally optional, not mandatory. Where reporting to the Office is mandatory, it is mandated by law (N.J.S.A. 52:27G-7.1 and 7.2), as interpreted by the New Jersey Supreme Court. Moreover, where such reporting is mandatory, it is not mandatory for any public or private facility, institution or business. The reporting requirement—where it exists—only makes reporting incumbent on natural persons, facility administrators, physicians, nurses, aides, physical therapists, speech therapists, social workers and other professional persons (not businesses) rendering care or employed to render care to the institutionalized elderly. Therefore, these rules have no impact—including capital expenditure impact—on any small business in New Jersey.

Full text of the proposed repeal may be found in the New Jersey Administrative Code at N.J.A.C. 5:100.

Full text of the proposed new rules follows:

CHAPTER 100
OFFICE OF THE OMBUDSMAN FOR THE INSTITUTIONALIZED ELDERLY: PRACTICE AND PROCEDURE

SUBCHAPTER 1. GENERAL PROVISIONS

5:100-1.1 Purposes and objectives of the Office of the Ombudsman

The basic objective of the Office of the Ombudsman for the Institutionalized Elderly is of promoting, advocating and ensuring, as a whole and in particular cases, the adequacy of the care received, and the quality of life experienced, by elderly patients, residents and clients of facilities offering health or health-related-services for the institutionalized elderly within New Jersey. The Office of the Ombudsman advocates for the health, safety and welfare, and the civil and human rights of the institutionalized elderly, age 60 or over, and takes such actions as are necessary, and within its jurisdiction, to secure same.

5:100-1.2 Definitions

The following words and terms, when used in this chapter, shall have the following meanings, unless the context clearly indicates otherwise:

"Abuse" means the willful infliction of physical pain, injury or mental anguish; unreasonable confinement; or the willfull deprivation of services which are necessary to maintain a person's physical and mental health. However, no person shall be deemed to be abused for the sole reason he or she is being furnished non-medical remedial treatment by spiritual means through prayer alone, in accordance with a recognized religious method of healing, in lieu of medical treatment.

An "act" of any facility or government agency shall be deemed to include any failure or refusal to act by such facility or government agency.

"Administrator" means any person who is charged with the general administration or supervision of a facility, whether or not such person has an ownership interest in such facility, and whether or not such person's functions and duties are shared with one or more other persons.

"Caretaker" means a person employed by a facility to provide care or services to an elderly person, and includes, but is not limited to, the administrator of a facility.

"Competent" means having a clear understanding of the nature of his or her illness and prognosis, and of the risks and benefits of the proposed treatment, and having the capacity to reason and make judgments about that information.

"Exploitation" means the act or process of using a person or his resources for another person's profit or advantage without legal entitlement to do so.

"Facility" means any facility or institution, whether public or private, offering health or health-related services for the institutionalized elderly, and which is subject to regulation, visitation, inspection, or supervision by any government agency. Facilities include, but are not limited to, nursing homes, skilled nursing homes, intermediate care facilities, extended care facilities, convalescent homes, rehabilitation centers, residential health care facilities, special hospitals, veterans' hospitals, chronic disease hospitals, psychiatric hospitals, mental hospitals, mental retardation centers or facilities, day care facilities for the elderly, and medical day care centers.

"Fully informed" means, with respect to a particular life-sustaining treatment decision, knowing his or her prognosis, the alternative treatments available, and the risks involved.

"Government agency" means any department, division, office, bureau, board, commission, authority, or any other agency or instrumentality created by the State or to which the State is a party, or by any county or municipality, which is responsible for the regulation, visitation, inspection or supervision of facilities, or which provides services to patients, residents or clients of facilities.

"Institutionalized elderly," "elderly" or "elderly person" means any person 60 years of age or older, who is a patient, resident or client of any facility.

"Office" means the Office of the Ombudsman for the Institutionalized Elderly.

"Ombudsman" means the administrator and chief executive officer of the Office of the Ombudsman for the Institutionalized Elderly.

"Patient, resident or client" means any elderly person who is receiving treatment or care in any facility in all its aspects, including, but not limited to, admission, retention, confinement, commitment, period of residence, transfer, discharge and any instances directly related to such status.

5:100-1.3 Contact with the Office; information about rights and entitlements; communications

(a) Any person may contact the Office to report any complaints concerning the health, safety and welfare, and the civil and human rights of institutionalized elderly persons.

(b) The Office may be contacted by calling its toll-free telephone number, 24 hours per day, any day of the year; or by writing to: The Office of the Ombudsman for the Institutionalized Elderly, CN 808, Trenton, New Jersey 08625-0808.

(c) Any correspondence or written communication from any patient or client of a facility to the Office shall, if delivered to or received by the facility, be promptly forwarded, unopened, by the facility to the Office. Any correspondence or written communication from the Office to any patient, resident or client of a facility shall, if delivered to or received by the facility, be promptly forwarded, unopened, by the facility to such patient, resident or client.

(d) The Office shall prepare and distribute to each facility written notices which set forth the address and telephone number of the Office, a brief explanation of the function of the Office, the procedure to follow in filing a complaint, and other pertinent information.

(e) The administrator of each facility shall ensure that such written notice is given to every patient, resident or client or his or her guardian upon admission to the facility and to every person already in residence or his or her guardian. The administrator shall also post such written notice in a conspicuous, public place in the facility.

(f) The Office shall from time to time publicize its existence, function and activities by informing patients, residents and clients, their families and friends, facility staff and other caretakers, government agencies and representatives, private organizations and community groups, and the general public, about the Office and its function and activities, through "in-service training" presentations at facilities and elsewhere, participation in seminars or other informational programs, contact with the press and other media, and direct communication, in person or in writing, including the submission for publication of scholarly and informational articles and other materials concerning the Office, its functions and activities.

(g) The Office shall make itself available for the purpose of informing and educating interested individuals and groups about general issues of concern affecting the civil and human rights of the institutionalized elderly.

5:100-1.4 Complaints

(a) The Office shall acknowledge all complaints.

(b) If the Office does not have jurisdiction, the Office shall advise the person making the complaint of this finding.

(c) If the Office has jurisdiction of the subject matter of the complaint, the Office, in appropriate cases, will utilize the following procedures:

1. If the Office discovers a deficiency in compliance with State or Federal laws or regulations or rules administered by any government agency, the Office shall refer the matter directly to the appropriate government agency for action.

2. If the Office discovers facts which the Office determines warrants the institution of civil proceedings by a government agency against any person or governmental agency, the matter shall be referred to the government agency with authority to institute such proceedings.

3. If the Office discovers information in relation to the misconduct or breach of duty of any officer or employee of a facility or a government agency, the matter shall be referred to the appropriate authorities for such action as may be necessary.

4. If the Office discovers information or facts indicating the commission of criminal offenses or violations of standards of professional conduct, it shall refer the matter, as appropriate, to the Attorney General, county prosecutor or any other law enforcement official who has jurisdiction to prosecute the crime, and to the relevant professional licensing board.

5. The government agency, prosecuting agency or professional licensing board, as the case may be, shall report to the Office on its findings and actions with respect to all such referrals within 30 days after receipt thereof and every 30 days thereafter until final action on each such referral. The Office may make disclosure of such information as appropriate and as may be necessary to resolve the matter referred.

6. In the event that the complaint of a patient, resident or client or class of patients, residents or clients of a facility or facilities, cannot be resolved satisfactorily through negotiation with the facility or the appropriate government agency, or that an act, practice, policy or procedure of a facility or government agency does or may adversely affect the health, safety, welfare or civil or human rights of a patient, resident or client, or class of patients, residents or clients, of a facility or facilities, the Office may recommend to the appropriate authorities civil litigation on behalf of such patient, resident or client, or class of patients, residents or clients, as it deems appropriate. The Office may also itself institute actions for injunctive relief or civil damages as it deems appropriate.

7. The Office shall notify the complainant of the specific action taken by the Office.

5:100-1.5 Investigations initiated by receipt of complaints

(a) In addition to the referral procedure described in N.J.A.C. 5:100-1.4, upon receiving a complaint, the Office may itself investigate any act, practice, policy or procedure of any facility or government agency that does or may adversely affect the health, safety, welfare or civil or human rights of any patient, resident or client of a facility.

(b) The Office need not investigate any complaint where it determines that:

1. The complaint is trivial, frivolous, vexatious or not made in good faith;

2. The complaint has been too long delayed to justify present investigation;

3. The resources available, considering the Office's established priorities, are insufficient for an adequate investigation; or

4. The matter complained of is not within the investigatory authority of the Office.

5:100-1.6 Investigation procedure

(a) During the course of any investigation conducted by the Office, the Office may:

1. Make the necessary inquiries and obtain such information as it deems necessary;

2. Hold private hearings or public hearings;

3. Enter, without notice, and after notifying the person in charge of its presence, inspect the premises of a facility or government agency and inspect there any books, files, medical records or other records that pertain to patients, residents, or clients which are required by law to be maintained by the facility or government agency;

4. Compel at a specific time and place, by subpoena, the appearance and sworn testimony of any person who the Office reasonably believes may be able to give information relating to a matter under investigation; and

5. Compel any person to produce at a specific time and place, by subpoena, any documents, books, records, papers, objects, or other evidence which the Office reasonably believes may relate to a matter under investigation.

5:100-1.7 Required reporting of suspected abuse or exploitation of institutionalized elderly persons; penalties for failure to make required report

(a) Any caretaker, social worker, physician, registered or licensed practical nurse, or other professional, who, as a result of information obtained in the course of his or her employment, has reasonable cause to suspect or believe that an institutionalized elderly person is being or has been abused or exploited, shall report such information to the Office within the time and in the manner required by N.J.A.C. 5:100-1.7(b) and (c).

(b) The individual reporting shall make a verbal report of the suspected abuse or exploitation in a timely manner by telephone to the Office.

(c) The individual reporting shall follow the verbal report within two business days with a written report, containing the following information:

1. The identity of the individual making the report;

2. The name, address and age of the elderly person who is the subject of the suspected abuse or exploitation, if known;

3. The name of the person accused of committing the alleged abuse or exploitation, if known;

4. The name and address of the facility involved;

5. A description of the nature of the suspected abuse or exploitation;

6. The date, time and specific location of the occurrence; and

7. The name and address of any witness to the suspected abuse or exploitation.

(d) Upon receipt of these reports, the Office shall follow the procedures for investigating the matter set forth in this subchapter.

(e) The name of any person who reports suspected abuse or exploitation pursuant to this section shall not be disclosed, unless the person who reported the abuse or exploitation specifically authorizes such disclosure or a judicial proceeding results from such report or disclosure is authorized under N.J.A.C. 5:100-1.10(a).

(f) Any person who reports suspected abuse or exploitation pursuant to this section or who testifies in any administrative or judicial proceeding arising from such report or testimony shall have immunity from civil or criminal liability on account of such report or testimony, unless such person has acted in bad faith or with malicious purpose.

(g) Pursuant to N.J.S.A. 52:27G-7.1(f), any person required to report suspected abuse or exploitation, as required herein, who fails to make the reports required by this section, may be fined up to $5,000. Such penalty will be collected and enforced by the Office in a summary proceeding brought pursuant to the Penalty Enforcement Law, N.J.S.A. 2A:58-1 et seq.

(h) Where the report pertains to withholding or withdrawing life-sustaining treatment from an elderly incompetent institutionalized patient, resident or client, reporting is governed by N.J.A.C. 5:100-2.

5:100-1.8 Investigations instituted by receipt of report of abuse or exploitation

(a) Any person having reasonable cause to suspect or believe that an elderly person is being or has been abused or exploited may report such information to the Office.

(b) Within 24 hours of receipt of a report of abuse or exploitation, the Office shall notify the Commissioner of Human Services and any other governmental agency which regulates or operates the facility that the report has been received.

(c) Upon receiving a report that an elderly person may be or may have been abused or exploited, the Office shall conduct a prompt investigation.

(d) The investigation shall include a visit with the elderly person and consultation with others who have knowledge of the particular case. When the investigation is completed, findings and recommended action shall be prepared in a written report and submitted to the Commissioner of Human Services.

(e) The person who reported the suspected abuse or exploitation shall be promptly notified that action is being taken.

(f) If a determination is made that an elderly person may have been criminally abused or exploited, the Ombudsman shall refer such findings, in writing, to the county prosecutor or any other appropriate prosecuting agency.

(g) The Office shall maintain a central registry of all reports of suspected abuse or exploitation and of all investigations, findings and recommended actions. No information received and compiled in such registries shall be construed as a public record.

(h) The name of any person who reports suspected abuse or exploitation pursuant to this subchapter shall not be disclosed, unless:

1. The person who reported the abuse or exploitation specifically requests such disclosure; or

2. A judicial proceeding results from such report; or

3. Disclosure is authorized under N.J.A.C. 5:100-1.10(a).

(i) Any person who reports suspected abuse or exploitation pursuant to this subchapter or who testifies in any administrative or judicial proceeding arising from such report or testimony shall have immunity for any civil or criminal liability on account of such report or testimony, unless such person has acted in bad faith or with malicious purpose.

5:100-1.9 Post-investigation procedures

(a) Following the completion of any investigation conducted by the Office, the Office shall take appropriate action, including, but not limited to, the following:

1. Reporting its opinions or recommendations to the appropriate agencies, facilities or persons;

2. Requesting the party affected by such opinions or recommendations to notify the Office within a specified time of any action taken by such party on the Office's recommendations;

3. Attempting to resolve the matter through negotiations;

4. Referring the Office's findings and recommendations to an appropriate person or agency; and/or

5. Instituting appropriate legal action.

5:100-1.10 Confidentiality of information; privileged communications

(a) The Office shall maintain confidentiality with respect to all matters in relation to any complaint or investigation, together with identities of the complainants, witnesses or patients, residents or clients involved, unless such persons authorize, in writing, the release of such information, except for such disclosures as the Ombudsman deems necessary to enable the Office to perform its duties and to support any opinions or recommendations that may result from a complaint or investigation. The investigatory files of the Office, including all complaints and responses of the Office to complaints, shall be maintained as confidential information. Release of pertinent records shall be at the discretion of the Ombudsman.

(b) Any statement or communication made by the Office relevant to a complaint received by, proceedings before, or investigative ac-

tivities of, the Office, and any complaint or information made or provided in good faith by any person, shall be absolutely privileged and such privilege shall be a complete defense in any action which shall allege libel or slander.

5:100-1.11 Prohibition of discriminatory, disciplinary or retaliatory action

No discriminatory, disciplinary or retaliatory action shall be taken against any officer or employee of a facility or government agency by such facility or government agency, or against any patient, resident or client of a facility or guardian or family member thereof, or volunteer, for any communication by him or her with the Office or for any information given or disclosed by him or her in good faith to aid the Office in carrying out its duties and responsibilities.

5:100-1.12 Hindrance of Office or refusal to comply; penalties

Any person who willfully hinders the lawful actions of the Office or willfully refuses to comply with any of its lawful demands, including the demand of immediate entry into and inspection of a facility or govenment agency or the demand of immediate access to a patient, resident or client thereof, may be fined up to $5,000. Such penalty shall be collected and enforced by the Office in a summary proceeding brought pursuant to the Penalty Enforcement Law, N.J.S.A. 2A:58-1 et seq.

SUBCHAPTER 2 REPORTING PROCEDURES REQUIRED PRIOR TO WITHHOLDING OR WITHDRAWING LIFE-SUSTAINING TREATMENT FROM ELDERLY, INCOMPETENT INSTITUTIONALIZED PATIENTS, RESIDENTS AND CLIENTS

5:100-2.1 Purpose

The New Jersey Supreme Court has rendered a series of decisions in which the Court addressed many complex and highly sensitive issues surrounding decisions to withhold or withdraw life-sustaining treatment, specifically *Matter of Peter*, 108 *N.J.* 365 (1987); *Matter of Conroy*, 98 *N.J.* 321 (1985); *Matter of Farrell*, 108 *N.J.* 335 (1987); *Matter of Jobes*, 108 *N.J.* 394 (1987); *In re Quinlan*, 70 *N.J.* 10, *cert. den. sub nom.* Garger v. New Jersey, 429 *U.S.* 922, 97 *S.Ct.* 319, 50 *L.Ed.2d* 289 (1976). In these cases, the Court specifically prescribed an 'audit' role which the Office of the Ombudsman must play in reviewing these decisions for elderly, incompetent institutionalized patients, residents and clients. This is only an audit role. The Office does not make any decisions for the elderly. The purpose of this subchapter is to set forth the reporting procedures in detail so that all persons involved in these complex decisions will be fully apprised of their duties and responsibilities to report to the Office. The Office's audit role requires a review of the decisionmaking process to ensure the procedural regularity of decisions made by others.

5:100-2.2 Scope

(a) The procedures set forth in this subchapter shall apply to all reportable determinations as to whether life-sustaining treatment may be withheld or withdrawn from an elderly institutionalized patient, resident or client of a facility, who is incompetent to make the decision for himself or herself (hereinafter an incompetent patient, resident or client). The reporting procedures set forth in this subchapter do not apply if the decision is:

1. Voluntarily made by a fully informed, competent patient who has not been otherwise determined to lack legal authority to make such a decision;
2. Based on a physician's good faith determination that the life-sustaining treatment is not medically necessary; or
3. Being reviewed by, or has been reviewed favorably by, a court of competent jurisdiction.

5:100-2.3 Required reporting procedures

(a) Any caretaker, social worker, physician, registered or licensed practical nurse or other professional, who, as a result of information obtained in the course of his or her employment, has reasonable cause to suspect that life-sustaining treatment has been, or is about to be, withheld or withdrawn from an incompetent patient, resident or client without notice to the Office, shall report this information to the Office within the time and in the manner required by (b) and (c) below.

(b) Any person required to report under (a) above and who knows of a proposal to withhold or withdraw life-sustaining treatment from an incompetent patient, resident or client shall immediately notify the Office of the Ombudsman of the proposal.

(c) The notification shall include the following information:

1. The identity of the person making the report;
2. The name, address and age of the incompetent patient;
3. The name and address of the facility involved;
4. If an incompetent patient, resident or client has designated a family member, another relative or a non-relative to make surrogate medical decisions, that person's name and address must be provided to the Ombudsman. If available, the names and addresses of all close family members (that is, a spouse, parents, adult children, or siblings) must also be provided to the Ombudsman; and
5. The name and address of the incompetent patient's guardian, if a guardian has been appointed.

(d) The Office's review shall proceed pursuant to the procedures set forth in N.J.A.C. 5:100-1.4 through 1.12. The Office's review may include, but is not limited to, the following information:

1. The report required by (b) and (c) above;
2. Evidence concerning the incompetent patient's, resident's or client's condition which must be provided to the Ombudsman by the incompetent patient's attending physicians, nurses and caretakers;
3. Medical opinions which confirm the incompetent patient's, resident's or client's medical condition, the medical alternatives available, the risks involved, the likely outcome if medical treatment is foregone and that there is no reasonable possibility of an incompetent patient, resident or client recovering from a terminal illness or to a cognitive, sapient state;
4. Evidence concerning the incompetent patient's wishes; and
5. Where the incompetent patient's wishes are not established by clear and convincing evidence, the assessment of the incompetent patient's designated decisionmaker, any close family member, any other relative or non-relative friend designated by the incompetent patient, resident or client or any guardian appointed by the court.

(e) At the conclusion of the review, the Office shall determine whether to defer to the proposal to withhold or withdraw life-sustaining treatment from an incompetent patient, resident or client.

(f) If the Office does not defer to the proposal, any party may then seek a judicial determination on the issue presented.

Commission Comments on Ombudsman's Proposed Administrative Rules as Published in *The New Jersey Register* June 5, 1989

September 5, 1989

Steele R. Chadwell, Esq.
General Counsel
Office of the Ombudsman for
the Institutionalized Elderly
28 West State Street, Room 305
CN 808
Trenton, NJ 08625-0808

Dear Mr. Chadwell:

The following comments are submitted on behalf of the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care (the "Commission") in response to the proposed adoption of new administrative rules regarding the Office of the Ombudsman for the Institutionalized Elderly (the "Ombudsman"), published in the June 5, 1989 *New Jersey Register*, Proposal Number PRN 1989-264.

As you are aware, the Commission has itself proposed legislation to govern health care decisionmaking in accordance with advance directives. The Commission's proposal, embodied in S-3320, has been approved by the New Jersey Senate and is now pending action in the General Assembly. The Commission believes that this proposal sets forth appropriate standards and procedures for those cases within its scope of coverage, and that regulatory action should be compatible with its provisions, to the extent permitted by existing law. For that reason, the Commission believes the Ombudsman should defer final action on its proposed regulations pending definitive legislative action on S-3320. If this is not possible, the regulations should be modified to bring them into greater conformity with the principles underlying the Commission's proposals. The following comments are intended to assist in that effort, and to assure that the process of Ombudsman review in the future be properly respectful of the appropriate roles and rights of patients and families while providing necessary safeguards of patient well-being in cases involving decisions to forego life-sustaining treatment subject to the Ombudsman's jurisdiction. The Commission's comments here are subordinate to and are not intended to modify, in whole or in part, any policies formally adopted by the Commission in its legislative proposal or policy statements approved in December 1988.

Subchapter 1. General Provisions

While the Commission's mandate principally concerns procedures under subchapter 2, we comment on those provisions of subchapter 1 relevant to cases of foregoing life-sustaining treatment.

Section 5:100-1.2 Definitions

1. "*Abuse*". While recognizing that the proposed regulatory definition is identical to that used in the Ombudsman's enabling statute, the Commission finds the language of "patient abuse" to be generally ill-suited to many or most situations in which physicians, close family members, and patients consider whether life-sustaining treatment should be withheld or withdrawn in accordance with the patient's wishes (expressed either contemporaneously or through a previously executed advance directive). The Commission recommends that the following sentence be added to the definition:

> The withholding or withdrawal of life-sustaining treatment pursuant to a contemporaneous or prior expression of the wishes of a competent patient, or in circumstances in which such treatment does not benefit the patient, when effectuated in accordance with the procedures required by these regulations, shall not be construed as a "willful deprivation of services" or as an instance of "abuse".

2. "*Competent*". The proposed regulations provide that there is no obligation to report to the Ombudsman decisions to withhold or withdraw life-sustaining treatment which are "voluntarily made by a fully informed, competent patient who has not been otherwise determined to lack legal authority to make such a decision". (Section 5:100-2.2(a)1.) This provision properly recognizes that under existing New Jersey law, competent patients generally have the legal right to refuse life-sustaining treatment without prior review by a public body, such as the Ombudsman. The proposed definition of "competent" requires that the patient must "[have] a clear understanding of the nature of his or her illness and prognosis, and of the risks and benefits of the proposed treatment, and [must have] the capacity to reason and make judgments about that information."

This proposed definition improperly conflates the concept of competence (which involves the patient's capacity) with the results of a process of informed consent. A proper definition of competence (the Commission prefers the term "decisionmaking capacity") should focus upon a patient's *abilities* to understand and deliberate about relevant information and to reach an informed decision. The Commission recommends that the following definition, which emphasizes a patient's decisionmaking abilities, be adopted:

> "Competence" means a patient's ability to understand and appreciate the nature and consequences of treatment decisions, including the benefits and risks of each, and alternatives to any proposed treatment, and to reach an informed decision.

This definition captures the essential features of our common understanding of what it means to make health care decisions, and provides criteria which physicians can more properly and accurately evaluate in making such determinations.

3. "*Fully informed*". There is potential confusion between *being informed* of one's medical condition and treatment choices and actually *knowing* or understanding this information. The standard for informed consent litigation, focusing on the potential tort liability of the physician, may differ from the standard appropriate in cases of foregoing life-sustaining treatment. To achieve the desirable clarity on this issue, the Commission recommends that the following definition be adopted:

> "Fully informed" means, with respect to a particular life-sustaining treatment decision, that a patient has been informed, in language understandable to the patient, of his or her diagnosis and prognosis, and the benefits, burdens and risks of the proposed treatment and its alternatives.

This amendment would clarify for physicians what information they are required to provide and discuss with patients. In order to give informed consent, the patient would also have to possess the requisite abilities to understand, to reason and to reach an informed decision based upon this information.

4. Since the central focus of the proposed regulations is on decisions to forego life-sustaining treatment, a definition of "life-sustaining treatment" should be included in the proposed regulations. The Commission recommends that the following definition be added:

> "Life-sustaining treatment" means the use of any medical device or procedure, drugs, surgery or therapy that uses mechanical or other artificial means to sustain, restore or supplant a vital bodily function, and thereby to increase the expected life span of a patient.

Sections 5:100-1.6 Investigation procedure; 5:100-1.8 Investigations instituted by receipt of report of abuse or exploitation

The Commission believes that a timely review process is essential to a sound process of decisionmaking and review. In order to assure respect for patient rights as well as to protect patient well-being, this process should be measured from the invocation of the Ombudsman's review until the completion of the review process and any necessary determinations and documentation. Therefore, the Commission recommends that the regulations incorporate a specific timeframe, as so measured, for completion of the Ombudsman's review process.

Section 5:100-1.9 Post-investigation procedures

For the reasons stated in the preceding comment, the Commission recommends that this section be amended to incorporate a specific timeframe within which the Ombudsman will take appropriate action following completion of its investigation. The Commission also strongly recommends that the Ombudsman's report of its opinions, recommendations or other action taken following completion of its investigation be in writing, and available to the patient, the institution, and other concerned parties.

Subchapter 2. Reporting Procedures Required Prior to Withholding or Withdrawing Life-Sustaining Treatment From Elderly, Incompetent Institutionalized Patients, Residents and Clients.

General Comments

In their present form, the proposed regulations would require reporting and Ombudsman review in a large number of cases in which a decision to forego life-sustaining treatment is contemplated. The Commission believes that the proposed regulations should go significantly further in establishing and making public a system of priorities for the Ombudsman's involvement in reviewing (or not reviewing) decisions to forego life-sustaining treatment.

Highest priority for full review should be accorded when there are specific indicia of abuse, potential abuse, or special vulnerability, such as irresolvable disagreements among family members or health care professionals; lack of an involved advocate for a vulnerable patient or evidence of indifference or ill motive by a surrogate; or particular classes of interventions posing special risks, as prerequisites for full prospective review.

Provisions should also be included (perhaps through the addition of a new section 5:100-2.2(b)) to provide for an expedited review process for classes of cases posing minimal risks of actual abuse. Specifically, this section should provide for expedited review of cases in which a decision to forego life-sustaining treatment is contemplated pursuant to the terms of the patient's advance directive, or where close and caring family members are involved in the patient's care and there is no disagreement among family and health care professionals that life-sustaining treatment should be withheld or withdrawn.

The Commission believes that local ethics committees, either institutionally or regionally based, can and should play an increasingly central role in the initial review process. Local review can effectively assure that the elements of sound decisionmaking are in place, and provide a handy mechanism for on-site expedited review in cases posing minimal risks of abuse. Such committees would also identify particular cases which warrant further review by the Ombudsman. Ethics committees are already well-established in hospitals, and have come to play an increasing role in nursing homes. As such committees become better established in nursing homes and other long-term care facilities, the Commission believes that the Ombudsman should rely on such committees for routine prospective review functions. If this recommendation is adopted, it will be necessary to consider more precisely what the Ombudsman's relationship to local ethics committees should be. Future regulations (or statutes) must define the circumstances in which further review by the Ombudsman will be required, and the sort of supervisory or audit role the Ombudsman should play to assure that such committees are functioning properly and effectively. The Commission believes cooperative efforts by the Ombudsman and the Commission, together with other interested parties, would be especially helpful here.

Section 5:100-2.2 Scope

The Commission applauds the apparent intent of this section to define *and limit* the scope of the Ombudsman's required review to those cases in which the protective role of the Ombudsman is most needed.

1. *5:100-2.2(a)1.* The Commission's comments regarding the operative defined terms in this provision are stated in comment to section 5:100-1.2.

This provision properly recognizes that reports need not be submitted, and the Ombudsman need not review decisions by competent patients who make informed and voluntary refusals of life-sustaining treatment. The Commission is concerned, however, with the lack of procedural specificity for determinations of lack of competence, and, in particular, whether this is a medical (physician-made) or legal (court-made) decision. This should be clearly stated in the regulations, as should any requirement of confirmation or documentation. The Commission's views on an appropriate process are set forth in section 8 of S-3320.

2. *5:100-2.2(a)2.* Again, the Commission strongly supports the apparent intent and purpose of this provision, but believes the language of this section is vague and should be more clearly stated.

The phrase "not medically necessary" is ambiguous. For example, a medical treatment might be considered "medically necessary" to treat a specific condition or illness, even when such treatment would not change or improve the patient's overall course (e.g., treating the pneumonia of an imminently dying cancer patient). It is also unclear whether what is "medically necessary" is measured solely from the physician's perspective, or instead, as the Commission believes it should, incorporates consideration of the patient's values and treatment goals, which may be different from those of the physician. In the Commission's view, the most important factor in determining medical necessity should be whether the life-sustaining treatment in question will be beneficial to the patient in light of the patient's overall medical condition and the patient's treatment objectives. Therefore, the Commission recommends the following alternative formulation:

> 2. Based on a physician's good faith determination, taking into consideration the patient's wishes and total medical condition, that the life-sustaining treatment is likely to be ineffective in prolonging life, or is likely to merely prolong an imminent dying process;.

Section 5:100-2.3 Required reporting procedures

1. *Section 5:100-2.3(d)3.* Confusion and controversy have attended past procedures for obtaining medical opinions to confirm the patient's diagnosis and prognosis in the course of Ombudsman review. The Commission believes that this section should clearly state the number of confirming medical opinions required (under current law, two) as well as who has responsibility for obtaining, and paying for, the services of consulting physicians. The Commission believes the State should defray these legally-mandated costs when not covered by insurance or other mechanisms.

This section also conflates the distinct standards under existing law for withholding or withdrawing life-sustaining treatment for a patient who is terminally ill with those applicable to a patient who is in a persistent vegetative state. It would be helpful to address each of these conditions separately.

2. *Section 5:100-2.3(d)5.* This section raises several critical issues which have arisen in a number of cases in which the Ombudsman has been involved in the past, and likely will be involved in the future. These issues should be addressed more clearly and with greater specificity in the proposed regulations.

Specifically, this section should clarify what review of the decisionmaking authority of designated decisionmakers and close family members entails. As stated previously, the Commission believes that provisions for expedited review should apply to many of these cases. This section should also address when those involved in the patient's care should seek appointment of a legal guardian for the patient, and who bears this responsibility.

The first clause of this section might be read to suggest that an incompetent patient's previously expressed wishes to forego life-sustaining treatment must be established by "clear and convincing evidence". In the context of decisionmaking by designated health care representatives, and in some circumstances family members, this standard may be higher than that required by the New Jersey Supreme Court. This point should be clarified in the proposed regulations.

3. *Section 5:100-2.3(e).* Consistent with the comments to sections 5:100-1.6, 5:100-1.8, and 5:100-1.9, this provision should establish a specific timeframe within which the Ombudsman will determine whether to defer to the proposal to withhold or withdraw life-sustaining treatment. The Commission strongly recommends that the facility and other appropriate parties be promptly informed, in writing, of whether the Ombudsman will defer to the proposal to withhold or withdraw life-sustaining treatment and of any other action taken by the Ombudsman, including a statement of the reasons for the Ombudsman's action.

Additional Comments

The Commission also suggests that the Ombudsman undertake to review and revise the proposed regulations in response to future legislative and judicial developments, and that this review be conducted in consultation with other agencies and members of the health care community. Specifically, the proposed New Jersey Advance Directives for Health Care Act (S-3320) which was approved by the New Jersey Senate on August 14, 1989, would modify certain existing legal provisions and would require the Ombudsman to adopt rules and regulations necessary to comply with the Act. Of particular note, sections 15(A)(4) and 16(A)(3) of that bill provide that in specified circumstances a local review process meeting standards established by law would be a legally recognized alternative to Ombudsman review for cases within the Ombudsman's jurisdiction. The Ombudsman may wish to re-evaluate its approach to cases involving advance directives should S-3320 become law.

In addition, the Commission is presently considering a more comprehensive approach to a prospective case consultation role for institutional and regional ethics committees, including the relationship between such committees and the role of the Ombudsman in reviewing life-sustaining treatment decisions. This work may result in proposed legislation in the future.

The Commission values the continued constructive participation of the Ombudsman in the Commission's work and would be pleased to discuss its comments and to answer any questions regarding the Commission's comments.

Respectfully submitted,

Daniel F. O'Connell, Esq.
Chairman

Part Five

The Commission's Task Forces

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Chapter One
Task Force on New Reproductive Practices

Following preparatory work at the staff level in 1987 and early 1988, the Bioethics Commission announced the expansion of its Ad Hoc Task Force on New Reproductive Practices on March 9, 1988. The Task Force was formed to assist the full Commission in fulfilling its statutory mandate "to provide a comprehensive and scholarly examination of the impact of advancing technology on health care decisions" in the area of new reproductive practices.

As initially constituted, the Task Force comprised 19 members, including five members of the Commission. In addition, the Commission's Chairman and Vice-Chairman sat ex officio as Task Force members.* The non-Commissioner Task Force members bring additional expertise in such areas as medicine, reproductive and molecular biology, public health, clinical and developmental psychology, social work, family law, adoption, women's rights, theology and philosophy. The Task Force was chaired from March 1988 till September 1989 by former Commissioner Linda G. Rosenzweig, then Director of the Division of Mental Health Advocacy in the Office of the Public Advocate, and subsequently by the Commission's Vice-Chair, Paul W. Armstrong.

The Task Force's charge from the Commission is to focus on the overall implications of the new reproductive technology, placing particular practices in the context of other closely related and rapidly evolving reproductive possibilities. The Task Force will assist the Commission, and ultimately the State Legislature, to respond to the Supreme Court's invitation in the celebrated New Jersey surrogacy case, *In the Matter of Baby M*, ("*Baby M*") to explore society's "values and objectives... in this troubling, yet promising, area".[1]

The Task Force's agenda is comprehensive and is likely to continue over several years. The Commission has asked the Task Force to prepare an initial report on surrogacy. Subsequently, the Task Force's work may expand to encompass more technologically complex reproductive practices and related genetic issues. This section of the Report will describe in some detail the Task Force's work to date on the subject of surrogacy.

Description of the Practice

Surrogacy is best described as a social arrangement, rather than as a medical "technology". The practice of surrogacy may take a variety of forms. The most common form occurs when a man and a woman (not his wife or sexual partner) contract with each other to produce a child who, although genetically related to both, will be reared by the man and his

*A complete list of Task Force members and capsule biographies can be found in Table 3 of Appendix B to the report.

wife.* The purpose of the arrangement is to allow a couple, which includes an infertile female partner, to have a child who will be genetically related to at least one of them, the male partner. In essence, the birth mother (the so-called "surrogate"**) agrees to be artificially inseminated with the man's sperm, to gestate the child and carry it to term, to give birth, to transfer the child to its natural father and his wife, and to relinquish her own parental rights. In return, the contracting woman is usually, although not necessarily, paid a fee. If a broker is involved in setting up the arrangement, she or he will also receive a fee, as will any professionals participating in the process (for example, attorneys, mental health practitioners, or physicians). It was this type of surrogacy arrangement that was at issue in the *Baby M* case.

A less common variant of the arrangement, involving more sophisticated reproductive technology, may be considered when the wife of the intending rearing couple is able to produce viable eggs, but is unable to carry a pregnancy safely to term without risk to her health or the health of the fetus. In this arrangement, an ovum is extracted from the wife (or in other variants, from another egg donor). The ovum is then fertilized *in vitro* with the husband's sperm. The resulting embryo is then transferred and implanted into the uterus of the contracting woman, who carries it to term and gives birth. In this arrangement, the child is genetically related to both members of the couple, and is not genetically related to the contracting woman, whose reproductive role is purely gestational. This practice, sometimes termed "gestational surrogacy", is at present used relatively rarely due to the high medical cost and comparatively low success rate of the *in vitro* fertilization technique. However, where permitted by law, the use of this technique may be expected to increase in the future.

Current Law in New Jersey

National attention was focused upon the legal, ethical and social aspects of the practice of surrogacy with the widely publicized *Baby M* case in New Jersey. The New Jersey Supreme Court's landmark decision in that case constitutes the current law on commercial surrogacy in this State.

The facts of the *Baby M* case can be summarized as follows: Mary Beth Whitehead and William Stern entered into a surrogacy agreement, where Mrs. Whitehead was to be artificially inseminated with Mr. Stern's sperm, carry the child to term, and immediately after birth surrender the child to Mr. Stern. The contract contemplated that Mrs. Whitehead's parental rights would be voluntarily terminated, thus allowing for the adoption of the child by Mr. Stern's wife, Elizabeth. Mrs. Whitehead was to receive $10,000 on surrender of the child. After the birth of the child, however, Mrs. Whitehead refused to surrender her parental rights and contested custody of the child.

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*The Task Force began its process with a working definition of "surrogacy", as reflected above. However, as discussed below, this working definition has undergone considerable expansion and refinement in the course of the Task Force's deliberations.

**The Task Force agreed with the observation made by the New Jersey Supreme Court in *Baby M* that the term "surrogate" was troublesome and somewhat of a misnomer. The Task Force therefore decided that the woman carrying and giving birth to the child should be referred to as the "so-called surrogate" or the "birth mother".

The trial court held the surrogacy contract valid and enforceable, terminated Mrs. Whitehead's parental rights, and awarded sole custody of the child to Mr. Stern. It then immediately granted Mrs. Stern an order for adoption. The court conflated its rationale for ordering specific performance of the contract with a determination that this remedy would be in the best interests of the child.[2]

The New Jersey Supreme Court reversed, holding that the contract was illegal and unenforceable, on two bases: first, that it violated New Jersey adoption statutes, and second, that it conflicted with New Jersey public policy, as expressed in both statutory and decisional law. The Court ruled that there was no basis to justify termination of Mrs. Whitehead's parental rights, and thereby to permit adoption by Mrs. Stern. In deciding the issue of custody, however, the Court affirmed the finding of the trial court that it was in the "best interests" of the child to be placed with the Sterns.* As to visitation, the Court ruled that Mrs. Whitehead was entitled to visitation "at some point", and remanded this limited issue for further hearings by an alternate trial judge. [3]

The New Jersey Supreme Court's ruling that the surrogacy contract conflicted with existing adoption statutes was based on three grounds: (1) it violated statutory prohibitions against certain uses of money in connection with an adoption; (2) it conflicted with laws requiring proof of parental unfitness or abandonment as a prerequisite to termination of parental rights; and (3) it was inconsistent with statutory provisions making surrender of custody and consent to adoption revocable in private placement adoptions.[4]

The Court's conclusion that the surrogacy contract was invalid because it conflicted directly with New Jersey public policy was based on a number of grounds. First, the Court pointed out that the basic premise of the surrogacy contract, namely, that the contracting natural parents would decide prior to the birth of the child which parent would have custody, is contrary to the policy that custody is to be determined by a court in accordance with the child's best interests. Second, the Court found that the contract contravened the policy that a child should be protected from unnecessary separation from her or his natural parents, since "[t]he surrogacy contract guarantees permanent separation of the child from one of its natural parents". [5] Third, the Court regarded the contract as inconsistent with the policy that the rights of the natural parents are equal at birth, stating that "[t]he whole purpose and effect of the surrogacy contract was to give the father the exclusive right to the child by destroying the rights of the mother".[6]

The Court also expressed concern regarding the potential for exploitation of the so-called "surrogate" inherent in such arrangements. In the Court's view, surrogacy was a practice likely to be used by the wealthy at the expense of the poor. While noting the lack of definitive empirical evidence on this point, the Court stated: "[W]e doubt that infertile couples in the low-income bracket will find upper income surrogates".[7]

*For a fuller discussion of the Supreme Court's treatment of the custody issue, see below.

The Court also described the following potentially harmful long-term effects of commercial surrogacy on all the participants involved: "the impact on the child, who learns that her life was bought...; the impact on the natural mother as the full weight of her isolation is felt along with the full reality of the sale of her body and her child; the impact on the natural father and adoptive mother once they realize the consequences of their conduct";[8] and the "potential degradation of some women that may result from this arrangement".[9]

Several other considerations were listed by the Court as relevant to its decision. Among them was the lack of protection afforded to the so-called "surrogate", who received "no counseling, independent or otherwise...no evaluation, no warning".[10] Further, the Court concluded there was insufficient protection for the contracting couple, who were given only scant information concerning the genetic make-up and psychological and medical history of the natural mother.[11] And, "worst of all", the Court felt that the contract totally disregarded the best interests of the child by failing to contemplate any inquiry as to the fitness (or "superiority") of the contracting couple as parents, or as to the effect on the child of not living with her natural mother.[12]

The Court also addressed the issue of informed consent, expressing its concern that the natural mother "never makes a totally voluntary, informed decision, for quite clearly any decision prior to the baby's birth is, in the most important sense, uninformed, and any decision after that, compelled by a pre-existing contractual commitment, the threat of a lawsuit, and the inducement of a $10,000 payment, is less than totally voluntary".[13] Furthermore, the Court maintained that even if the natural mother's consent were informed, it was "irrelevant" - money could not purchase Mrs. Whitehead's consent, because "[t]here are, in a civilized society, some things that money cannot buy".[14]

Although the New Jersey Supreme Court mentioned a number of constitutional issues in its decision, it did not assess their applicability to surrogacy arrangements in any detail, and specifically declined to rest its decision on federal or state constitutional grounds. That is, the Court's discussion of state public policy, and its ultimate legal holdings, were rooted in statutory and common law, and thus susceptible to potential modification by legislative action, at least within constitutional limits that the Court declined to specify in its opinion. The Court was quite explicit in acknowledging this point and in inviting legislative action if the legislature should reach different conclusions on fundamental policy issues.

The Work of the Commission and Task Force

Stage One

The Commission's approach to the area of new reproductive practices was, from its beginnings, guided by the legislative mandate to conduct a comprehensive scholarly examination. Following an initial presentation by one of the nation's leading scholars and the formation of a distinguished and diverse Task Force, the Commission scheduled a full-day public hearing to listen to the concerns of New Jersey's citizens (including representatives of religious, feminist, minority, professional and advocacy groups). The Task Force, which has met on eighteen

occasions as of May, 1990,* then set upon an extended process of self and public education, deliberately refraining from discussing ultimate policy issues until all members could participate in a common learning process and speak from a shared base of knowledge and experience. All of these educational sessions were open to the public, and many were reported in New Jersey's print media.

In September 1987, Dr. Jay Katz, professor of law and psychoanalysis at Yale Law School and a leading scholar in bioethics, addressed the full Bioethics Commission on the subject of reproductive technologies. Professor Katz raised a host of social and legal issues presented by current technologies, such as *in vitro* fertilization and cryopreservation, as well as by more distant technologies such as genetic manipulation. One of the major questions stressed by Professor Katz for consideration by the Commission was the degree to which the State should intervene in reproductive decisionmaking. Professor Katz's presentation helped to set the stage for the Commission's mandate to the Task Force.

The Commission and the newly empanelled Task Force held a joint public hearing on surrogacy in Newark in May 1988. The first part of the hearing focused on the sharply differing perspectives of "The Lessons of Baby M". The Commission and Task Force heard three attorneys involved in that landmark case, Lorraine Abraham, Gary Skoloff, and Harold Cassidy.

Under the heading, "Perspectives on Infertility", several witnesses described various dimensions of the problem of infertility. Professor Nadine Taub of Rutgers Law School identified the medical and social factors causing or contributing to infertility, and urged greater attention to them at the policy level. Kathryn Quick, a member of Resolve (an organization concerned with issues of infertility), and Jerrold Kaminsky, an attorney representing Resolve, described the social and psychological problems faced by infertile couples. Candace Mueller, from the New Jersey Committee for Adoption, addressed infertility from the perspective of adoption. Dr. Betsy Aigen, director of the Surrogate Mother Program in New York, advocated surrogacy as a solution to the problem of infertility, and described some aspects of her center's operation. Dr. Phyllis Chesler, a feminist author, provided a sharply contrasting feminist perspective on infertility and challenge to surrogacy. R. Alta Charo, a legal scholar working with the federal Office of Technology Assessment, summarized some of the main findings of OTA's 1988 report, entitled *Infertility: Medical and Social Choices*.[15]

Part of the day's hearing was devoted to the issue of religious and communal perspectives. In this session, testimony was heard from Rabbi Edward Feld of Princeton University Hillel Society; Reverend Elizabeth Maxwell, Rector of St. Matthew's Church in Paramus; and Bernice Davis, Director of One Church, One Child of New Jersey. A written submission was received from the New Jersey Catholic Conference. At the end of the day, time was allowed for the Commission and Task Force to hear a number of additional public views, including presentations from Alison Ward of Concerned United Birth Parents, and from Patricia Coyle, a representative of the New Jersey Right to Life Committee.

*A list of meetings of the Task Force is found in Table 8a of the report.

In addition to this public hearing, the Task Force devoted its first several meetings to informing itself about the historical, legal and social context of surrogacy. To provide some initial background and framework for its work, the first meeting of the Task Force began with several staff presentations. Ms. Anne Reichman gave a presentation which reviewed the reports of several of the more influential study commissions addressing surrogacy and related topics in jurisdictions around the world. The review was thematic and topical in nature, and attempted to identify and analyze the central issues pervading these commission reports. The scope of the presentation extended beyond surrogacy to other reproductive practices, such as artificial insemination, *in vitro* fertilization followed by embryo transfer, *in vivo* fertilization followed by lavage and embryo transfer, and cryopreservation of gametes.

A staff presentation by Ms. Adrienne Asch focused on the social context of surrogacy, in particular on the meaning of parenthood and family. This presentation examined some of the social and psychological implications arising from the separation of reproduction from sexuality, and from the division of parenthood into social, genetic and gestational components. It explored the effect that the new reproductive practices, and the new family constellations created thereby, may have on our understanding of notions of family and of sexuality.

At the next meeting, Dr. Gerson Weiss, a Task Force member with special expertise in reproductive endocrinology, described the medical aspects of the problem of infertility. He outlined the causes of infertility, the means of prevention, and some of the treatments available. The topic of infertility was further explored by Dr. Steven E. Perkel, who described the social aspects of infertility. His talk centered around the psycho-social problems encountered by an infertile couple in a pro-natalist society.

Recent advances in human reproductive technology, and prospects for more startling changes that may be available in the not-so-distant future, were described by the Task Force's molecular biologist, Professor Lee Silver. Among the possibilities: the potential to increase the success rate of embryo transfer, *in vitro* fertilization, and cryopreservation; embryo biopsy and genetic analysis; embryo manipulation; and alternative sites (i.e., other than human females) for gestation.

The subject of adoption was examined in some depth by the Task Force, because adoption was considered to provide the clearest illustration, and the most fully developed legal structure, for creating a legally recognized parent-child relationship, outside the context of natural reproduction. A psychological perspective on adoption was provided by Dr. David M. Brodzinsky, a clinical and developmental psychologist. This presentation examined possible psychological risks associated with adoption, and ways of ameliorating those risks. The talk described the influence of biological, personal and environmental variables, as well as cognitive appraisals and coping efforts on patterns of adoption adjustment.

Ms. Cecilia Zalkind, a Task Force member specializing in child welfare, reviewed adoption law, policy and practice in New Jersey. She discussed the public policy considerations in adoption, the basic statutory provisions pertaining to termination of parental rights and

finalization of adoption, and the major regulations governing adoption practice. Also on the subject of adoption, Ms. Anne Reichman presented an analysis of the New Jersey Supreme Court's use of the adoption framework in the *Baby M* case. This presentation was intended to explore in more general terms the similarities and differences between adoption and surrogacy. The major issue discussed was whether the policies underlying the adoption scheme provided an appropriate model for surrogacy, or whether the distinctive features of surrogacy might justify a somewhat different analysis and possibly the application of a different model.

Recognizing the potential implications of surrogacy for societal conceptions of the nuclear family, the Task Force invited two outside speakers to provide contrasting perspectives on the constitution, significance and definition of family. Dr. Sidney Callahan, professor of psychology at Mercy College in New York, emphasized the significance of the bond of genetic kinship in evaluating the new reproductive technologies. Dr. Callahan noted the similarities in her secular analysis to many of the theologically derived conclusions in contemporary Catholic teachings. William Ruddick, professor of philosophy at New York University, proposed a rather different paradigm of the family, which accorded greater weight to the social, as opposed to biological, aspects of parenthood, in considering variants on traditional marital and family forms.

Drawing on the work of Callahan, Ruddick and several other writers, Ms. Adrienne Asch presented an analysis of current cultural understandings of "family" and of the possibilities and limits of social tolerance regarding changing definitions of "family". The analysis focused on the lessons of existing experience with artificial insemination by donor (A.I.D.), examining whether and how the practice of A.I.D. can inform policy decisions about surrogacy. Among the topics addressed were secrecy, donor anonymity, matching of donors with couples, counseling, professional or government control of access to the techniques, and payment for providers of reproductive materials.

The Task Force also devoted considerable time to informing itself on theological perspectives on surrogacy. In addition to religious presentations at the Commission's public hearing, described above, the Task Force examined some of the teachings of the Roman Catholic religious tradition concerning sexuality and procreation, including the Vatican *Instruction on Respect for Human Life in its Origin and on the Dignity of Procreation.*[16] Reverend Robert E. Harahan, a Catholic theologian who has served both as a Commissioner and Task Force member, led the discussion. Father Harahan summarized the main principles set forth by the Vatican statement, and placed the document in historical context by tracing the development of Roman Catholic teaching on marriage and sexuality over the past several centuries. Professor David Smith, Director of the Poynter Center for the Study of Ethics and American Institutions at Indiana University, then explored the broader issue of whether, and how, the teachings of diverse religious traditions can inform secular law and policy.

Feminist perspectives on surrogacy formed another important area of study for the Task Force. Two Task Force members with special interests in feminism, Ms. Mary Sue Henifin, an attorney, and Professor Mary Gibson, a Rutgers University philosopher, reviewed diverse feminist perspectives on surrogacy, highlighting particular concerns and tensions existing within

the feminist community on such issues as bonding, custody, and payment.

Stage Two

Following this initial learning process, the work of the Task Force moved into a second stage, in which questions of social policy, ethics, and, increasingly, the role of law, came to the fore. During this period of its work, the Task Force discussed, debated, and sought to achieve consensus both on an overall approach to surrogacy and on resolution of particular policy questions.

Recognizing potential differences of view on appropriate policies toward different forms of surrogacy (particularly with regard to the policy relevance of whether or not the woman carrying the child is its "genetic mother"), the Task Force explored the legal, ethical, and social implications of the technological possibility of separating biological motherhood into genetic and gestational components. Three Task Force members, Professor Ruth Macklin, Dr. Emily Arnow Alman, and Professor Lee Silver addressed particular social concerns that could arise in gestational surrogacy, and participated in a broader discussion aimed at defining conceptual, social and morally relevant factors to be considered in resolving competing claims between the genetic mother and the gestational mother. Despite initial beliefs by several Task Force members that "gestational surrogates" had lesser claims, fuller discussion and concerns about potential for racial and socioeconomic discrimination led most Task Force members to view both forms of surrogacy as posing serious social concerns.

Concerns that surrogacy, particularly in its commercial form, would lead to the "commodification" of children, women, and reproductive capacities, occupied two especially lively sessions of the Task Force. Michael Walzer, professor of social science at the Institute for Advanced Study in Princeton, was invited to speak at the first of these meetings. Professor Walzer summarized the analytic framework presented in his book, *Spheres of Justice*,[17] to describe how a society understands the meaning of certain social goods and how those goods are distributed. Professor Walzer then applied this theoretical framework to surrogacy, concluding that commercial surrogacy should be a "blocked exchange", falling outside the permissible ambit of market relations (that is, that children should not be viewed as entities which are available through purchase), if we are to attain justice in our society and if the moral fabric of society is to be preserved. The implication of this view is that commercial surrogacy should be legally discouraged or banned, while so-called "altruistic" or non-commercial surrogacy, particularly among close relatives or friends, might be legally permissible.

The topic of payment in surrogacy was further pursued by Ms. Anne Reichman in a presentation which examined some of the main arguments for and against a market in surrogacy. Of particular interest was the question of whether societal or legal acceptance of commercial surrogacy might adversely affect social attitudes toward women and children, leading to a view of children as "commodities" and an excessive identification of some or all women with their reproductive capacities and roles. The Task Force spent a full meeting debating the moral basis, if any, for allowing or prohibiting payments to the so-called "surrogate", and to the other participants involved in facilitating the surrogacy arrangement.

Following these discussions, the Task Force reviewed regulatory approaches potentially applicable to either commercial or non-commercial surrogacy, or both. Policy options ranged from total prohibition at one extreme to government enforcement of private contractual arrangements at the other; most of the discussion focused on less absolute strategies involving varying degrees of regulation or legal involvement by the courts. Most Task Force members concluded that commercial payments to so-called "surrogates" and to brokers should be ruled out.

Included in the discussion of policy options was an examination of distinctive issues which might be presented by non-commercial surrogacy, both where the arrangement involves "family and friends" and where it takes place among strangers on an altruistic basis. In the case of non-commercial surrogacy involving "family and friends", the Task Force considered at some length whether (and on what basis) the State should intervene in a familial setting, or whether it should respect the especially strong privacy interests of the participants in such a setting. The Task Force questioned whether non-commercial surrogacy among strangers would be a sufficiently frequent occurrence as to justify State intervention, except perhaps to supply information on a purely voluntary basis.

In its final meeting of 1988, the Task Force heard a report from two staff members who had visited three selected surrogacy centers, all located outside New Jersey. Ms. Adrienne Asch and Ms. Anne Reichman described interviews they had conducted with the directors of the centers and with various professionals, as well as with so-called "surrogates" and contracting couples. The presentation also described overall impressions of the three centers, and highlighted differences regarding their philosophies, application processes, screening criteria, and contracts.

Stage Three

The Task Force's meetings in 1989 focused specifically on the legal and policy issues that will underlie its forthcoming recommendations. The first meeting of this third stage, held in January, 1989, examined directions the Task Force might wish to take in proposing recommendations for resolving custody disputes in surrogacy arrangements, where the so-called "surrogate" changes her mind about her willingness to relinquish the child to the biological father. This issue is relevant even under a legal regime which aims to prohibit commercial surrogacy, because it is foreseeable that some people may enter surrogacy arrangements despite such legal prohibitions, and therefore that some children are likely to be born as a result of the practice. In such cases, if the birth mother refuses to relinquish the child, and if the biological father and his wife (and, in gestational surrogacy, possibly the genetic mother as well) also seek custody, then the rights and responsibilities of the respective parties must be addressed.

Some of the psychosocial issues arising in custody disputes after a failed surrogacy arrangement were examined Ms. Adrienne Asch in a presentation which provided a description, analysis, and critique of psychological literature on the mother-infant tie and "bonding". The presentation pointed to certain problems with the concept of "bonding" as defined in that literature, and noted conflicting findings which raise questions about the applicability of social science "bonding" theory to custody determinations. The presentation also explored studies addressing the impact of relinquishment on women in adoption. The analysis focused on the

methodology of these studies, the interpretations that have been made of their findings, and the applicability of their findings to surrogacy. It noted that the applicability of these studies to the surrogacy context is subject to certain questions, insofar as it is not possible to discern whether the grief, loss and sadness experienced by the relinquishing women in the studies occurred as a result of the fact of relinquishment, or rather as a result of certain aspects of the relinquishment experience present in adoption but less likely to be present in surrogacy. These factors include regret relating to the unintended pregnancy, concern about secrecy surrounding the whereabouts and well-being of the child after relinquishment, or regret caused by the lack of voluntariness of the decision to relinquish.

Task Force members then heard a presentation, based on a discussion draft distributed to Task Force members, by Ms. Anne Reichman, examining potential legal approaches in resolving competing custody and parental rights claims by parties involved in a surrogacy arrangement. The discussion began by analyzing the complex approach adopted by the New Jersey Supreme Court in *Baby M.* Even though the Court stated that it was applying a best interests standard, with no presumption or rule favoring either parent on the basis of gender, and even though on the particular facts of the case the Court accepted the trial court's conclusion that the child's best interests were served by awarding custody to the biological father, the effect of the decision is to make it highly likely in future cases that, absent extraordinary factors, the birth mother will generally be awarded custody. The Court's strong directive to trial court judges to make the initial (theoretically temporary) custody order in favor of the birth mother, barring a substantial likelihood that the life or health of the child would thereby be endangered, coupled with the Court's emphasis on continuity of care, achieves indirectly a result that the Court declined to adopt more explicitly. Under this regime, in many cases the initial order, and the consequent opportunity for the birth mother to establish a strong psychological relationship with the child, will largely determine the final custody award, virtually by default, unless there is a very large disparity between the birth mother and the adoptive parents in other respects. It is very difficult to quantify or calibrate how this would work in particular cases. There is reason for concern that this approach may well invite unnecessary, prolonged, and potentially destructive litigation.

Following this analysis of the Court decision, the presentation explored alternative approaches to the legal standard to be employed in resolving custody disputes in surrogacy. The best interests standard, which is the traditional and determinative standard used in custody determinations following dissolutions of marriage, and which purports to focus on the interests of the child in a highly individualized fashion, presents a number of serious problems when applied to the surrogacy context.

First, being essentially a comparative standard, the best interest test invites lengthy and bitter litigation involving negative, destructive attacks on parental capacity, thereby creating a record of rancor which could have an enduring negative effect on the child and leaving the child's permanent status unsettled for a potentially lengthy period. This destructive result, while not limited to the surrogacy context, may be especially likely in such cases. Second, the best interests standard invites an inquiry as to the relative social and economic status of the parties, which raises concerns on at least two levels. First, there is a risk that some judges (as well as

some "expert" witnesses) may associate a constellation of features, including wealth, education and social class, with better parenting capabilities, and will equate "favorable" patterns with the best interests of the child. Such judgments may say more about social biases and stereotypes than about welfare of children. This risk too is present in traditional custody disputes, but is further heightened in surrogacy, because in surrogacy the litigation arises between biological parents from predictably disparate backgrounds, at a time when the child is a newborn. Unlike the situation in custody cases following the dissolution of a marriage, where there will generally be an established relationship between the child and its parents and a track record of sorts for assessing the parents' capacity for parenting, in surrogacy the judge has virtually no such information. This increases the likelihood of speculation and with it, the possibility of inappropriate class and economic bias.

Moreover, relative economic status is relevant in a second sense, inasmuch as the wealthier party is likely to have greater resources to spend on attorneys, psychological experts, etc. (as well as greater sophistication and contacts among fellow professionals), and, as the *Baby M* case illustrated, may be at a considerable advantage in working with experts prior to and during the litigation. If potential adoptive couples considering a surrogacy arrangement perceive that in the event of a custody dispute, their chances of succeeding in the ensuing litigation are very high, as they might be under a conventional best interest test, then much of the deterrent effect of the underlying law and policy seeking to discourage the practice of surrogacy would be undermined.

A plausible alternative to a best interests standard is a rule or presumption which could be applied in a more predictable and mechanical fashion to grant custody to one or the other parent, assuming that the parent is able and willing to provide for the needs and welfare of the child. Such a rule would assure a basic standard of well-being of the child, but might avoid some of the worst features of the best interests standard, including delays, unnecessary uncertainties, destructive attacks on parenting capacities, and the likelihood of class and economic bias. The substantive content of such a rule or presumption could vary widely. An "intent standard", which would generally favor the biological father, would meet some of these criteria, but would severely undercut the Task Force's policy of discouraging surrogacy. A presumption favoring the birth mother would also meet these criteria, and would be more consistent with a legal regime which seeks to discourage surrogacy. A staff proposal developing such a presumption (favoring the birth mother, consistent with assuring the interests of the child) was distributed to and discussed by Task Force members.

At its twelfth meeting, held on March 1, 1989, the Task Force considered a set of preliminary policy recommendations, previously distributed to the Task Force, concerning commercial and non-commercial surrogacy. Following extensive discussion, clarification, and several amendments, all of the policy recommendations voted upon were unanimously approved by the Task Force.*

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* The text of the approved policy recommendations is attached as an appendix at the end of this chapter.

Recommendation 1, as adopted, calls upon the State of New Jersey to "enact legislation to prohibit the practice of commercial surrogacy". A prior draft of this recommendation provided that the State of New Jersey "should enact legislation to discourage the practice of commercial surrogacy and to prohibit its most offensive features". Task Force members felt that the amended version was preferable, because it made unmistakable the Task Force's negative view on commercial surrogacy.

Recommendation 2 states that existing prohibitions on the payment or receipt of money or other valuable consideration in connection with the placement for adoption of a child should be extended to apply to broker/intermediaries and to birth mothers in a surrogacy arrangement. With respect to the birth mother, it exempts payments or reimbursements of "medical and hospital expenses" currently allowable under adoption law. A prior draft of this recommendation exempted "medical, hospital or other similar expenses". Task Force members felt that the amended version would better ensure that covert payments could not be subsumed under "other similar expenses" in a way that would circumvent the intended prohibition on payments to the birth mother.

Much of the discussion on Recommendation 2 centered around the desirability of extending existing adoption legislation regarding payment for expenses as a model for surrogacy. The Task Force acknowledged that surrogacy is a distinct phenomenon and that the adoption model should not be followed in uncritical fashion, but nonetheless recognized the simplicity and appeal of extending the existing ban on "baby-selling" in the adoption context to apply to commercial surrogacy. The Task Force deferred more specific discussion of the nature of the prohibition (criminal or civil) and of the appropriate penalties for the different participants, including the familial parties, broker-intermediaries, and other professionals, until concluding its review of the basic policy recommendations.

Recommendation 3 renders certain contractual agreements in association with surrogacy arrangements illegal and unenforceable. Specifically, the relevant contractual agreements are: agreements to pay money or other valuable consideration (other than expenses specifically exempted, as noted above) to a birth mother or to a broker-intermediary; agreements by a birth mother, prior to the conclusion of a specified waiting period following the birth, to surrender or transfer custody or to relinquish or waive other parental rights; and agreements purporting to limit the liberty of the birth mother with respect to control over fundamental medical or lifestyle decisions during the pregnancy. After some discussion as to what might be encompassed under "fundamental medical or lifestyle decisions", the Task Force agreed to return in subsequent deliberation to further refinement of this issue, including possible extension of the general principle to the period preceding establishment of pregnancy.

Recommendation 4, which concerns non-commercial surrogacy agreements, engendered a considerable amount of debate among Task Force members, reflecting a variety of views regarding the appropriate role of the State in these arrangements. A prior draft of Recommendation 4 had stated that New Jersey "should not legally prohibit non-commercial surrogacy arrangements", provided these arrangements did not violate the foregoing

recommendations. However, some Task Force members believed that this version imported a tone of implied approval of non-commercial surrogacy, which failed to reflect accurately their view that the practice was undesirable. These Task Force members felt that the recommendation should explicitly call upon the State to prohibit non-commercial, as well as commercial, surrogacy. Some other Task Force members argued that non-commercial surrogacy contracts should be unenforceable, but should not be legally prohibited, because the negative consequences of intervention by the State in non-commercial, private, and particularly in familial arrangements, and the problems of enforcement in that setting, were so great as to outweigh any potential benefit to society in prohibiting such agreements. Following debate and conciliation, Task Force members agreed on semantic modification to Recommendation 4, to reduce any implied legitimation of surrogacy, even in its non-commercial forms. As modified, Recommendation 4 provides that the State would not enforce any type of surrogacy arrangement, commercial or non-commercial, but that only commercial contracts would be specifically prohibited.

The Task Force spent most of the next meeting, held in April, 1989, considering Recommendation 5. Discussion focused largely on what the appropriate standard should be for the resolution of custody disputes in "failed" surrogacy arrangements. A proposed standard, which formed the basis for the discussion, provided (in part) as follows:

> In cases of contested custodial claims among participants in a surrogacy arrangement, there shall be a legal presumption favoring custody by the individual giving birth to the child. This presumption may be overcome by a demonstration, based on clear and convincing evidence, that the individual giving birth to the child is not willing or able to meet parenting standards societally recognized as adequate to the needs and welfare of the child, and by a further demonstration, by the child's other biological parent or parents, that he, she, or they do meet such parenting standards and can appreciably better promote the child's interest in a safe and healthy upbringing. The fact that one or more of the individuals claiming custody participated in the surrogacy arrangement, or did or did not abide by the terms of such arrangement, shall not in and of itself constitute evidence relevant to any such determination.

There was general agreement favoring the replacement of the traditional "best interests" standard with an alternative custody standard embodying a presumption of custody by the birth mother in a failed surrogacy situation. Discussion focused on the appropriate circumstances in which this presumption might be overcome, resulting in a custodial determination favoring the biological father. Some Task Force members expressed concern that the language used in the proposed standard, particularly the phrase "is not willing or able to meet parenting standards societally recognized as adequate to the needs and welfare of the child", might invite subjective social judgments leading to a comparative evaluation of the biological parents, which may import undesirable social and economic biases. Others disagreed, however, noting that the proposed formulation is essentially a non-comparative standard, as no comparison between the birth mother and the other biological parent or parents comes into play unless the presumption is overcome by clear and convincing evidence relating solely to the birth mother's parenting capacities.

Discussion centered around whether the standard for overcoming the birth mother presumption should be the "unfitness" standard traditionally used in termination of parental rights cases, or whether a somewhat less stringent standard (still far more stringent than "best interests") was appropriate. Some Task Force members were concerned that a less stringent standard would run counter to the policy of deterring surrogacy arrangements, because if couples intending to enter into a surrogacy arrangement perceive that they have a good chance of overcoming the presumption, then the deterrent effect of the policy will be significantly undermined. Some other Task Force members, however, felt that the "unfitness" standard was too demanding and insufficiently protective of the child, and that a standard more attentive to the child should be employed. Those holding this view believed that it was unfair to leave a child in a very inadequate environment, when the alternative was not a foster placement or institutional arrangement by the state (as in traditional parental rights terminations), but custody by another, concededly caring and fit biological parent.

Another aspect of the discussion of "unfitness" as a standard was whether it should be explicitly defined by statute for the purposes of surrogacy, or whether existing legal understandings would be sufficient. There was considerable variation among the lawyers present concerning just how clearly "unfitness" is defined in existing law, and what the term really means in practice. Ultimately, Task Force members agreed that more discussion about the legal meaning of "unfitness" was needed, and should be further explored at the next meeting.

The remainder of the April meeting was spent discussing issues relating to the scope of the parental rights of the non-custodial parent, focusing on support and visitation. Ms. Anne Reichman gave a presentation which highlighted some of the major arguments for and against the non-custodial parent being granted visitation rights and the imposition of support obligations.

Several points emerged in the discussion of visitation and support. First, as the Supreme Court emphasized in *Baby M*, while it is in the child's interests to have contact with both parents, and while the parents' interests must also be taken into account, ultimately it is the child's best interests that are paramount.[18] Second, scientific literature on the subject of shared parenting is far from dispositive. Some theories claim that maintaining contact with all genetic parents is in the child's best interests, while others claim that this can be very disruptive and confusing for the child. Third, under traditional family law principles, an unwed father is liable for the support of his child. It is clear that the purpose of support obligations is to benefit the child, not to punish the parent. Fourth, visitation rights and support obligations are not mutually dependent - in other words, support obligations are not a way of "buying" visitation rights, and, conversely, a parent who chooses not to have any contact with the child is not thereby automatically relieved of support obligations. Fifth, while it may be that the imposition of support obligations on the non-custodial biological father may operate to deter him from entering the arrangement, and while allowing the non-custodial biological father visitation rights may operate to deter the so-called "surrogate" from entering the arrangement, considerations of deterrence should be less important than a consideration of the child's interests.

At its meeting in May, 1989, the Task Force resumed its consideration of the proposed standard for custody determinations in failed surrogacy arrangements. At that time, Task Force members voted unanimously to adopt Policy Recommendation 5, which reads:

> The State of New Jersey should enact legislation to govern the determination of custody, parental rights, and support obligations in the event of disputes arising pursuant to surrogacy arrangements. Such legislation should establish a legal presumption favoring custody by the birth mother, consistent with assuring satisfaction of the needs and welfare of the child.

The Task Force then resumed its discussion concerning the appropriate circumstances in which the presumption in favor of the birth mother might be overcome, resulting in a custody award to the biological father. In light of the conclusion reached at the last meeting that there was a need for further discussion to clarify the legal meaning of "unfitness", Ms. Anne Reichman gave a presentation focusing on the meanings and uses of "unfitness" as a legal standard. The presentation highlighted the different family law contexts in which the term "unfitness" has been used, the sometimes sloppy and inconsistent ways in which the term is invoked, and the more systemic variations in meaning depending upon the context. "Unfitness" has been used most frequently and defined most precisely in the context of involuntary, permanent termination of parental rights by the State. In that setting it has been interpreted by courts as requiring circumstances which are extremely detrimental to the interests of the child. The rights of parents are weighted heavily against the interests of the child, and unfitness is rarely found except where there is a very substantial showing that serious harm to the child would result were the parent-child relationship to continue.

The Task Force decided that "unfitness" as defined in the termination of parental rights context constitutes too stringent a standard for overturning the presumption of custody by the birth parent in surrogacy. There was general agreement that a different standard was required, which would be more protective of the child's interests, but would at the same time uphold the basic policy in favor of the birth mother. Several alternative statutory formulations for such a standard were considered. After some discussion, it was agreed that staff would continue working on refining the exact wording of these formulations. It was also agreed that it should be explicitly stated, in whichever formulation is finally agreed upon, that economic and social class factors should not play any role in determining the child's interests and welfare.

A further agenda item at the May meeting concerned the subject of non-commercial surrogacy. The Task Force heard from Sister Jane Frances Brady, who highlighted the main points set out in her March 31, 1989 letter, which had previously been distributed to Task Force members. Sister Jane's deeply held view was that surrogacy, even in its non-commercial form, is an abhorrent practice which tears at the moral fabric of our society and should be prohibited by law. The major concerns identified by Sister Jane included the potential of the practice to undermine respect for human life and the dignity of the human person; the negative effect of the practice upon the resulting child, who is not valued as a unique individual but rather is treated as a "commodity"; the threat posed by the practice to the stability and integrity of the family unit; and the psychological damage inflicted by the practice upon the birth mother.

There was considerable accord among Task Force members with many of the sentiments expressed by Sister Jane, and a conviction that the report on surrogacy should clearly and strongly voice the Task Force's concerns with non-commercial, as well as commercial, surrogacy arrangements. Many Task Force members, however, expressed additional concerns over whether it was necessarily desirable for the state to intervene in private, non-commercial surrogacy arrangements that did not violate the specific policy recommendations previously approved by the Task Force and that did not involve enforcement or recognition by the state. It was felt that enforcement of a ban on non-commercial arrangements might lead to unduly intrusive investigations of the parties' intent and motives in especially sensitive domains of their sexual and reproductive lives. The Task Force concluded unanimously that the concerns and moral analysis voiced in Sister Jane's letter and presentation should be clearly articulated in the discussion of non-commercial surrogacy in the Task Force's report to the Commission, but did not re-open the prior vote concerning the scope of the legal prohibition approved by the Task Force.

A third issue considered by the Task Force at the May meeting concerned the use of the sanctions to be imposed upon the participants in a prohibited commercial surrogacy agreement. The Task Force agreed that severe criminal sanctions, including the possibility of imprisonment, as well as professional disciplinary actions for licensed professionals, were justified to deter and to punish broker/intermediaries involved in commercial surrogacy transactions. As for professionals who knowingly facilitate commercial surrogacy arrangements (e.g., physicians who perform the artificial insemination procedure), the Task Force felt that professional disciplinary measures, including possible suspension or revocation of licensure, would be the appropriate penalty.

With regard to the birth mother and the contracting couple, there was considerable discussion concerning the appropriate approach. There was substantial agreement that imprisonment (especially for a first offense) would be excessively harsh, and might well be destructive for the child. Task Force members expressed concerns that a fine might be regarded as merely another cost of the transaction, and would discriminate unfairly based on economic circumstances. On balance, the Task Force agreed that criminal, rather than civil, sanctions were probably justified and necessary, since the prospect of a criminal record would operate as a significantly greater deterrent. Task Force members concluded that a penalty consisting of an appropriate form of required community service would be most suitable, provided that the service was sufficiently exacting and could be effectively monitored.

The Task Force agreed that it would be helpful to request an expert in criminal and family law to write a paper for the Task Force, addressing in greater detail current law and practice with regard to penalties and sentencing in black market adoption and related areas, and proposing an approach to sanctions for prohibited surrogacy arrangements. Such a report was subsequently commissioned.

At its meeting in June, the Task Force resumed its discussion concerning the showing necessary to overcome the proposed presumption favoring the birth mother in a surrogacy custody dispute. In its attempt to define a standard that would assess the birth mother's capacity

to meet the child's basic needs, while avoiding the prospect of purportedly expert testimony that might indulge biases concerning the socio-economic status of the parties, the Task Force agreed unanimously upon the following formulation:

> ...This presumption may be overcome by a demonstration, based on clear and convincing evidence, that:
>
> > The individual giving birth fails to meet minimal parenting standards necessary to satisfy the basic needs and welfare of the child. Such determinations shall not be based on considerations of economics or social class.

The Task Force also returned, at this meeting, to its earlier consideration of support obligations and visitation rights in a failed surrogacy arrangement. Task Force members concluded that an obligation of support should be imposed upon the non-custodial biological parent in a surrogacy arrangement, in a manner consistent with existing law regarding support by a non-custodial parent. Task Force members also concurred that a support obligation should not be extended to the spouse of the non-custodial biological parent. This issue is of particular relevance in the event of the death of the non-custodial biological parent. The Task Force was concerned about the potential unfairness of burdening a spouse with continuing support obligations in such circumstances, especially given the possibility that the surviving spouse may have participated with some reluctance in the original surrogacy agreement.

As regards visitation, the Task Force was of the view that there should be a presumption in favor of the non-custodial biological parent having visitation rights, but that the terms and frequency of visitation should be determined on a case-by-case basis, in accordance with the best interests of the child. The existence of conflicting views among experts in child psychology and in family law as to whether or not legally imposed visitation orders serve the interests of the child was noted. The Task Force determined that the proposed recommendation should recognize that the child may have competing interests in psychological stability and in maintaining contact with her or his biological parent(s), and that both interests should be considered in individual case determinations. The Task Force agreed unanimously to adopt the following policy recommendations (nos. 6 and 7) on support and visitation:

> 6. The State of New Jersey should enact legislation recognizing an obligation of support on the non-custodial parent in a surrogacy arrangement. Contractual disclaimers of support obligations shall not be effective in such cases.
>
> 7. The State of New Jersey should enact legislation addressing the visitation rights of the non-custodial parent in a surrogacy arrangement. Such legislation should embody a presumption in favor of visitation unless it is demonstrated that such visitation would be contrary to the best interests of the child. The extent and conditions of visitation should be considered on a case-by-case basis, with due regard for the child's interests both in psychological stability and in the maintenance of contact with the child's biological parents.*

* It should be noted that references to the "non-custodial parent" in policy recommendations 6 and 7 are not intended to apply to persons whose sole role in the arrangement is to provide sperm or eggs, without any intent or expectation of serving as a rearing parent.

A further issue discussed by the Task Force concerned how the timing of the birth mother's decision and actions should affect the implementation and application of the policy recommendations. Policy Recommendation 3(c) refers to a "specified waiting period" in which the so-called "surrogate" may have an opportunity to assert her claim to custody. This raises two distinct questions: first, how long should the waiting period be? And second, from what point should it be calculated -- the date of the child's birth, the date that the so-called "surrogate" transfers physical custody of the child to the intended rearing parents, or perhaps some other point? Ms. Adrienne Asch gave a presentation which discussed these two questions. The presentation noted that in the private placement adoption process, the birth mother has a period of not less than two and not more than three months during which she may re-assert her claim to the child, dating from the time the intending adoptive parents file a Notice of Complaint with the court. The Notice of Complaint may be filed either at the time of the child's birth or subsequently, although as a general practice, it is filed at the time of the birth. The potential advantages and disadvantages of applying such a time frame in surrogacy were examined. Questions that arose during the discussion included the following: how much time might be required for the birth mother to recover from pregnancy and childbirth, and to be physiologically and psychologically in a condition to make such a consequential and irrevocable decision? After what point in time might a child become sufficiently attached to a primary caretaker (either the birth mother or the intended rearing parents), so that disruption of the relationship would be traumatic for the child? What is the likely impact on a child of being removed from the home of the intended rearing parents, if the child had been turned over to them, and returned to the birth parent in the first several months of life? The presentation noted that social science data concerning post-birth experiences of women and "attachments" by children were scarce and inconclusive, particularly in this context.

There was considerable variation of opinion among Task Force members regarding the appropriate length of the waiting period, with views ranging from one month or less, to six months or more. There was also uncertainty as to whether, in a case where a birth mother retains physical custody of the child for weeks or months after birth, then transfers custody, and subsequently decides that she wishes to regain custody, a different time period should apply. In this circumstance the birth mother should be allowed a brief, but reasonable opportunity to experience life without the child, so that her decision is properly informed. Further discussion of specific time periods was deferred for a subsequent meeting.

The Task Force next heard a presentation by Ms. Adrienne Asch on the subject of "The Unwanted Child", addressing policy questions that might arise if neither the intending parents nor the so-called "surrogate" desired custody of the child upon birth. This situation might occur if, for example, the child is born with a disability, or if the intended rearing couple ceases to be intact. It was noted that the Task Force's recommendations discouraging surrogacy would help to minimize such occurrences; nonetheless, the Task Force was not convinced that the fact of the child's origin in a surrogacy arrangement warranted a different social or legal response than that applicable to children otherwise similarly situated. The Task Force went on to consider the following questions: (1) Is the existing system of dealing with unwanted children adequate for children unwanted after a surrogacy arrangement? (2) What responsibilities, if any, should the

child's biological parents be expected to assume? (3) How should financial responsibility be allocated?

Task Force members considered a number of perceived shortcomings in the ability of existing mechanisms to deal adequately with unwanted children, but concluded that these problems lie outside the scope of the Task Force's project on surrogacy. While the Task Force agreed that the final report should enunciate some of the more general concerns in this area, the report could not and should not advance proposals for systemic reform of a complicated, long-established system. The report would, however, emphasize the importance of counselling and support for the biological parents, in order to assist (and perhaps encourage) one of them to keep the child. The Task Force also agreed that the law should impose upon the so-called "surrogate" and the intended rearing genetic parent (although not that parent's spouse) a legal obligation to support a relinquished child. Financial support should be assessed to the same degree and on the same basis as for relinquishing parents under existing law.

The final item on the agenda for the June meeting concerned the definition of "surrogacy". Discussion centered around the following proposed technical definition, drafted by Mr. Weisbard:

> *"Surrogacy"* describes an arrangement, whether or not embodied in a formal contract, among two or more persons (including, but not necessarily limited to, (a) the woman who will gestate and give birth to the child, and (b) one or more persons who intend to rear the child, at least one of whom will be a genetic parent of the child), who agree to conceive and gestate a child, through natural or artificially-assisted reproductive means, or to implant and gestate an embryo, with the intention (shared by the essential parties designated under (a) and (b) above), formed prior to conception or, in the case of artificially-assisted implantation, formed prior to implantation, that the woman giving birth to the child will relinquish, or will agree not to assert, some or all parental rights or claims to the child, including any right or claim to primary physical custody, in favor, directly or indirectly, of one or more parties to the arrangement designated under (b) above. This definition shall not be construed to apply to arrangements solely between two persons legally married to one another.
>
> Under this definition, the woman who will gestate and give birth to the child may, but need not, also be the genetic mother of the child. The term "child" employed in this definition may also refer to two or more children gestated simultaneously.

This draft definition, which is intended to specify what behavior fits within the understanding of "surrogacy" as that term is employed by the Task Force, and to provide a technical legal basis for interpretation of its policy recommendations, is designed to encompass the range of reproductive possibilities currently available and those imaginable in the not-so-distant future. It was recognized that additional provisions beyond simple definition, such as special evidentiary requirements, may need to be incorporated in proposed legislation to provide safeguards against the possibility that persons engaged in surrogacy may lie, or misrepresent their behavior, to avoid the operation of relevant legal prohibitions.

Key questions recognized and addressed by the proposed definition include: whether "surrogacy" is limited to artificially assisted insemination or implantation, or also applies to insemination by sexual intercourse; whether the time of forming the intent to relinquish the resulting child is critical, and when that intent must be formed; whether there needs to be a formal or a written contract; whether at least one of the intended rearing parents must be a genetic parent of the child; and the question of which rights or claims must be relinquished by the gestating woman for the arrangement to constitute surrogacy. The Task Force recognized that for legal purposes, a precise technical definition of surrogacy might be desirable, but agreed that a shorter and simpler formulation of the definition should be further explored.

The Task Force next convened in July, 1989, at a joint meeting of the full Bioethics Commission and the Task Force, at the Commission's Annual Retreat. The agenda for this meeting consisted of a series of presentations by Task Force members and staff, designed to provide an overview of the principles and policy considerations underlying and informing the Task Force's work.

The first presentation consisted of an overview by Ms. Anne Reichman, describing the Task Force's process and progress to date and summarizing the range of issues canvassed by the Task Force. This was followed by a presentation by Task Force Chair Linda Rosenzweig, who described some of the themes and policy perspectives running through the Task Force's work. Ms. Rosenzweig focused on the respects in which a surrogacy arrangement may result in harm, pointing out potential harms to the child born of the arrangement, harms to the so-called "surrogate", and harms to the social fabric.

Dr. Ruth Macklin then addressed the Task Force's decision not to recommend a legal prohibition (and legal penalties) on non-commercial surrogacy arrangements, but to prohibit enforcement of surrogacy contracts, including non-commercial contracts. Dr. Macklin explained that the Task Force's conclusion was based, at least in part, on the perception by some Task Force members that it is not necessarily surrogacy itself that is intrinsically morally and socially unacceptable; rather, certain aspects of commercial surrogacy arrangements are most likely to be especially harmful and socially problematic. Dr. Macklin noted that the Task Force was initially divided on whether surrogacy should be prohibited. After summarizing the main arguments for and against extending a legal prohibition from commercial to non-commercial arrangements, Dr. Macklin explained that, ultimately, the Task Force's decision not to so recommend was based in significant measure on concerns about enforcement, including a reluctance to provide a precedent for inappropriate State intervention in private, consensual, non-commercial sexual and reproductive matters.

Ms. Mary Sue Henifin reviewed the alternative policy approaches considered and ultimately rejected by the Task Force. These approaches included, at the extremes, a comprehensive ban on all forms of surrogacy, with criminal penalties imposed on some or all of the participants, and a market-place or laissez-faire approach, in which the State would promote surrogacy by enforcing contractual arrangements among the adult parties, with the only limitations being those provided by the market, and by traditional legal protections against fraud

and duress. A third, less absolute strategy would employ legal regulations to establish some fundamental matters, to provide minimum standards of conduct for familial participants, intermediaries, and professionals, and to facilitate the practice of surrogacy consistent with these standards. Ms. Henifin noted the consensus among Task Force members that widespread surrogacy, even subject to such a regulatory regime, would lead to significant social harm. She contrasted these rejected alternatives with the approach ultimately agreed upon by the Task Force, which prohibits commercial payments to so-called "surrogates" and intermediaries, proscribes certain other practices, and refuses to enforce contractual arrangements in both commercial and non-commercial settings.

Ms. Cecilia Zalkind's presentation examined the Task Force's recommendations concerning custody, visitation, and support in cases of "failed" surrogacy arrangements, where parties engaged in surrogacy despite legal prohibitions or discouragement, and ended up with competing claims on the child. Ms. Zalkind explained why application of the traditional best interest standard in custody determinations was especially problematic in the context of surrogacy, and why the Task Force had concluded that a non-comparative presumption in favor of custody by the birth parent was necessary. In addressing the question of the showing that would be required to overturn that presumption, Ms. Zalkind recounted the Task Force's extensive consideration of the "unfitness" standard, and explained why the Task Force ultimately favored a different standard that would recognize the claim of the birth parent, avoid undesirable social and economic bias, yet be more protective of the child than some interpretations of an unfitness standard. Ms. Zalkind also outlined the Task Force's recommendations regarding the visitation rights and support obligations of the non-custodial biological parent in "failed" surrogacy arrangements.

Dr. Gerson Weiss described some of the more recent developments in the evolving field of new reproductive technologies, and noted the impact that these developments may have on the practice of surrogacy. Dr. Weiss shared his reflections on the physician's role and responsibility in participating in the new reproductive practices, and on the kinds of sanctions that should be applied to physicians whose behavior violates stated legal and professional norms.

Mr. Alan Weisbard described the work of the Task Force and staff in developing a definition of "surrogacy". He explained key features of the proposed definition, and noted in particular that the definition would allow for insemination by sexual as well as artificially assisted means, for "gestational" as well as conventional surrogacy, and for the possibility that the genetic relationship to the child may be achieved through the mother (via donation of her egg and gestation by another woman), as well as, in the more familiar case, through the father. It was pointed out that the definition would *not* apply in the absence of a genetic parenting relationship to the child by at least one of the intended rearing parents, and was noted that the Task Force will have to consider whether this analogous yet distinct arrangement should be treated like surrogacy for most or all policy purposes.

The Commission was informed that two commissioned scholarly papers were recently prepared for the Task Force. The first paper, by Professor Walter P. Loughlin of Rutgers Law

School, Newark, addresses the issue of appropriate penalties for violations of legal prohibitions in surrogacy arrangements. The second paper, by Professor Susan Frelich Appleton of Washington University School of Law, examines conflicts of laws issues posed by surrogacy in considerable detail.

During a lively and extended exchange among Commissioners and Task Force members, a number of issues were raised, including: whether it was appropriate for the Task Force to condemn too strongly the practice of non-commercial surrogacy; whether the narrowly-drawn reference in Policy Recommendation 2 to "medical expenses" should be extended to include certain incidental expenses, such as maternity clothing and nutrition; whether there was a strong rationale justifying the presumption in favor of the birth mother in the event of a custody dispute; whether the Task Force's Policy Recommendations might allow or encourage an unscrupulous individual to enter a surrogacy arrangement intending from the outset to refuse to give up the baby, and to collect (or extort) support payments; the meaning and moral and legal significance of gestation in establishing a parent-child relationship; the availability and relevance to surrogacy of social science data regarding relinquishment in adoption; whether the practice of non-commercial surrogacy would pose a significant social problem if discouraging measures were not introduced; whether a so-called "surrogate's" motive in having a child in order to provide a gift to another person in a non-commercial arrangement can be said to be a "worse" motive than the reasons many other people decide to have children; and whether a child can be said to be "harmed" (as distinct, in philosophical terms, from "wronged") by being born of a surrogacy arrangement when the alternative is non-existence.

Following this discussion, the Commission voted 14-1 to approve the Task Force's seven Policy Recommendations in principle. The Commission also directed the Task Force to continue its work on its Report to the Commission.

Current Status

The Task Force has already made considerable progress in its study of several additional issues, but has not yet adopted formal policy recommendations embodying its conclusions. Among the remaining issues identified for final deliberation and resolution by the Task Force are the nature of the penalties to be imposed on participants in a commercial surrogacy arrangement; the potential legal liability, if any, of intermediaries or professionals, such as attorneys, psychologists, and physicians, who provide professional services in connection with non-commercial surrogacy arrangements; the calculation of the length of a waiting period, if any, during which the custodial presumption in favor of the birth mother may operate; and the extent to which there might be qualifications to the principle that contractual undertakings regarding medical and lifestyle restrictions upon a so-called "surrogate" are invalid and unenforceable. The Task Force expects to transmit its completed recommendations and accompanying Report to the full Commission in the spring of 1990, prior to transmittal of the Report and recommendations to the Governor and the Legislature.

Future Agenda

Following completion of its work on surrogacy, the Task Force on New Reproductive Practices will turn its attention to a range of more "high tech" reproductive practices, some of which are already in use, and some of which are visible on the horizon. The Task Force also plans to review existing law and experience with A.I.D., which constitutes one of the oldest of the "new" reproductive practices.

The Task Force's examination of A.I.D. will include an analysis of the legal framework in which A.I.D. operates, the medical and psychological screening, and the psycho-social impact of A.I.D. on the parties involved, including the child born of the arrangement. As A.I.D. is one of the best established of the "new" reproductive practices, it provides an illustration of how some of the novel legal and ethical issues that have potential relevance for other new reproductive practices may be confronted and resolved. In this way, the lessons of A.I.D. may prove useful in shaping policy about the kind of framework the State wishes to establish for the newer reproductive technologies. Moreover, the social and legal response to surrogacy that has been developed by the Task Force may inform, and perhaps reshape, some of the State's thinking about donor insemination. Thus, in its subsequent work on new reproductive practices, the Task Force will look back at A.I.D., as well as forward to other, more technologically sophisticated, forms of assisted reproduction.

In its future study of reproductive technologies currently in use, the Task Force plans to consider *in vitro* fertilization followed by embryo transfer, *in vivo* fertilization followed by lavage, gamete intra-fallopian transfer, and cryopreservation of sperm and embryos. Each of these possibilities raises significant legal, ethical, and social issues which deserve serious attention on a continuing basis by the Task Force and by the Commission. The recent case of *Davis v. Davis* [19] in Tennessee, involving the fate of seven frozen embryos in the aftermath of a divorce between the potential mother and father, with disagreement between the parties as to the appropriate disposition of the embryos, illustrates some of the complex questions that need to be addressed. Careful study of such issues may allow government to anticipate the challenges posed by advances in reproductive and genetic technologies, and to respond to them with intelligence and foresight, rather than being forced to react after the fact.

Notes

1. *In the Matter of Baby M,* 109 N.J. 396, 469, 537 A.2d 1227, 1264 (1988).
2. *In the Matter of Baby M,* 217 N.J. Super. 313, 525 A.2d 1128 (1987).
3. The issue of visitation was decided in *In the Matter of Baby M,* 225 N.J. Super. 267 (1988).
4. 109 N.J. at 422-34, 537 A.2d at 1240-46.
5. *Id.* at 435, 537 A. 2d 1227 at 1246.
6. *Id.* at 436, 537 A. 2d at 1247.
7. *Id.* at 440, 537 A.2d at 1249.
8. *Id.* at 441, 537 A. 2d at 1250.
9. *Id.* at 442, 537 A. 2d at 1250.
10. *Id.* at 436, 537 A. 2d at 1247.
11. *Id.* at 437, 537 A. 2d at 1248.
12. *Id.*
13. *Id.*
14. *Id.* at 440, 537 A. 2d at 1249.
15. *Infertility: Medical and Social Choices,* U.S. Congress, Office of Technology Assessment (Washington, DC: U.S. Government Printing Office, May 1988).
16. *Instruction on Respect for Human Life in its Origin and on the Dignity of Procreation,* Congregation for the Doctrine of the Faith (Vatican City, 1987).
17. Michael Walzer, *Spheres of Justice: A Defense of Pluralism and Equality* (Basic Books, Inc., 1983).
18. 109 N.J. at 466, 537 A.2d at 1263.
19. 15 Fam. L. Rep. 2097 (1989).

Task Force on New Reproductive Practices
Policy Recommendations on Surrogacy

Approved in Principle by the New Jersey
Bioethics Commission July 11, 1989

1. The State of New Jersey should enact legislation to prohibit the practice of commercial surrogacy.

2. The State of New Jersey should enact legislation explicitly extending existing prohibitions on the payment or receipt of money or any valuable consideration in connection with the placement for adoption of a child to apply to (a) any payments to a broker/intermediary, and (b) any payments (other than payment or reimbursement of medical and hospital expenses currently allowable under adoption law) to birth mothers, in connection with a surrogacy arrangement.

3. The State of New Jersey should enact legislation rendering the following contractual agreements in association with surrogacy arrangements illegal and unenforceable:

   (a) agreements to pay money or any valuable consideration to a broker/intermediary;

   (b) agreements to pay money or any valuable consideration (other than payment or reimbursement of medical and hospital expenses currently allowable under adoption law) to a birth mother, in connection with the surrender or transfer of custody or relinquishment or waiver of parental rights;

   (c) agreements by a birth mother, prior to the conclusion of a specified waiting period following the birth of the child or children,* to surrender or transfer custody or to relinquish or waive parental rights;

   (d) agreements purporting to limit the liberty of the birth mother with respect to control over fundamental medical or lifestyle decisions during the course of her pregnancy.

4. The State of New Jersey should not enforce any surrogacy arrangements, including but not limited to any arrangements that violate recommendation (2) above or that include contractual agreements violative of recommendation (3) above.

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*Whether the calculation of the waiting period should be based in whole or in part on the transfer of custody, rather than on the birth, is yet to be discussed and decided by the Task Force.

5. The State of New Jersey should enact legislation to govern the determination of custody, parental rights, and support obligations in the event of disputes arising pursuant to surrogacy arrangements. Such legislation should establish a legal presumption favoring custody by the birth mother, consistent with assuring satisfaction of the needs and welfare of the child.

6. The State of New Jersey should enact legislation recognizing an obligation of support on the non-custodial parent in a surrogacy arrangement. Contractual disclaimers of support obligations shall not be effective in such cases.

7. The State of New Jersey should enact legislation addressing visitation rights of the non-custodial parent in a surrogacy arrangement. Such legislation should embody a presumption in favor of visitation unless it is demonstrated that such visitation would be contrary to the best interests of the child. The extent and conditions of visitation should be considered on a case-by-case basis, with due regard for the child's interests both in psychological stability and in the maintenance of contact with the child's biological parents.

Chapter Two
Task Force on Institutional Ethics Committees

Revolutionary advances in medical knowledge and technology have fundamentally altered the nature and context of the decisions patients, families, physicians and society are required to make. Today, critical health care decisions most often arise in institutional settings such as hospitals and nursing homes. More than ever before, the treatment choices presented bear directly on the length and quality of an individual's life. They implicate some of society's most fundamental values and at the same time remain intensely personal in character. In the face of such dilemmas, it is necessary to identify sound medical, legal and ethical principles to apply, to select appropriate decisionmakers, and to assure that they deliberate in an environment that fosters patient autonomy while providing safeguards against possible abuse. The quest for a new approach to resolving the difficult legal and bioethical issues which emerge has led to consideration of what are known as "institutional ethics committees" and of the role they can play in assuring public confidence in and private comfort with the process and outcome of such decisionmaking.

The characteristic of institutional ethics committees which typically distinguishes them from other resources found in clinical care settings is their multidisciplinary composition, intended to provide diversity of perspectives and expertise. This characteristic has suggested their special usefulness in complex health care decisionmaking, particularly in a consultative role. While there remain substantial differences of opinion as to how medical knowledge and technology should be employed to affect the length and quality of a human life, there is widespread recognition that such ostensibly medical decisions raise profound "moral, social, technological, philosophical and legal questions involving the interplay of many disciplines. No one person or profession has all the answers."[1]

While ethics committees in health care institutions commonly engage in educational and policymaking activities, such bodies are increasingly called upon to provide prospective case consultation with respect to a specific patient. The concept (and practice) of utilizing multidisciplinary ethics committees in a consultative role in health care decisionmaking is of particular significance in New Jersey. The landmark decision of the New Jersey Supreme Court in the *Quinlan*[2] case, known principally for calling attention to the dilemmas posed by life-sustaining treatment decisions, is also credited with bringing the concept and role of institutional ethics committees into the mainstream of bioethical debate. In subsequent opinions, the Supreme Court of New Jersey has pursued its concern for ways to promote a sound decisionmaking process, both through the use of such committees in hospital settings and by fashioning a reviewing role for the Office of the Ombudsman for the Institutionalized Elderly in nursing homes. Building upon this judicial legacy, the Commission has strongly endorsed use of ethics

committees (or comparable entities) for prospective case consultation. This endorsement is expressly reflected in the consultative role defined for such committees in carefully specified circumstances by the Commission's proposed New Jersey Advance Directives for Health Care Act.* In light of the perception, shared by Commissioners and by many members of the health care community in New Jersey, that there is a critical need to assess the appropriate role, possibilities, and limitations of ethics committees in health care decisionmaking, the Commission established a Task Force on Institutional Ethics Committees (the "Task Force"), to perform this task in a comprehensive and scholarly manner.

The Task Force

The mandate of the Task Force is to (i) study the operation and experience of existing ethics committees and the legal and regulatory environment in which they function; (ii) evaluate potential roles for ethics committees engaged in prospective case consultation in a variety of institutional settings, including hospitals, nursing homes and other long-term care facilities, as well as the possibility of developing multi-institutional or regional models for such committees; (iii) analyze the potential interaction between ethics committees and the Office of the Ombudsman; and (iv) on the basis of the foregoing, develop recommendations for consideration by the Commission, including, where appropriate, proposed legislation or legislative guidelines.

Following preparatory work at the staff level and two organizational meetings, the Task Force became fully operational in September of 1988. The Task Force is composed of a core group of Commissioners, including the Commission Chair and Vice-Chair sitting *ex-officio,* and additional individuals selected for their expertise and experience in fields relevant to the Task Force's work. The Task Force includes persons with expertise and experience in medicine, nursing, health care administration, theology, law and ethics and counts among its members representatives of the New Jersey Hospital Association, the New Jersey Association of Health Care Facilities, the New Jersey Association of Non-Profit Homes for the Aging, the New Jersey State Nurses Association, and the Office of the Ombudsman.** To date, the full Task Force has convened ten times. The Task Force has engaged in a process of continuing self-education based upon readings and materials developed and compiled by Commission staff members, as well as presentations by staff members, consultants, and guest speakers.

In order to facilitate rigorous analysis of the complex and often technical legal issues inherent in the Task Force agenda and to foster careful drafting of a statutory proposal or legislative guidelines embodying a comprehensive approach to the functioning of ethics committees engaged in prospective case consultation, the Task Force empaneled from among its members a Subcommittee on the Legal Status of Ethics Committees. Over the course of three meetings held in April and May of 1989, this subcommittee, with the assistance of Commission

*The proposed Advance Directives for Health Care Act is discussed in Part Three of the report.

** A list of the Task Force members, with capsule biographies, is included in Table 3 of Appendix B to the report.

staff, developed a working draft of a legislative proposal to govern the functioning of institutional and regional ethics committees engaged in prospective case consultation. This working draft, which was based upon discussions at the Task Force level as well as the deliberations of the subcommittee, was presented to and discussed by the Task Force at its meeting in June 1989, and was subsequently reviewed (again in its preliminary form) by the full Commission in July 1989. Further refinements of the legislative proposal, perhaps in the form of guidelines for legislation, will be developed by the full Task Force.

A second Task Force subcommittee will study how to establish and operate ethics committees in long-term care settings, both on an institutional and regional basis. Through this subcommittee the Task Force will explore the possibility of establishing pilot programs for ethics committees in this setting, in cooperation with the long-term care community. It is anticipated that a third subcommittee will propose and oversee empirical research designed to facilitate and evaluate implementation of the Commission's recommendations in this area.

Foremost on the Task Force agenda at this time is refinement of a statutory proposal or guidelines for legislation based on continuing analysis of the legal, ethical and practical issues presented by the utilization of ethics committees in the prospective case consultation role. The discussion below is intended to highlight the principal issues with which the Task Force has been and will continue to be concerned.

Quinlan And Its Legacy

The starting point for the work of the Task Force has been careful consideration of the judicial perspective on the role of ethics committees in health care decisionmaking, with particular attention to the *Quinlan* decision and the subsequent refusal-of-treatment opinions of the New Jersey Supreme Court. Review of the *Quinlan* opinion is useful both in understanding its significance in the development of institutional ethics committees, in New Jersey and nationwide, and in appreciating the context in which legal, ethical and professional concerns presented by life-sustaining treatment decisions must be evaluated.

The Quinlan Case

In *Quinlan*, the Court was asked to determine (i) who should be given responsibility for making decisions regarding medical treatment for Karen Quinlan, a young woman who at the time the case arose was in a persistent vegetative state and was being sustained by a variety of medical interventions, including a respirator; and (ii) whether those responsible for such decisions could authorize withdrawal of life-sustaining treatment without incurring criminal or civil liability. Karen Quinlan's father, who sought appointment as her guardian, requested permission to authorize withdrawal of the respirator (which was believed to be sustaining her) in the face of opposition by the attending physician and the hospital and eventually, of the county prosecutor and state Attorney General who asserted that such action would give rise to criminal liability.

To resolve the question whether withdrawal of life-sustaining treatment was a permissible option with respect to a patient in this condition, the Court reviewed evidence as to the moral and

theological foundations for Mr. Quinlan's request to remove the respirator, the relevant medical standards and practices, the questions of constitutional law presented by the case, and the prevailing moral and legal standards of the community. On the basis of its review, the Court determined that a balancing of the relevant interests and considerations was necessary. It decided that the State's interest in the preservation and sanctity of human life, as well as the right of physicians to administer medical treatment according to their best judgment, must be weighed against the individual patient's right of privacy. In the circumstances presented in *Quinlan*, Karen's right to privacy, understood to include the right to refuse treatment, was held to outweigh competing interests of the physicians or the State.[3]

Underlying the Court's opinion in *Quinlan* was its rejection of the proposition that the perceptions of the attending physicians and the health care institution as to the prevailing medical standards should be determinative of a patient's right to refuse life-sustaining treatment. The Court's unwillingness to allow perceptions of applicable medical standards and practice alone to govern such decisions seems to have been partly attributable to the inherently multifaceted nature of the inquiry required to resolve these dilemmas. It was also based in part on what the Court identified as a widening ambiguity in the medical standards themselves in the context of life-sustaining treatment decisions[4] and on its recognition that

> [t]he modern proliferation of substantial malpractice litigation and the less frequent but even more unnerving possibility of criminal sanctions would seem, for it is beyond human nature to suppose otherwise, to have bearing on the practice and standards as they exist . . . a strong influence.[5]

In furtherance of its conviction that "there must be a way to free physicians, in pursuit of their healing vocation, from possible contamination of self-interest and of self-protective concerns which would inhibit their independent medical judgments for the well-being of their dying patients",[6] the Court proposed an innovative technique for resolving some of the problems associated with life-sustaining treatment decisions. That technique was to involve multidisciplinary ethics committees in the medical decisionmaking process.

The procedure developed by the *Quinlan* Court was intended, among other things, to assure that Karen's physicians could determine and confirm her prognosis and make and implement the necessary treatment decisions free of distracting concern for liability. The Court held that, if the appropriate procedures were followed (*i.e.*, confirmation of Karen's prognosis by an institutional "ethics" committee or similar entity within the hospital), withdrawal of the life-support system could be effected "without any civil or criminal liability therefore on the part of any participant, whether guardian, physician, hospital or others."[7] The Court's grant of immunity to the participants in the decision to discontinue life-sustaining treatment was a significant precedent with respect to the legal and practical impact of ethics committee involvement.[8]

Although the *Quinlan* Court's discussion of ethics committees leaves a number of questions unanswered, several important points emerged. First, introduction of an ethics committee into the decisionmaking process in a consulting role need not displace the traditional

decisionmakers -- the patient, family and physician. While the deliberations and recommendations of such a committee would be "professional in nature", the Court pointed out that the family views would be considered, for "[d]ecision-making within health care...should be controlled primarily within the patient-doctor-family relationship."[9] Second, the New Jersey Supreme Court believed that judicial review of life-sustaining treatment decisions is generally inappropriate and "impossibly cumbersome"[10] and that diminishing the role of the judiciary is a significant concern. *Quinlan* suggests that a multidisciplinary ethics committee which consults on individual cases "could lend itself well to a legal status which would allow courses of action not now undertaken because of concern for liability."[11] Although the Court did not elaborate on this suggestion, in the context of the opinion it seems clear that the Court believed the need for judicial involvement in life-sustaining treatment decisions could be diminished through effective use of ethics committees and that such a possibility should be pursued.

The Quinlan Legacy

What then is the legacy of *Quinlan* as it relates to ethics committees? It is ambiguous at best. The confusion derives largely from the dichotomy between the broad role apparently contemplated for the multidisciplinary ethics committee of the type described by the Court and the narrow task actually assigned to such a committee in the case -- pure medical prognosis confirmation. Because the task actually delegated to the committee with respect to Karen Quinlan has been interpreted as the narrow one of prognosis confirmation and the Court's grant of legal immunity specifically referred to prognosis confirmation for a patient who is permanently unconscious (here, in a persistent vegetative state) and will not return to a cognitive, sapient state, it was that type of so-called "prognosis" committee which first came to be widely utilized in New Jersey.[12] Nonetheless, the Court's call to consider the suitability of a more expansive role for multidisciplinary ethics committees in the resolution of ethically sensitive treatment dilemmas has also been heeded, both in New Jersey and nationwide.[13]

Following the *Quinlan* decision, discussion of institutional ethics committees intensified. The role of such committees has been analyzed and discussed widely by academics, medical professionals, policymakers and advisors, as well as the judiciary. The oft-cited analysis of the President's Commission[14] regarding the role of ethics committees in life-sustaining treatment decisions has been particularly influential in promoting their greater use. That Commission concluded that such committees, composed of diverse members, might effectively play a broader role than did the committee actually utilized in *Quinlan* and do so without displacing the primacy of the traditional decisionmakers. Such a committee could

> advise patients, families and practitioners who are trying to make informed decisions, particularly for decisions that have life-or-death consequences for incompetent patients. [Ethics committees] could seek to insure that the interests of all parties, especially those incapacitated, are adequately represented in the decisionmaking process and provide for efficient review without regularly incurring the liabilities of judicial review.[15]

In addition, a number of professional organizations have encouraged a role for institutional ethics committees, particularly in decisions concerning life-sustaining treatment.[16] For example, a Task Force of the New Jersey Hospital Association has stated that an institutional ethics committee is an excellent approach to help address new and constantly challenging ethical issues by promoting sound decisionmaking practices and responsible and timely assessment of medical and ethical issues.[17] That group concluded that ethics committees would serve these goals by enhancing, not replacing "the all-important patient/family/physician relationship and afford[ing] support for decisions being made within that triad, relying on the courts only as a last resort."[18]

Since its groundbreaking opinion in *Quinlan*, New Jersey's highest court has often reasserted its reluctance to be involved in life-sustaining treatment decisions. This appears to be based largely on the belief that substantive and procedural issues related to life-sustaining treatment decisions, including presumably the role of the Ombudsman and of ethics committees, should be resolved in comprehensive fashion through the legislative process. The Court has observed that, in contrast to an adversarial judicial proceeding, in the legislative process "fact-finding can be less confined and the viewpoints of all interested institutions and disciplines can be presented and synthesized."[19] In keeping with this conviction, when the Court has had to grapple with such issues, the call for legislative participation has been reiterated. For example, in a significant concurring opinion in the 1987 *Jobes* decision, Justice Pollock strongly endorsed the proposition that greater use of institutional ethics committees might play an important role in life and death medical determinations.[20] Justice Pollock's concurrence cited an array of authorities supporting the establishment of institutional ethics committees which, in his view, "can not only perform an educational and policy-making role, but also act as an advisor to the patient's family and physician."[21] His opinion was tempered by the recognition that "creation and implementation of ethics committees raises questions concerning the structure, function and duties of the committee, as well as the confidentiality of its records and immunity from suits of its members."[22] Justice Pollock insisted that "(a)s the Court returns the decisionmaking authority to patients' families and physicians, the answers to those questions merit the consideration of health care officials and the Legislature."[23]

The Office of the Ombudsman

Notwithstanding its reluctance to assume the task of crafting procedures for resolving life-sustaining treatment dilemmas, the New Jersey Supreme Court's interest in assuring that appropriate procedural guidelines be in place to safeguard the interests of patients and to facilitate proper decisionmaking led it to define a role for the Office of the Ombudsman in life-sustaining treatment decisions for elderly patients in the nursing home setting. The role of the Ombudsman fashioned by the Court in *Conroy* and *Peter* was apparently based in substantial measure on a belief that the hospital and nursing home settings differ in significant respects and that additional procedural safeguards are generally warranted in the nursing home context. The Court felt that the *Quinlan* ethics committee procedures, which at that time were in an early stage of development, were "not entirely appropriate for patients...confined to nursing homes,...a particularly vulnerable population."[24] Nonetheless, the Court's assessment of nursing homes and

ethics committees has been closely scrutinized and, in the wake of the *Conroy* and *Peter* decisions, a recurring theme in discussions among lawyers, scholars, and members of the health care community has been the possibility of using ethics committees as a legally recognized alternative to consultation or review by the Ombudsman regarding life-sustaining treatment decisions for elderly nursing home patients in certain situations.*

The Task Force's Deliberations and Agenda

In keeping with its mandate from the Commission and mindful of the pressing need to evaluate the potential uses of ethics committees in a manner sensitive to the dilemmas posed by modern health care decisionmaking, including, in New Jersey, the role of the Ombudsman, the Task Force has made analysis of the procedural aspects and legal implications of ethics committees engaged in prospective case consultation one of its primary objectives. The Task Force has thus far reached several conclusions which form the foundation for its continuing work.

The Value of Ethics Committees

Both the Task Force and the Commission firmly believe that multidisciplinary ethics committees can, in appropriate cases, make a valuable contribution to the resolution of health care issues for individual patients. In this context, committees should act as consultants, advisors and facilitators, not as decisionmakers. Such committees can enhance the ability of health care professionals, institutions, patients, and their surrogates and families to engage effectively in a process of shared decisionmaking. A sound decisionmaking process would in turn minimize the need for judicial or other governmental involvement in a traditionally private arena. Ethics committees can provide a basis for public confidence that health care decisions made by and on behalf of potentially vulnerable patients are being made carefully, compassionately, fairly and with respect for the patient, the standards and values of the physician and other health care professionals, and with sensitivity to fundamental societal interests. Accordingly, the Task Force has sought to develop recommendations and proposals which would foster a legal environment and climate of public awareness in which informed and well-intentioned participants in the health care decisionmaking process can exercise sound judgment, free of inappropriate constraints and concerns. At the same time, such proposals should provide safeguards against the unusual but real situations in which a patient's wishes and best interests are not promoted.

A Statutory Approach

Although a definitive judgment has not been made on the extent to which the activities of ethics committees engaged in prospective case consultation in New Jersey should be governed by statute, the Commission and the Task Force have jointly concluded that it is appropriate to develop and refine recommendations for a statutory approach, recognizing that such an approach is likely to be most effective if supplemented by some combination of administrative regulations,

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* The role of the Office of the Ombudsman in life-sustaining treatment decisions is discussed at length in Part Four of the report.

institutional guidelines, and effective professional and public education. A coherent, well-defined yet flexible framework for the establishment and operation of ethics committees cannot be provided by the courts or by health care institutions acting without benefit of statutory guidelines.

There are a number of reasons for this conclusion. First, there are presently a number of significant legal uncertainties surrounding the role and implications of ethics committee participation in prospective case consultation. As discussed below, these uncertainties include the absence of (or ambiguity respecting) norms governing confidentiality of committee proceedings, the application of the physician-patient privilege to information that comes before a committee, and the potential exposure to suit and legal liability of committees, their members, their sponsoring institutions, and those who act to effect committee recommendations. Such uncertainties can best, and perhaps only, be resolved by statute. Second, legislation seems to be the most appropriate vehicle to establish the minimum requirements necessary to assure public confidence in the authority and effectiveness of ethics committees. Such requirements might pertain, for example, to committee membership and to access to and documentation of the committee process. A statutory approach is also best suited to establishment of a legally recognized mechanism for overseeing or accrediting ethics committees to assure initial and continuing compliance with applicable legal and professional standards governing the functioning of such committees. Finally, the Task Force believes that a statutory response is needed to refine the role of the Ombudsman in health care decisionmaking in nursing homes and to clarify the respective roles of ethics committees engaged in case consultation and the Ombudsman, and in some instances other state agencies with related functions.

The Office of the Ombudsman

The Task Force is committed to the view that ethics committees meeting appropriate standards should be a legally recognized alternative to Ombudsman review of life-sustaining treatment decisions in certain situations. Such committees properly serve a function complementary to that of the Ombudsman. They should provide an appropriate vehicle for a local response in most cases that require review, thereby permitting the Office of the Ombudsman to focus its attention and resources where most needed, such as in cases with identifiable indicia of actual or potential abuse. To better delineate the roles of ethics committees and the Ombudsman, the Task Force will continue to consider how such indicia of abuse might be defined, when the Ombudsman should defer to ethics committee involvement and when the active participation of the Ombudsman would be most valuable. In order to facilitate an optimal relationship between ethics committees and the Ombudsman, the Task Force will also consider the spectrum of cases an ethics committee might confront and whether there should be mandatory ethics committee consideration of any particular categories of cases.[25]

A Mandated Role for Ethics Committees

Early in its development of a draft legislative proposal, the Task Force considered whether the State should mandate the establishment of ethics committees to provide prospective

case consultation, and if so, in what kinds of institutions. The Task Force's preliminary conclusion is that although the needs and resources of hospitals and nursing homes are different in certain relevant respects, it would be appropriate for New Jersey to require hospitals and nursing homes (and perhaps other kinds of health care institutions) to maintain or participate in what are referred to in the draft proposal as "bioethics consultation committees." This term was adopted to distinguish committees engaged in bioethics case consultation, which would be the focus of a legislative approach, from two types of committees already quite common in health care institutions -- those involved primarily in bioethics education and policymaking activities, on one hand, and those given prognosis confirmation responsibilities on the other. It is contemplated that any proposal to require institutions to create or maintain bioethics consultation committees would incorporate a phase-in period or delayed effective date. This would be designed to permit affected institutions to marshall existing resources and develop new ones appropriate for the implementation of a qualified bioethics consultation committee in that setting.

Cognizant of institutional differences not only between hospitals and nursing homes, but also among various long-term care facilities, the Task Force will continue to refine its understanding of the potential role of committees organized on a multi-institutional and regional basis. The Task Force intends that those institutions which find it difficult either to tailor an existing institutional ethics committee to fit the statutory requirements or to establish a new entity within the institution, would be permitted (and perhaps encouraged) to participate cooperatively in a multi-institutional bioethics consultation committee, such as a committee organized on a regional basis. Developing a model for the organization and functioning of bioethics consultation committees serving multiple and diverse institutions is one of the objectives the Task Force plans to pursue.

Balancing the Need for Institutional Autonomy and Accountability of Committees

The decision of the Task Force to develop recommendations for a statutory approach to prospective case consultation by bioethics consultation committees was made in recognition of an overriding need to appropriately allocate responsibility for resolving the issues such a role presents among the Legislature, an accrediting authority, professional organizations and individual health care institutions. This requires a balancing of the competing interests -- the desire to maintain institutional and professional autonomy and the need to maintain accountability and assurances of quality. It is presently contemplated that in addition to a statutory framework governing bioethics consultation committees, each health care institution which maintains or participates in such a committee should be required to develop a written policy addressing a variety of issues governing the committee process. Institutions would be accorded a substantial degree of discretion to develop such policies within bounds prescribed by statute or regulation. While the principal purpose of requiring the development of written institutional policies would be to implement and make known an acceptable process for committee consultations, such policies might also be subject to review by an accrediting authority or other appropriate body. This approach is intended to assure appropriate accountability without unduly limiting flexibility at the institutional level.

In the course of its deliberations, the Task Force has considered a broad range of matters which sponsoring or participating institutions might be asked to address in a bioethics consultation committee policy statement. Among the matters to be addressed are the mandate of the committee and its relationship to the professional and administrative staffs, existing institutional committees and other resources within the sponsoring institution, the criteria and procedures for selection, removal, terms of office and other terms of service of members of the committee, and procedures for initiation of a consultation and the method and criteria by which cases are screened for consultation. Institutional policies might also address the committee's approach to and the components of the consultation process, including delegation of specified responsibilities to subcommittees or individual members of the committee; gathering of information and procedures to assure appropriate access to the committee for those who wish to present their views, timely conclusion of a consultation and communication of any recommendations rendered; and recordkeeping practice. Institutional policies should also describe the initial and continuing education required of committee members with respect to their service, the means by which patients, families, health care professionals and others will be informed of the role and operation of the committee, and should include a procedure to assure that a statement of the rights and responsibilities of patients, families, physicians and others with respect to committee consultations is available to all concerned. In the context of developing a statutory framework and complementary guidelines for institutional policy with respect to bioethics consultation committees, the Task Force is seeking ways to promote meaningful involvement by professional organizations, institutional associations and government.

The nature of the project the Task Force has taken on necessitates consideration of a broad range of topics which are central to the development of a statutory proposal regarding bioethics consultation committees. A brief review of some of the principal topics being considered is set forth below.

Committee Objectives

A central goal of any legislative proposal mandating the creation and maintenance of bioethics consultation committees is a careful definition of the objectives of such committees. Those objectives would then inform decisions concerning the basic composition, structure and organization of a bioethics consultation committee, as well as the nature of the legal environment in which they should function. As presently envisioned, the primary purposes of a bioethics consultation committee would be to provide a forum for deliberation and discussion. Committee members, with the assistance of those knowledgeable about a patient's case, would develop the personal and medical information relevant to the decisions facing a specific patient, his or her physician and family, identify the governing legal principles and relevant ethical standards, evaluate the available information and issues in an effort to identify the acceptable course(s) of action in the case, and develop advisory recommendations for the benefit of those responsible for the patient's care. In this fashion, the committee might facilitate the decisionmaking process and help to resolve disputes when they arise. Although the structure and composition of bioethics consultation committees would be tailored to the role of prospective case consultation, it is anticipated that institutions might involve such committees in retrospective case analysis,

development and review of institutional policies, and educational functions as well.

Committee Membership

The scope and nature of a committee's agenda should, in turn, shape the character of its membership. Determining the extent to which questions concerning membership should be resolved by the Legislature or left to institutional discretion is especially difficult, as the desire to preserve institutional autonomy may be at odds with the need to establish appropriate minimum standards which assure a solid basis for public trust. The Task Force believes that individual institutions should retain substantial control of committee membership, subject to minimum requirements designed to assure sound functioning and promote public confidence. At the same time, it recognizes that if a bioethics consultation committee has the authority to confer some form of legal immunity for participants in the decisionmaking process, or is available in nursing homes as an alternative forum for review of cases that otherwise would be considered by the Ombudsman or the judiciary, the minimum requirements pertaining to committee membership should be more rigorous than those for a committee whose review of cases has less legal significance. These minimum requirements must recognize the desirability of diverse perspectives and expertise as well as the variety in resources available in different institutional settings. Very importantly, such requirements must be consistent with the need to facilitate a workable committee process. The number of members should permit the committee to be convened (as a whole or in part) in a timely fashion and their qualifications should permit discussions to proceed in a disciplined and focused manner, based on sound legal and ethical principles and accurate medical information. The minimum requirements must also take into account the variation in resources and capacities of the range of institutions to which they will apply, while remaining consistent with common goals of all such committees.

Committee Procedures

An understanding of the practical functioning of a bioethics consultation committee and the development of a statutory framework therefor also demands delineation of alternative approaches to and procedures for the conduct of consultations. The committees' proper functioning and authority depends upon appropriate access to and utilization of such committees. The first question which arises is how a case will come to the committee. Committee procedures must assure that those concerned with and affected by the committee's work (*e.g.*, staff, patients, and family) are adequately informed concerning its purpose and operation and that the committee will be available in appropriate cases. The Task Force thus seeks to develop minimum procedural standards to assure appropriate access to the committee process, including the provision of notice of committee proceedings to appropriate parties. It is considering how to define such safeguards in a way that provides adequate guidance while reserving to individual institutions discretion to shape policies to their particular needs.

Timing considerations are among the most sensitive in establishing procedures for effective consultation. Many health care situations, some involving life and death decisions, require speedy deliberation and action. A major concern with judicial and regulatory

involvement in these matters is the difficulty in securing prompt and appropriate review. Ethics committees, particularly those affiliated with the institution involved, offer the prospect of timely consideration. While bioethics consultation committees should facilitate a thorough and structured consideration of all relevant information and issues, they should not undermine their comparative advantage by adopting an unnecessarily protracted or excessively formalized deliberative process. The Task Force is considering whether statutory guidelines would be helpful in this regard.

Once a case has been brought to a committee, the nature of the issues involved must be identified so that the proper expertise and procedures can be brought to bear. To achieve this objective, the Task Force is contemplating the wisdom of requiring institutions to develop a procedure for screening of requests for consultation. The Task Force's efforts to facilitate smooth and effective committee functioning are grounded upon the belief that sound procedures for delegating responsibility within a bioethics consultation committee are essential to making such committees a successful participant in health care decisionmaking. If the committee process is too cumbersome, it will not be possible to successfully integrate it into the traditional decisionmaking process. The Task Force has discussed the circumstances in which a bioethics consultation committee should be permitted to delegate to one or more members or other qualified persons aspects of a consultation which are more appropriately conducted by a smaller or more specialized group or by an individual. One example might be the determination of a patient's diagnosis and prognosis. The Task Force is considering whether statutory guidelines may be appropriate in this area.

For purposes of analysis, the process of case consultation can be described as having three stages: investigation, deliberation, and recommendation. The initial stage requires "fact-finding" from a variety of sources. One task of a committee is to determine what those sources should be and how the necessary information can be obtained. The Task Force is conscious of the desirability of integrating existing institutional resources and procedures as much as possible at this stage and any legislation should permit substantial flexibility in this regard. The deliberative phase may be the least susceptible to procedural standardization, since the nature of the discussion will depend upon the kinds of issues being addressed and other circumstances of the case. Nonetheless, certain procedural guidelines may be useful and, for example, the Task Force is considering the possibility of developing guidelines, perhaps in "checklist" or outline form, to guide bioethics consultation committees in this deliberative phase.

Upon completion of its deliberations, a bioethics consultation committee will presumably attempt to reach closure and arrive at some conclusions. At this stage, a number of important and difficult procedural questions must be addressed, many of which bear on the potential moral force and legal significance to be accorded the recommendations of a bioethics consultation committee. The Task Force has just begun to analyze a variety of paradigms and approaches to achieving closure in the context of a bioethics consultation. Some of the questions the Task Force is considering in this context are whether the committee should attempt to define a range of acceptable outcomes or to recommend a "right" result; what degree of agreement, if any,

should be required; how fundamental disagreements among members should be resolved or expressed; and whether the committee should speak with one voice or should also record and make known concurring and dissenting views, as in the case of judicial opinions. With respect to all of these questions the Task Force must again decide which policy judgments should be made by the Legislature and which should be left to the discretion of each committee or its sponsoring institution(s).

Regardless of how these questions are answered, the committee's advice needs to be communicated to the appropriate parties. The Task Force is reviewing alternative means of requiring minimum standards to be met in this regard to assure that patients, families and members of the health care team are adequately informed of the committee's work.

The Task Force is also addressing the question whether such committees should have responsibility to recommend resort to the judiciary or to refer cases to the Office of the Ombudsman, another state protective agency, or to a prosecutor in appropriate cases. Again there is a need to balance competing concerns, here the value of the information and insights committee members could provide against the desire to avoid perception of the committee as a watchdog or a policing body.

Recordkeeping

In all three phases of a consultation, there are a number of significant issues that relate to recordkeeping. Decisions must be made concerning the kind of records a bioethics consultation committee will keep and how they will be used. The Task Force has concluded preliminarily that a bioethics consultation committee should maintain a "case record" for each patient whose case is the subject of a prospective case consultation. Such a record might contain relevant portions of the patient's medical record (including a written summary of the committee's recommendations and a copy or summary of medical opinions addressing the patient's diagnosis and prognosis), a written statement of the committee's proceedings, deliberations and recommendations, and minutes of committee meetings.

Confidentiality

In connection with questions of recordkeeping, the Task Force has focused on dual concerns facing all ethics committees involved in case consultation -- the desire to maintain an appropriate level of confidentiality for sensitive patient information and committee proceedings and the desire to minimize exposure of the sponsoring institution and committee members to publicity and perhaps unwarranted litigation. Whereas common law and custom have traditionally played an important role in establishing standards of confidentiality in health care, the protections currently afforded to the records and proceedings of various types of hospital committees are typically provided by statute. This is a reflection of the complexity of issues presented by introduction of institutional committees into the health care delivery system, as well as the relatively recent development of such committees. The current state of statutory and decisional law in New Jersey does not appear to adequately address the particular problems and

concerns relating to confidentiality that are posed by bioethics consultation committees in the context of prospective case review.[26] The Task Force has concluded that statutory attention to the confidentiality of committee records and proceedings has ample precedent and would be well advised.

Determining the degree of confidentiality that can realistically and appropriately be afforded the proceedings and records of bioethics consultation committees functioning in a consultative role involves a difficult balancing of competing considerations. Interests deserving consideration include the patient's interest in maintaining privacy regarding personal medical information and the associated moral dilemmas; the committee's need to investigate thoroughly, deliberate freely and come to sound conclusions free of distracting concern about unwarranted exposure to liability; the need to permit reasonable review of a committee's functioning in order to assure confidence in the quality of the process among patients, professionals, the institution and the public; and the desirability of allowing the legal system to respond appropriately in situations where the committee process might go seriously awry, for instance, in cases involving conflicts of interest or bad faith. The Task Force will carefully examine the scope and legitimacy of claims for disclosure from each category of claimant, considered in light of their relationship to the decisionmaking process, *i.e.*, some may participate in decisionmaking while other claimants may have oversight responsibility with regard to bioethics consultation committees, or more broadly the quality of patient care. The Task Force is committed to developing an approach which is sensitive to these issues.

Issues of Liability

One of the most troubling and difficult issues the Task Force seeks to resolve is the extent to which those involved in making health care decisions should receive immunity from liability for acting in accordance with the advice of a bioethics consultation committee and, conversely, whether failure to act in accordance with such advice should expose decisionmakers to a greater risk of civil or criminal liability for those actions. It was largely in response to the chilling effect of that uncertainty about legal consequences that the *Quinlan* Court first raised the possibility of introducing ethics committees into the process, and the New Jersey courts remain concerned about that effect more than a decade later.

In considering the issue of potential liability, two distinct sets of problems demand attention. The first relates to the effect bioethics consultation committee participation in decisionmaking should have in judging the propriety of treatment decisions and therefore, on the potential liability of the traditional decisionmakers and others who are involved in life-sustaining treatment cases. In other words, what weight, if any, should be given to the fact that the decisionmaking process includes a committee consultation and should the fact that certain actions are, or are not, consistent with the committee's advice affect the standards or procedures for determining liability?[27]

The second set of problems involves determining what standards for assessing liability are appropriate to committee members and their sponsoring institutions with respect to their

participation in the prospective case consultation process. Cognizant of the importance of permitting those involved in health care to participate in decisionmaking without concern for unwarranted legal liability, the Task Force seeks to find an acceptable way to provide participants in the decisionmaking process with an appropriate degree of insulation from legal entanglements without imposing a degree of non-judicial oversight on the process that would stifle the independence and autonomy traditionally enjoyed by health care institutions, physicians, patients and their families. This is a critical issue with implications of fundamental importance to the entire effort.

As to statutory protection for committee members themselves, although none of the current New Jersey statutes which effect limits on liability in the hospital setting are specifically addressed to ethics committees, these statutes indicate the Legislature's willingness to respond to problems posed by unrestricted exposure to liability in a variety of health care contexts.[28] A challenge facing the Task Force in this regard is thus to assess the issues and develop a suitable legislative response to the distinctive problems presented by the potential liability of bioethics consultation committee members and the sponsoring institution when they participate in prospective case consultation.*

Current Status and Plans

The Task Force plans to move forward in developing a workable, balanced approach to prospective case consultation for mandated bioethics consultation committees. The Task Force expects to conclude its deliberations and transmit recommendations to the full Commission, in the form of a report and accompanying recommendations for legislative action, in the Fall of 1990. Upon completion of this phase of its work, the Task Force plans to develop a pilot project addressing the establishment and operation of ethics committees, including in particular, the use of multi-institutional and regionally-based bioethics consultation committees in the State. This project will be undertaken in cooperation with appropriate government agencies, health care institutions and professional associations, as will the follow-up work of evaluating the impact of the Commission's recommendations. This phase of the Task Force's work may entail some empirical research. In addition, the Task Force plans to examine other roles for ethics committees, such as institutional policymaking and education, in its 1990 agenda.

* The Task Force also plans to study whether existing insurance arrangements would apply, in whole or in part, to the activities of bioethics consultation committees, their members and sponsoring institutions.

Notes

1. *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 *cert. denied sub nom. Garger v. New Jersey*, 429 U.S. 922 (1976).

2. *Id.*

3. *Id.* at 40-41, 355 A.2d at 664.

4. *Id.* at 46, 355 A2d at 667.

5. *Id.* at 46, 355 A.2d at 666, 667.

6. *Id.* at 49, 355 A.2d at 668.

7. *Id.* at 54, 355 A.2d at 671.

8. The Court held that, with the benefit of its opinion, if the attending physician, the guardian and family together decide that there is no reasonable possibility of Karen Quinlan ever emerging from her present condition and that her life-support apparatus should be discontinued,

> they shall consult with the hospital "Ethics Committee" or like body of the institution in which Karen is then hospitalized. If that body agrees that there is no reasonable possibility of Karen's ever emerging from her present comatose condition to a cognitive, sapient state, the present life-support system may be withdrawn. *Id.* at 54,355 A.2d at 671.

9. *Id.* at 50, 355 A.2d at 669.

10. *Id.*

11. The description of ethics committees in *Quinlan* consisted almost entirely of excerpts from a brief law review article by a pediatrician. *Id.* at 669 (citing Karen Teel, "The Physician's Dilemma: A Doctor's View: What the Law Should Be", *Baylor Law Review* 27(1987): 8-9.

12. In 1987, the New Jersey Supreme Court noted in *In re Jobes*, 108 N.J. 394, 421, 529 A.2d 434, 448 (1987), that the "*Amicus* New Jersey Hospital Association has informed us that since *Quinlan* was decided, approximately eighty-five percent of New Jersey's acute care hospitals have established prognosis committees that check the attending physician's prognosis when withdrawal of life support from a vegetative patient is under consideration. Thus it appears that the *Quinlan* procedure is functioning in the setting for which it was intended."

13. In *Quinlan*, the Court did not have the luxury of reviewing a case where the family and physicians had previously consulted with an institutional ethics committee to inform their decisionmaking. In certain respects, the analysis underlying the decision can be seen as a model for ethics committee deliberation in future cases. The Court analyzed the legal, theological and moral implications of allowing Mr. Quinlan to authorize withdrawal of life-sustaining treatment for his daughter. In this inquiry, based on evidence and relevant literature drawn from diverse disciplines, the Court tested the soundness of the contemplated treatment decision and derived and applied a substantive standard for evaluating the positions of the traditional decisionmakers. Because the Court was not presented with up-to-date medical evidence necessary to make a contemporaneous judgment concerning Karen's prognosis, this task was delegated to a "committee" with the capacity to update and confirm the medical information previously developed at trial.

14. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment: Ethical, Medical and Legal Issues in Treatment Decisions* (U.S. Govt.P.O., 1983).

15. *Id.* at 164-169.

16. For example, The American Hospital Association (*see, e.g.*, letter to Institutional Membership and Allied Association Executives on the subject of Biomedical Ethics Committees (June 1984)); the American Academy of Pediatrics (*see, e.g.*, "Guidelines for Infant Bioethics Committees," (April 1984)); and the American Medical Association (*see* Norman Fost & Ronald Cranford, "Hospital Ethics Committees", *Journal of the American Medical Association* 253 (1985): 2687 (noting AMA's House of Delegates resolution supporting institutional ethics committees).

17. New Jersey Hospital Association (Ethics Task Force), Considerations and Recommendations for Institutional Ethics Committees (1986), pp. 1, 7.

18. *Id.*

19. *In re Farrell*, 103 N.J. 335, 343, 529 A.2d 404, 407-08 (citing *In re Conroy*, 98 N.J. at 344-45, 486 A.2d at 1221).

20. *In re Jobes*, 108 N.J. 394, 450-53, 529 A.2d 434, 461-64 (1987) (Pollock, J., concurring).

21. *Id.* at 450, 529 A.2d at 463.

22. *Id.* at 453, 529 A.2d at 464.

23. *Id.*

24. *In re Conroy*, 98 N.J. at 375, 486 A.2d at 1237.

25. This approach is adopted in the proposed New Jersey Advance Directives for Health Care Act, which provides that in the circumstances specified in sections 15(A)(4) and 16(A)(3) of the proposal a contemplated decision to forego life-sustaining measures must be reviewed by an ethics committee or by the Ombudsman prior to its implementation.

26. There are no New Jersey statutes or judicial decisions which specifically address the issue of confidentiality in ethics committee consultations. Among the New Jersey statutes relevant to consideration of these issues are: *N.J.S.A.* 2A 84A-22.2 (West 1968) (physician-patient privilege), *N.J.S.A.* 47: 1A-1 *et seq.* (West 1963) (Right To Know Law), and *N.J.S.A.* 2A: 84A-22.8 (West 1979) (Utilization Review Committee).

27. While the New Jersey judiciary has been willing to accord great deference to ethics committee consultation in the context of determining the liability of those involved in making life-sustaining treatment decisions, a number of other jurisdictions have been less willing to immunize decisionmakers acting on the advice of an ethics committee, or to diminish the role of the judiciary. *See e.g., Superintendent of Belchertown v. Saikewicz*, 373 Mass. 728, 370 N.E. 2d 417, 434 (1977).

28. *See N.J.S.A.* 2A: 84A-22.9 (West 1970); *N.J.S.A.* 2A: 84A-22.10 (West 1987); and *N.J.S.A.* 2A: 53A-7.1(b) (West 1988).

Chapter Three
Task Force on Public and Professional Education

The Task Force on Public and Professional Education was one of the Commission's first Task Forces, beginning its work informally in the early part of 1988. It was created to advance the Commission's strong commitment to reach out both to professional communities and to the general public, in order to enhance awareness and deepen understanding of bioethical issues in general and of the work of the Bioethics Commission in particular. The primary objective of this Task Force is to play an active and visible role in promoting informed discussion and debate on these issues throughout New Jersey.

The Task Force is chaired by Commissioner Mary Strong and consists of 20 members, six of them members of the Commission, plus the Commission's Chair and Vice-Chair, sitting ex-officio.* Non-Commissioner members, who joined in June of 1989, bring additional expertise in such areas as medical and professional education, health care, public service, public relations, and the media. To date, much of the work of the Task Force has been preparatory, as expansive educational initiatives are awaiting final legislative action on the Commission's proposed legislation on the declaration of death and advance directives for health care. However, substantial progress has been made in a number of areas.

The Task Force held its first formal meeting on September 14, 1988. It determined that its first priority would be to develop public outreach strategies for providing the public and professional communities with information about Commission proposals and reports. In achieving these aims, the Task Force felt that each of its educational undertakings should provide the necessary scientific, medical and historical background required to fully understand the issues and problems addressed by the recommendations and proposals of the full Commission. Accordingly, as its first project, the Task Force began developing materials for the public and professional communities to improve understanding of the Commission's first legislative proposal on the declaration of death.

To this end, the Task Force is developing an informational pamphlet to describe the concept of "whole brain death" and to address areas of potential concern or confusion among professionals and the public. It has also discussed the possibility of developing videotaped educational materials. To assist with this project, a neurologist with special expertise in this area has been working with the Task Force to help identify some of the important educational issues concerning the declaration of death on the basis of neurological criteria. As a result of this

*A list of Task Force members and their capsule biographies are included in Table 3 of Appendix B to the report.

work, a draft pamphlet is near completion. This pamphlet addresses some of the areas which have been particular sources of confusion among physicians, other health care professionals, families, and the broader public, such as the anatomy and physiology of the brain; the differences between whole brain death and other conditions, such as persistent vegetative state; how physicians determine whether brain death has occurred; the reliability of the diagnosis; and the explanation of the right to a personal religious or moral exemption from the declaration of death on the basis of whole brain death criteria.

The Task Force has also made substantial progress in developing materials related to its proposal concerning advance directives. The expanded Task Force has been divided into two subcommittees. One subcommittee was charged with drafting sample advance directive forms, while the second subcommittee was asked to plan the marketing and distribution of those documents. Both of these subcommittees have been meeting on a regular basis. Staff, in cooperation with Task Force members, has completed three sample forms which are appended to the Commission's Advance Directives for Health Care Act (see Part Two, Chapter II of this report). Additional materials are being developed, and the Task Force and Commission expect to complete an educational brochure for advance directives for health care in early spring of 1990.

The advance directives brochure is intended for broad public distribution. It is designed to assist interested individuals in preparing a directive suited to their personal circumstances which accurately reflects their preferences and values concerning their future health care. The brochure contains introductory material describing the different kinds of directives, durable powers of attorney for health care, instruction directives and integrated directives, and the strengths and limitations of each option. Given the Commission's commitment to encouraging individuals to think carefully about their preferences and to discuss them candidly with others, the brochure also contains planning materials designed to promote these efforts.

In addition to the publication of written materials, Commissioners and staff members are regularly called upon to speak to organizations interested in bioethical issues. These organizations have included, nursing homes, adult residential communities, businesses, educational institutions from high school through law and medical schools, health care providers, professional organizations and others. The Commission is committed to the further development of its public outreach activities.

For the future, the Commission has asked the Task Force to continue its work in developing educational materials regarding the Commission's two legislative proposals. Specifically, it has been requested to proceed with the development of additional materials and educational activities aimed at meeting the needs of health care providers and related professionals, such as attorneys, social workers and others.

Part Six

Future Agenda

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Future Agenda

During its first triennial period, with the generous support of the legislature and the participation and goodwill of professionals and citizens, the Commission has been able to provide guidance and leadership to the public, professionals and policymakers on a variety of issues. The importance of keeping abreast of the impact of advancing technology on health care decisions is perhaps greater now than it was four years ago when the Commission was created. As a permanent legislative study commission, the Commission is charged with the responsibility to examine emerging legal and ethical problems on a continuing basis. In providing guidance to citizens, professionals and policymakers alike, the enabling legislation mandated the Commission to:

- examine ways to protect the rights of citizens to determine the course of their own health care while safeguarding vulnerable patients against potential abuse;
- ascertain the facts and identify the problems most relevant to supporting informed decisionmaking on the part of patients;
- develop recommendations which improve the dialogue and communication between professionals, patients and families;
- find ways to facilitate appropriate decisionmaking regarding termination or refusal of medical care;
- study ways to encourage the development of humane means of caring for the terminally ill;
- reduce the need for judicial intervention in medical treatment decisions; and
- suggest improvements in public policy with respect to access to health care.

These problems must be addressed anew as circumstances change and new situations arise. Advances in health care and medical science continue to be accompanied by new and recurring ethical and legal dilemmas which require attention if we are to enjoy fully the benefits of these achievements. For example, issues involving AIDS, the problems associated with the care and treatment of the seriously ill and dying, new reproductive technologies, the rights of patients and the responsibilities of professionals, have become more prominent. This agenda poses significant challenges. With this in mind, and building on its past accomplishments, the Commission has developed a plan for the next phase of its work.

Future Plans

The Commission's legislative recommendations call upon the Department of Health to promulgate regulations designed to implement the statutory requirements of both its advance

directives and declaration of death proposals. Pending favorable legislative action on its proposals, the Commission expects to work cooperatively with the Department and other public agencies in developing sound regulations reflecting the spirit and concerns of its statutory recommendations.

Of equal importance to sound law and public policy is the development of effective educational materials and programs to assist both health care professionals and the public in understanding their rights and responsibilities. The Commission is directed by statute to undertake educational efforts. Projects currently underway include the completion and dissemination of an educational pamphlet about advance directives with sample advance directive forms; the completion and distribution of a pamphlet explaining the declaration of death on the basis of neurological criteria (whole brain death); the development of audiovisual materials for use by hospitals and other health care institutions providing additional guidance on implementing Commission recommendations; and the initiation of a pilot project on institutional ethics committees involving the public and private sectors. The Commission will continue to provide information and guidance on request to interested citizens and professionals on issues falling within the scope of the Commission's expertise and resources.

In addition to these educational efforts, the Commission will begin to develop guidelines for decisionmaking for incompetent patients who have not written an advance directive, and plans to devote substantial efforts and resources to studying many of the difficult legal, ethical and societal issues surrounding AIDS.

These projects will be completed through the combined efforts of both the full Commission and its several Task Forces. In fulfilling its legislative mandate, the Commission has instituted a policy of using *ad hoc* panels composed of Commissioners and selected experts. This approach permits the Commission to focus its efforts on specific areas, making use of the considerable range of expertise provided by Commission members, supplemented by the talent of other citizens and professionals from New Jersey's health care community. The work of the Task Forces currently in operation is described in detail in Part Five of the report. The Commission plans to make operational two additional Task Forces -- a Task Force on AIDS and a Task Force on Protecting Vulnerable Patients, each to include among its members representatives of other government agencies and the private sector. What follows is a summary of the Commission's future plans as they relate to each of the Commission's Task Forces. As has been the case pursuant to Commission policy, all Task Force recommendations are (and will be) made to the full Commission, and the Commission retains responsibility for recommendations made to the Governor, Legislature and public.

Institutional Ethics Committees

The Task Force on Institutional Ethics Committees (the IEC Task Force) plans to continue its efforts to develop a workable, balanced approach to prospective case consultation for mandated ethics committees ("bioethics consultation committees"), as discussed at length in Part Five of the report. The IEC Task Force expects to conclude its deliberations and transmit its recommendations to the full Commission, in the form of a report and accompanying guidelines

for legislation, in the late Spring or early Fall of 1990. Upon completion of this phase of its work, and cognizant of its responsibility to provide assistance in implementing its recommendations, the IEC Task Force will develop a pilot project on the establishment and operation of ethics committees. As currently envisioned, this project will involve working cooperatively with relevant government agencies, institutions and professional associations to establish a model approach to the use of multi-institutional and regionally-based bioethics consultation committees serving several affiliated health care institutions. In addition to the pilot project, the IEC Task Force expects to engage in a follow-up evaluation study to assess the impact of its recommendations on health care decisionmaking. This project will be undertaken in cooperation with appropriate government agencies, health care institutions and professional associations, and may entail some empirical research. The IEC Task Force will also examine other existing and potential roles for ethics committees, including education and institutional policymaking, and the ways in which these important functions can best be implemented in different institutional settings.

Acquired Immune Deficiency Syndrome (AIDS)

The need to respond effectively and sensitively to the AIDS crisis is strongly felt by the State of New Jersey and by the Commission. While important advances have been made in the care and treatment of patients with AIDS and AIDS-related conditions, the HIV virus continues to spread steadily.

New Jersey currently has the fourth largest number of reported cases of HIV infection, and the second highest rate of pediatric cases, of any state in the country.[1] Every county in New Jersey has facilities presently caring for AIDS patients, with the greatest concentration of patients being in the urban, northeastern part of the state. In 1989, the number of AIDS patients in New Jersey totalled nearly 6,000. An estimated additional 70,000 - 105,000 New Jerseyans have the HIV infection.[2] The New Jersey Department of Health predicts that by 1992, 25,000 cases of AIDS will have been diagnosed in the State.[3] Once considered a disease that primarily afflicts homosexuals or intravenous drug users, recent reports indicate that the HIV virus is beginning to spread to the general population, especially to heterosexual young adults.[4]

Sensitive to this crisis, and to the State Commissioner of Health's request that the Commission study the ethical and legal issues affecting patients afflicted with AIDS and AID-related conditions, the Commission has developed a working agenda for a Task Force on AIDS identifying issues of critical importance. The Commission plans to expand this Task Force, making it fully operational in the very near future. In order to address the many important issues confronting New Jersey in an orderly fashion, the AIDS Task Force will need to work cooperatively with government agencies and the health care community to extend and combine the collective resources and expertise among those in government and the private sector. This method will provide the State with a comprehensive and coordinated approach to the important legal, ethical, medical and societal issues which we confront in this area.

The nature and effects of the AIDS virus are such that its impact has social, legal, psychological, economic, and public health dimensions, requiring response on many levels. Certain features of AIDS combine in a way that compels consideration of a host of extremely significant issues at a policy level. These features include the high fatality rate of AIDS patients; the fact that the "high risk" groups are segments of the population which traditionally have been disfavored (namely, homosexuals, intravenous drug users, and prostitutes); the fact that transmission of the virus occurs primarily through private and consensual acts (sexual intercourse and intravenous drug abuse); the lengthy latency period often ensuing between time of exposure and manifestation of symptoms; the lack of any known "cure"; and the enormously high cost of caring for AIDS patients.

Among the many important policy issues raised by the AIDS crisis are patient testing, informed consent, confidentiality, insurance coverage, access to treatment and to experimental therapies, access to comprehensive residential care, protection against discrimination, and the economic impact combatting the disease will have on the total cost of health care. All of these and other issues need to be dealt with thoroughly and with sensitivity to ethical and legal considerations, if efforts to confront the disease are not to be tragically hampered.

The issue of testing for HIV infection has stirred controversy over a range of questions, including informed consent for HIV testing; mandatory screening of "high risk" groups, or of other selected sections of the population (*e.g.*, prison inmates, patients at sexually transmitted disease clinics, and hospital patients undergoing surgery); and the advantages and disadvantages of voluntary testing. A related yet distinct concern is what should be done with testing information; for example, to whom is there a duty to disclose an individual's HIV positive status? While privacy concerns are clearly very significant, situations may nevertheless arise where disclosure to third parties may be viewed as necessary to protect those parties from the risk of exposure to the virus. The Task Force will address, among other issues, in what, if any, circumstances it might be justifiable to disclose an individual's HIV test results without that individual's consent; what procedures should be adopted to ensure that appropriate confidentiality will be maintained; who may, or must, be notified if disclosure is justified, *e.g.*, a spouse, sexual partner, a sexual assault victim, mortician, or employers; and whether contact tracing should be mandated to monitor and protect against the spread of HIV infection.

A related issue is mandatory reporting. All states require reporting of AIDS cases (as defined by the Centers for Disease Control) to the health department, but many states do not require reporting of HIV-positive test results. While reporting of HIV status assists in achieving effective partner notification and contact tracing, it also raises concerns about potential breaches of confidentiality, and the possible chilling effect that a reporting requirement may have on voluntary testing. A top priority for the Task Force will be to study the scope and implementation of the AIDS reporting bill (S-3104) signed into law by Governor Kean on January 12, 1990.

The combined effect of a fatal and contagious disease primarily affecting groups which traditionally have met with some hostility in our society, and which disproportionately

affects racial minorities,[5] means that special efforts are needed to address the potential for discrimination against HIV-positive individuals. The Task Force will consider whether the current state of the law in New Jersey is sufficiently protective of HIV-infected individuals and their families. A further question arises as to whether New Jersey should extend existing legislation, or whether it should enact new anti-discrimination legislation specifically addressing AIDS.

AIDS is an illness which calls for a comprehensive and integrated system of services, operating on a number of levels. Special attention needs to be focused on services available for children with AIDS. Also, in some cases entire families are AIDS patients, and require a coordinated network of services which can respond to the needs of the family as a whole. The Task Force plans to survey the services currently available in New Jersey in order to assess the need for additional care, treatment, support, and preventative services.

As a general principle, health care professionals have an ethical obligation to provide competent, compassionate, and respectful treatment to patients with AIDS and AIDS-related conditions. Yet, the risk of infection, such as through needle stick or exposure to blood during surgery, has raised questions regarding the circumstances, if any, in which physicians or nurses may refuse to treat and elect to withdraw from the patient's case. Although health care facilities follow "universal precautions" as set forth by the Centers for Disease Control, in rare cases health care professionals have become infected in the course of patient care. Thus, the scope of the health care professional's duty to treat presents an important issue in the delivery of treatment and care for AIDS patients. The Task Force will need to address what policies should be followed by health care institutions in this regard.

The cost of the AIDS epidemic is staggeringly high. Because such a high proportion of New Jersey's AIDS population are intravenous drug users, many of whom are indigent, almost 65% of the cost will be borne by the public (through Medicare, Medicaid, and the Uncompensated Care Trust Fund).[6] The Task Force plans to study potential ways to respond to this financial burden, as well as ways in which expensive resources, such as the therapeutic drug azidothymidine (AZT), can best be allocated.

Dissemination of information to the general public regarding prevention of transmission of the virus is clearly of critical importance. In addition, health care professionals may require educational and counselling programs that respond to their specific needs. The Task Force will examine, in conjunction with the Commission's Task Force on Public and Professional Education, ways in which educational objectives regarding AIDS may best be pursued.

Protecting Vulnerable Patients

The New Jersey Supreme Court has been among the nation's most active in addressing treatment decisions for incompetent and otherwise vulnerable patients, and has created a multifaceted legal framework for resolving these cases. The Commission decided early in its history to focus its initial efforts on two projects where the prospects for legislative consideration

and favorable action seemed especially promising: the declaration of death and advance directives for health care. (The Commission's work in these areas is discussed in Parts Two and Three of the report.) This approach was predicated on the belief that progress in these areas was both important in its own right and would provide a necessary and appropriate foundation for confronting the still more difficult questions of ethics, law and policy posed by incompetent patients who have never stated their treatment preferences in writing.

Recent surveys suggest that approximately 85% of New Jersey's citizens have not expressed their future health care wishes by writing an advance directive. While favorable legislative action on the proposed Advance Directives for Health Care Act and the continuing educational efforts of the Commission and others in New Jersey's health care community are expected to increase significantly the number of persons who plan ahead for their health care needs, the number of persons who have not done so will still remain substantial. When the patient's clearly expressed wishes no longer present a firm basis for a treatment decision, those responsible for deciding on the patient's behalf are confronted with complex issues involving evaluation of the patient's best interests, and the respective roles of family members, committees, state agencies and the courts in decisionmaking. The care of particular patient groups, such as those with mental retardation and those without close and caring family members, as well as patients in particular institutional settings, raises issues warranting special attention. Current law, in New Jersey and elsewhere, leaves many important questions and concerns unanswered.

The Commission is strongly committed to exploring the issues presented by the care of this large and diverse patient population, and plans to expand and make operational its Task Force on Protecting Vulnerable Patients (the PVP Task Force) to include a panel of experts. During this past year Commission staff and consultants have developed several memoranda setting forth an agenda for the PVP Task Force, and have reviewed the relevant court decisions in New Jersey and other jurisdictions in addition to relevant bioethical literature. This Task Force's work will complement the efforts of the Commission's Task Force on Institutional Ethics Committees.

The PVP Task Force will address, as its first priority, issues surrounding life-sustaining treatment decisions for incompetent patients who have not previously expressed their treatment preferences, including incompetent patients who have not executed advance directives, and patients who have never been competent. The Task Force will examine both substantive principles for decisionmaking and the roles of family members, physicians and other health care professionals, institutional authorities, and others, in health care decisionmaking for such patients. Of particular concern here is decisionmaking for incompetent institutionalized patients who lack close and caring family members. Among the topics to be considered by the Task Force are: identifying particular groups within the total patient population in need of special attention and possibly special protection; identifying treatment issues and contexts that warrant close scrutiny; determining the decisionmaking capacity of adult patients who are receiving care in institutional settings; defining appropriate substantive standards for decisionmaking, including the appropriate scope, if any, for "quality of life" considerations; determining the appropriate decisionmaker; and determining appropriate procedural safeguards for decisionmaking. The PVP

Task Force will also consider whether and how features of the Commission's approach to advance directives for health care can and should be applied to previously competent patients residing in state institutions, and where special protections or modifications to that general approach may be necessary and appropriate in such settings.

In addition to this work, the Task Force hopes to address a number of other issues in coming years, including the implementation of the "Baby Doe" procedures for imperiled newborns, the consequences of the *Grady* decision and existing statutory provisions governing nonconsensual sterilizations (see Part Four of the report), and the refusal of non-life-sustaining treatments by patients with impaired decisionmaking capacity.

Public and Professional Education

The Commission is committed to increasing the understanding of bioethical issues among health care professionals, government officials and the public at large. If Commission recommendations are to influence the nature of health care, effective education for the lay public and professionals will be increasingly important. The Task Force on Public and Professional Education (the PPE Task Force) was established for this purpose. Its work has a dual relationship to the work of the Commission and the other Task Forces. Its agenda is aimed at providing education and information concerning the Commission's recommendations to the health care community and the public to assist them in better understanding their rights and responsibilities, and to increase awareness of bioethical issues within the various communities the Commission serves. To this end, the PPE Task Force will develop ways to introduce the regular study of bioethics into public and professional educational programs.

The professions touched by the concerns addressed by the Commission are extremely diverse. The Commission's recommendations have an impact on those directly responsible for the physical and emotional care of patients, such as physicians and nurses, social workers, the clergy and the family. In addition to those providing direct services and support, the Commission's work is important for administrators of health care institutions, attorneys, policymakers and educators. Each of these professions brings a different set of skills, responsibilities and concerns to the field of health care. In situations where ethical considerations become paramount these differences can be highlighted, increasing the possibilities for conflict. Task Force efforts in these contexts are aimed at helping to reduce the misunderstandings and disagreements that can frequently beset parties when difficult questions of law, medicine and ethics need to be resolved. As ethical questions cut across disciplines and professions, the PPE Task Force has a responsibility to address particular educational needs and interests while encouraging trust and communication among diverse professional groups.

The Task Force's agenda for the future is reflected in several projects which are now being completed and in those planned for the coming year. The expanded PPE Task Force will soon complete a booklet on understanding and executing an advance directive. If sufficient funds are available, the Commission anticipates the publication and distribution of this booklet to the public and health care community. Additional educational activities would include developing

programs to assist professionals in counseling individuals and in helping them to understand and complete advance directives; providing information to the public and health care providers concerning their responsibilities in making decisions about life-sustaining measures; and providing information to health care providers regarding the determination of brain death and their obligations to families. The Task Force will also be responsible, along with the IEC Task Force, for implementing the Commission's pilot project concerning the establishment of multi-institutional bioethics consultation committees available to health care institutions throughout the state.

New Reproductive Practices

As described in Part Five of the report, the full Commission has approved recommendations developed by the Task Force on New Reproductive Practices (the NRP Task Force) which would severely restrict if not eliminate altogether the practice of commercial surrogacy and discourage non-commercial surrogacy in the State of New Jersey. There remain a number of issues which the Task Force expects to resolve in the near future. Among the remaining issues identified for final deliberation and resolution by the Task Force are the nature of the penalties to be imposed on participants in a commercial surrogacy arrangement; the potential legal liability, if any, of intermediaries or professionals, such as attorneys, psychologists, and physicians, who provide professional services in connection with non-commercial surrogacy arrangements; the calculation of the length of a waiting period, if any, during which the custodial presumption in favor of the birth mother may operate; and the extent to which there might be qualifications to the principle that contractual undertakings regarding medical and lifestyle restrictions upon a so-called "surrogate" are invalid and unenforceable. The NRP Task Force expects to transmit its completed recommendations and accompanying report to the full Commission in the Spring of 1990, prior to transmittal of the report and recommendations to the Governor and the egislature.

Following completion of its work on surrogacy, the Task Force on New Reproductive Practices will turn its attention to a range of more "high tech" reproductive practices, some of which are already in use, and some of which are visible on the horizon. The Task Force also plans to review existing law and experience with A.I.D., which constitutes one of the oldest of the "new" reproductive practices.

The Task Force's examination of A.I.D. will include an analysis of the legal framework in which A.I.D. operates, the medical and psychological screening, and the psycho-social impact of A.I.D. on the parties involved, including the child born of the arrangement. As A.I.D. is one of the best established of the "new" reproductive practices, it provides an illustration of how some of the novel legal and ethical issues that have potential relevance for other new reproductive practices may be confronted and resolved. In this way, the lessons of A.I.D. may prove useful in shaping policy about the kind of framework the State wishes to establish for the newer reproductive technologies. Moreover, the social and legal response to surrogacy that has been developed by the Task Force may inform, and perhaps reshape, some of the State's thinking about donor insemination. Thus, in its subsequent work on new reproductive practices, the Task Force will look back at A.I.D., as well as forward to other,

more technologically sophisticated, forms of assisted reproduction.

In its future study of reproductive technologies currently in use, the Task Force plans to consider *in vitro* fertilization followed by embryo transfer, *in vivo* fertilization followed by lavage, gamete intra-fallopian transfer, and cryopreservation of sperm and embryos. Each of these possibilities raises significant legal, ethical, and social issues which deserve serious attention on a continuing basis by the Task Force and by the Commission. The recent case of *Davis v. Davis* [7] in Tennessee, involving the fate of seven frozen embryos in the aftermath of a divorce between the potential mother and father, with disagreement between the parties as to the appropriate disposition of the embryos, illustrates some of the complex questions that need to be addressed. Careful study of such issues may allow government to anticipate the challenges posed by advances in reproductive and genetic technologies, and to respond to them with intelligence and foresight, rather than being forced to react after the fact.

Conclusion

The support provided to the New Jersey Bioethics Commission by the Legislature, Governor, health care professionals and citizens throughout the past several years has assisted the Commission in making significant inroads in fulfilling major elements of its original legislative mandate. The legislature believed that sound solutions to difficult bioethical problems required the support of a cross section of New Jersey's citizenry. To this end the Legislature created a Commission whose membership would reflect the values and concerns of diverse perspectives, interests, concerns and professions. Among its members are physicians, nurses, social workers, concerned citizens, attorneys, hospital and nursing home administrators, government administrators, legislators and members of the clergy. The Commission's deliberations are shaped by this diversity, and its proposals are the result of a unique blend of the theoretical and practical.

Over the past several years, the Commission has become enmeshed in the web of institutions, public and private, which contribute to the making of public policy in New Jersey. The Commission has assumed a role which enables it to work cooperatively with both institutions and individuals, and has become a place where differences of belief, professional obligations and interests can be expressed, defended, studied and treated respectfully and thoroughly. The achievements of the Commission would not have been possible without the thoughtful participation of the efforts of a broad range of individuals. As this description of the Commission's future agenda indicates, there is much that remains to be accomplished. All Commissioners look forward to continuing to work with all interested government agencies, professional groups, and citizens in fulfilling the duties and responsibilities eloquently set forth by the Legislature when it originally created the Commission in 1985.

Notes

1. Presentation by Dr. Molly Joel Coye, New Jersey State Commissioner of Health, to the New Jersey Bioethics Commission on November 30, 1988.

2. *AIDS: A Report. The Human Immunodeficiency Virus Epidemic in New Jersey*, p.i. Dr. Molly Joel Coye, State Commissioner of Health, March, 1989.

3. Id.

4. 40% of the people with AIDS in New Jersey are heterosexual drug users -- this constitutes almost triple the national average of 14.7%. *Id.* The total percentage of intravenous drug user cases of AIDS, which includes the drug users, their sexual partners, their children, and the children of their sexual partners, amounts to 60% in New Jersey, as compared with 30% throughout the country. Presentation by Dr. Molly Coye, *supra*, note 1.

20% of New Jersey's AIDS cases are among individuals in their 20's. *Supra*, note 2, p. iii. Approximately 70% of all AIDS cases reported in New Jersey are among patients 25-44 years old. *Id.* p. 17.

5. *supra*, note 1, p. 3.

6. *supra*, note 1, p. 20.

7. 15 Fam. L. Rep. 2097 (1989).

Appendices

P. L. 1985, CHAPTER 363, *approved November 12, 1985*

1985 Assembly No. 3316 (*Second Official Copy Reprint*)

AN ACT creating a *permanent* commission to study legal and ethical problems in the delivery of health care, and making an appropriation.

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

1. The Legislature finds and declares that:

a. New Jersey is a national leader in addressing the legal and ethical dilemmas in the delivery of health care posed by modern advances in science and medicine. In keeping with this leadership responsibility and the principles enunciated by the New Jersey Supreme Court in its landmark decisions in the *Quinlan, Grady* and *Conroy* cases, the Legislature seeks, through the establishment of the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care to provide a comprehensive and scholarly examination of the impact of advancing technology on health care decisions. The work of this commission will enable government, professionals in the fields of medicine, allied health care, law, and science, and the citizens of New Jersey and other states to better understand the issues presented, their responsibilities, and the options available to them.

b. Attention must be paid to ways of facilitating appropriate decision making regarding the termination or refusal of life-sustaining and other forms of care and treatment. Particular attention must be given to how decisions are to be made on behalf of incompetent persons in a variety of residential settings. An appropriate balance must be struck between the need to foster this decision making and the need to protect persons with severe disabilities from the abuses of arbitrary decision making.

c. There is a need to explore and encourage the development of innovative programs, such as hospices and homemaker services which are designed to make the final days of terminally ill persons more comfortable, dignified, and humane.

EXPLANATION—Matter enclosed in bold-faced brackets [thus] in the above bill is not enacted and is intended to be omitted in the law.

Matter printed in italics thus is new matter.

Matter enclosed in asterisks or stars has been adopted as follows:

*—Assembly committee amendments adopted April 15, 1985.

**—Senate committee amendments adopted June 17, 1985.

2. There is created a **permanent** commission to be known as the "New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care." The commission shall consist of *[17]* **[*25*]** ***27*** members to be appointed as follows: the *[Commissioner of]* **[*Ombudsman for the Institutionalized Elderly in*]** ***Commissioner of*** the Department of Community Affairs, the Commissioner of the Department of Health, the Commissioner of the Department of Human Services, the Public Advocate, ***the Ombudsman for the Institutionalized Elderly*** or their designees; two members of the Senate, to be appointed by the President of the Senate, not more than one of whom shall be of the same political party; two members of the General Assembly, to be appointed by the Speaker of the General Assembly, not more than one of whom shall be of the same political party; nine public members, two to be appointed by the President of the Senate: two to be appointed by the Speaker of the General Assembly and five to be appointed by the Governor, who are distinguished in one or more of the fields of medicine, health care and health administration, law, ethics, theology, the natural sciences, the social sciences, the humanities, and public affairs.

In addition to the nine public members described above, there shall be on the commission five other public members who shall not be from health-related disciplines nor from the immediate families of persons in health-related disciplines. Of these five members, three shall be appointed by the Governor, one by the President of the Senate, and one by the Speaker of the General Assembly. In appointing these members an effort shall be made to insure that diverse viewpoints are represented on the commission.

*Also on the commission shall be a representative of the New Jersey Hospital Association, a representative of the New Jersey State Nurses' Association, **[and]** a representative of the New Jersey Association of Health Care Facilities **and a representative of the New Jersey Association of Nonprofit Homes for the Aging, Inc.***. These representatives shall be selected by their organizations.*

Members of the commission shall serve for three-year terms or

*until a successor is appointed. However, the term of every member initially appointed shall expire on December 31, 1988.**

Vacancies in the membership of the commission shall be filled in the same manner as original appointments were made*, *and the term of any person reappointed or appointed to fill a vacancy shall only run for the balance of the three-year term that had commenced when the reappointment was made or the vacancy occurred**. *[Members shall continue to serve until their successors are appointed.]* Members shall serve without compensation but shall be reimbursed for the reasonable **travel and other out-of-pocket** expenses incurred in the performance of their duties.

3. It shall be the duty of the commission to:

a. Clarify the issues posed by a rapidly developing health and science technology and highlight the facts that appear to be most relevant for informed decision making by persons as it relates to their care and treatment;

b. Gather data about how New Jersey and other jurisdictions handle decision making regarding the termination and refusal of care and treatment;

c. Assess the need for additional programs and services relating to medical decision making;

d. Suggest improvements in public policy relating to medical treatment at various levels, not exclusively at the level of State government, and through various means including legislation;

e. Through its reports, offer guidance for people involved in making decisions, though not dictate particular choices on moral grounds.

4. The *[commission shall organize as soon after the appointment of its members as is practicable. The commission shall elect a chairman from among its members]* **organizational meeting of the commission shall be held on the 60th day after the effective date of this act at a time and place to be designated by the Governor. The Governor or his designee shall give at least 10 days' notice of this meeting. A majority of those appointed to the commission shall elect a chairperson from among its members** and shall appoint a full-time executive director. The executive director shall serve at the pleasure of the commission and shall be a person qualified by training and experience to perform the duties of the office.

5. a. For purposes of gathering information and the views of interested parties, the commission shall hold public hearings. The commission may establish ad hoc panels comprised of physicians, health care providers and administrators or other persons with relevant backgrounds to assist with information gathering and

analysis of complex issues. Panel members shall serve without compensation but shall be reimbursed for the reasonable **travel and out-of**-**pocket** expenses incurred in the performance of their duties.

b. The commission shall be entitled to call to its assistance and avail itself of the services of 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, and to employ counsel and stenographic and clerical assistants and incur traveling and other miscellaneous expenses as it may deem necessary, in order to perform its duties, and as may be within the limits of funds appropriated or otherwise made available to it for its purposes.

6. The commission shall *[submit a final report to the Governor, Legislature and public within 36 months of the commission's organization. The commission may submit interim reports as it deems desirable. The final report shall include:]* ***make its report to the Governor, Legislature and public on December 31, 1988 and every three years thereafter. The commission may submit interim reports as it deems desirable. The initial report and each report submitted at three-year intervals shall include:***

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;

c. An examination of the use in **this State and** other states of advance directives, such as living wills, durable powers of attorney, and a determination of the approach best suited for New Jersey.* *For example, in this examination, especially with regard to legislation enacted in this State, the commission shall review whether the legislation enacted has reduced the number of applications to the court; whether it has encouraged a better dialogue between hospital administrations, hospital physicians' committees, physicians, and patients' families; whether it has promoted the preservation of life; whether the potential conflicting religious issues have been addressed; whether, consistent with the preservation of life, organ donor programs have been promoted; and whether it has reduced needless suffering for the terminally ill**:

d. An identification of issues still in need of resolution in the aftermath of *Conroy* and a recommendation of a legislative solution, if necessary;

e. An examination of areas of special need, concerning persons with disabilities and a determination of what additional safeguards are required. Particular attention shall be given to the delivery of care to seriously disabled newborns and the implementation of federal legislative requirements in this area;

f. An exploration of related issues, such as the determination of death for the purpose of an organ transplant, and the value of hospices as an alternative to hospital care.

Accompanying the *[report]* **reports***, the commission shall submit any proposed legislation which it may desire to recommend for enactment.

7. There is appropriated to the commission from the General Fund the sum of $95,000.00 to effectuate the purposes of this act.

8. This act shall take effect immediately.

Table 1 (a)

Commissioners
(Periods of Service)

Daniel F. O'Connell, Esq., Chairman
(April, 1986 to Present)

Paul W. Armstrong, Esq., Vice-Chairman
(April, 1986 to Present)

William R. Abrams, Esq.,
Ombudsman for the Institutionalized Elderly
(April, 1989 to Present)

Senator Gabriel M. Ambrosio
(March, 1988 to Present)

Rabbi Shmuel Blech
(April, 1986 to Present)

Sr. Jane Frances Brady
(April, 1986 to Present)

Assemblywoman Stephanie Bush
(March, 1988 to Present)

Senator Gerald Cardinale
(April, 1986 to Present)

Senator Richard J. Codey
(April, 1986 to January, 1988)

Diana Czerepuszko, L.N.H.A.
(April, 1988 to Present)

Jack R. D'Ambrosio, Esq.
Ombudsman for the Institutionalized Elderly
(April, 1986 to April, 1988)

Robert W. Deaton
(December, 1987 to Present)

Assemblyman Thomas Deverin
(April, 1986 to September, 1986)

David Eckstein, M.D.*
(April, 1986 to June, 1987)

Martin Epstein, M.D.,
representing the Commissioner of Human Services
(September, 1986 to November, 1987)

Joseph Fennelly, M.D.
(April, 1986 to Present)

Robert Fischer, D.D.S.
representing the Commissioner of Human Services
(September, 1988 to December, 1988)

Franklyn Gerard, M.D.
(April, 1986 to April, 1988)

Donald L. Gilmore
(April, 1986 to November, 1987)

J. Richard Goldstein, M.D.
(September, 1989 to Present)

Rev. Robert E. Harahan
(April, 1986 to December, 1988)

Noreen Haveron, R.N.
(April, 1986 to Present)

Assemblyman C. Richard Kamin
(November, 1986 to Present)

Rabbi Charles A. Kroloff
(April, 1989 to Present)

Paul Langevin
representing the Commissioner of Health
(December, 1987 to Present)

Mary K. Lindner, R.N.
(April, 1986 to Present)

Rev. Ernest S. Lyght
(April, 1988 to January, 1989)

Rita Martin
(December, 1987 to Present)

Elmer Matthews, Esq.
(April, 1986 to November, 1988)

Russell I. McIntyre, Th.D.
(March, 1990 to Present)

Rev. Marvin McMickle
(April, 1986 to September, 1986)

Sarah Mitchell, Esq.
representing the Public Advocate
(September, 1989 to Present)

*Deceased.

Lois Mulcahy, R.N.
(April, 1986 to May, 1988)

Patricia Ann Murphy, R.N., Ph.D.
(April, 1986 to Present)

Dr. Michael Nevins
(April, 1986 to December, 1988)

Anne Perone, Esq.
(April, 1989 to Present)

Hector Rodriguez, Esq.
Ombudsman for the Institutionalized Elderly
(April, 1988 to January, 1989)

David Rogoff
(February, 1989 to Present)

Linda Rosenzweig, Esq.
representing the Public Advocate
(April, 1986 to September, 1989)

John H. Rutledge, M.D., J.D.*
representing the Commissioner of Health
(April, 1986 to November, 1987)

William I. Strasser, Esq.
(April, 1986 to December, 1988)

Mary S. Strong
(April, 1986 to Present)

Edward Tetelman, Esq.,
representing the Commissioner of Human Services
(February, 1989 to Present)

Harris S. Vernick, M.D.
(January, 1990 to Present)

Ann Zahora
representing the Commissioner of Community Affairs
(April, 1986 to Present)

*Deceased.

Table 1 (b)
Commissioners

Daniel F. O'Connell, Esq., Chairman, is a partner in the law firm of Shanley and Fisher. Mr. O'Connell is counsel to Somerset Medical Center, the Morristown Memorial Hospital medical staff and the Morris County Medical Society. He was formerly a partner at Lanigan and O'Connell. He is a graduate of Villanova University and the Rutgers University School of Law.

Paul W. Armstrong, Esq., Vice-Chairman, served as counsel to the families of Karen Ann Quinlan and Nancy Ellen Jobes before the Supreme Court of New Jersey, and to the American Hospital Association, as Amicus Curiae, before the United States Supreme Court in the case of Nancy Beth Cruzan. He is a widely published author holding an M.A. in history from the University of Dayton, a J.D. from the University of Notre Dame, and an LL.M. from New York University School of Law. An Adjunct Professor at Rutgers Law School and Robert Wood Johnson Medical School, Mr. Armstrong was the recipient of the 1989 Citizen's Award of the Academy of Medicine of New Jersey and the 1990 Victoria Fellowship in Contemporary Issues at Rutgers University.

Rick Abrams, Esq., is New Jersey's **Acting Ombudsman for the Institutionalized Elderly.** Mr. Abrams' office is charged with protecting the rights and welfare of people over 60 years of age who reside in long-term care facilities within the State. A graduate of Seton Hall University School of Law, Mr. Abrams was formerly Assistant Counsel to Governor Thomas H. Kean.

Senator Gabriel M. Ambrosio, Esq., (D), Assistant Senate Majority Leader, has been a member of the New Jersey Legislature since March of 1987 and is a member of the Senate Judiciary Committee. An attorney in private practice, and counsel to the Passaic Valley Sewerage Commission, he received his B.A. from Rutgers University and his J.D. from Seton Hall University School of Law.

Rabbi Shmuel Blech, a scholar in ethics and biblical studies, was ordained in 1958 at the Rabbi Jacob Joseph Rabbinical Seminary in New York. After receiving the Advanced Rabbinic degree at Beth Medrash Gavoha, he remained there as a fellow. He has subsequently served as Scholar-in-Residence at the Rabbi Aaron Kotler Institute.

Sr. Jane Frances Brady, M.S., M.B.A., representing the **New Jersey Hospital Association,** is President and Chief Executive Officer of St. Joseph's Hospital and Medical Center. A Board of Directors member and Trustee of many leading health care organizations, and past President of the New Jersey Conference of Catholic Health Care Facilities, she received her M.B.A. from Seton Hall University and her M.S. in Hospital Administration from Columbia University.

Assemblywoman Stephanie R. Bush, Esq., (D), is a member of the Assembly Financial Institutions and Senior Citizens Committees. She is a practicing attorney in East Orange. President of the Association of Black Women Lawyers of New Jersey, she received her B.A. from Cornell University and her J.D. from American University Law School.

Senator Gerald Cardinale, D.D.S., (R), has served in the New Jersey Legislature since 1980 and is a member of the Labor, Industry, and Professions Committee, a Board of Trustee member for Dumont Mental Health Center, and has established several community programs for the elderly. Following receipt of his D.D.S. at New York University College of Dentistry, he served as Assistant Professor at Columbia University.

Diana Czerepuszko, R. N., L.N.H.A., representing the **New Jersey Association of Health Care Facilities,** is Administrator at the Delaire Nursing & Convalescent Center in Linden. A graduate in nursing of Trenton State College, she has 20 years experience in acute and long term health care and has held positions from staff nurse to Nursing Director. She has participated in numerous committees and made presentations regarding the care of the elderly.

Robert Deaton, is Director of Long Term Care for the Diocese of Camden, and represents the **New Jersey Association of Non-Profit Homes for the Aging, Inc.** Currently responsible for the administration of the Diocese's four skilled nursing facilities, he previously served as Director of Finance for the Diocese of Camden. Mr. Deaton is a graduate of Rutgers University with a major in Accounting.

Joseph Fennelly, M.D., is Vice-Chairman of both the New Jersey Medical Society's Committee on Biomedical Ethics and the Citizens Committee on Biomedical Ethics. He is the Medical Director of the King James Nursing Home and also chairs ethics committees at King James and Morristown Memorial Hospital. He has participated in numerous panels and programs in bioethics.

J. Richard Goldstein, M.D., is President of Stopwatch, Inc., a health care firm dealing primarily with AIDS patients. From 1983 to 1986, Dr. Goldstein was New Jersey's Commissioner of Health and Chairman of the Health Care Facilities Financing Authority. Prior to his service as Commissioner, Dr. Goldstein was president of a health planning consulting firm. He received his M.D. from the Ohio State University College of Medicine and an M.A. from Harvard University.

Noreen Haveron, R.N., B.S.N., is Acting Nursing Supervisor of the Nutley Nursing Service. She was formerly a Public Health Staff Nurse and Hospice Coordinator at Nutley, in addition to holding staff nurse positions at various hospitals. Ms. Haveron received her B.S.N. from Thomas A. Edison State College.

Assemblyman C. Richard Kamin, (R), a member of the Joint Appropriations Committee, is Vice President of a financial publishing firm. He has served as President of Mt. Olive Township Council and Chairman of the Township Board of Health. He is a graduate of Temple University, where he majored in business and economics.

Rabbi Charles Kroloff, is a graduate of Yale University and Hebrew Union College and has been the Rabbi of Temple Emanu-El since 1966. He is an adjunct lecturer in Pastoral Counseling and Jewish Theology at Hebrew Union College and is a clinical member of the American Association of Marriage and Family Therapists.

Paul R. Langevin, B.S., M.A., Assistant Commissioner for Health Facilities Evaluation, representing the **Commissioner of Health,** directs the licensure and inspection process for nearly 1,000 health care facilities regulated by the Department of Health. Mr. Langevin received his B.S. from Rutgers University and his M.A. from Rider College.

Mary K. Lindner, R.N., M.A., is Senior Vice President, Patient Services and Executive Director of Nursing at Overlook Hospital. She is a member of the Council on Professional Practices of the New Jersey Hospital Association and is on the advisory board of the Citizens Committee on Biomedical Ethics. She holds a B.S. in nursing from Skidmore College and an M.A. in human development from Fairleigh Dickinson University.

Rita Martin is Legislative Director for Citizens Concerned for Life - NJ and a past President of the NJ Right to Life Committee. Ms. Martin is also a member of the NJ Hospice Organization. She attended St. Joseph's College and Temple University in Philadelphia.

Russell L. McIntyre, Th.D., is an Associate Professor of Medical Ethics at the University of Medicine and Dentistry of New Jersey-Robert Wood Johnson Medical School. Dr. McIntyre is also the Director of Programs in Medical Humanities for the medical school. A graduate of Wagner College, he received a divinity degree from the Lutheran Theological Seminary at Philadelphia and two Masters Degrees from Wittenberg University. He received a Doctorate in Ethics from the University of Toronto and was a Fellow in Medical Ethics at Harvard Medical School. Dr. McIntyre is the Editor of INFO TRENDS: MEDICINE, LAW AND ETHICS.

Sarah Mitchell, Esq., representing the **Public Advocate,** is Director of the Division of Advocacy for the Developmentally Disabled, with overall responsibility for New Jersey's federally designated protection and advocacy program for the developmentally disabled and Client Assistance Program. Formerly Assistant Dean at Rutgers University School of Law, and an Associate at Dechert Price and Rhoads, Ms. Mitchell has lectured widely on disability rights and issues. A graduate of the University of Pennsylvania, she received her Masters Degree in Social Work at the University of Michigan and her J.D. at the University of Pennsylvania Law School.

Patricia Ann Murphy, R.N., Ph.D., represents the **New Jersey State Nurses Association.** She is an Associate Professor of Nursing and Clinical Assistant Professor of Surgery at the University of Medicine and Dentistry (UMDNJ). Her practice is as a Clinical Specialist in Bereavement at UMDNJ-University Hospital in Newark, New Jersey. She lectures widely on both bereavement and health care ethics.

Anne Perone, Esq., is a graduate of Rutgers University and received her J.D. from Seton Hall University School of Law in Newark. Ms. Perone practices law in North Plainfield, and was formerly Counsel to the New Jersey Right to Life Committee.

David Rogoff, M.S., is Director of the Haven, a hospice program at the John F. Kennedy Medical Center in Edison, and a member of the hospital's Ethics Committee. Trained as a psychologist and psychotherapist, Mr. Rogoff is a Phi Beta Kappa graduate of Rutgers University.

Mary S. Strong, is one of the founders of The Citizens' Committee on Biomedical Ethics and currently serves as its Chair. She was formerly Executive Director of the Schultz Foundation and continues to serve as a consultant, as well as an Advisor to the New Jersey Hospice Association. In addition, Ms. Strong has served as Chair of the New Jersey Task Force on Transplant Organ Retrieval, and as a member of the Planning Committee and Hospice Committee of Overlook Hospital, the Summit Commission on Drug Abuse, and the Board of Trustees of Visiting Nurse-Home Health Care Services. Mrs. Strong was the recipient of the 1988 Citizen's Award of the Academy of Medicine of New Jersey.

Edward H. Tetelman, Esq., representing the **Commissioner of Human Services,** is Assistant Commissioner for Intergovernmental Affairs. A former employee of the N. J. Department of the Public Advocate, where he specialized in health care issues, particularly access to health care for low and middle income persons, Mr. Tetelman received his J.D. at Case Western Reserve School of Law.

Harris S. Vernick, M.D., is a specialist in internal medicine, with a private practice in Westfield. He received his medical degree from Hahnemann Medical College in Philadelphia.

Ann Zahora, representing the **Commissioner of Community Affairs,** is Director of the Division on Aging. She also chairs the State Interdepartmental Committee on Aging established in 1984 by Governor Kean. Previously, she was Director of the Cape May County Office on Aging for 17 years. **Theresa Dietrich** attends Commission meetings for Mrs. Zahora.

Table 2 (a)
Staff

Robert S. Olick, Esq., Acting Executive Director, is a masters candidate currently enrolled in the doctoral program at Georgetown University and the Kennedy Institute of Ethics. Mr. Olick received his B.A. from Colgate University and his J.D. from the Duke University School of Law. He joined the staff in August of 1987, having formerly practiced law in Washington, D.C. Mr. Olick, who previously served as the Commission's Assistant Director, has served as Acting Executive Director since December of 1989. He is the Project Director for the Commission's first comprehensive report entitled *Problems and Approaches in Health Care Decisionmaking: The New Jersey Experience*, and has had primary responsibility for the Commission's work in the areas of death and dying.

Adrienne Asch, M.S., Associate in Social Science and Policy, is currently a doctoral candidate at Columbia University. Formerly a Senior Human Rights Specialist for the New York State Division of Human Rights, she joined the Commission in September of 1987. Ms. Asch is Project Co-Director for the Commission's Task Force on New Reproductive Practices and also serves as Project Co-Director for the Task Force on Protecting Vulnerable Patients. A graduate of Swarthmore College, Ms. Asch received her M.S. from the Columbia University School of Social Work in Community Organization and Planning.

Janice M. Chiantese, Director, Government Relations, is one of the Commission's first employees, joining the staff in August of 1986. In addition to her duties as Director of Government Relations, she serves as Project Co-Director of the Task Force on Public and Professional Education. Ms. Chiantese, formerly Executive Assistant to the New Jersey State Commissioner of Health, is currently a B.A. candidate at Rutgers University.

Ellen Friedland, Esq., Consultant, has been a member of the staff since October 1988. Her primary responsibilities have been focused on the Task Force on Protecting Vulnerable Patients, with particular emphasis on the "Baby Doe" and Grady issues. Prior to joining the Commission, Ms. Friedland was a partner at Berkowitz and Friedland. She received her B.A. from Brandeis University and her J.D. from Cardozo School of Law, Yeshiva University.

Anne C. Reichman, LL.B., LL.M., Associate in Law, joined the staff in February of 1988 and serves as Project Co-Director of the Task Force on New Reproductive Practices. Ms. Reichman received her Masters degree in Law from Yale University, and her LL.B. and B.A. from Monash University in Australia. She is currently a doctoral candidate at Yale Law School, writing in the area of reproductive technologies. She was a Bigelow Fellow and Lecturer in Law at the University of Chicago Law School, and will be assuming an appointment as an Assistant Professor at the University of Pittsburgh Law School in the fall of 1990.

Eve Sundelson, Esq., Consultant, has served with the Commission since September of 1988 in connection with its work on death and dying, principally with respect to institutional ethics committees. Ms. Sundelson serves as Project Co-Director of the Task Force on Insitutional Ethics Committees. Formerly an attorney at Davis Polk & Wardwell in New York City, she is a graduate of Yale College (*summa cum laude*, Phi Beta Kappa) and Harvard Law School.

Michael Vollen, M.A., Associate Director (Administration and Public Affairs), was formerly associated with The New School in New York City as a member of the faculty and Associate Dean of both Undergraduate and Adult Education. Mr. Vollen, who joined the staff in November of 1987, is responsible for the general administration of the Commission, including budget preparation and oversight. Mr. Vollen serves as the Commission's Public Information Officer and as Project Co-Director of the Task Force on Public and Professional Education.

Elizabeth Manousos, Secretary, is a graduate of Princeton High School and the Career Training Institute of Mercer County Community College, and has worked for several years as a secretary and word processor. Ms. Manousos joined the staff in September of 1988.

Table 2 (b)
Former Staff

EXECUTIVE DIRECTOR

The Commission's first Executive Director, **Constance A. Myers** served from April of 1986 to October of 1986. Ms. Myers was formerly an aide to Assemblyman Weidel, an early member of the Commission.

Herbert Hinkle, Esq., a former official in the New Jersey Public Advocate's Office, and a practicing attorney in Lawrenceville, served as Interim Acting Director of the Commission from November of 1986 until February of 1987.

Alan J. Weisbard, Esq., formerly Associate Professor of Law at Benjamin N. Cardozo School of Law, Yeshiva University, served as Executive Director of the Commission from July 1, 1987 through February 1, 1990.

STAFF

Donna Horak Mitsock, a doctoral candidate at Georgetown University's Kennedy Institute of Ethics, served as **Associate in Ethics** from September of 1986 to October of 1987.

Jessica Raymond served as the Commission's secretary from September of 1987 to July of 1989.

Theresa San Juan, served as the Commission's part-time secretary from September of 1989 through March of 1990.

Table 2(c)
Student Interns

Moshe Levy Yale University	June, July, 1989
Brenda Mears Rutgers Law School, Camden	September, 1989 - May, 1990
Daniel Newman Brown University	January, 1990 - February, 1990
Krista Robbins George Washington University	June - September, 1988 and 1989
Scott Styles Princeton University	September - December, 1989

Table 3 (a) 1

New Reproductive Practices Task Force Members

Commissioners

Paul W. Armstrong, Esq.
(Chair: September, 1989 to Present)
(Member: March, 1988 to Present)

Sr. Jane Frances Brady
(March, 1988 to Present)

The Hon. Stephanie R. Bush
(March, 1988 to Present)

Rev. Robert E. Harahan
(March, 1988 to December, 1988)

Mary K. Lindner, R.N.
(March, 1988 to Present)

Non-Commissioners

Dr. Emily Arnow Alman
(March, 1988 to Present)

Dr. David Brodzinsky
(March, 1988 to February, 1989)

Dr. Mary Gibson
(March, 1988 to Present)

Dr. Michael Grossman
(March, 1988 to Present)

Mary Sue Henifin, Esq.
(March, 1988 to Present)

Marcia Potter Katz
(March, 1988 to February, 1989)

Dr. Ruth Macklin
(March, 1988 to Present)

Dr. Artist Lesley Parker
(March, 1988 to August, 1989)

Dr. Steven E. Perkel
(March, 1988 to January, 1989)

Linda Rosenzweig, Esq.
(March, 1988 to September, 1989)
(former Commissioner and served as Task Force Chair from March, 1988 to September, 1989)

Professor Lee Silver
(March, 1988 to Present)

Dr. Nelson S. T. Thayer
(March, 1988 to May, 1989)

Dr. Gerson Weiss
(March, 1988 to Present)

Cecilia Zalkind, Esq.
(March, 1988 to Present)

Advisor
Professor Jay Katz
(March, 1988 to Present)

Table 3 (a) 2
Institutional Ethics Committees Task Force Members

Commissioners

Paul W. Armstrong, Esq., Co-Chair
(September, 1988 to Present)

William R. Abrams, Esq.
(April, 1989 to Present)

Diana Czerepuszko, L.N.H.A.
(September, 1988 to Present)

Robert W. Deaton
(September, 1988 to Present)

Joseph Fennelly, M.D.
(September, 1988 to Present)

Patricia Murphy, Ph.D., R.N.
(September, 1988 to Present)

Non-Commissioners

Flora Barlotta, M.D.
(September, 1988 to Present)

Rev. William J. Fallon
(September, 1988 to Present)

Leonard Fishman, Esq.
(February, 1989 to Present)

Janet Fleetwood, Ph.D.
(September, 1988 to Present)

John R. Heher, Esq.
(September, 1988 to Present)

James T. Holmes, Esq.
(February, 1989 to Present)

Betty Lou Miccio
(September, 1988 to Present)

Michael Nevins, M.D.
(September, 1988 to Present)
(former Commissioner and Task Force Co-Chair)

Robert Pickens, M.D.
(September, 1988 to Present)

Cathie Pignatello
(September, 1988 to Present)

David Price, Ph.D.
(September, 1988 to Present)

Hector Rodriguez, Esq.
(September, 1988 to January, 1989)

Mrs. Anne Somers
(September, 1988 to Present)

Cynthia J. Stolman, Ph.D.
(September, 1988 to Present)

William I. Strasser, Esq.
(September, 1988 to Present)

TABLE 3 (a) 3
Public and Professional Education Task Force Members

Commissioners

Mary S. Strong, Chair
(September, 1988 to Present)

Robert W. Deaton
(September, 1988 to Present)

Theresa Dietrich
(September, 1988 to Present)

Noreen Haveron
(September, 1988 to Present)

Rev. Ernest S. Lyght
(September, 1988 to December, 1988)

Rita Martin
(September, 1988 to Present)

Non-Commissioners

Rabbi Richard F. Address
(June, 1989 to Present)

Mr. Kenneth Dolan
(June, 1989 to Present)

Dr. Joseph C. d'Oronzio
(June, 1989 to Present)

Ms. Lois Forrest
(June, 1989 to Present)

Ms. Sheila Paris Klein
(June, 1989 to Present)

Mr. Michael Rappeport
(June, 1989 to Present)

Mrs. Ritamarie G. Rondum
(June, 1989 to Present)

Dr. Teresa Schaer
(June, 1989 to Present)

Dr. Marguerite K. Schlag
(June, 1989 to Present

Mr. Joseph Slavin
(June, 1989 to Present)

Ms. Helen Handin Spiro
(June, 1989 to Present)

Table 3 (b) 1

Task Force On New Reproductive Practices
Non-Commissioner Members

Emily Arnow Alman, J.D., Ph.D., is both an attorney, specializing in family law, and a sociologist. She is a member of the New Jersey Task Force on Gender Bias in the Courts, the Middlesex County Bar Association's Matrimonial and Women's Committees, and the Board of Middlesex County Legal Services. She is also Professor Emeritus of Sociology at Rutgers University. Dr. Alman received her J.D. from Rutgers Law School, her Ph.D. and M.A. from the New School for Social Research, and a B.A. from Hunter College. She has also produced several films, one of which won First Prize at the American Film Festival in 1984.

Mary Gibson, Ph.D., is Associate Professor of Philosophy at Rutgers University. A member of the American Philosophical Association, the Society for Philosophy and Public Affairs, and the Institute for Reserach on Women, Dr. Gibson's areas of special interest include social and political philosophy, philosophy and public policy, and philosophical issues in feminism. She has published articles on such contemporary issues as workers' rights, the link between morality and rationality, autonomy, informed consent, and risk. She received her B.A. from Hunter College and her Ph.D. from Princeton University.

Michael B. Grossman, D.O., is President of the New Jersey State Board of Medical Examiners and Associate Professor of Clinical Obstetrics and Gynecology at the UMDNJ-School of Osteopathic Medicine in Camden. He also serves as Medical Director of the Ambulatory Care Center at Kennedy Memorial Hospital-UMC in Stratford, New Jersey. Dr. Grossman received his B.A. from Rutgers University and his D.O. from the Philadelphia College of Osteopathic Medicine.

Mary Sue Henifin, J.D., M.P.H., is an attorney with special interests in public health and women's rights. She received her B.A. in Biology from Harvard, M.P.H. in Environmental Science from Columbia University's School of Public Health, and J.D. from Rutgers University School of Law (where she is now an Adjunct Professor). Currently Deputy Attorney General, Environmental Prosecutions Task Force, New Jersey Division of Criminal Justice, Ms. Henifin is a member of the Project on Reproductive Laws for the 1990s of the Rutgers University Institute for Research on Women, and has published widely on reproductive and environmental health issues.

Ruth Macklin, Ph.D., is Professor of Bioethics in the Department of Epidemiology and Social Medicine at Albert Einstein College of Medicine, in New York. Previously associate for behavioral studies at the Hastings Center, Dr. Macklin lectures widely on biomedical ethics, has served as a consultant to local and federal government agencies, and has authored numerous leading books and articles in this field. She received her B.A. from Cornell University and was awarded a Masters and Ph.D. from Case Western Reserve University.

Linda Rosenzweig, Esq., was appointed Camden County Counsel in September of 1989. Formerly the Public Advocate's representative on the New Jersey Bioethics Commission, she was appointed the first Chair of the Task Force on New Reproductive Practices. Ms. Rozenzweig was the Director of the Divison of Mental Health Advocacy and a member of both the Supreme Court Task Force on Mental Commitments and the Insanity Defense Study Commission. A graduate of Rutgers Law School, she has served as panelist for numerous programs on the rights of mentally ill persons.

Professor Lee Silver, Ph. D., is Associate Professor of Molecular Biology at Princeton University. He is co-organizer of a Policy Task Force on "Reproductive Technologies and Human Embryo Manipulation" being conducted at the Woodrow Wilson School of Public and International Affairs. He is also Associate Editor of the Journal of Heredity. Dr. Silver received his B.A. and M.S. in Physics from the University of Pennsylvania, and his doctorate in biophysics from Harvard University.

Gerson Weiss, M.D., is Professor and Chairman of the Department of Obstetrics and Gynecology at UMDNJ-New Jersey Medical School, Newark. He is also Chief of Service of the Department of Obstetrics and Gynecology at UMDNJ-University Hospital in Newark. He received his B.A. from New York University and his M.D. from New York University School of Medicine. His field of special expertise is reproductive endocrinology.

Cecilia Zalkind, J.D., is the Assistant Director of the Association for Children of New Jersey, Newark. She specializes in advocacy and legislation for child welfare, emphasizing foster care and adoption issues. She received her B.A. and M.A. from New York University and her J.D. from Rutgers University Law School. She has published articles on child welfare, including a training manual for pro bono attorneys.

Jay Katz, M.D. (Advisor) A graduate of Harvard Medical School, Dr. Katz is the John A. Garver Professor of Law and Psychoanalysis at Yale Law School and one of the nation's leading scholars on informed consent, human experimentation and law and psychiatry. The author of many leading works on law and medicine, Dr. Katz is a member of the National Academy of Science's Institute of Medicine, a consultant to numerous national commissions, and a training and supervising psychoanalyst at the Western New England Institute for Psychoanalysis. Dr. Katz is now developing teaching materials for his law school course on Reproductive Technologies.

Table 3 (b) 2

Task Force On Institutional Ethics Committees
Non-Commissioner Members

Flora M. Barlotta, M.D., is a hematologist who practices at St. Barnabas Medical Center in Livingston, N.J. She received her M.D. degree from Seton Hall College of Medicine (now the University of Medicine and Dentistry of New Jersey). Dr. Barlotta chairs the Ethics Committee at St. Barnabas Medical Center.

Reverend William J. Fallon, a Roman Catholic Priest, is a member of the Moral Board of the Diocese of Camden and the Medical Ethics Advisory Committee of Kennedy Memorial Hospitals. Father Fallon is Associate Pastor of St. John's Church in Paulsboro, and is an Associate Professor of Medical Ethics at Gwynedd Mercy College in Gwynedd Valley, Pennsylvania. A graduate of St. Mary's College in Kentucky, he also received an A.B. in Classical Language, and an M.A. in Religious Education from the University of Louvain in Belgium.

Janet Fleetwood, Ph.D, is Assistant Professor of Community and Preventive Medicine, Division of Medical Humanities, at the Medical College of Pennsylvania. A medical ethicist, she has worked with several institutional ethics committees in developing hospital policies and educational programs, and presently coordinates the Delaware Valley Ethics Committee Network. Dr. Fleetwood received her M.A. and Ph.D. in philosophy from the University of Southern California. Her doctoral dissertation examined the issue of equitable allocation of health care resources.

Leonard Fishman, Esq., a partner in the Health Care Department of Cohen, Shapiro, Polisher, Shiekman and Cohen, is Counsel to the New Jersey Association of Non-Profit Homes for the Aging, which represents over 125 nursing homes, continuing care retirement communities and senior housing developments. A member of New Jersey's Continuing Care Advisory Council, he is also Chair of the Legal Committee of the American Association of Homes for the Aging. Mr. Fishman is the former Administrative Assistant to the Speaker of the New Jersey General Assembly.

John R. Heher, Esq., is a partner in the Trenton law firm of Smith, Stratton, Weiss, Heher and Brennan, specializing in health and hospital law. Mr. Heher is Chairman of the New Jersey Hospital Association's Council on Hospital Governance and has been a Trustee of the New Jersey Hospital Association since 1964. He has also served as President of two Health Planning Councils in New Jersey and is a Trustee of the Mercer Medical Center, serving as Chairman in 1976-1979. Mr. Heher received his B.S., cum laude, from Georgetown University and his J.D. from Michigan Law School.

James T. Holmes, Esq., is General Counsel to the New Jersey Hospital Association. Mr. Holmes was formerly Director of Medical-Legal Affairs at the University of Chicago. He received his J.D. from American University in Washington, D.C. and holds a Masters in Public Health from the University of Illinois.

Betty Lou Miccio, formerly Vice President of Professional Practice and Quality Assurance of the New Jersey Hospital Association, has degrees in both nursing and health care administration. She is widely published in the area of risk management and quality assurance and is recognized as an expert on those subjects. Ms. Miccio serves as a trustee of the New Jersey Hospice Organization and the Citizens' Committee on Biomedical Ethics. She is a member of several task forces, consumer groups, and professional organizations, including the American College of Healthcare Executives. Ms. Miccio is currently a consultant with Touche Ross in Newark.

Michael Nevins, M.D., an internist practicing in Westwood, is former Governor for New Jersey of the American College of Physicians and Chairman of that organization's subcommittee on aging. He is also Chairman of the Bioethics Committee at Pascack Valley Hospital. Dr. Nevins is a member of the Citizens' Committee on Biomedical Ethics, a Clinical Associate Professor of Medicine at the University of Medicine and Dentistry of New Jersey, and the author of numerous articles on bioethics.

Robert L. Pickens, M.D., is a board certified urologist who practices in Princeton, New Jersey. He is currently Chairman of the Committee on Biomedical Ethics of the Medical Society of New Jersey. Dr. Pickens also serves as Chairman of the Biomedical Ethics Committee of the Medical Center at Princeton, and is a member of the Biomedical Ethics Committee of the New Jersey Hospital Association. Dr. Pickens received his A.B. degree from Princeton University and his M.D. degree from Yale University. He is a past president of the medical and dental staff of the Medical Center at Princeton, and is a member of its Board of Trustees.

Catherine Pignatello, M.P.H., R.N., of Caldwell, is currently Director of Professional Services of the Visiting Health Services of New Jersey, Inc., a home health agency which provides home health and hospice services to residents of Passaic, Bergen and Morris Counties. Ms. Pignatello also serves as Chairman of the Ethics Committee of the Home Health Agency Assembly of New Jersey, the state association representing home care agencies throughout New Jersey. She has worked in home health care since 1974. Ms. Pignatello received her B.S.N. from Seton Hall University and her M.P.H. from Columbia University.

David M. Price, Ph.D., teaches health care ethics at the University of Medicine and Dentistry of New Jersey - New Jersey Medical School in Newark. A member of the Department of Pediatrics, he is also on the staff at Children's Hospital of New Jersey. His responsibilities at both institutions include ethics case consultation, policy formulation and leadership for ethics committees. At UMDNJ, he serves on the Research Committee (IRB) and Animal Care and Use Committee. He has degrees from the University of Michigan, Yale University and Michigan State University. His current interests include genetic counseling, various aspects of critical care, and AIDS.

Anne R. Somers, D.Sc. (hon.), of Princeton, is Adjunct Professor, Department of Environmental and Community Medicine, University of Medicine and Dentistry of New Jersey-Robert Wood Johnson Medical School. She has specialized in geriatric health care policy, preventive gerontology, and health economics. She is the author, co-author, or editor of numerous books and over 200 articles or chapters of books on these subjects, including The Geriatric Imperative: An Introduction to Gerontology and Clinical Geriatrics. Professor Somers is a director of the Pennswood Retirement Community, Newtown, Pennsylvania. A member of the National Academy of Sciences - Institute of Medicine, Professor Somers has also served on numerous public and private boards and advisory committees.

Cynthia J. Stolman, Ph.D., of Short Hills, is Curriculum and Evaluation Coordinator of the residency training program, Department of Pediatrics, Children's Hospital of Newark/University of Medicine and Dentistry of New Jersey-New Jersey Medical School. She was previously affiliated with the Cardiopulmonary Department of Overlook Hospital, Summit, in the capacity of project director for a research study of patients with do not resuscitate orders. An expert in bio-medical ethics, Dr. Stolman serves as a member of the ethics committees of three acute care hospitals. She received her B.A. from The City University of New York-Brooklyn College and an M.Ed. and Ph.D. from The State University of New York at Buffalo.

William I. Strasser, Esq., a partner in the Nutley law firm of Donohue, Donohue, Costenbader and Strasser, represented the family of Claire Conroy in the landmark New Jersey Supreme Court case (1985). He has published several works on decisionmaking for the terminally ill. He received his J.D. from Seton Hall University.

Table 3 (b) 3

Task Force On Public and Professional Education
Non-Commissioner Members

Rabbi Richard F. Address, M.A.H.L., of Mantua Township, is the Regional Director of the Union of American Hebrew Congregations in Philadelphia and National Staff Coordinator for the UAHC Committee on Bio-Ethics. He is Chaplain for the Children's Hospital in Philadelphia and a member of the hospital's Ethics Committee. A graduate of Temple University and Hebrew Union College, he also co-chairs the Medical Ethics and AIDS Committees of the Board of Rabbis of Greater Philadelphia.

Theresa Dietrich, of West Trenton, is a Program Development Specialist in the New Jersey Division on Aging and also serves as State Coordinator of the Senior Health Insurance Program, a statewide network of volunteers trained to assist Medicare beneficiaries with questions or problems concerning health care insurance. A graduate of Georgian Court College, she received her Master of Arts in Social Gerontology from the University of Pennsylvania. Ms. Dietrich represents the Commissioner of Community Affairs and the Director of the Division on Aging Ann Zahora on the Bioethics Commission and the Task Force.

Joanne Drake, of Flemington, is President of the Hunterdon County Chapter of Citizens Concerned for Life, and represents Assemblyman Dick Kamin on the Bioethics Commission and the Task Force. A former student at Dutchess Community College in New York and the Worcester Art Museum School of Design, Ms. Drake is currently involved with the Adolescent Pregnancy Project at Hunterdon Medical Center.

Kenneth Dolan, B.S., M.P.A., of Bloomfield, is Executive Director of the Home Care Council of New Jersey, the state association of voluntary non-profit homemaker-home health aide agencies. A graduate of Michigan State University and the University of Michigan, Mr. Dolan chaired the Long-Term Care Funding and Reimbursement Committee of the Governor's Long Term Care Task Force.

Lois Forrest, LNHA, of Medford, has been the Executive Director of Medford Leas Continuing Care Retirement Community since 1979. She is the current President of the New Jersey Association of Non-Profit Homes for the Aging and has also served as Chair of the Association's Continuing Care Retirement Community Committee. Formerly the Executive Director of YWCA of Philadelphia, Ms. Forrest holds a B.S. from Edison College.

Sheila Paris Klein, B.A., of Westfield, is currently Director of Public Relations for the Jersey City Medical Center in Jersey City. She was formerly the Director of Public Relations for the New Jersey State Department of Health, where she created and edited Healthline, the Health Department's periodical, covering major health care and regulatory issues. A graduate of Brooklyn College, Ms. Klein is a member of the Editorial Board of Hospital News.

Joseph C. d'Oronzio, Ph.D., M.P.H., of Summit, is the Administrative Director of Medical Education at Overlook Hospital. He serves on the Bioethics Exeuctive Committee and edits Critical Choice, the hospital's quarterly forum for bioethics. Educated at Syracuse, Columbia and Harvard Universities, Dr. d'Oronzio lectures at UMDNJ-Robert Wood Johnson Medical School in Piscataway and the Rutgers University Graduate Program in Public Administration in Newark. He is on the editorial board of HEC Forum, an interdisciplinary journal on hospitals' ethical and legal issues.

Michael Rappeport, Ph.D., of Princeton, is a Partner at RL Associates, a public opinion and survey research firm with special expertise in health care issues. A graduate of Rensselaer Polytechnic Institute, Yale and New York Universities, he has directed health-related research for the Citizens' Committee on Biomedical Ethics, the American Association of Retired Persons, several Continuing Care Retirement Centers, and a number of hospitals.

Ritamarie G. Rondum, of Lawrenceville, is a retired career New Jersey State employee who developed and administered a variety of state-wide service programs for the elderly and the disadvantaged. She is the author of Aging in Action, the first independent report of the New Jersey State Division on Aging, the editor of the AARP State Legislative Committee NJ News, and was a newspaper columnist for many years. She is a member of the Older Women's League and WAVES National, an organization of US Navy Veterans. She is a graduate of Temple University.

Teresa Schaer, M.D., of New Brunswick, is Director of Geriatric Programs at St. Peter's Medical Center in New Brunswick and Medical Director of the McCarrick Care Center in Franklin Township, in addition to teaching Geriatric Medicine to medical students, residents and geriatric fellows. Dr. Schaer is a graduate of the University of California-San Diego School of Medicine. Her Internal Medicine Residency was at NYU-Bellevue Medical Center in New York City, followed by a Fellowship in Geriatric Medicine at George Washington University Medical Center in Washington, D.C.

Marguerite K. Schlag, R.N., Ed.D., of Belle Mead, is Director of Nursing Education and Development at Robert Wood Johnson University Hospital in New Brunswick and Clinical Assistant Professor at Rutgers College of Nursing in Newark. A graduate of Rutgers, Case-Western and Villanova Universities, Dr. Schlag also chairs the New Jersey State Nurses Association's Cabinet on Continuing Education.

Joseph Slavin, of West Trenton, is Executive Director of the New Jersey Catholic Health Association and Vice President of the New Jersey Hospital Association. A graduate of Villanova and Rutgers Universities, he is a member of the Governor's Emergency Services Council and the Board of Trustees for the Presbyterian Homes of New Jersey.

Helen Handin Spiro, J.D., of Princeton, is currently Executive Director of the Environmental and Occupational Health Sciences Institute, a joint venture of UMDNJ-Robert Wood Johnson Medical School and Rutgers University. She previously headed a publishing and information services firm. A graduate of Yale University and the University of California, Berkeley, Ms. Spiro received her law degree at Rutgers School of Law, Newark, and served as Special Assistant to Chief Justice Wilentz of the New Jersey Supreme Court.

Table 4
Consultants and Invited Speakers

The Bioethics Commission has employed several outside experts as consultants for specific projects, including a review of its legislative proposal on Advance Directives for Health Care, and two projects relating to the Commission's Task Force on New Reproductive Practices. In addition, the Commission has frequently invited guest speakers from around the country to address the Commission on particular issues relevant to its work. The Commission has been fortunate to have had several speakers from the Hastings Center and various universities, including Yale, Rutgers, Chicago, New York, Princeton and Indiana. These consultants and invited speakers are listed below:

Consultants

R. Alta Charo, Esq.
Office of Technology Assessment
Washington, D.C.

Frank P. Grad, Ph.D.
Columbia Law School
New York, N.Y.

Morton Winston, Ph.D.
Trenton State College
Trenton, N.J.

Susan Frelich Appleton, Esq.
Washington University
St. Louis, Missouri

Walter P. Loughlin, Esq.
Rutgers School of Law
Newark, New Jersey

Invited Speakers

Robert Cassidy, Ph.D.
University of Medicine and Dentistry of New Jersey-Robert Wood Johnson Medical School

Russell I. McIntyre, Th.D.
University of Medicine and Dentistry of New Jersey-Robert Wood Johnson Medical School

Norman Cantor, Esq.
Rutgers Law School

Steven H. Miles, M.D.
University of Chicago

Kathleen Nolan, M.D.
The Hastings Center

Nicholas A. Rango, M.D., Ph.D.
Village Nursing Home

Daniel Callahan, Ph.D.
The Hastings Center

Jay Katz, M.D.
Yale Law School

Robert Burt, J.D.
Yale Law School

Bruce Jennings, Ph.D.
The Hastings Center

David Smith, Ph.D.
Indiana University

The Honorable Molly J. Coye, M.D.
New Jersey State Commissioner of Health

Table 5
Public Hearing Witnesses

November 21, 1986
Craig Becker, Vice President/Director of Government Relations, New Jersey Hospital Association
Timothy Ames, M.D., Philip Barber Family Health Center, Lambertville, New Jersey
Ruth Theis, B.S.N., Executive Director, New Jersey Hospice Organization

December 17, 1986
Alan J. Weisbard, Esq., as a citizen
David Price, Ph.D., Chair, Ethics Committee, Dept. of Pediatrics, UMDNJ
Robin Ince, Medical/Surgical Clinician, Union Hospital, Union, New Jersey
Catherine H. Pignatello, Administrator of Professional Services, West Essex Community Health Service
Rev. Joseph W. Kukura, Vice President, Ministry and Ethics, Health Corporation, Newark, New Jersey
Richard Traynor, Esq., Traynor and Hogan, Morristown, New Jersey
Kendall Sprott, M.D., Pediatric Intensive Care Unit, Children's Hospital, Newark, New Jersey
Rubin Fernandez, R.N., Vice Chair, Ethical Practice Committee, New Jersey State Nurses Association
Russell I. McIntyre, Th.D., Robert Wood Johnson Medical School, UMDNJ

January 21, 1987
Vincent Maressa, Executive Director, Medical Society of New Jersey
John Tomicki, President, New Jersey Right to Life Committee
James Cunningham, Executive Director, New Jersey Association of Health Care Facilities
Lois Forrest, Administrator, Medford Leas Retirement Community
William Reitsma, R.N., Executive Director, Transplant Foundation of New Jersey, Inc.
Ray Waters, President, Special Needs Involvement Project, Tinton Falls, New Jersey
Ruth Theis, B.S.N., Executive Director, New Jersey Hospice Organization
Diane Mikell, R.N., Muhlenberg Regional Medical Center
Rita Martin, Citizens Concerned for Life, Trenton, New Jersey
Diane Czerepuszko, L.N.H.A., Administrator, Delaire Nursing and Convalescent Center, Linden, New Jersey
Dorothy Franklyn, Administrator, Valley Nursing Home

February 24, 1988
David Zweibel, Esq., Director of Government Affairs, Agudath Israel of America
Craig Becker, Vice President/Director of Government Relations, New Jersey Hospital Association
James Cunningham, Executive Director, New Jersey Association of Health Care Facilities
Ruth Theis, B.S.N., Executive Director, New Jersey Hospice Organization
Robert Bayly, M.D., Medical Director, ICU, Muhlenberg Hospital
Diane Mikell, R.N., Director of Quality Assurance, Muhlenberg Hospital
Joseph Stanton, M.D.
M. Rose Gasner, Esq., Society for the Right to Die
Giles Scofield, Esq., Concern for Dying
John Tomicki, Executive Director, New Jersey Right to Life Committee
Marie Niemeyer, Legislative Director, New Jersey Right to Life Committee
Patricia Coyle, Assistant Legislative Director, New Jersey Right to Life Committee
Reverend Monsignor Aloysius Welsh, representing the New Jersey Catholic Conference

April 13, 1988
Henry R. Liss, M.D., Overlook Hospital
Stewart Fox, M.D., Morristown Memorial Hospital
Anne Perone, Esq., Counsel, New Jersey Right to Life Committee
T. Patrick Hill, Director of Public Information, Citizens' Committee on Biomedical Ethics
Mary Lartolla, President, Medical Ethics Education and Legal Defense Fund, Inc.
Richard Traynor, Esq., President, New Jersey Right to Life Committee
Margaret Dedrick, New Jersey Dietetic Association
Don Perdue, as a citizen
Jerry Belsh, M.D., Robert Wood Johnson University Hospital
Babette Pachence, M.D., Lawrenceville, New Jersey
Joseph Ryan, M.D.
Mrs. Jeryl Turco-Maglio, Lincoln Park Convalescent Center
Pat Mahoney, as a citizen
Madeline Schwartz, Joan Slinger, Charlotte Kalamar, as citizens
Ann Farese, Lincoln Park Convalescent Center
Margaret Curran, Officer, New Jersey Advocate for the Disabled

May 11, 1988
Gary Skoloff, Esq., member of the law firm of Skoloff and Wolfe
Lorraine Abraham, Esq.
Harold Cassidy, Esq., member of the law firm of Cassidy, Despo, Foss and San Filippo
Professor Nadine Taub, Professor of Law, Rutgers Law School, Newark
Dr. Betsy Aigen, founder and director of the Surrogate Mother Program, New York
Jerrold Kaminsky, Esq.
Kathryn Quick, Resolve, Central New Jersey
Candace Mueller, New Jersey Committee for Adoption
Phyllis Chesler, Associate Professor of Psychology, College of Staten Island, City University of New York
R. Alta Charo, Esq., Office of Technology Assessment, Washington, D.C.
Bernice Davis, Director of One Church, One Child of New Jersey
Rabbi Edward Feld, Chaplain, Princeton University Hillel Society
Reverend Elizabeth Maxwell, St. Matthew's Church, Paramus, New Jersey
Allison Ward, Concerned United Birth Parents
Patricia Coyle, New Jersey Right to Life Committee

November 29, 1988
Ruth Theis, B.S.N., Executive Director, New Jersey Hospice Organization
William Bolan, Executive Director, New Jersey Catholic Conference
M. Rose Gasner, Esq., Society for the Right to Die
Giles Scofield, Esq., Concern for Dying
Anne Perone, Esq., Counsel, New Jersey Right to Life Committee
John Tomicki, Executive Director, New Jersey Right to Life Committee
James Cunningham, Executive Director, New Jersey Association of Health Care Facilities
Kaye Quigley, American Association for Senior Citizens

Table 6

New Jersey Bioethics Commission
Meetings

1986

April 16, 1986
June 18, 1989
September 3, 1986
October 22, 1986

1987

February 18, 1987
March 18, 1987
May 20, 1987
June 17, 1987
July 15, 1987
August 19, 1987
September 8-9, 1987 (Retreat)
October 21, 1987
November 18, 1987
December 16, 1987

1988

January 14, 1988
January 27, 1988
February 10, 1988
March 9, 1988
June 8, 1988
July 18, 19, 20, 1988 (Retreat)
October 12, 1988
November 16, 1988
November 29, 1988
November 30, 1988
December 14, 1988
December 29, 1988

1989

March 22, 1989
May 24, 1989
July 10, 11, 1989 (Retreat)

1990

February 7, 1990
March 20, 1990

Table 7

New Jersey Bioethics Commission
Public Hearings

1986

November 21, 1986
December 17, 1986

1987

January 21, 1987

1988

February 24, 1988
April 13, 1988
May 11, 1988
November 29, 1988

Tables 8a, b, c
Schedule of Meetings of Commission Task Forces

a. Task Force on New Reproductive Practices

1988

March 16, 1988
April 27, 1988
June 1, 1988
June 22, 1988
July 20, 1988
September 7, 1988
October 5, 1988
October 19, 1988
November 2, 1988
December 7, 1988

1989

January 25, 1989
March 1, 1989
April 5, 1989
May 3, 1989
June 7, 1989
July 11, 1989 (Retreat)

1990

April 4, 1990
May 3, 1990

b. Task Force on Institutional Ethics Committees

1988

August 10, 1988
September 14, 1988
October 12, 1988
November 9, 1988

1989

February 22, 1989
April 7, 1989
April 26, 1989 (Subcommittee)
May 10, 1989 (Subcommittee)
May 12, 1989
May 31, 1989 (Subcommittee)
June 16, 1989
July 10, 1989 (Retreat)

1990

May 9, 1990

c. Task Force on Public and Professional Education

1988

April 14, 1988
June 3, 1988
September 14, 1988

1989

June 14, 1989
July 19, 1989

1990

March 21, 1990

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