

Incapacitated and Alone:

Health Care Decision-Making for the Unbefriended Elderly

Naomi Karp and Erica Wood



American Bar Association
Commission on Law and Aging

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Naomi Karp and Erica Wood
ABA Commission on Law and Aging

Executive Summary

A bioethicist at a major urban hospital attests that “the single greatest category of problems we encounter are those that address the care of decisionally incapable patients...who have no living relative or friend who can be involved in the decision-making process. These are the most vulnerable patients because no one cares deeply if they live or die.”

Decision-Making for these patients was the subject of a 2002-2003 study by the American Bar Association Commission on Law and Aging, with support from the Fan Fox and Leslie R. Samuels Foundation, and in collaboration with The Samuel Sadin Institute on Law, Brookdale Center on Aging of Hunter College. This report presents the findings of the study. In the report, we define “the unbefriended elderly” patient as follows:

- The patient does not have decisional capacity to give informed consent to the treatment at hand;
- The patient has not executed an advance directive that addresses the treatment at hand and has no capacity to do so; and
- The patient has no legally authorized surrogate, and no family or friends to assist in the decision-making process.

While many younger persons with mental retardation or developmental disabilities may fit this category, our primary focus is on older patients.

In most states, the legal framework for making treatment decisions on behalf of these isolated unbefriended individuals is insufficient. As a result, they may be subject to over-treatment, under-treatment, or treatment that does not reflect their values or best address their well-being. Our study aimed to determine the current state of law and practice in health care decision-making for the unbefriended elderly and identify workable solutions. We performed background statutory

and literature research and surveyed target groups; conducted 26 in-depth interviews, five site visits and two focus groups; and convened a groundbreaking interdisciplinary symposium and a follow-up state strategy session.

Project Findings

- **Little existing study.** Very few writings exist on health care decision-making for unbefriended patients, and there are no previous in-depth studies. This reflects a sad lack of public attention to the needs of this frail elderly population.
- **Difficult but compelling data.** Data are lacking on the size of the unbefriended elderly population. Estimates differ, but show the number is significant. Moreover, estimates are problematic because of the informal and widely varying nature of capacity determinations. Experts have speculated that about 3 to 4 percent of the total nursing home population is unbefriended, and this coincides with observations made during our study, but has no statistical basis. Broader demographic data show converging trends that underscore the urgency of the problem—the older population is increasing, the number of individuals with dementia is increasing, persons with mental retardation and developmental disabilities are aging, a high percentage of nursing home residents have some degree of cognitive impairment, and there is a substantial number of incapacitated individuals in need of guardians or other surrogate decision-makers without willing and available relatives or friends.
- **Societal loners.** Unbefriended patients are people who frequently have been socially isolated much of their lives. Often, they have fallen through societal cracks and are in a no

man's land without traces of their past or preferences, and without advocates. The majority are encountered in hospitals or nursing homes, and frequently have multiple chronic conditions that may require timely and wrenching decisions on major medical or life-sustaining treatment.

- **Existing legislative mechanisms.** Our study identified four existing legislative paths to health care decision-making for unbefriended patients:
 - (1) Eight states have enacted statutory authorization for health care consent when no surrogate is available. Many of these provisions give a key role to the attending physician, either alone or in consultation with others—a role that has marked drawbacks as well as benefits.
 - (2) Three states have enacted laws authorizing external committees of trained volunteers to make health care decisions on behalf of unbefriended individuals. These programs focus on persons with mental retardation, developmental disabilities, and mental illness rather than on the frail, incapacitated long-term care population, but are instructive as working models.
 - (3) Many states and localities have enacted public guardianship programs for both health care and financial decision-making for the unbefriended population. Guardianship is frequently costly, time-consuming, and cumbersome; and public guardianship programs often are either underfunded and understaffed or simply unavailable. The needs currently far outstrip the resources, and will escalate with the aging of the population.
 - (4) At least five states have enacted a court process to seek consent for health care or appointment of an individual to give consent, and additional states provide for a similar procedure by court rule. One

judicial route is a “temporary medical treatment guardian.”

- **Existing institutional practice.** When state law does not provide an available mechanism for surrogate decision-making on behalf of incapacitated patients, health care institutions are in a quandary. Our research identified three approaches:
 - (1) Some hospitals and nursing homes have ethics committees or procedures, but these generally engage in education, policymaking, case consultation, and retrospective review, stopping short of decision-making. Our study revealed a few cutting-edge systems or examples in which ethics committees do make decisions on behalf of unbefriended patients.
 - (2) One large long-term care facility has instituted an innovative informal surrogate system to address the decision-making needs of potentially unbefriended residents.
 - (3) Frequently, health care providers and institutions simply develop their own ad hoc procedures for consent to treatment. Sometimes these rely on concepts of “administrative consent.” Sometimes physicians faced with critical treatment needs have nowhere to turn and simply go ahead and make the determination they think best, acting as an informal and ad hoc guardian—following ethical dictates but skirting legal requirements.

Symposium Statement

Our study featured a lively one-day, interdisciplinary symposium of experts to tackle the problem of health care decision-making for the unbefriended elderly. Participants included physicians, bioethicists, attorneys, a state court judge, guardianship agency personnel, law professors, a state legislator, state agency representatives, social

workers, adult protective services staff and elder advocates. The group discussed the nature and extent of the problem, preventive approaches, the pros and cons of internal vs. external facility approaches, the extent of formality and procedural safeguards required, the varying roles of ethics committees and surrogate panels, and the need for cultural sensitivity in medical decision-making. The meeting produced a consensus statement included at page 42.

Policy Suggestions

The report's policy suggestions build on the symposium statement and on the range of interviews we conducted. They seek to ensure that solitary patients with no advocate and no track record of values and life history are the focus of a *deliberative process* of both medical and ethical scrutiny.

- (1) Research should analyze federal data on long-term care residents to shed light on the unbefriended population.
- (2) Further study should include a focus on cultural diversity and health care decision-making.
- (3) Long-term care staff should play a greater role in investigating and conveying resident values and preferences.
- (4) Long-term care facilities should develop procedures for collecting and using resident histories and values information.
- (5) Health care professionals should improve techniques for assessing and enhancing patient decisional capacity; and medical institutions should provide training for health care professionals in assessment of capacity for informed consent.
- (6) In developing decision-making mechanisms for unbefriended elderly patients, policymakers should seek to incorporate hallmark characteristics that will best serve this vulnerable population.
- (7) Facilities should develop and/or strengthen internal decision-making mechanisms; and states and communities should develop external bodies to make health care decisions for patients lacking surrogates.
- (8) Facilities should develop, and funders should support, demonstration projects involving ethics committee decision-making on behalf of unbefriended patients.
- (9) States with existing surrogate decision-making systems should test their use for the unbefriended elderly population.
- (10) State health care consent laws and their practical application to the unbefriended population merit further study.
- (11) States and localities should develop temporary medical treatment guardianship programs.
- (12) States should support public guardianship programs that are adequately funded and staffed; and research should explore key questions about the quality of care and decision-making in public guardianship programs.

I. Introduction

A. The Problem: Voiceless and Vulnerable Patients

The director of bioethics consultation at a major New York City academic medical center, Nancy Dubler, recently wrote:

The single greatest category of problems we encounter are those that address the care of decisionally incapable patients who have been transferred for care from nursing homes and who have no living relative or friend who can be involved in the decision-making process. These are the most vulnerable patients because no one cares deeply if they live or die. That is not to say that staff are not concerned to do what is right and in the best interest of the patient, but no one's life will be fundamentally changed by the death of the patient. We owe these patients the highest level of ethical and medical scrutiny; we owe it to them to protect them from over-treatment and from under-treatment; we owe it to them to be certain that they are not a statistic in a study that demonstrates that over 50 percent of patients who die do so in moderate to severe pain; we owe it to them to help them to live better or to die in comfort and not alone.

Dubler is describing a population termed the “unbefriended elderly”—patients who lack the capacity to make their own health care decisions and have no surrogates to act in their stead. These vulnerable patients are decisionally incapable, either because they have lost their former capacity or, for those with certain significant mental impairments, they never had capacity to make health care choices. The second hallmark of this population is that they are alone—they have neither legally authorized surrogates nor de facto

surrogates. They are truly isolated, with no obvious proxy to decide whether they should receive treatment, what type, how much, or when to stop.

In this report, we define “the unbefriended elderly” to include patients that: (1) do not have decisional capacity to give informed consent to the treatment at hand; (2) have not executed an advance directive that addresses the treatment at hand and have no capacity to do so; and (3) have no legally authorized surrogate, and no family or friends to assist in the decision-making process.

In the current legal framework in most states, there is no clear mechanism for making treatment decisions on behalf of such isolated unbefriended individuals. Advance directives and health care consent statutes provide little help, since this population lacks natural surrogates, and going to court for guardianship is problematic at best and clearly a last resort. Grave problems for this vulnerable population result from the lack of decision-making mechanisms:

Over-treatment. Hospitals, nursing homes, and individual providers often err on the side of over-treatment when the patient cannot decide and there is no authorized surrogate. Bioethicists and providers interviewed in our study reported that treating patients aggressively is often considered a “medical imperative.” If a 90-year-old in terminal condition is presented to the hospital, some believe that in the current climate, foregoing resuscitation efforts “is a brave act. The hospital acts aggressively but this is nonsensical.”

Over-treatment of the unbefriended results from a spectrum of incentives or disincentives.

Doctors are taught that the goal of care is to preserve life, and often have trouble letting go. One palliative care physician blamed overly aggressive clinicians and said “some doctors philosophically don’t believe in death.” He also described perverse economic incentives—pulmonologists getting paid to care for patients on ventilators, for example. While his view may be cynical, he underscores the existence of causes bearing little relationship to the best interests of these patients.

Fear of regulators also stimulates over-treatment of incapacitated patients without surrogates. A nursing home medical director stated, “medical practitioners think they know what to do, what is in the best interest of the patient, but the legality of it gets in the way.” There’s a perception by the nursing home staff that the state regulators would cite them for deficiencies if they let someone die in the facility without full evidence of a decision by a guardian, or without an advance directive—and they don’t want to raise any questions.

Civil liability also is perceived by practitioners as a threat. In the nursing home arena, there appears to be a substantial number of tort suits against nursing homes, particularly in certain states, with many of these suits naming physicians as defendants in addition to the facilities, and with more than half of the claims in a recent study involving deaths (Stevenson & Studdert 2003). A focus group of medical directors in our study from an East Coast state referred to worries about “the daughter from California” coming after them with her lawyers. The fear is that an absent relative, perhaps motivated by guilt, may believe that “everything should be done.” Physicians may treat aggressively for fear of malpractice suits if they refrain.

Under-treatment. While providers and institutions often feel compelled to treat in the absence of a surrogate, in other cases they are loath to provide care without someone to give informed consent. Some providers stated that “one main approach for decision-making for the unbefriended is to wait until the need for treatment becomes an emergency and consent is no longer necessary.” The harm to patients caused by that

approach is obvious—unnecessary delay, added illness, discomfort, indignity, and morbidity.

Drain on public resources. Resort to the guardianship system to designate a health care decision-maker can drain public resources. In Massachusetts, guardianship costs for patients on Medicaid have been estimated at up to \$750 for the court appointment of a guardian and up to \$50 per hour for ongoing guardianship services (Ford 2000). Florida’s Statewide Public Guardianship Office reports that the cost of public guardianship varies from \$600 to \$2,000 per ward per year (Florida 2000).

This irrational system of care for unbefriended elderly patients—motivated by factors unrelated to the health and well-being of these vulnerable patients—is unacceptable to medical practitioners, social workers, elder law attorneys, aging network personnel, institutional administrators, and policy-makers who truly care about vulnerable older persons in our society. The lack of clear pathways for decision-making on behalf of this population, moreover, causes confusion and disarray. In the words of one elder law attorney and hospital ethics committee member, such situations “are nightmares for the hospitals to figure out” and everybody is “sick and tired of not knowing what to do.”

One bioethicist states, “for patients with no advance directives, no track record of preference, and no advocate or spokesperson, the process is the same: hit or miss, luck of the draw, roll of the dice.”

B. Project Methodology

This report presents findings of a study by the American Bar Association Commission on Law and Aging, in collaboration with The Samuel Sadin Institute on Law, Brookdale Center on Aging of Hunter College. The study sought to help the incapacitated unbefriended elderly “to live better or die in comfort and not alone” by

improving approaches to providing effective health care agency for these individuals. The specific objectives were:

- To determine the current state of the law and practice regarding health care decision-making on behalf of incapacitated unbefriended patients;
- To develop policy recommendations on the best mechanisms for health care decision-making for this population;
- To disseminate widely information on the state of the art and recommendations for change; and thereby
- To enable legislators, policymakers, and practitioners to implement mechanisms and procedures that enhance health care decision-making for and protect this vulnerable population.

The project aimed to inform health care professionals, administrators, attorneys, regulators, advocates, legislators, and other policy-makers about existing law and practice, barriers to optimal decision-making, cutting edge solutions, and options for the future. Further, it sought to share information about promising laws, systems and practices, to sensitize involved professionals and others about the needs and vulnerabilities of the unbefriended population, and to motivate them to develop and pilot better approaches to surrogate decision-making. Through these efforts, we hoped to enhance medical decision-making on behalf of these isolated adults, reduce over-treatment and under-treatment, and improve the quality of care delivered in acute care, long-term care and the community.

The project took a three-pronged approach: background research; an interdisciplinary symposium of experts and follow-up local strategy session; and dissemination of findings and recommendations. Because the Fan Fox and Leslie R. Samuels Foundation, the project's funder, has a particular focus on New York, we over-sampled New York in our interviews and

site visits, and held our two major roundtable discussions in New York.

1. Background Research

a. Statutory Research

Project staff performed statutory and regulatory research in all 50 states and the District of Columbia. We identified all states with statutory provisions that address some facet of health care decision-making for incapacitated patients without legal guardians or health care proxies, and with no relatives or friends who can make decisions pursuant to a family consent statute.

b. Literature Search

Project staff performed a literature search using such search engines as PubMed (focusing on biomedicine) and Bioethicsline (covering ethics and related public policy issues in health care and biomedical research), two databases of the National Library of Medicine of the National Institutes of Health. Staff also scanned a variety of journals on bioethics, elder law, and gerontology and numerous relevant professional listserves. As originally suspected, very little has been written of relevance to health care decision-making for the unbefriended elderly. Existing literature is summarized below in Chapter II (A) of this report.

c. Survey of Target Groups

Project staff composed a short inquiry seeking information about decision-making processes in place for the unbefriended. We asked:

- In your setting or locale, is there a process (other than guardianship) for health care decision-making on behalf of persons with diminished capacity who lack formal or informal surrogates (e.g., appointed proxies or family members/close friends under health care consent laws)?
- What is the source of this process?—state law, state regulation, local or institution policy/practice, or other?

The inquiry was posted on at least twelve listserves, including: Elderbar and Elder Abuse (ABA Commission); National Academy of Elder Law Attorneys; Metropolitan Washington Bioethics Network; National Guardianship Association; Alzheimer's Association public policy list; New York State Bar Association Elder Law Section; American Association of Homes and Services for the Aging; Community/State Partnerships (Midwest Bioethics Center); Assisted Living Federation of America state executives; National Association of State Ombudsman Programs; and Gerontological Society of America's mental health and aging list. We also sent the inquiry to at least twelve additional organizations, and they may have posted our inquiry or otherwise circulated it.

We received approximately 80 responses to our inquiry. They yielded a wealth of information about law, institutional policy, and individual practice in many states. They have aided us in our statutory research, in identifying interviewees and site visits, and in getting a broad picture of the national scene.

d. Interviews

Project staff identified a list of key interview subjects and developed a detailed written interview protocol. We conducted 26 in-depth interviews between March and October of 2002. We interviewed geriatricians, other physicians, state court officials, clinical ethicists, law professors, elder law practitioners, social workers, elder advocates, adult protective services workers, and other aging network professionals. Interviewees work at hospitals, nursing homes, community agencies, state government agencies and in private practice. While a significant number work in New York City or State, we also interviewed individuals in California, Iowa, Maryland, District of Columbia, New Mexico, Texas, West Virginia, Florida, Georgia, and Massachusetts. The interviews generally covered the following topics:

- Background on the interviewee and his/her experience with the unbefriended population;

- How decisions are made in the absence of a clear decision-making mechanism;
- Guardianship;
- Health care consent statute;
- Other specific decision-making mechanism available.

e. Site Visits

We conducted three in-depth site visits, two shorter site visits, and two focus groups. The site visits aimed at developing a more complete and nuanced understanding of decision-making on behalf of the unbefriended elderly within a specific legal or practice context and from the perspectives of a variety of involved professionals. Our site visits and focus groups included:

- *Academic Medical Center in New York City.* We conducted in-depth discussions with physicians, lawyers, bioethics consultants, social workers, and nurses from several hospital departments or divisions including Palliative Care, Geriatrics, and Legal. They provided us with numerous case examples and described the thorny issues posed by these and other cases in the context of New York law.
- *Large nursing home in Massachusetts.* This facility has an academic affiliation, a staff of salaried physicians, conducts research, and has an active ethics program. We met with the physician-in-chief, a staff psychiatrist who heads the ethics committee, the full ethics committee, and a social worker. This facility has conducted an innovative program for unbefriended residents since 1997. (Technically, this facility is licensed as a chronic disease hospital but resembles a nursing home.)
- *Commission on Quality of Care, Surrogate Decision-Making Committee, New York.* Article 80 of New York's Mental Hygiene Law provides for hearings by inter-disci-

plinary volunteer panels to decide whether an incapacitated patient with a mental disability should undergo a particular medical treatment or procedure. We observed five full hearings held at Creedmoor Psychiatric Hospital in Queens, New York and interviewed key participants.

- *Iowa Surrogate Decision-Making Board.* Iowa has a statutory process for decision-making on behalf of incapacitated persons who lack surrogates. We interviewed the director of the state board and the legal services developer from the Iowa Department of Elder Affairs.
- *Texas Department of Mental Health and Mental Retardation.* Texas has a surrogate consent committee system for individuals with mental retardation in intermediate care facilities. We met with the program coordinator for that system and with the director of the Guardianship Alliance of Texas.
- *Metropolitan Washington Bioethics Network and District of Columbia Hospital Association Continuum of Care Committee.* We held a focus group at a joint meeting of these two entities. This group of approximately twenty physicians, lawyers, social workers, hospice workers, nurses, ethicists, and administrators discussed the ways in which decisions are made for the unbefriended elderly, problems with the guardianship system, and ideas for changing current practices.

- *Nursing home medical directors group, Bucks County, Pennsylvania.* Approximately fifteen nursing home medical directors met with us in a focus group to discuss the numbers of unbefriended elderly residents in their facilities, how decisions are made, the role of guardianship, ethics committees, and suggestions for the future.

2. Symposium and Strategy Session

The key gathering of our project was a full-day invitational symposium in New York City on November 1, 2002. Participants were an interdisciplinary group including lawyers, judges, social workers, physicians, bioethicists, state agency officials, legislators, foundation staff and others. The symposium aimed at developing some exploratory recommendations on health care decision-making for the unbefriended elderly. A complete description of the symposium and its outcome is in Chapter V, page 41.

We convened a second meeting in New York on January 16, 2003. Dubbed the “New York Strategy Session,” this gathering of sixteen lawyers, bioethicists, hospital staff, social workers, researchers, elder advocates and a legislator focused more specifically on the status of the unbefriended in New York State. Participants discussed at length the proposed state health care consent law, which includes specific provisions on decision-making for patients without surrogates. The group brainstormed about best practices, policy options and next steps.

II. Background

A. Existing Literature

Very few writings exist on health care decision-making for the unbefriended elderly, and no in-depth studies. This lack of information and literature “reflects the lack of public attention to the needs of these patients” (Miller 1997).

The 1987 *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying* by The Hastings Center raised the issue early on, dubbing it “one of the most difficult problems in medical decision-making” and recognizing that “no decision-making mechanism is widely available to find attentive surrogates for the many people without them. There is also as yet no consensus on the proper solution.” The guidelines urged that “someone other than the patient’s responsible health care professional” should act as surrogate, and that “some form of institutional review should be available for decisions about life-sustaining treatment” (The Hastings Center 1987).

A 1990 study, “Old and Alone: Surrogate Health Care Decision-Making for the Elderly without Families,” explored the attitudes of elderly people who live alone and have no family toward advance planning. The findings showed that such isolated older people at that time had not engaged in much advance planning, and that they exhibited “frequent denials that there is any potential risk to themselves should they become cognitively impaired and unable to make decisions for themselves” (High 1990). The study did not focus on individuals who already had lost decisional capacity.

The 1992 report of the New York State Task Force on Life and the Law offered another early focus on the unbefriended population. It proposed guidelines for decision-making for patients who lack capacity to give informed consent and have not signed an advance directive. It recommended that for major medical treatment, the attending

physician should make a decision in consultation with other health care professionals who are involved in the patient’s care, and with the concurrence of a second physician. For decisions about life-sustaining treatment, the report set out special standards, and provided that the decision must be reviewed and approved by a multi-disciplinary committee in the health care facility (New York State Task Force 1992).

A 1995 issue of the *Journal of Ethics, Law and Aging* shined a light on the dilemma of decision-making for unbefriended elderly. The journal’s opening editorial coined the term “unbefriended” and noted that “decision-making for the unbefriended tends to be a haphazardly jerry-built affair, characterized by reliance on the emergency exception to normal informed consent requirements, important decisions deferred or foregone, or health care and human service providers acting as de facto surrogates but often covertly and with hesitation” (Kapp 1995).

A 1995 journal issue coined the term “unbefriended” and noted that health care decision-making for this population “tends to be a haphazardly jerry-built affair. . . .”

Dr. Muriel Gillick wrote a seminal article in the journal issue entitled “Medical Decision-Making for the Unbefriended Nursing Home Resident,” exploring pathways for addressing the problem. The article reviewed existing approaches—having the physician decide, having the physician assume maximum care is required absent evidence to the contrary, use of guardianship, and use of ethics committees. It found them all problematic. The author proposed an in-house surrogate system in which a facility staff member not directly caring for a resident at risk of becoming “unbefriended” would develop a relationship with the resident prior to loss of

capacity, to learn about his/her beliefs and values, and then would be positioned to make—or help make—substituted judgments on his/her behalf. She observed that while nursing homes might be hesitant about adopting such a system, “surely a well-thought-out mechanism for making medical decisions for the unbefriended is preferable to the current reality in which direct caregivers make the decisions” (Gillick 1995). Iris Freeman replied in a second article in the same journal issue, criticizing the notion of an in-house surrogate as fraught with potential conflict of interest and emphasizing the need to get information on values and preferences much earlier (Freeman 1995).

The plight of unbefriended patients resurfaced in a key 1997 article “Treatment Decisions for Patients Without Surrogates” that reviewed existing alternatives and supported the model developed earlier by the New York Task Force on Life and the Law. The authors charged that physicians often decide about treatment for these vulnerable patients without legal authorization, and that this “undermines the well-being of patients, some of whom may receive unnecessary treatment while others may not receive treatment they need. For many, decisions will be made without the consultation or explicit guidelines that shape decisions for other patients” (Miller et al. 1997). This article later was adapted and updated with a focus on nursing home residents, concluding that:

Ideally, treatment decisions for incapacitated residents without surrogates should be the same as those that would be made by the residents themselves. To achieve this goal, nursing homes should make a concerted effort to identify resident’s treatment preferences before the resident loses decision-making capacity. When decisions must be made for incapacitated residents who have not left advance instructions and no natural surrogate exists, professional staff should avoid making decisions in isolation. Going to court or seeking some other type of outside authorization may be necessary for major medical decisions or decisions about life-sustaining care (Coleman & Petruzzelli 2001).

Finally, in 2000, the Joint Conference on Legal and Ethical Issues in the Progression of Dementia (cosponsored by the Alzheimer’s Association, the Borchard Center on Law and Aging, the ABA Commission on Legal Problems of the Elderly, and the National Academy of Elder Law Attorneys) adopted policy recommendations addressing health care decision-making for the unbefriended elderly, urging that:

“Government agencies, legislatures, foundations, and/or other funders should support study of the issue of health care decision-making on behalf of incapacitated individuals who have not executed advance directives and have no family members or other potential surrogates pursuant to state surrogacy statutes. Such study should explore questions about:

- a. Appropriate alternatives to guardianship;
- b. Who may appropriately serve as decision-maker;
- c. Whether a patient’s health care provider or a facility ethics committee can be an appropriate surrogate;
- d. The appropriate standard for decision-making;
- e. Incorporating cultural considerations;
- f. State laws, regulations, pilot projects, or other existing models.” (Alzheimer’s Association, Final Recommendations 2001).

B. Legal Framework for Health Care Decision-Making

Health care decision-making is rooted in the concept of informed consent. Informed consent is based on the principle that a patient has the right to prevent unauthorized contact with his or her

person, and therefore a physician has a duty to disclose information to the patient so that he or she can make an informed decision about treatment. This principle was first articulated by Justice Cardozo in often quoted language in *Schloenforf v. Society of New York Hospitals*, 105 N.E. 92, 93 (N.Y. 1914) (see Meisel 1999; Furrow et al. 1995). If a patient cannot make this decision him/herself, a surrogate authorized under state law can make the decision on the patient's behalf.

Evaluating possible solutions to address the needs of unbefriended patients requires an understanding of laws about surrogate health care decision-making in general. State laws enacted in piecemeal fashion, especially during the past two decades, provide a partial framework for health care decision-making for incapacitated patients. Charles Sabatino of the American Bar Association Commission on Law and Aging has summarized this framework concisely as “the Four D’s”—directed, delegated, devolved, and displaced decision-making.

1. “Directed” Decision-Making allows an individual to direct certain decisions ahead of time by establishing written instructions, as in a living will or anatomical gift designation. A living will is a written statement spelling out an individual's instructions about treatment, or about the withholding or withdrawing of treatment in the event he/she has a terminal or end-stage condition or is permanently unconscious. Forty-seven states and the District of Columbia have living will laws, and all states recognize them. Standing alone, however, a living will is a very limited document, since it usually applies only to end-of-life decisions, and is frequently too general to provide adequate guidance. Moreover, a living will is simply a piece of paper without an agent to bring it to life and to speak on the person's behalf. An unbefriended patient either does not have a living will or the document does not address sufficiently the treatment decision at hand—and the patient has lost the capacity to execute one.

2. “Delegated” Decision-Making allows an individual to delegate authority to make health care decision to a surrogate through a health care power of attorney. A health care power of

attorney is a document appointing an agent (or proxy or representative) to make health care decisions in the event of incapacity. A proxy is expected to weigh alternatives at the time they are known and in light of the patient's personal values. It is a flexible tool that can give an agent as much or as little authority as the individual wishes. All 50 states and the District of Columbia have health care power of attorney statutes. Some state statutes, as well as the Uniform Health-Care Decision Act (National Conference 1993), have begun to move toward greater simplification and greater flexibility by combining living wills and health care powers of attorney into comprehensive advance directive acts. By mid-2000, some 18 states had such comprehensive laws. (Sabatino, ABA Commission, annual legislative updates).

The idea of advance directives is that they allow a person to maintain autonomy by designating who will decide about treatment and what factors the decision will take into account in the event of later incapacity. Advance directives are a way of reaching into the future to preserve some degree of control. But there are limits to advance directives—people often fail to execute such documents, the language may be too general to guide treatment decisions (Teno 1997), providers may not be aware of the directive or may not consult it, and isolated individuals may have no one to name as proxy. As with a living will, an unbefriended patient does not have an effective health care power of attorney and no longer is able to execute one.

3. Devolved Decision-Making Authority. What if there is no advance directive and decisions must be made for an incapacitated person? In the past, physicians often informally relied on family members to make health care decisions. Within the last few decades, however, over 35 states and the District of Columbia have enacted statutes specifically authorizing family consent (O'Connor 1996; Sabatino 2002 update). The Uniform Health Care Decisions Act also provides for decisions by family surrogates.

There are basically two kinds of statutes. The majority include a hierarchy of family and other decision-makers—for example, spouse,

adult child, parent, sibling, other relatives. The highest available person in the hierarchy becomes the authorized decision-maker. The laws generally do not help when there is no traditional family available, although a growing number of states include “close friend” in the list of permissible surrogates. A minority of statutes provide for “interested persons” among a designated list to decide by consensus who should make the decision. In addition, the statutes vary by scope of decisions covered, the handling of disagreements between or among surrogates, and the procedure for challenging a surrogate decision. For unbefriended individuals without natural surrogates (or whose natural surrogates are not available), health care consent laws are of little value—with the exception of those that go beyond family and close friends as decision-makers (as outlined in Chapter IV(C)(1)).

4. “Displaced” Decision-Making refers to judicial intervention by means of guardianship

proceedings or special court transactions. Guardianship is a relationship created by law in which a court gives one person (the guardian) the duty and power to make personal and/or property decisions for another (the incapacitated person or “ward”). All states and the District of Columbia have guardianship laws, and many have significantly reformed these laws during the past 15 years (Wood, ABA Commission, annual legislative updates). Some states have created public guardianship laws and programs for individuals without willing or available friends or relatives to serve (Schmidt 1981; Seimon 1993).

Guardianship is a significant judicial intervention into private lives and health care. It can provide for needs and offer necessary protection with court oversight, yet it is costly, restrictive, often slow, and also removes basic human rights. While indicated in some circumstances, guardianship is generally a last resort to be avoided through “less restrictive alternatives” whenever possible (American Bar Association Commission 1989; Stetson 2002).

III. Case Examples

To provide some initial background and life to this report, we first provide some profiles of real unbefriended elderly individuals described to us during our interviews and site visits. We have given them fictional names and changed a few facts to protect their identities.

Some unbefriended individuals have never had friends or connections, and have had hard and lonely lives. Others have outlived family and friends, and now have no one in their hour of need.

A. Willie O'Donnell

Willie O'Donnell is 89 years old. Ten years ago, he was admitted to Bronx Gardens Nursing Center. At that time, he had been hospitalized for heart problems and was unable to return to his apartment because the hospital social workers believed he could no longer live independently. He already had Alzheimer's disease. The nursing home social worker asked his cousin Frank to cosign his admissions contract so he could get a bed. Frank died two years later. Willie was never married and has no kids. In his early days at the nursing home, Frank and his daughter Stella used to visit on Christmas and occasionally on other days, but no one has visited Willie in quite a few years. The aides at the nursing home know him better than anyone, but they didn't know him before he developed dementia. Staff turnover is high, and most facility staff members do not last more than about two years.

Willie has been getting progressively worse over the years. Last year he was hospitalized for

an infection, and they had to amputate his foot. Hospital staff treated it as an emergency, since he was running a high fever. Nurses report that he has gone downhill even more. He is contracted, has decubiti, and has sepsis for the third time. He's been admitted again to Bronx Academic Medical Center. They do not know whether they should treat him aggressively. The house staff has brought in the palliative care team, but there's nobody to make decisions on Willie's behalf.

B. Mollie Rozofsky

Mollie Rozofsky was one of the "government girls." She came to Washington, D.C. from New York City in 1940 to work for the federal government. She was 22, and there were lots of young women like her then—they were single, there was a war on, and the government had lots of good jobs for bright women who wanted to work. She began working for the Bureau of Labor Statistics, and stayed there until she was 65 and retired. She was the youngest in her family, and a brother was killed in the war. Her older sister and her husband always lived in New York, but her sister died of cancer a few years ago and now her brother-in-law is in a nursing home. She had a good life in Washington, lived in a nice apartment, and kept busy after she retired. But things have gotten harder in the past couple of years. She's 84 now. Some of her neighbors have been worrying about her, and suggesting that she move to assisted living. But she does not want any part of that. She feels that she's always managed on her own just fine. She employed a woman to clean her apartment every other week.

Two weeks ago, Mollie didn't answer the door when the housecleaner arrived. The housecleaner got the building manager to open the door, and found Mollie on the floor unconscious. The

apartment was pretty messy, and there was no food in the refrigerator. They called an ambulance, and rushed her to George Washington Hospital. Her diabetes was out of control and she had gone into a diabetic coma. They found some heart irregularities too. The psychiatrist brought in to interview Mollie says she has dementia. Now she has been in the hospital for two weeks, and hospital discharge planners say they can't find a nursing home to take her because she has no one responsible for her, despite having some money in the bank. Hospital personnel are talking about filing for guardianship.

C. Dora Smith

Dora Smith is a 63-year-old woman who lives in a group home. As a young child, she was diagnosed as having a moderate level of mental retardation. She lived with her mother until her death fourteen years ago. At that time, she was participating in a sheltered workshop in her community. Social workers at the sponsoring agency helped her move to the group home, an arrangement made by Dora's mother before she died. No family members have ever visited Dora since she moved to the facility. Dora has a hearing impairment, wears two hearing aids, and communicates to some extent with a verbal-signing combination. Her caregivers report that she makes simple decisions about food and clothing. She exhibits extremely fearful responses to medical treatment. Recently, Dora had some abnormal blood test results, indicating a thyroid problem. Thyroid cancer is a possible cause. A physician

has recommended a partial thyroidectomy under general anesthesia.

D. Kalman Shapiro

Mr. Shapiro is a 79-year-old Holocaust survivor living in the New York area. He has been admitted to the medical center from the Sinai Nursing Home. An attending surgeon recommends an above-the-knee amputation due to an intractable leg infection and a resultant acute illness. According to the nursing facility, Kalman has been unable to make his own decisions or communicate for the past three years. He has no known next of kin, but has a friend, Moses Zuckerman, who has been closely involved and has been visiting him in the hospital daily. Mr. Zuckerman tells the hospital social worker that he and his wife have been taking care of Mr. Shapiro for seven years, since his second wife died.

When Mr. Shapiro became unable to care for himself about four years ago, Mr. Zuckerman helped make the arrangements to move him to the nursing home. Mr. Zuckerman now requests that the amputation be performed. He relates that he and Kalman Shapiro both are members of the Lubavitch Chassidic sect of Judaism. When the question of the amputation arose, Mr. Zuckerman asked the advice of the "Lubavitcher Rebbe," the sect's religious leader. The Rebbe's response was that it is imperative to do everything possible in order to avoid shortening a human life, even if the treatment involves its own risks. Mr. Zuckerman believes that Kalman Shapiro would want to follow the Rebbe's advice.

IV. Findings

A. Unbefriended Patients

1. How Many Patients?

Data are lacking on the number of socially isolated or unbefriended individuals who have lost decisional capacity. Moreover, estimates of the size of the population are problematic because of the informal and widely varying nature of capacity determinations. There is no “bright line” for capacity to make health care decisions, and individual capacity may fluctuate over time. Additionally, the status of being “unbefriended” is not always readily evident. Reported surrogates may turn out to be unavailable, and conversely investigations may identify surrogates not previously known.

With these caveats, both Gillick and Miller cite studies estimating that about 3 percent of nursing home residents are unbefriended (Gillick 1995; Miller 1997). Gillick concluded that the total population of nursing home residents who are unbefriended may be approximately 60,000. Interestingly, a figure of 3 to 4 percent of total nursing home residents coincides with estimates made during our study by a focus group of facility medical directors. One medical director noted that

The number of unbefriended elderly is unknown, but some studies estimate that it is at least three to four percent of the nursing home population, plus additional patients from the community and the streets. Widely varying capacity assessments make the determination problematic.

in a 110-bed home, there are some three to five unbefriended residents at any one time; while another observed that during the year the county nursing home had sought guardianships for 15 unbefriended individuals out of its total of 360 residents—both roughly 4 percent of the facility population.

Other estimates by interview respondents varied. A medical director of four skilled nursing facilities in an urban area reported that “it’s almost a daily occurrence, at least once a week, that are in this category—probably out of 200 residents, some 80 may become unbefriended at some point [but not at the same time].” A hospital bioethicist said she faced unbefriended patients “probably up to ten times in a year.” Staff of a social service program reported that they handle approximately 250 calls per year regarding end-of-life decisions about people who have impaired decision-making capacity and no designated decision-maker. A large local probate court reported that of 90 recent petitioners, 13 were in need of medical decisions and had no family or friends to help.

The Hastings Center on bioethical research in New York uses a somewhat different definition and estimates a higher proportion of unbefriended individuals. The Center has categorized “isolated and unbefriended persons in long-term care” as those who may or may not retain decision-making capacity but who: (1) have no relative, guardian or responsible party named in the medical record; (2) whose listed relative cannot be contacted; (3) whose relative is unresponsive or uninvolved; and (4) have not received a visitor during the past two years. Using these broad parameters, the Center estimates that “a substantial number of long-term care residents are isolated and unbefriended, perhaps as high as 30 percent or more in some facilities” (Jennings 2001).

Supplementing these estimates are demographic data that may bear on the number of unbefriended, socially isolated elders, and that demonstrate an escalating problem:

- **Graying population.** The U.S. population age 65 and older numbered 35 million in 2000—about one in every eight Americans or almost 13 percent of the total population. The older population will burgeon between the years 2010 and 2030, with the Baby Boomers approaching old age. By 2030, one in five people—a total of about 70 million people—will be age 65 or older. Moreover, the older population itself is getting older, with rapid growth among the 85+ group. By 2050, the percentage in this age group is projected to increase to almost five percent of the U.S. population (www.aoa.gov). The accelerating demographic bulge in the aging population over the next 30 years, coupled with the increased incidence of dementia correlated to age, suggests a substantial growth in the population of unbefriended individuals without decisional capacity.
- **Growing dementia population.** An estimated four million Americans have Alzheimer's disease, the most common dementia. By the mid-21st century, as many as 14 million may have Alzheimer's, unless a cure or prevention is found. One in 10 persons over 65 and nearly half of those over 85 have Alzheimer's disease (<http://www.alz.org/AboutAD/Statistics.htm>).
- **Older adults living alone.** In 2000, about 30 percent (9.7 million) of all non-institutionalized older persons lived alone (7.4 million women, 2.4 million men). They represented 40 percent of older women and 17 percent of older men. As these numbers suggest, older women face potential social isolation at a higher rate than men. The proportion living alone increases with advanced age. Among women aged 75 and over, for example, half (49.4 percent) lived alone (www.aoa.gov/aoa/stats/).
- **Nursing home residents.** In 2000, approximately 1.56 million older individuals representing 4.5 percent of the 65+ population lived in nursing homes. The percentage increases dramatically with age, ranging from 1.1 percent for individuals age 65-74 years to 4.7 percent for those age 75-84 years and 18.2 percent for the 85+ age group (www.aoa.gov/aoa/stats). Historically women represent about 75 percent of residents in nursing homes. In 1997, 1,093,000 women age 65 or older lived in nursing homes, compared to only 372,000 men in that age group (Gabrel 1997). Moreover, the majority of these elders in nursing homes suffer from cognitive impairment (Gruber-Baldini 2000).
- **Nursing home residents without advance directives.** Recent estimates show that approximately 56 percent of nursing home residents have some kind of advance directive “although completion rates vary widely within and between states.” (New York University 2000, citing AHCA 1999). In a single state, more than 80 percent of residents in some homes had a health care proxy, but in other homes the completion rate was only 20 to 25 percent (Teno 1997). This leaves a very significant percent without advance directives—although not all of these residents will have cognitive impairment, and some percentage have family decision-makers under health care consent laws or have guardians.
- **Number in need of guardianship.** While data sources on adult guardianship are scant, a few states have sought to estimate the number of individuals, frequently indigent, in need of a guardian and without willing relatives or friends. According to a Virginia legislative study, there are over 2,000 indigent, incapacitated persons in the state for whom no one is willing or able to act as guardian (Select Committee 2002). Florida's Statewide Public Guardianship Office reports that the need for public guardianship is approaching crisis proportions, and estimates that 1.5 guardianships could be needed per 1,000 in the

population—or close to 2,400 persons (Florida 2000). A Massachusetts expert estimates that 10,000 Medicaid-eligible nursing home residents needed but did not have guardians in 2000 (Ford 2000). The variability of the estimates underscores the need for accurate information.

Thus, existing data sources dance around the central question of the size of the unbefriended population. All that can be gleaned with certainty is that the numbers are significant.

2. Who Are They?

The defining characteristics of the “unbefriended” population are that they are decisionally incapacitated and they are alone. The population is made up of two distinct groups that may require different approaches toward decision-making: (1) those who had capacity and lost it, including many frail elders in nursing homes and hospitals; and (2) those who never had capacity, including persons with mental retardation or developmental disabilities—populations that are aging as medical technology allows for longer lifespans.

For both groups, unbefriended patients are people who frequently have been socially isolated much of their lives. Often, they have fallen through societal cracks and are in a no man’s land without traces of their past or preferences. Dr. Gillick reported in 1995 that “the majority [of unbefriended individuals] live in nursing homes. A few live on their own, and some live in the streets. The combination of cognitive impairment and isolation from family is, for the most part, incompatible with independent living in the community” (Gillick 1995). Respondents described this voiceless and vulnerable group:

- “They are frequently loners who are not and have never been connected.”
- “Little or nothing is known of their past lives, values, choices, histories—by and large, it has vanished. There is no track record of their preferences.”

- “When the decision comes up, we find them most frequently in hospitals and nursing homes. A few are in the community. They are sometimes homeless people who have been in a shelter, go to the hospital and then to a nursing home. They may go back and forth between a nursing home and hospital several times until eventually they die.”
- “They are very old, lonely, primarily institutionalized women.”
- “For the isolated and unbefriended, ethnic or cultural background factors may be harder to clarify and accommodate.”
- “They may have a difficult combination of dementia and severe mental illness, along with lots of physical conditions.”

Unbefriended elders, marginal to society and without advocates, often have multiple chronic conditions that may require immediate decisions when any one of these becomes exacerbated or acute. Interviewees told of unbefriended patients with Alzheimer’s, schizophrenia, pulmonary difficulties, HIV, substance abuse, cardiac problems, diabetes, cancer, alcoholism, high blood pressure, kidney failure and other serious, chronic, sometimes fatal conditions.

The unbefriended elderly: voiceless and vulnerable; frequent loners with multiple chronic conditions, subject to frequent transfers between nursing home and hospital and back. Little or nothing is known of their past lives and values.

While a patient may initially appear to be alone and isolated, sometimes a search can identify contacts who have important information about the person’s past, values, and preferences. A hospital geriatric team in our study explained that “While they may have no family or friends, sometimes the super in their building checks up on

them and brings them to the attention of adult protective services, so in this sense they are not totally unbefriended, although in the legal sense they are. Usually there is somebody to help make decisions. The environment can be remarkably supportive.” Long-term care staff can be an excellent source of information. Some have served residents over time and have become a friend or de facto family. Too often, though, there is simply no one.

B. Health Care Decisions

1. What Kinds of Decisions?

Health decisions might fall roughly into four categories: emergency, routine, major medical, and end-of-life. The boundaries between them may be shifting and uncertain. Moreover, *the same treatment may be viewed very differently* depending on the underlying condition of the patient. Surrogate health care decision-making is concerned primarily with the latter two.

According to longstanding common law, consent for emergency treatment is implied. “The legal requirement for obtaining consent before the rendering of medical care has always been tempered by the privilege to render emergency medical care without the patient’s consent. This privilege is based on the theory of implied consent. The law assumes that [a patient] would consent to emergency care if the patient were . . . able to consent. This is a ‘reasonable man’ standard; that is, the law assumes that a reasonable person would want medical care in an emergency” (Medical and Public Health Law). Thus, medical providers can treat an unbefriended patient in an emergency situation.

What constitutes an emergency varies from state to state, and may be defined by statute and case law. Several respondents we interviewed commented that the emergency exception is sometimes stretched in practice to allow consent when there is no surrogate. “Some cases aren’t emergencies, but if you say that the case will become an emergency if you don’t treat, this is a big loophole,” explained one hospital bioethicist.

Others noted that practitioners may at times “wait until the situation becomes an emergency and then treat”—a sad practice that seems to thwart the basic creed and ethical responsibility of physicians. It “compromises patient care by waiting for a crisis and allows no orderly consideration of a decision . . .” (Hastings 1987).

At the other end of the spectrum, consent generally is not required for “routine” treatment. What is “routine” of course varies by interpretation. Most would agree that absent objections by the patient, consent could be presumed for regular non-invasive monitoring such as checking the heart rate by stethoscope or checking blood pressure, extracting of bodily fluids for analysis, and administration of some medications. Yet a bioethicist in our study pointed out that “decisions like use of an anti-cholesterol drug may seem routine, but can be irritating [to the intestines or stomach] and expensive.” The Veterans’ Administration handbook describes routine treatment not requiring consent as “treatments and procedures that are low risk and are within broadly accepted standards of medical practice (e.g., administration of most drugs or for the performance of minor procedures such as routine X-rays)” (*VHA Handbook*). For unbefriended patients, routine “treatments that would normally be provided to [individuals] with capacity or to incapacitated [individuals] for whom a surrogate exists (for example, medications for pain management) should not be withheld from [those] without surrogates because of misplaced concerns about the need for specific consent” (Coleman & Petruzzelli 2001).

That leaves major medical care and end-of-life treatment. Major medical treatment includes any treatment “that involves significant risk, significant invasion of bodily integrity, or significant pain” (Coleman & Petruzzelli)—for example, surgery requiring general anesthesia or the administration of psychotropic drugs. End-of-life treatment might include ventilator support, artificial nutrition and hydration, antibiotic therapy, and decisions concerning hospitalization for aggressive care. Decision-making solutions may lump these both together — or may outline different procedures for each,

increasing the accountability mechanisms for patients who are in a terminal condition.

Respondents we interviewed described a range of situations requiring a surrogate decision for unbefriended patients—including cases in which patients needed diagnostic or treatment interventions and frequently were transferred repeatedly from long-term care to acute care, sometimes several times:

- An elderly schizophrenic nursing home resident with dementia failed to eat. Should he have a feeding tube inserted?
- A younger mentally retarded individual required extensive dental work under anesthesia.
- An elderly unbefriended patient was sent from a nursing home to the hospital with a prolapsed rectum. A consulting physician recommended that the patient's colon be removed and that the patient should have a colostomy bag.
- An elderly patient was admitted to the hospital with squamous cell cancer of his nose. He was a former alcoholic. Upon admission, he was delirious, confused and short of breath. He had pneumonia.

Numerous sources, as well as respondents in our study, point out that there is no necessity to provide the option of consent for treatment that is not medically indicated or considered “futile.” “If there is no medical justification for providing the treatment (i.e., if the treatment is not consistent with the prevailing standard of care), it should not be given to the resident regardless of his or her ability to provide consent” (Coleman & Petruzzelli 2001). Of course, there is no consensus on the definition of “futility” and “futile treatment,” and there is significant medical and legal literature on ethical issues arising from differing interpretations (Schneiderman, Jecker & Jonsen 1996; Daar 1995; Basta 2001).

Much of the literature on medical futility involves cases in which patients or surrogates

demand certain care and the physician judges it is futile and refuses to provide it. This scenario, of course, does not apply to unbefriended patients. Rather, futility might arise in cases where a physician does not offer certain treatment procedures as options, deeming the treatment in his/her best professional judgment to be not medically indicated—and because the patient is alone, this is never challenged. Participants in our symposium observed that physicians sometimes may rely on the concept of futility as a way out—a means of making decisions for the unbefriended population without the need for obtaining consent or identifying a surrogate. To what extent this occurs is unknown.

Decisions requiring consent concern major medical and dental treatment and end-of-life treatment. Decisions not requiring consent include those characterized as “routine,” “emergency,” or in which the care would be “futile”—but these terms are malleable and depend on the underlying condition of the patient.

2. Who Are the Decision-Makers?

Unbefriended individuals by definition lack surrogates. However, the population might be significantly narrowed by a diligent search for surrogates for patients who initially present as being completely alone. For example, the director of a hospital ethics committee explained that “patients who appear to be unbefriended actually may have people who can make decisions or at least give information to help ascertain the patient's wishes. Sometimes patients arrive who don't speak English and who seem to be unbefriended but if you make the effort to communicate and investigate, you find out that they're not alone.” Frequently, however, there is no time to search for these contacts—or a search is fruitless. The question then becomes who should be the decision-maker of last resort.

Much of our study revolved around who should make decisions for unbefriended

individuals, and particularly whether the decision-maker(s) should be internal to a hospital, nursing home, or other facility or external and thus perceived as more independent. The universe of statutory and de facto decision-makers we encountered included:

- Physicians—treating physicians, and other physicians giving concurring opinions;
- Social workers or others in the helping professions, such as clergy; even an owner, operator, or employee of a residential facility in one state;
- Adult protective services workers;
- Hospital or long-term care ethics committees or ethics consultation teams;
- External committees such as regional ethics committees or decision-making committees;
- Guardians—including plenary guardians, as well as limited guardians appointed solely for the purpose of making the treatment determination. Guardians could be from public or private agencies, and could be staff or volunteers;
- Judges—in a general court, or a limited jurisdiction courts such as probate or family court.

Legislative solutions and institutional practices—and the pros and cons of each—involving these players, and the roles of each, either alone or in combination, formed the primary focus of our study and are described below.

3. How Are Decisions Made?

The problem is not only who will make the decisions but how the decisions will be made. Health care decision-making law and literature outline two standards for making treatment determinations: (1) the “substituted judgment” standard, in which the surrogate decision-maker uses the values, preferences, instructions, and wishes of the patient, to the extent they are

known; and (2) the “best interest” standard in which the surrogate is guided by what a reasonable person might choose, weighing the benefits and burdens of the medical options (Uniform Health Care Decisions Act; Beauchamp & Childress 1983; Hastings 1987). Most state health care decision-making laws and guardianship laws provide a two-step procedure—the substituted judgment standard will be used if there is information on patient values, but the fallback will be the best interest standard if there is not.

The dilemma for unbefriended patients is that their values and histories generally are unknown, precluding a substituted judgment. This leaves “best interests” as the guiding force—a vague measure inevitably subject to the life-view of the decision-maker, who may not have the same ethnic or cultural context as the patient. Sometimes, however, there may be scattered bits and pieces of information, clues from a patient’s past, to inform the best interest approach to a limited extent. The patient’s ethnic and cultural background, if known, may provide a useful framework—yet the danger is a rote or stereotypical decision based only on ethnic mores when in fact individual preferences, if known, might be entirely different.

In any case, the decision frequently will be a tough one and a messy one—and several of our interview respondents maintained it should be. One bioethicist remarked that “these cases have to be messy. It would not be good to have a smooth, easy protocol for dealing with the decisions. . . . You need someone to say ‘stop, lets see what to do about this person.’” Another observed that “sometimes the decision-making may be messy and this may be better than a slick model that does not afford adequate attention to individual needs.” Many recommended a team approach with nuanced discussion and consensus building.

“These cases have to be messy. It would not be good to have a smooth, easy protocol for dealing with the decisions.”

C. Legislative Solutions

Our study identified four legislative paths to health care decision-making for unbefriended patients:

- (1) authorization under state health care consent laws or specific consent statutes;
- (2) statutorily created surrogate decision-making committees;
- (3) public guardianship; and
- (4) Specific court authorization for treatment; or limited temporary medical treatment guardians.

1. Authorization Under Health Care Consent Statutes

A handful of states have enacted statutory authorization for health care consent when no surrogate is available—that is, statutory consent of last resort. In some states, the designation of a last resort decision-maker is part of the health care consent statute—a provision added at the end of the listed hierarchy of mostly family decision-makers. In other states, lawmakers have simply identified a decision-maker for unbefriended patients, most frequently a physician, generally in consultation with other medical personnel, frequently with specific limitations (*see* “Statutory Authorization for Treatment” chart, pages 20-21).

These provisions give clarity—helping to avoid a purely ad hoc procedure without legal basis on the one hand, and a court procedure with attendant time and expense on the other hand. Provisions that require consultation (Alabama, Arizona, Texas general provision, West Virginia) at least on their face encourage a stronger and more thorough process than those that rely on a single individual alone. “Patients are well served by a decision-making process that involves more than one person’ (Miller 1997).

State staff in Texas noted that the phrase “a member of the clergy” is very broad, and could

include someone with no knowledge of individual values, or even a member of a denomination with opposing values—“There have been rumblings about possible revisions to narrow it to a clergy member with whom the person has a relationship, but there are fears that this would narrow it so much as to make it unworkable. Sometimes a hospital has an in-house clergy, and this person makes decisions for unbefriended individuals.”

Under the West Virginia code, the wording allows the Department of Health and Human Resources to serve when there is no one else. In practice, the decision may be made by a Department social worker, in collaboration with or with approval of the social worker’s supervisor. The social worker may seek guidance from an institutional ethics committee, but ultimately has the final say. If there is no local ethics committee and the social worker needs guidance, a Department-coordinated state ethics committee may be available to meet by telephone. (*See* Chapter IV(D)(1), page 33.)

Most of the provisions give the key role to the *attending physician*. While consultation with others may be added as a safeguard, there are still significant drawbacks, as observed by the 1997 article by Miller et al. First, especially with the growth of managed care, decisions could be driven by financial incentives. Second, decisions may be subject to the personal values of the physician. Miller points out that “unless the treatment is futile, in the sense that it offers no physiological benefit, decisions to forgo life-sustaining treatment are social and ethical, not medical judgments. They are often deeply personal decisions and, if left to individual

There are pros and cons of attending physicians as decision-makers. On the one hand, they could be driven by financial incentives and personal values, and there is no review and accountability. On the other hand, physicians are bound by strong ethical standards, have vast medical experience, and may have had an ongoing physician-patient relationship.

| Statutory Authorization for Treatment | | |
|--|---|--|
| State & Citation | Decision-Maker | Limitations |
| <p>Alabama Ala. Code §22-8A-11(d)(7). Part of health care consent statute.</p> | <p>Patient's primary treating physician and facility ethics committee, acting unanimously, or if no ethics committee, by unanimous consent of a committee consisting of: (i) the primary treating physician; (ii) the chief of medical staff or designee; (iii) the patient's clergyman or member of the clergy associated with, but not employed by or an independent contractor of the facility, or social worker associated with but neither employed by nor independent contractor of facility.</p> | <p>Patient must be in terminal condition or permanently unconscious.</p> |
| <p>Arizona Ariz. Rev. Stat. Ann. §36-3231. Part of health care consent statute.</p> | <p>Attending physician, after consulting with institutional ethics committee, or if none, second physician.</p> | <p>Surrogate may not make decisions to withdraw nutrition or hydration.</p> |
| <p>Connecticut Conn. Gen. Stat. Ann. §19a-571(a)</p> | <p>Attending physician.</p> | <p>Limited to withholding or withdrawing of life-sustaining treatment from patient in terminal condition, if the physician has considered the patient's wishes as communicated to any person.</p> |
| <p>Mississippi Miss. Code Ann. §41-41-211(9) & §41-41-215(9)</p> | <p>Owner, operator or employee of residential long-term care institution where patient resides.</p> | <p>Does not extend to decisions to withhold or discontinue life support, nutrition, hydration, or other treatment, care or support.</p> <p>Physician must determine that medical treatment is necessary.</p> |
| <p>New York N.Y. Pub. Health Law §2966</p> | <p>Attending physician.</p> | <p>Limited to issuance of a DNR (do not resuscitate) order for patients in terminal condition if resuscitation would be medically futile.</p> |

| Statutory Authorization for Treatment, Continued | | |
|---|---|---|
| State & Citation | Decision-Maker | Limitations |
| North Carolina N.C. Gen. Stat. §90-322(b) | Attending physician. | Limited to extraordinary means or withholding or discontinuance of artificial nutrition or hydration for patients in terminal condition. |
| North Dakota N.D. Cent. Code §23-06.4-06.1(3). | Attending physician. | Limited to withdrawal or withholding of nutrition or hydration if nutrition or hydration cannot be physically assimilated or would be physically harmful or cause unreasonable physical pain. |
| Oregon Or. Rev. Stat. §127.635(3) & (4). Part of health care consent statute. | Attending physician, after consultation with case manager. (Note: A separate section provides for surrogate consent for adults with developmental disabilities, with participation of Individual Support Plan team members.) | Limited to withdrawal or withholding of life-sustaining procedures, and patients who are in terminal condition, permanently unconscious or who meet other conditions. |
| Texas Tex. Health & Safety Code Ann. §166.039(e). Part of health care consent. | Attending physician and independent concurring physician or representative from ethics or medical committee of facility. | |
| Texas Tex. Health & Safety Code Ann. §313.004 | A member of the clergy. | Patients in hospitals and nursing homes. |
| West Virginia W. Va. Code §16-30-8 | Attending physician or advanced practice nurse in collaboration with attending physician authorized to select a surrogate, including any person or entity including but not limited to public agencies or officials, public and private corporations or others which department of health and human resources may designate in rules. | |

physicians, will inevitably reflect the physician's own views and values."

Third, traditionally, doctors in the American health care system are not surrogate decision-makers and may not be comfortable in that role. "When family members or friends decide for patients, the physician performs a vital role in recommending treatment options, reviewing decisions, and challenging those that seem clearly wrong. This safeguard is lost if one person acts as both surrogate and physician." Finally and significantly, there is no review and accountability for the decision, and thus these critical and intimate decisions "will remain largely private choices at the discretion of each physician."

On the other hand, some of the physicians in our study expressed a different view. They asserted that physicians are bound by ethical standards, have vast experience with medical outcomes, frequently consult with others—and that in a dire situation they "know what to do, and just do what seems best." In addition, attending physicians sometimes may have had some prior relationship with the patient, and may have developed some rapport over time—whereas a hospital clergy member or social worker likely would not have had this opportunity to get to know the patient at all.

Clearly, the approach of health care consent and similar statutes is to designate one or more decision-makers *internal* to the health care facility. Some experts maintain that this is most efficient and allows decision-making closest to the patient. Others argue that the risk of bias is simply too great, and that only a body *external* to a facility ensures sufficient objectivity and independence. The remaining statutory paths all designate external.

2. Surrogate Decision-Making Committees

Three states have enacted laws authorizing external committees to make health care decisions on behalf of unbefriended individuals. These statutory statewide systems focus primarily on persons with mental retardation, mental illness or developmental disabilities rather than frail

incapacitated long-term care residents, but are instructive as a working model of external decision-making. Moreover, the mental disability population increasingly is aging. These systems are summarized on the "Provisions Concerning Surrogate Decision-Making Committees" chart on page 23.

a. New York Surrogate Decision-Making Committee Program

In 1984, the New York State Commission on Quality of Care for the Mentally Disabled conducted investigations and hearings on the problem of getting informed consent for major medical treatment for individuals with mental disabilities. The Commission found untenable delays in obtaining court authorization for necessary surgical and other medical procedures, as well as dental treatments requiring general anesthesia. Patients were left in pain and deteriorating health while awaiting a frequently pro forma court review, and providers were skirting the concept of informed consent to give needed and timely treatment (Sundram 1997).

As a result, the New York State Legislature enacted the Surrogate Decision-Making Committee Program in 1985 (N.Y. Mental Hyg. Law art. 80). The law—known as "Article 80"—empowered committees of trained volunteers to exercise medical decision-making authority on behalf of incapacitated residents with mental disabilities who are without legal surrogates. (New York has no health care consent law, so this sometimes includes individuals with family members.) After an independent evaluation, the legislature made the program permanent and authorized its expansion from an early demonstration project. The program has been statewide since 2001. It is operated by the New York Commission on Quality of Care for the Mentally Disabled. Key features include:

- **Population served.** The program covers residents of mental hygiene facilities—who may have mental retardation, mental illness or developmental disabilities—and those living in the community under a Medicaid waiver who qualify for mental hygiene facility care.

| Provisions Concerning Surrogate Decision-Making Committees | | | |
|---|--|---|---|
| State & Citation | Population Served | Decision-Makers | Scope of Treatment |
| New York N.Y. Mental Hyg. Law art. 80 | Residents of mental hygiene facilities (who may have mental retardation, mental illness, or developmental disabilities; and those in community under Medicaid waiver). | Trained volunteer panel—attorneys, medical professionals, family members or consumers, advocates. | Major medical treatment decisions. Excludes decisions about withdrawal of or discontinuance of life-sustaining treatment, electro-convulsive therapy, sterilization, termination of pregnancy. |
| Texas Tex. Health & Safety Code Ann. Chp. 597 | Residents of intermediate care facilities for the mentally retarded (ICF-MR facilities). | Trained volunteers - health care professionals, consumers or family, attorneys, advocates, persons with expertise. | Major medical or dental treatment decisions that physician certifies is needed. Includes decisions about psychotropic medication or highly restrictive behavior even if there is a surrogate. Excludes life-sustaining treatment decisions. |
| Iowa Iowa Code Ann. §§135.28 & 135.29 | No stated limitation on population, but most of requests from state institutions for persons with mental retardation or developmental disabilities. | State and local substitute medical decision-making boards of volunteers comprised of medical professionals and lay persons. | Major medical treatment and placement decisions. Excludes life-sustaining treatment decisions. |

- Medical treatment included.** The program targets consent for decisions concerning major medical treatment. This includes medical, surgical, dental or diagnostic interventions or procedures that involve use of a general anesthetic, significant invasion of bodily integrity or significant risk. The program excludes withdrawal of or discontinuance of life sustaining treatment, electro-convulsive therapy, sterilization and termination of pregnancy, as well as routine and emergency treatments.
- Volunteer panels as decision-makers.** The Commission recruits and appoints volunteers for two-year terms. The volunteers serve on panels of four, and are immune from liability for their decisions. There are four types of

panel members: attorneys; medical professionals; persons who have family members who have been consumers of mental hygiene services or who have been consumers themselves; and advocates with expertise or interest in the mental disability population. All panelists receive a minimum of one day of training. The statewide listing includes more than 950 volunteers.

- **Case procedure.** An interested person such as a nurse or social worker from the facility may initiate consent to medical treatment for a mental hygiene patient by filing an application with the Commission. The case is then sent to one of seven local offices for scheduling. The local office calls together a panel of volunteers from the roster, sets a date for a quasi-judicial hearing, and gives at least five days notice to the patient and others concerned. The patient is represented by a Mental Hygiene Legal Services attorney in every case. The hearing takes place in the county where the individual resides, and may be held at a central location or hospital, the mental hygiene facility, a residence or other convenient place. The patient, the patient's caregiver, and any others concerned come to the hearing and sit at the table with the four panel members.

The hearing begins with formal introductions and the chair reads a statement on hearing procedures and rights. The panel asks questions—beginning with questions to the patient—and reviews the information provided to them in advance. The panel members then confer privately and make a decision. The average hearing time is about 25 minutes, plus a short period for panel deliberations. Generally, cases are resolved within about 13 days, but expedited cases are heard within five days. The hearing is tape recorded, in case questions arise later. The consent lasts for 60 days. The decision does not include a stated rationale. There is an appeal process for court review, but this rarely occurs

- **Decision-Making process.** The panel members must make three determinations: (1) Is the patient unable to consent to medical treatment, as shown by clear and convincing evidence? (2) Are there no authorized surrogates willing and available to make the decision, as shown by clear and convincing evidence? (3) Is the proposed major medical treatment in the best interest of the patient, as shown by a fair preponderance of the evidence? “Best interest” is defined in the law as “promoting personal well-being by the assessment of the risks, benefits, and alternatives to the patient of a proposed major medical treatment, taking into account factors including the relief of suffering, the preservation or restoration of functioning, improvement in the quality of the patient's life with and without the proposed major medical treatment, and consistency with the personal beliefs and values known to be held by the patient” (N.Y. Mental Hyg. Law 80.03(d)). Three panel members must concur in each of the three questions.

To date, the program has heard about 7,000 cases, with some 1,200 in the most recent year. In some 96 percent of cases, the panel votes to go forward with the medical procedure. The program director reports the approximate cost per case at about \$260. What kinds of cases are these? Examples are illustrative:

- A patient with schizophrenia had developed a massive hernia, but denied having the hernia and refused an operation (Lipton 2002).
- A mentally retarded woman with a hearing impairment had a biopsy that identified cancer cells and the physician recommended a partial thyroidectomy.
- A 49-year-old man with mental retardation needed dental work under general anesthesia.
- A 56-year-old woman with mental retardation had a physician's recommendation for a colonoscopy to screen for colon cancer.

The program's coordinators observe that the system "works extremely well." A review of the first ten years of program operation noted that it is "not only . . . a viable alternative to the judicial process, but it is a preferable one, given the general lack of expertise courts have in mental disabilities and major medical care The procedure gives dignity to patients who are mentally disabled by ensuring not only that they are present at the hearings, but that they are given an opportunity to be heard and have the opportunity to hear medical witnesses describe the benefits and risks of the proposed medical treatment, in language intelligible to the laypersons who serve on the panels An unexpected discovery has been the strength of the spirit of volunteerism and the dedication to the well-being of the persons with disabilities" (Sundram 1997). A physician commented that "This program is an exceptionally humane way to provide care for individuals who are incapacitated. It expedites treatment . . . The people who are [making the decision] are genuinely interested in the patient's medical well-being and looking out for [the patient] legally and making sure that this procedure really needs to be done" (Lipton 2002).

Some of the respondents in our study questioned whether volunteers had sufficient training and time to make complex medical decisions taking into account patient preferences and values. An article about the program observed that since the committee decisions follow the physician recommendations in all but a few cases, "review of decisions by an outside committee may not substantially improve decisions reached at the facility level" (Miller 1997). Yet the committees seem to provide a valuable service, giving attention through a structured, interdisciplinary process to decisions that otherwise might lack accountability—or fall by the wayside and just never get made.

Could the Article 80 surrogate decision-making committee program be expanded through legislation to serve an elderly population with dementia? The program coordinators say yes—"it could work well and would be a good alternative to guardianships. It is very efficient and high quality. Although nursing home residents may

have multiple chronic conditions and might need multiple health care decisions, that is not so different from the current population. Some clients have come before the committees as often as 30 times." The ten-year review agreed: "The program could serve other populations in need—such as the frail elderly in nursing homes . . ." (Sundram 1997). Miller et al. see it differently, finding it "unlikely that the Article 80 system could be expanded to cover treatment decisions for all patients, including older patients, who lack surrogates in hospitals and nursing homes. Given the volume of cases likely to arise, committees comprised of volunteers would be difficult to establish and administratively complex to manage" (Miller 1997).

Could external surrogate decision-making committee systems targeted for patients with mental retardation and developmental disabilities be expanded to serve an elderly population with dementia?

b. Texas Surrogate Decision-Making Program

Based on the experience of New York, Texas enacted a similar program of surrogate decision-making committees in 1993 (Tex. Health & Safety Code Ann. chp. 597). The Texas program is limited to residents of intermediate care facilities for the mentally retarded (ICF-MR facilities). Unlike New York, Texas has both a general health care consent statute and a special health care consent statute for the ICF-MR population. The ICF-MR statute requires that family and other decision-makers be "actively involved." The surrogate decision-making committees of trained volunteers serve in cases where: (1) an interdisciplinary team in the facility has assessed that the resident lacks capacity to consent; (2) there is no actively involved surrogate; and (3) there is a need for a decision about psychotropic medication or "highly restrictive behavior procedures," regardless of whether there is an involved surrogate. The program is coordinated by the

Texas Department of Mental Health and Mental Retardation. If an ICF-MR facility determines that a case falls into these categories, the facility applies to the Department for appointment of a surrogate committee. The committee of three to five volunteers, who are immune from liability, includes some of the following: health care professionals, persons with mental retardation or relatives of such persons, attorneys, advocates, and persons “with demonstrated expertise or interest in the care and treatment of persons with mental disabilities.” The patient and those involved receive notice, and the committee holds a review. The hearings are generally at the facilities, but may be at a nearby community location. The patient is entitled to be present and to present evidence. The committee makes a determination based on clear and convincing evidence of whether the proposed treatment promotes the individual’s best interest. In assessing best interest, “the committee shall consider fully the preference of the client as articulated at any time” (Tex. Health & Safety Code §597.049).

According to Department staff, most of the applications are for decisions concerning psychotropic medication. The surrogate committees heard over 490 cases last year. The system includes only those counties in the state that have ICF-MR facilities—about 20 percent of the counties. The Department maintains a list of over 450 volunteers.

Could the program be expanded to serve an elderly population with dementia? Department staff maintained that it could, but this would require an infusion of considerable funding. “There would have to be committee members with the proper qualifications, which might differ from current committee members. Hospital ethics committees might offer a good source of expertise for expanding the volunteer base. There would have to be significant additional training, and there is not enough training as it is.”

c. Iowa Substitute Medical Decision-Making Board

In 1989, before the state of Iowa had a medical power of attorney law and a health care consent law, the legislature enacted a statute estab-

lishing a state substitute medical decision-making board and local boards as well (Iowa Code Ann. §§135.28 & 135.29). The local boards may “act as a substitute decision-maker for patients incapable of making their own medical care decisions if no other substitute decision-maker is available to act.” The state board is to formulate policy and guidelines for the local boards and “to act if a local substitute medical decision-making board does not exist.”

Both the state and local boards are to be “comprised of medical professionals and lay persons,” and members are immune from liability for their decisions. The members of the state board are appointed by the director and the state board of health, and the members of the local boards are appointed according to state rules. Panel members include physicians, clinical social workers, lawyers, nurses, and service providers. All board members are volunteers. The state decision-making board is operated by the Department of Public Health. Currently there are nine local boards covering about one-tenth of the state. There is no state funding for the process. Local board cases are very rare. A member of one local committee said to her knowledge the committee had never been convened to make a decision. The state board also receives few cases—the coordinator estimated about five cases per year.

The boards may act “in situations where there is sufficient time to review the patient’s condition, and a reasonably prudent person would consider a decision to be medically necessary.” The boards do not cover end-of-life decision-making. A 2002 opinion from the Attorney General’s Office authorized the boards to make long-term care placement decisions in addition to major medical treatment decisions. When a request comes in to the state board, the patient is notified and is seen by the board whenever possible. Because of the vast rural areas of the state, some of the board meetings are conducted via video conferencing. According to the state coordinator, there is usually a four-person panel. The boards must determine whether the person lacks the capacity to consent, and then must make the medical decision. A recent case described by the coordinator involved a Bosnian immigrant who had lost his job and had severe depression. He had staples in the side of his

head, causing brain damage, and a surgical procedure was needed.

While there is no limitation on the population to be served, most of the requests come from state institutions for persons with mental retardation or developmental disabilities. Most of the cases are for consent for surgery. Nursing homes generally do not use the process, and hospitals usually insist on appointment of a guardian. The coordinator views the board process as “a good thing. It’s not a rubber stamp, but rather renders well thought out decisions. It fills a gap.”

3. Public Guardianship

Many states and localities have addressed the need for both health care and financial decision-making of the unbefriended population by creating public guardianship programs. In other areas not-for-profit and for-profit agencies or solo professional guardianship practitioners seek to fill this need—especially for individuals with sufficient resources. A public guardian, as distinguished from other guardian service providers, is an entity that receives most if not all of its funding from a governmental entity. Public guardianship programs are funded through state appropriations, Medicaid funds, county monies, fees from the ward, or some combination. In 1980, some 34 states had a statutory provision for public guardianship (Schmidt 1981). Today, most or all state laws either make explicit statutory provision for a “public guardian” or implicit reference to a process to identify a guardian of last resort. Public guardianship programs may serve older incapacitated persons, as well as individuals with mental retardation and/or developmental disabilities. They may be operated from one statewide office or have local/regional components—and in addition, a number of local jurisdictions have developed their own public guardianship programs.

In 1981, the Florida State University Institute for Social Research published a comprehensive report of a study funded by the U.S. Administration on Aging, *Public Guardianship and the Elderly* (Schmidt et al.), which still stands as the seminal work on public guardianship. Professor Schmidt classified public guardianship

programs into the following models: (1) independent state agency; (2) government agency providing social services; (3) private sector via volunteers or contract; (4) government employee not providing social services; and (5) other. Current examples demonstrate the range of programs within these broad classifications. Alaska’s Office of Public Advocacy is an independent state public guardianship agency. Virginia’s Public Guardianship and Conservatorship Program is located in the Department for the Aging, and contracts for nine regional programs throughout the state. In Idaho, the legislature authorizes each county’s board of commissioners to create a board of community guardian. The Kansas Guardianship Program is an independent, quasi-governmental, non-profit corporation using volunteers throughout the state. In Maryland, area agencies on aging serve as guardian for older individuals.

The 1981 report observed that “naming social service agencies to act as public guardians represents an inherent or potential conflict of interest.” The report also urged that programs that petition for adjudication of incapacity should not be allowed to serve as guardians; and that strict procedures should accompany public guardianships. The report concluded with forthright recommendations:

Public guardianship is being endorsed, but only if it is done properly. By ‘properly’ we mean with adequate funding and staffing, including specified staff-to-ward ratios, and with the various due process safeguards that we have detailed. . . . The office should be prepared to manage guardianship of person and property, but it should not be dependent upon the collection of fees for service. The functions of the office should include the coordination of services, working as an advocate for the ward, and educating professionals and the public regarding the functions of guardianship. The office should also be concerned with private guardianship, in the sense of developing private sources and to some extent carrying out an oversight role (Schmidt 1981).

Since the landmark 1981 report, public guardianship has grown significantly. During the past 15 years, a number of states have established statewide public guardianship programs: Indiana (1989, program within department of human services, to contract for regional services); New Mexico (1995, consolidated guardianship services in various state agencies into program within attorney general's office); Virginia (1998, program within department for the aging, to provide funding to local/regional projects throughout state); Utah (1999, program within department of human services, may contract with local providers, may recruit volunteers); Florida (1999, program within department of elderly affairs, may establish local programs); and most recently Oklahoma (2001, pilot project established, with statewide expansion to depend on evaluation and funding). Several other states made statutory changes in existing programs, established study commissions on public guardianship, or addressed the authority for social services agencies to be appointed as guardian (Wood, *Directions of Reform*).

Despite the growth of public guardianship, only a handful of state and local studies (Steinberg 1985; Schmidt et al. 1988; Teaster & Schmidt 1997; Teaster & Roberto 2001 & 2002; TCSG 2001) have examined the institution of public guardianship. Several of these studies have identified serious systemic problems, especially as to accountability and staffing. In an effort to update the 1981 Schmidt study, researchers re-analyzed state statutes in 1993, and interviewed staff in a number of state programs. They found public guardianship offices “understaffed and underfunded . . . approaching the saturation point in number of wards” (Siemon, Hurme & Sabatino 1993). A 1998 survey of its members by the National Guardianship Association showed that

Many states and localities have public guardianship programs, but some are woefully underfunded and understaffed. The last comprehensive national research on public guardianship was in 1981.

public guardianship staff often strained under dangerously high caseloads (1:41 to over 1:141). (NGA Agency Directory 1998). This staffing crunch may intensify as states face grim budget shortfalls.

There is widespread agreement by experts in the aging and disability fields on the need for increased attention to guardianship practices generally and public guardianship specifically. The 2001 national “Wingspan” Guardianship Conference urged that “states provide public guardianship services when other qualified fiduciaries are not available”; that “the public guardianship function [should] include broad-based information and training”; that “guardianship agencies . . . should not directly provide services such as housing, medical care, and social services to their own wards, absent court approval and monitoring”; and that “funding for development and improvement of public . . . guardianship services” should be identified and generated” (*Stetson Law Review* 2001).

Because of the lack of in-depth, systemic research on public guardianship systems, key questions that bear directly on the quality of care and quality of life for their unbefriended clients remain largely unanswered. Research on the following questions might help to indicate what populations might best be served by public guardianship programs as opposed to the kinds of external committees described above:

- **Holistic view, continuity, follow-up.** Can and do public guardianship programs provide more continuity and depth to surrogate decision-making than a program that makes only one-time health care determinations? In practice, which modes offer more individualized attention to complex and intimate health care needs of an individual who is alone, at-risk and neglected by society? For example, do public guardianship programs better integrate health care and any financial decisions? Do they follow up and monitor health care decisions as they are implemented? Do they develop values histories and decisional logs in client case files to guide individual decisions? Are public guardianship

programs advantageous when there may be need for multiple health care decisions?

- **Timeliness.** Are public guardianship programs able to act quickly enough on critical health care decisions? If there is no guardianship in place, can a guardianship be initiated in a timely manner when a health decision is needed?
- **Judicial monitoring.** Are there benefits in the court oversight of health care decisions through public guardianship programs, as compared with surrogate boards that are under the aegis of administrative agencies?
- **Cost.** What is the cost of public guardianship programs and are they prohibitive as a means of making health care decisions quickly and efficiently?

Regardless of the merits of public guardianship as a solution for health care decision-making for unbefriended patients, the need currently far outstrips the resources, and will escalate dramatically with the aging of the “baby boom” cohort. Public guardianship is needed—but it can be only one piece of the puzzle.

4. Judicial Authorization for Treatment and Temporary Medical Treatment Guardians

An additional approach in state law is judicial authorization for treatment. Some states have enacted a court process to seek consent for health care or to seek appointment of an individual to give consent. Either there is a “single court transaction” in which the judge makes a health care determination and orders the treatment, or there is court designation of a very limited guardianship—a “temporary medical treatment guardian” for the sole purpose of making the health care decision. These judicial processes generally are simpler and quicker than a full-fledged guardianship proceeding.

a. State Judicial Authorization Provisions

Statutes in at least five states (and judicial rules in at least two additional states) describe a judicial process for authorization for treatment. This gives a stamp of approval—a “moral certainty,” as one bioethicist observed—that some might find lacking in volunteer boards or ethics committees, yet is not as cumbersome or expensive as guardianship. The question, of course, is whether “judges at the bedside” are best qualified to act. Judges stand far from the incapacitated person at risk, and their knowledge of the treatment options may be scant. They may “have only the sketchiest understanding of the medical issues involved, may have never seen what the patient is suffering, and may base their decisions on a brief legal hearing. . . . Judges bring differing degrees of skill to the enterprise [and are] at the greatest distance from the wishes of the person in the bed” (Dubler 1992). However, the statutes, as profiled below, serve as an additional surrogate decision-making mechanism, offering some protection and public oversight (*see* “Examples of Judicial Authorization Provisions” chart, page 30).

- In **California**, a person may file a petition in probate court to determine that a person lacks capacity to give informed consent to a specified medical treatment, and for an order authorizing a designated person to give consent to such treatment. The treatment must be “in accordance with the patient’s best interest, taking into consideration the patient’s personal values to the extent known to the petitioner.” Placement in a mental health treatment facility, experimental drug treatment, convulsive treatment, and sterilization are excluded.
- A **Florida** probate rule allows “any interested adult person” to file a petition for expedited judicial intervention concerning medical treatment for an individual who “lacks the capacity to make the requisite medical treatment decision.” The patient and others must receive notice of the petition, and the

| Examples of Judicial Authorization Provisions | |
|---|---|
| State & Citation | Provisions |
| California Cal. Probate Code §§3200 - 3212 | Petition to probate court for order authorizing designated individual to give consent for treatment. |
| Florida Probate Rule 5.900 | Petition to court for expedited judicial intervention concerning medical treatment procedures. |
| Georgia Ga. Code Ann. §§31-36A-1 | Petition to court for authority to make health care placement decision. |
| Indiana Ind. Code Ann. §16-36-1-8 | Petition to probate court for health care decision or appointment of representative to make decision. |
| New Jersey N. J. Court Rule 4:83-12 | Court may appoint special guardian for medical treatment. |
| South Dakota S.D. Codified Laws §34-12C-4 through 6 | Petition to circuit court for health care decision or appointment of representative to make decision. |
| Virginia Va. Code §37.1-134.21 | Petition to circuit court for treatment decision. |

court must hold a preliminary hearing within 72 hours, and either rule on the request or conduct a full evidentiary hearing within four days.

- **Georgia** health facilities experienced longstanding problems with discharging unbefriended persons from a hospital and transferring them to long-term care facilities or elsewhere. Historically, facilities tried to use the emergency guardianship procedure. In 1999, the legislature enacted a Temporary Health Care Placement Decision-Maker for An Adult Act. The law sets out a priority list of persons authorized to make discharge, transfer and admission decisions, and provides that if there is nobody available, any person can petition for authority to place the

person. A hearing is not required. The court order must state that the move is in the adult’s best interest; it is “the most appropriate” placement available that provides the “least restrictive and most appropriate level of care;” and alternative placements including home and community based care were considered. The process is being used and according to a respondent in our study, “it seems to be working—hospitals get what they need to discharge patients” with attention to their needs and preferences.

- **Indiana** law permits health care providers or other interested individuals to petition the probate court to make a health care decision or order health care for a person incapable of consenting, or to appoint a representative to

act for the person. The court must find that a decision is required and there is no individual authorized to consent (or an authorized individual is unavailable, refuses to act or is not acting in the patient’s best interest). The statute requires notice and a hearing, which can be waived if the court finds that delay will adversely affect the person’s health. A respondent in our survey commented that hospitals sometimes use this provision “when they have someone in the hospital whom they cannot place, usually to a nursing home, without a court order . . . but I have not seen other providers doing this.”

- A **New Jersey** court rule adopted in 1986 provides for a “special medical guardian” on the application of a hospital, nursing home, treating physician, relative or other appropriate person. The court may appoint a special guardian if the patient is unable to consent to medical treatment, there is no “general or natural guardian” and if prompt treatment is necessary because of “a substantial threat to the patient’s life or health.”
- **South Dakota** has a judicial authorization for treatment provision that allows the circuit court to order health care, direct a health care decision, determine who is authorized to make the decision, or appoint its own representative to make the decision, if there is no person available to consent. The law requires notice and a hearing on the petition, but the court may waive this if delay will affect the person’s health. The court may appoint a guardian ad litem.
- **Virginia** law allows a circuit court, on a petition from “any person,” to authorize “the provision, withholding or withdrawal of a specific treatment or course of treatment for a mental or physical disorder” if no legally authorized person is available to give consent, if the court finds on clear and convincing evidence that the person is incapable of making an informed decision, and if the proposed action is in the best interest of the

person. The law requires notice and a hearing. An attorney must represent the unbefriended person at the hearing. The court may schedule an expedited hearing. The law does not cover sterilization, abortion, psychosurgery, admission to a mental health facility, or restraint of the person, and places limits on administration of anti-psychotic medication and electro-convulsive therapy.

In addition, adult protective services statutes frequently authorize APS staff to petition the court for emergency medical treatment. A few states may go beyond emergency situations to specify that adult protective services may petition for judicial orders for non-emergency medical treatment as well.

b. Temporary Medical Treatment Guardian Model Statute

Prior to the enactment of most of these statutes, the Institute of Public Law at the University of New Mexico piloted a unique Temporary Medical Treatment Guardian Program and developed a Model Medical Treatment Guardian Statute. While the model statute has not been enacted, it stands as one guide for legislatures concerned about unbefriended patients.

The idea for a temporary medical treatment guardian arose in the 1980s with the recognition that hospitals and nursing homes were finding “solo citizens”—“elderly persons [who are] alone, without friends or family, while coping with medical problems and failing mental faculties” (Downing 1988). During this time, ethics committees in Albuquerque, New Mexico hospitals “began to get requests for consultation around a certain category of cases—patients in need of urgent—not emergency—medical services, who do not have the capacity to make decisions for themselves and who have no family or identified decision-maker to assist or even take over the decision-making responsibility” (Gibson 1990).

In response to this problem, the Institute of Public Law developed and received funding for a demonstration program using volunteers as

temporary medical treatment guardians. The program recruited and trained volunteers who were appointed by the court for medical decision-making for hospitalized, decisionally incapacitated, frail elderly patients who had no surrogate. Sometimes the volunteers found a family member and assisted with the decision, mooted the need for court appointment. The volunteers used a substituted judgment standard of decision-making and were guided by a “values history” form with which they sought information on individual patient preferences where possible. The New Mexico program was later incorporated into a statewide guardianship program, without the volunteer component. (It also sparked the development of a Minnesota program of “Volunteer Medical Decisions Advocates.”)

The New Mexico program allowed for great attention to each individual and the probing of his/her values by the volunteers. In 1990, the Senior Citizens Law Office in Albuquerque received funding from the ABA Commission on Legal Problems of the Elderly for development of a Model Medical Treatment Guardian Statute (Leitzer 1990). The unpublished model sets out a petitioning process for appointment of a Medical Treatment Guardian, with notice, hearing and appointment of an attorney.

Under the act, the court order must include findings that the temporary medical treatment guardian is “the least restrictive form of intervention consistent with the preservation of the civil rights and liberties of the incapacitated person” and the guardian is “both qualified and suitable and is willing to serve.” The guardianship should not exceed six months unless otherwise ordered by the court. The act sets out a hierarchy of persons to serve as guardian, including an adult “nominated from a list of willing, responsible and trained candidates who have no potential conflict of interest” as well as “any other person.”

In making health care decisions, the medical treatment guardian must “visit and consult with the incapacitated person and consider [his/her] expressed opinions and values;” must consult with the physician or other medical professional, any interested relatives or friends; and review all relevant medical records. The medical treatment guardian also may make application for public

benefits on the patient’s behalf, and may authorize discharge, transfer and admission to or from a hospital or long-term care facility. The guardian must report to court within seven days of appointment, and every three months thereafter. The project also developed forms for the medical treatment guardian’s report, the petition, and several court orders.

The model temporary medical treatment guardian act offers a useful guide for policymakers concerned about unbefriended patients.

Our study did not identify jurisdictions that have adopted the model Temporary Medical Treatment Guardian Act. It stands ready for scrutiny by policymakers as the needs for health care decision-making swell near the breaking point.

D. Institutional Practice

When state law does not provide a formal mechanism for surrogate decision-making on behalf of incapacitated patients, health care institutions are in a quandary. Do they initiate a formal guardianship proceeding so they can find a nursing home bed or decide whether to amputate a leg? Or do they resort to an in-house procedure that may not be sanctioned by law, or make a completely informal and perhaps even undocumented decision on behalf of the patient? Which individuals in the hospital or nursing home take the responsibility for making the decision? Do practitioners worry that they’ll be sanctioned by a state enforcement agency, or even sued by a long-lost relative who flies out of the sunset?

Through our research, we found that these questions are particularly troublesome in states without health care consent laws providing a defined hierarchy of possible decision-makers, and perhaps even authorizing friends, clergy or providers to act as surrogates. In these states, the

only statutorily authorized mechanisms tend to be advance directives and guardianship. For the majority of individuals who lack advance directives, is guardianship a realistic or necessary alternative in every case? Are there people available to serve as guardians? Is there a public guardianship program for those without resources?

Our research identified three approaches taken by institutions or communities when law provides no clear options other than guardianship:

- **Ethics committees:** use of acute or long-term care institutional ethics committees to make, facilitate, or share in making decisions
- **Informal surrogate system:** a long-term care in-house process to foster relationships between unbefriended residents and facility staff, so that those staff members can take a decision-making role if the individual becomes incapacitated.
- **“Flying below the radar screen”:** a catch-all collection of approaches that may not be formalized but help institutional staff act when action is needed.

1. Ethics Committees

Healthcare ethics committees may play an important role in addressing ethical dilemmas arising in acute and long-term care facilities. While these committees were rare in the early 1980s, by 1985 more than 60 percent of American hospitals with over 200 beds and about 8 percent of nursing homes had established committees (American Hospital Association News 1988; Glasser, Zweibel, and Cassel 1988). A 1993 study by the American Association of Homes and Services for the Aging (AAHSA) found that 31 percent of not-for-profit nursing homes and 28 percent of for-profit homes had ethics committees (AAHSA 1993). In 1992, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) began requiring that approved institutions have in place some mechanism for addressing ethical concerns (Hoffmann, Boyle, and Levenson 1995). This accreditation

requirement, along with the federal Patient Self-Determination Act (requiring health care providers to supply staff, patients and the community with information about advance directives and their rights to direct their own healthcare) and relevant state laws and regulations, provided motivation for facilities to set up ethics committees.

Among their many possible functions, ethics committees may serve as patients’ advocates, clinicians’ advisors, and, in some circumstances, as health care decision-makers.

In 1999, a survey of 346 hospitals found that most hospitals have ethics committees, and that 86 percent of the committees engage in case consultation, but only 5 percent issue binding decisions regarding a specific patient’s care (McGee et al. 2001). Hospital ethics committees also perform retrospective review of cases, self-education and policy formulation. There has been no comparable recent study of nursing home ethics committees.

Our research uncovered some incipient efforts to use ethics committees, in acute care, long-term care or the community, to participate in decision-making or serve as decision-makers for unbefriended patients.

a. Department of Veterans Affairs, Veterans Health System

The nation’s health system for veterans, run by the federal Department of Veterans Affairs (VA), impacts health care delivery for a huge number of patients. The VA’s health care system has at least 163 hospitals, with at least one in each of the 48 contiguous states, Puerto Rico, and the District of Columbia. VA operates more than 850 ambulatory care and community-based outpatient clinics, 137 nursing homes, 43 domiciliary care facilities, and 73 comprehensive home-care programs. VA health care facilities provide a

broad spectrum of medical, surgical, and rehabilitative care. More than 4.2 million people received care in VA health care facilities in 2001. The VA is used annually by approximately 75 percent of all disabled and low-income veterans. In 2001, the VA treated about 587,000 patients in VA hospitals and contract hospitals, 87,000 in nursing homes, and 45,000 in domiciliary care facilities. The VA's outpatient clinics registered approximately 42.9 million visits. (<http://www.va.gov/pressrel/vafacts.htm>)

The VA provides health care and benefits to more than 100,000 homeless veterans each year. This population may be particularly likely to be unbefriended, as they may be estranged from family and friends, and lacking in traditional support networks. The VA is the only federal agency that provides substantial hands-on assistance directly to homeless people. (<http://www.va.gov/homeless>)

The VA's regulations (38 CFR §17.32(f) and *VHA Handbook* (VHA Handbook 1004.1(8(c)), January 29, 2003) specify how health decisions should be made on behalf of incapacitated patients who have no surrogates. There are three levels of treatments and procedures, each requiring a different process. As described below, a facility ethics program or committee may be consulted in the first two levels, and a multi-disciplinary committee must be extensively involved in decision-making at the third level.

- **Treatments and Decisions That Do Not Require Signature Consent.** These are low-risk and are within broadly accepted standards of medical practice (e.g., administration of most drugs, X-rays). In these situations, the practitioner must decide based on substituted judgment or, if the patient's values and wishes are unknown, best interests. The practitioner may consult with the local ethics program and/or VA Regional Counsel. Even if the patient lacks capacity, the practitioner must attempt to explain the nature and purpose of the proposed treatment to the patient, and write a progress note in the patient's record describing the treatment and its indications. If the treatment will continue indefinitely, the

treatment team must review the treatment plan, and someone outside the team must review the plan at least every six months.

- **Treatments and Procedures That Require Signature Consent.** These treatments include the use of sedation, anesthesia, or narcotic analgesia; those that can produce significant discomfort, or carry significant risk of complication or morbidity; certain injections; HIV testing; or other listed procedures. In these situations, the attending practitioner follows all of the steps described above, and the Chief of Service or designee also must provide a signed and dated concurrence in the record.
- **Withholding and/or Withdrawal of Life-sustaining Treatment.** In these cases, first the attending practitioner discusses the withholding or withdrawal of treatment with the treatment team and makes a recommendation in the chart. Then, a multi-disciplinary committee appointed by the facility Director considers the procedural and ethical validity of the recommendation. The committee functions as the patient's advocate, and does not include treatment team members. The committee uses the substituted judgment standard where possible, and seeks input from the representatives of the patient's cultural, ethnic, or religious group. The committee's written report with recommendation goes to the facility Chief of Staff, who must approve or disapprove the committee's recommendation. Finally, the decision goes to the facility Director, who may concur, not concur or request review by regional counsel. The facility Director must concur in any withdrawal or withholding of life-sustaining treatment.

While all VHA facilities must comply with the policy spelled out in the regulations and handbook, each facility adopts its own specific guidelines. According to the VA's National Center on Ethics, this approach is successful because it is seen as a positive alternative to guardianship.

b. Santa Clara County Medical Association Ethics Committee Model Policy

This California County Medical Association has a bioethics committee that meets quarterly and considers cases retrospectively. At a meeting in February 2000, two cases came up for discussion involving elderly developmentally disabled patients lacking surrogates. One involved a 74-year-old patient who was admitted to the hospital repeatedly for inhalation of food. The committee viewed these cases as nightmares for the hospitals to figure out. The county public guardianship program was not a viable option because it takes too long. California has an extremely limited health care consent law (Cal. Probate Code §4711-4727 (West 1999)), and the committee sought alternatives less cumbersome and more immediately responsive than formal judicial authorization for treatment. Everyone on the committee “was sick and tired of not knowing what to do.”

To create a model policy addressing this thorny situation, the Medical Association’s ethics committee formed a 27-member interdisciplinary task force including physicians, attorneys, court personnel, public guardians, a long-term care ombudsman and a private conservator. In 2001, the Medical Association approved the policy developed by the task force for potential adoption by hospitals and nursing facilities (*see* Appendix 1). The goals of the policy are “to make and effect health care decisions in accordance with a patient’s best interest, taking into consideration the patient’s personal values and wishes to the extent that these are known” and “to establish uniform procedures” for unrepresented patients. The policy appears to be the first of its kind adopted by a medical/legal association or group. The task force incorporated elements of the VA’s model when developing the new policy.

The policy prescribes a process for decision-making in two distinct circumstances. In the case of major medical treatment decisions requiring informed consent, an ethics consultant from the facility’s ethics committee (or elsewhere if there is no ethics committee) will provide advice about

the process of medical decision-making, ensuring that decisions are consistent with the Medical Association policy and making reasonable efforts to learn about the patient’s medical treatment preferences. For medical decisions about withholding or withdrawing life-sustaining treatment, the procedure is somewhat more complex. First, the medical team will obtain a second opinion about the decision from an independent physician. Then, the chair of the facility’s ethics committee will appoint a sub-committee to act as surrogate decision-maker and review the proposed decision to ensure that the decision was based on sound medical advice and conforms to the Medical Association policy. One member of the sub-committee must be “non-medical,” and if the patient is in a long-term care facility, an ombudsman must be included.

The sub-committee is directed to interview the relevant providers and others closely involved with the patient. The inquiry should cover: “the process to determine the decision-making capacity of the patient, the attempts made to learn about the patient’s medical preferences and to locate a surrogate decision-maker, the medical basis for the conclusion that medical treatment should be withheld or withdrawn, and about the other available medical options and their likely outcomes.” In making its recommendation, the sub-committee should “consider the patient’s cultural, ethnic, or religious perspectives, if known,” and “the likelihood of restoring the patient to an acceptable quality of life” (Santa Clara County Medical Association Ethics Committee 2001). The sub-committee can seek further medical opinions. If the sub-committee disagrees with the initial medical decision or cannot reach a general agreement, the facility Chief of Staff will assist in resolving disagreements. Any decision to withhold or withdraw life-sustaining treatment must be approved by the Chief of Staff. In cases of extreme conflict, the facility can seek resolution by a court.

Shortly after the Medical Association adopted its policy, a case arose involving a hospitalized elderly schizophrenic patient with an aortic aneurysm. The chair of the Ethics Committee at a large academic medical center

sought a court order granting authority to make health care decisions pursuant to the California judicial authorization for treatment process (*see* Cal. Probate Code §3201, page 30). In granting authority, the judge appended a copy of the newly developed policy. The policy is still a cutting-edge document, largely untried. But it represents a rational and bold attempt to bring clarity to seemingly intractable cases troubling to all.

c. West Virginia Department of Health and Human Resources Social Service Ethics Committee

Pursuant to the West Virginia Health Care Decisions Act (W. Va. Code §16-30-8 & 9) the West Virginia Department of Health and Human Resources may act as health care surrogate when there is no one else to serve. There are two possible procedures. First, the Department's Bureau of Social Services can convene its statewide social services ethics committee. Bureau staff would contact the physician, nurse, social worker, medical ethicist, and clergy member who sit on the committee. That committee would meet by conference call, come to a collegial decision, and inform the attending physician. Alternatively, a Department social worker could make the health care decision. These social workers often come to a decision by consulting with the involved facility's ethics committee or, if there isn't one, the social workers can consult with the Bureau's ethics committee.

While the Department does not keep ethics committee data, according to our interview respondents in 2002 the state committee met about half a dozen times. The process includes a range of decisions—major medical, end-of-life care, palliative care, dental, and ventilators, among others.

d. Example of Hospital Ethics Committee Protocol

One hospital's staff bioethicist described how her facility ethics committee has addressed decision-making for unbefriended patients. The state has no health care consent law. The

committee has a policy that aims to honor the patient's wishes and to find clear and convincing evidence of those wishes. The goal is to recreate the patient's "personhood" and let it guide the decision process. Ethics committee members interview family, friends and any other contacts they can find. If these individuals cannot provide "direct quotations" as evidence of the patient's wishes and values, the committee extrapolates from anecdotes and other evidence. While not based on clear authority in statute or regulation, the process nonetheless is stringent, public and open to scrutiny. In fact, when the hospital sought court approval for a surgical procedure a number of years ago, the judge told the hospital personnel that they should have performed the surgery and not sought judicial intervention. The staff bioethicist noted that "we are very proud of our process."

Kalman Shapiro's case (*see* page 12) was based on a case encountered at this hospital. The patient was very demented when admitted, and his only visitor was his neighbor who had helped care for him for several years. From this visitor, the ethics committee pieced together the patient's life story and his connection to the Lubavitcher sect. Based on religious and philosophical views gleaned from this community, the hospital staff was convinced that this patient would "choose life" and proceeded with an amputation despite their personal disinclination to do so.

Another bioethicist praised this approach to unbefriended patients. "[The hospital's ethics center director] tries to portray each patient as a unique individual. By describing the patient as someone who loved ice cream or had a drawing a visitor brought, decision-makers are reminded to think about the patients carefully. Putting these references into the clinical record provides a very helpful sense of the person. In a hospital world in which these patients can eat up your time and it is easy to dehumanize them, it is important to remember that they feel pain and appreciate a human touch."

To summarize, the notion of ethics committees as proxy decision-makers is relatively new and controversial. As one health care consumer advocate explained, while they

may be praiseworthy as review, advisory, and educational forums, “they are unlikely to be fast as firetrucks, and a growing agenda of individual care decisions would soon crowd out the original mission” (Freeman 1995). Yet the dearth of other alternatives for the unbefriended population makes them an increasingly attractive option.

2. The Informal Surrogate System

With the few exceptions detailed above, ethics committees do not make health care decisions, but only stand behind, offering assistance to decision-makers and providing retrospective review. How, then, can an ethically sensitive long-term care facility make treatment decisions without resorting to a cumbersome guardianship system? The Hebrew Rehabilitation Center on Aging in Boston, a very large nursing home with a closed medical staff and a very active ethics committee, has developed its own innovative system and has implemented it during the past five years. While the staff has made few independent surrogate decisions utilizing this process, the informal surrogate system is a unique model worth examining.

The Center has over 700 beds, and full-time staff physicians, including psychiatrists. Residents live on 17 units, grouped by level of function. There is tremendous longevity among the staff, including nurses and nursing assistants who have worked at the facility for over 20 years. The ethics committee, with about 14 regular members from varied disciplines including an administrator, meets frequently, and members receive bioethics training. Teams of two ethics committee members perform case consultation, and the full committee retrospectively reviews these cases. Few residents have guardians, and the state lacks a health care consent law. However, the Center has a very “social work-initiated” and “family-oriented” culture, and recognizes family members as decision-makers even when there is no health care proxy.

In 1997, the facility developed a novel informal surrogate system and began operating

this program to deal with the unbefriended problem under the auspices of the facility ethics committee. The purpose is to designate an ethics committee member to serve as an informal surrogate if facility social workers determine that a resident has no available family or designated proxy. The system has written guidelines describing the informal surrogate’s responsibilities (*see* Appendix 2):

Informal surrogates will be asked about treatment decisions in much the way that family members or proxies are involved in decision-making. They will be expected to get to know the resident and to learn about his or her current or previously expressed wishes and personality in order to guide decision-making. Documentation of discussions about preferences should be entered in the Advance Directives section of the medical record. (Guidelines for the Unbefriended, 1997)

The written policy acknowledges that “informal surrogates are not empowered legally to make decisions for nursing home residents” and that the system will not function if a resident is transferred to an acute care hospital. To minimize possible conflicts of interest, informal surrogates “will not be directly involved in the care of the residents whose interests they are representing” and their decisions will be subject to review by the ethics committee at regular monthly meetings.

Ethics committee members described how the system operates. When a consult request presents the case of a new resident identified as lacking surrogates or a long-term resident whose next-of-kin has died, the ethics committee chair decides which committee member is likely to be

Ethics committee members report many benefits to the informal surrogate system: they have time and the capacity to get to know the resident; they provide needed social contact; they are objective; and they are ethically trained and ethically sensitive.

the best informal surrogate. The informal surrogate continues to serve until the resident dies or the staff member leaves employment. The relationship between the ethics committee member and the resident usually begins while the resident retains at least some decision-making capacity. The staff member obtains consent from the resident to serve as informal surrogate (but not a written consent or formal advance directive). The surrogate begins a series of informal conversations with the resident, discussing pathways and goals of care (e.g., pain control, maintaining independence, longevity despite pain or loss of function) rather than specific types of treatment to obtain or forgo. These discussions must occur at least every six months and are documented in the chart.

The informal surrogates observed that thus far they generally have acted as support persons for decisions made by residents or relatives, rather than as independent decision-makers for incapacitated residents. In one case, a clergy member served as informal surrogate for a resident whose cousin was reluctant to be a surrogate decision-maker. A question arose regarding non-emergency surgery. The designated informal surrogate worked with the cousin as a “surrogate team” and together they decided that surgery was appropriate. The hospital accepted this decision of the informal surrogates, the resident underwent surgery, and she returned to the long-term care facility.

In another case, a staff speech pathologist is developing an informal surrogacy relationship with a resident with an extensive psychiatric history. The resident is verbal but finds decision-making very difficult. Discussion between the two began very informally and, after they developed a rapport, they began discussing health care decision-making issues over coffee together each week. The informal surrogate expects to advise on health decisions when the need arises. Since this system was implemented, informal surrogates have acted as support persons for decisions about half a dozen times, and perhaps only once as actual independent decision-makers.

Ethics committee members acknowledged that this process is more challenging if a resident

has very little or no initial decision-making capacity upon admission. In one case, a resident had limited capacity. The social services department did some research and a social history, and got an “emotional sense” of the person and of the communications to which the resident tended to respond. This approach would be difficult with a totally non-verbal resident.

When the notion of an informal surrogacy system in nursing homes first was floated in a journal article, it was attacked in a counterpoint article for potential conflict of interest and lack of transparency:

[T]he resident’s decisional capacity is being judged by the facility; the resident’s surrogate is being chosen by the facility; the resident’s surrogate is on the facility’s payroll, and the implementation of the decision is being carried out largely by facility employees. Call me overly cautious, but I think that is too much of an inside job. (Freeman, 1995)

Staff members believe that in their setting they avoid conflicts of interest. The facility is large, decision-makers are not pressured by administration, and the ethics committee is available for review. They acknowledge that a trained community member of the ethics committee might be even more appropriate than facility staff. The facility appears not to focus on risks of liability for treatment decisions.

We found no examples of other facilities that had implemented explicit informal surrogacy systems like this one, although social workers and lawyers mentioned other groups in community settings that had considered establishing a similar “buddy system” approach to avoiding the unbefriended dilemma. This program has not been formally evaluated.

3. “Flying Below the Radar Screen”

When there is no clear statutory route for identifying a surrogate decision-making mechanism on behalf of incapacitated patients, health care professionals and institutions may

develop their own ad hoc processes. These practices or individual remedies are sometimes dubbed “flying below the radar screen.” In the course of this project, we heard this phrase frequently in New York State, where many perceive an unfortunate situation created by the lack of a health care consent statute, an overburdened guardianship system, and case law imposing barriers to good decision-making for end-of-life treatment. “Flying below the radar screen” carries an implication of evasive or illicit behavior—it refers to developing a sub-culture of practice that may be seen as skirting the boundaries of legally authorized action—and yet the practice may be ethically sound and preferable to other alternatives. Below are several patterns of decision-making or justifications for practices that may not be clearly delineated or supported in law.

Each institution has its own culture, its own process, with its own integrity. These processes do not always fall within the conservative interpretation of state law.

a. Administrative Consent in Acute Care

One bioethics consultant working in the acute care setting described the concept of “administrative consent” as follows: “In routine medical situations involving routine treatment, ‘administrative consent’ is the legal fiction developed to allow someone to sign off on the standard of care.” Another bioethicist similarly said that one way to get authority to make health care decisions is through administrative consent by the hospital’s medical director. A third referred to “administrative approval” by a hospital administrator, often in an emergency situation. “Administrative consent” may stretch the concept that informed consent by the patient may be waived where the care is “routine” or “emergent.”

All interviewees saw the use of administrative consent bearing a direct connection to assessment of risks. In facilities where the fear of liability is great, administrators are more likely to seek out legal intervention, or to “err on the side of maintaining life” in end-of-life situations. In “standard, low-risk care situations,” administrators are more likely to be comfortable with the legal fiction of administrative consent. When a facility has the resources and the institutional philosophy supporting a deliberate, defined process utilizing ethics committees or consultants, it may be more willing to go out on a decision-making limb without clear legal authority.

b. Nursing Home Administrator Consent to Acute Care

Another “below the radar screen” process was described by a nursing home administrator who had worked at several facilities. At two of these facilities, residents needed in-patient procedures and had no surrogates. A hospital risk manager told her that it was traditional for the nursing home administrator to act on behalf of the resident. She consulted with two physicians at the hospital, who explained the rationale for the recommended treatment, and she signed the consent forms. When she moved to the second nursing home, a different hospital required her to use the same procedure. In her experience, this was an accepted practice with no basis in statute. She believes that the hospital administrators would prefer the nursing home administrator’s consent to the hospital’s use of its own administrative consent process. The hospital has a possible conflict of interest because it may gain a financial benefit from treating the patient.

c. Physician As Ad Hoc Guardian

Perhaps most frequently, however, “flying below the radar” referred to situations in which physicians faced with critical treatment needs have nowhere to turn and simply go ahead and make the determinations they think best. They “just do it”—do what makes sense and what is sound medically and ethically at the moment that

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a decision needs to be made. As stated by a nursing home medical director, “In the real world in most cases, the M.D. is the guardian.” Treatment classified as routine on the one hand and emergency on the other requires no consent—and established legal practice may permit practitioners to stretch these concepts when necessary. Moreover, when treatment would be futile, medical professionals can justify “just not

doing it.” These rationales—sometimes fictions at best—may allow providers to follow perceived ethical dictates, but they skirt legal requirements. One practitioner explained that in 90 percent of cases treatment of isolated incapacitated patients might proceed with physicians simply making the decisions, but in the rare cases in which this is questioned, the physicians will seek guardianship.

V. Symposium

Consensus Statement

The centerpiece of the ABA’s project was a one-day symposium on health care decision-making for the unbefriended incapacitated patient. Participants at this invitational conference included physicians, bioethicists, attorneys, a state court judge, guardianship agency personnel, law professors, a New York State legislator, state agency representatives, social workers, foundation staff and elder advocates. After participants presented background information on health care decision-making law and practice, existing models and proposed legislation in New York, the bulk of the day was spent exploring issues and challenges, and brainstorming on policy recommendations for the future. Participants broke into working groups, drafted consensus recommendations in the small groups, and came back together to discuss them. Some key points made during the discussion were:

A 2002 interdisciplinary symposium of experts focused on health care decision-making for the unbefriended elderly and crafted a consensus statement.

- attendees maintained that only an external body ensures sufficient objectivity, while others preferred an internal group.
- Participants differed on the extent of formality and procedural safeguards that should be built into decision-making, with one member asserting that “we should avoid the due processization of medical decision-making.”
- Participants discussed ethics committees. One attendee noted that ethics committees have substantial education and practical experience compared with surrogate decision-making panels. But ethics committees don’t exist everywhere, and some are lacking in independence.
- Participants also discussed the use of surrogate decision-making panels. The panels currently in use for mentally retarded individuals are well-trained, and have personal contact with each unbefriended individual. Moreover, the panels are not prescribing treatment, but merely consenting to treatment recommended by a medical professional. The panels begin with a presumption of capacity.
- Participants stressed the need for cultural sensitivity in medical decision-making. Problems of unbefriended elderly are compounded by inadequate translation—both linguistic and cultural translation. In addition, hearing loss and inability to vocalize may mask capacity.
- Some patients have medical and psychiatric issues combined. A one-size-fits-all model will not accommodate the diverse situations,
- A threshold question in approaching each patient is capacity assessment. Sensitive evaluation and enhanced communication techniques may reveal that a patient is able to make the decision at hand.
- There were differences of opinion on whether medical treatment decisions should be made by an internal facility-based group, an external body, or a blended model. Some

medical conditions and treatment options. States may need more than one mechanism to meet the varying needs of unbefriended elderly patients.

- Existing models should be carefully evaluated, and further research pursued on a variety of topics.

While the fruits of this one-day meeting are not formal policy recommendations, there was significant agreement on a number of issues and directions for the future. The following Consensus Statement reflects the ideas and sentiments of the inter-disciplinary group.

Consensus Statement of Symposium on Health Care Decision-Making for the Unbefriended Elderly, November 2002

1. Preamble

- a) “Unbefriended elderly patients” are individuals who lack capacity to provide informed consent to health care, have not executed an advance directive [covering the treatment at hand] and lack capacity to do so, have no guardian, and have no family member or other available surrogate. While there is little data on the magnitude of this group, anecdotal evidence suggests that health care professionals regularly encounter this population in hospitals, nursing homes and, occasionally, in community settings.
- b) These isolated patients are distinctly vulnerable to under-treatment as well as over-treatment, and merit special concern when developing mechanisms and standards for surrogate decision-making.
- c) In this consensus statement, “health care decisions” include choices on major medical treatment as well as end-of-life care. For emergency medical treatment, the common law provides for implied consent.

2. Existing mechanisms for health care decision-making on behalf of these individuals include:

- a) guardianship—plenary, limited, temporary—and judicial authorization statutes
- b) surrogate decision-making committees authorized under state law to give informed consent under specific circumstances (Iowa, New York, Texas)
- c) health care or family consent laws authorizing individuals other than family members or close friends to consent (e.g., physicians, ethics committees, clergy)

- d) facility-based ethics committees (or other facility-based procedures for investigation, review, and consultation).

Guardianship is frequently unavailable, and may be costly, cumbersome, and lacking in timeliness. The remaining mechanisms are relatively rare, recent, and largely lack evaluation for their effectiveness.

3. Preventive and “pre-crisis” approaches. Community groups, health care professionals, lawyers, educators, and others should work to reduce the numbers of individuals who become “unbefriended,” by:

- a) appropriately assessing decisional capacity and using communication techniques to enhance capacity
- b) diligently searching for existing surrogates
- c) identifying those at risk of becoming unbefriended and incapacitated, and educating them about advance directives and other planning options
- d) educating and sensitizing professionals about the diverse approaches to health care decision-making in various cultures
- e) developing de facto surrogacy relationships between elderly patients and volunteers/facility staff/ethics committee members through a “buddy system” or “Operation Match” approach, to learn life history and preferences before the patients lose capacity.

4. Decision-Making mechanism. In designing a decision-making mechanism, the emphasis should be on a thoughtful process rather than on specific outcomes. When a health care decision must be made on behalf of an unbefriended patient, a group decision-making entity should be authorized to review the provider or care team decision and to consent to the proposed decision. This entity may be internal to the facility or an external committee. (A combined process, involving review of an internal ethics committee’s decision by an external group, also may be appropriate if it can be completed in a timely manner.)

- a) **Internal model.** An acute or long-term care facility’s ethics committee may review the provider or care team’s proposed decision. This interdisciplinary committee should include independent community members who are not employees of the facility (or related to others who are) and who respect the patient’s cultural background.
- b) **External model.** A trained interdisciplinary, culturally diverse surrogate decision-making committee, unaffiliated with a specific health care institution, may be authorized to decide whether an unbefriended patient receives proposed health care services.

5. **Standard for health care decisions.** Bioethicists, health care professionals, lawyers, and others should use a substituted judgment standard to the extent that decision-makers have gathered sufficient information about the individual's values and preferences, and should otherwise use a best interests standard.
6. **Hallmarks of a well-designed system.** In developing a system for decision-making on behalf of unbefriended patients, policymakers should strive to incorporate and effectuate the following characteristics: focus on the patient; independence and freedom from conflicts of interest; continuity of care; applicability to a full range of decisions; emphasis on least restrictive alternatives; promptness; cost-effectiveness; accountability; expertise; and credibility.
7. **Role of court.** Judicial remedies, such as guardianship and judicial authorization of health care treatment and placement, should serve as a last resort when other decision-making mechanisms have failed or conflict over decisions has remained unresolved.
8. **Research and experimentation.** There has been little research on health care decision-making for the unbefriended elderly. Existing models are relatively new and have not been fully evaluated. Health care facilities, academic institutions, private foundations, and government entities should support pilot projects and empirical studies—including outcome data — to assess existing and proposed laws, models, and practices. Research and evaluation could focus on:
 - a) **process of health care decision-making:** health care decision-making by guardians, ethics committees, surrogate decision-making committees, and decision-makers authorized under state health care consent statutes
 - b) **sub-populations and diverse groups:** decision-making on behalf of specific sub-populations such as the homeless, mentally ill persons, and persons with mental retardation/developmental disabilities as well as among diverse ethnic and racial groups
 - c) **decision-making standards:** factors and information necessary for decision-making using the substituted judgment and best interest standards on behalf of the unbefriended elderly, bearing in mind that these standards pose special problems when applied to persons with long histories of social isolation.

VI. Policy Suggestions

This study sought to examine approaches for health care decision-making on behalf of unbefriended elderly patients. The policy suggestions below build on the Symposium Consensus Statement and the range of interviews, site visits, and focus groups we conducted. The suggestions seek to ensure that solitary older adults with no advocate and no track record of values and life history are the focus of a *deliberative process* of both medical and ethical scrutiny. “A process,” writes one bioethicist, “is the best thing you can do to protect patients from over-treatment and under-treatment” (Spann 2001).

The suggestions offer next steps and public policy alternatives for making the hard choices for those who are alone in the medical world, in the face of often perverse economic, time, and liability pressures—to help them “to live better or die in comfort and not alone.” Finally, it is important to note that the suggestions are not presented in order of priority—rather, the initial points focus on further research; followed by those that advocate early investigation of information on patient lives and values; and those that address the various decision-making mechanisms, with guardianship last, as it is a last resort.

We must begin to develop policy for those who have no track record of preference, who can’t make their own decisions, and who have no one to make these hard choices.

1. Research should analyze federal data on long-term care residents to shed light on the unbefriended population.

Our study uncovered very little data on the number of socially isolated incapacitated

individuals—and without this information, policymakers are working in the dark. Yet there is a source of data on nursing home residents that has never been examined. The federal Centers for Medicare and Medicaid Services (CMS) maintains data on all residents of Medicare- and Medicaid-certified long-term care facilities. This information is gathered by all participating facilities as part of the care planning process using the “minimum data set” and “resident assessment instruments.” At the time of initial assessment and at each annual assessment, the data shows whether a resident has a guardian, durable power of attorney and/or a family member as a “responsible party” (<http://cms.hhs.gov/quality/nhqi/DraftMDS30.pdf>).

This information can provide a statistical picture of surrogate decision-making in nursing homes. Researchers can approximate the number of unbefriended nursing home residents based on this data. Moreover, a research project could correlate this information on surrogacy with socio-demographic factors such as economic status, age, gender, race, ethnicity, medical diagnoses, treatment decisions, and functional status. The data also could be used to compare care plans of residents with and without surrogate decision-makers, thereby glean important information about the possible impact of surrogate status on care planning.

2. Further study should include a focus on cultural diversity and health care decision-making.

Symposium participants recommended further study of health care decision-making among diverse ethnic and racial groups. For example, should a hospital ethics committee or external surrogate decision-making committee look to a clergyperson for help in making

decisions on behalf of an unbefriended patient known to practice a particular religion? Can we assume that such a patient would want a religious leader to guide decisions made on his or her behalf? Does this lead to stereotypical choices? Should all ethics committees be culturally diverse—or is a focus on the patient’s cultural and ethnic background more critical?

Little attention has been paid to questions of ethnic or cultural diversity within the bioethics community, and philosophical studies of the relevance of cultural differences to bioethics and decision-making are only beginning (Institute of Medicine 1997). As our multi-cultural society refines mechanisms for making health care decisions on behalf of patients without surrogates, we must explore issues focusing on the implications of cultural diversity.

How do cultural considerations affect decisions by a “stranger surrogate” attempting to use a substituted judgment standard? Do racial, ethnic and other cultural identities enter into decisions about what is in the patient’s best interests? Do culturally diverse patients have different levels of willingness to delegate decision-making to physicians and other health care providers? How would diverse groups view issues of quality of life versus quantity of life? Might lack of familiarity with a patient’s language and culture influence a determination of decisional capacity? These are some of the many questions yet to be fully explored in the context of developing best practices on behalf of unbefriended patients.

3. Long-term care staff should play a greater role in investigating and conveying resident values and preferences.

Sometimes direct care staff in nursing homes and assisted living are a lifeline for unbefriended elderly residents—their only opportunity for meaningful human communication. “Staff form attachments to residents. . . . Nursing assistants, particularly . . . grieve when the resident dies” (Mezey et al. 2000). Other times, certified nursing assistants (CNAs) are too pressured and turnover is too great to foster any ongoing relationships.

Long-term care staff can play a pivotal role in collecting information at an early point that later will be of great value to decision-makers. They also can promote the use of advance directives when appropriate.

- Communication with residents—especially those who are alone and at risk of becoming incapacitated—should be recognized and supported as a critical component of the CNA job. Time should be built into the resident care plan and the nursing assistant’s routine to allow for this.
- CNAs need education on health care decision-making, and on their potential role in learning about residents’ lives and values and the recording of this information for others.
- If an unbefriended patient has been transferred from a long-term care facility to acute care, the hospital providers and ethics committee should contact key long-term care staff from the facility to see if they have information that might assist in the decision-making process.
- Facilities should initiate “buddy systems” to pair up staff members and isolated residents, and should foster those relationships.

4. Long-term care facilities should develop procedures for collecting and using resident histories and values information.

The Patient Self Determination Act recognized the importance of collecting information on advance directives and making residents aware of the benefits of advance directives upon admission. But facilities should look beyond this to methods of recording information soon after admission on the lives of the residents, their values, and preferences. This will help to shape good decisions if the residents later become incapacitated.

Facility staff should review and update this information on an ongoing basis. It should be readily available to providers and caregivers in

resident records, in portable forms that travel with hospitalized residents—and selected highlights (with resident consent, respecting privacy) could be posted in resident rooms to inform new aides about the individual’s past and interests. Facility staff should learn about existing values history assessments such as the Values History Form by the Health Sciences Ethics Program, University of New Mexico, <http://www.unm.edu/~hsethics/valueshist.htm>; the “Five Wishes” Aging with Dignity form, <http://www.agingwithdignity.org/5wishes.html>, and the “Caring Conversations” form by the Midwest Bioethics Center, <http://www.midbio.org/workbook.pdf>.

5. Health care professionals should improve techniques for assessing and enhancing patient decisional capacity; and medical institutions should provide training for health care professionals in assessment of capacity for informed consent.

Bioethicists have recognized that “while there are more than a dozen tests that seek to assess decisional capacity, there is no ‘gold standard.’ . . . Disagreement with a health care professional’s recommendation about treatment, by itself, is not evidence of incapacity, nor is inappropriate behavior, memory loss, temporary inability to communicate, noncompliance with care regimens, inability to follow simple directions, or a diagnosis of dementia” (Mezey, Dubler & Mitty 2001; *also see* Silberfeld & Fish 1994). Moreover, capacity can fluctuate over time—patients may have “windows of lucidity” or experience “sundowning” in which capacity declines toward the end of the day.

Providers should not be too quick to label patients who are alone as lacking in decisional capacity. Better interview and assessment tools are required to assist health care professionals confronted with decisions for isolated patients. With support, time, good communication techniques and sufficient attention, patients may be able to make basic decisions about their care that at first blush appeared not possible—thus narrowing the pool of unbefriended individuals.

Professional associations for physicians and other health care professionals should develop curricula reflecting these concepts.

6. In developing decision-making mechanisms for unbefriended elderly patients, policymakers should seek to incorporate hallmark characteristics that will best serve this vulnerable population.

Participants in our project’s 2002 Symposium set out a list of “hallmarks of a well-designed system” in their Consensus Statement. These characteristics offer a blueprint to policymakers and practitioners in grappling with the tough task of addressing the decisional needs of unbefriended patients. The hallmarks include:

- **Focus on the patient.** Any system should be patient-centered.
- **Independence and freedom from conflicts of interest.** There should be sufficient objectivity so that decisions are not subject to undue personal and institutional biases.
- **Continuity of care.** Care should not be disrupted or needlessly postponed while the process operates.
- **Applicability to a full range of decisions.** While any one mechanism might be limited in scope (for example, specifically excluding end-of-life treatment decisions), the system as a whole should cover the gamut of medical treatment.
- **Emphasis on least restrictive alternatives.** Options that stress patient involvement where possible and that do not unnecessarily remove fundamental rights are preferred. Thus, guardianship, which strips individuals of basic rights and puts their lives and medical treatment in the hands of the court, is truly a last resort.

- **Promptness.** Decisions should be timely. As with justice, care delayed is often care denied.
 - **Cost-effectiveness.** As states and localities face budgetary crises, they must prove that systems are economical. Careful tracking may show that effective decision-making mechanisms for this at-risk population can actually save public dollars over time.
 - **Accountability.** Decisions should be tracked and regularly evaluated to ensure a high quality system.
 - **Expertise.** Decision-makers should have sufficient background and/or receive training on health care law and ethics and on communicating with elderly patients—and should have timely access to sufficient expertise on clinical issues.
 - **Credibility.** The system should be recognized as a qualified arbiter on health care decisions and should have the trust and confidence of professionals and the public.
- 7. Facilities should develop and/or strengthen internal decision-making mechanisms; and states and communities should develop external bodies to make health care decisions for patients lacking surrogates.**

As our research indicates, cutting-edge efforts to develop thoughtful, workable decision-making mechanisms for this population have included internal institutional collaborative processes as well as external committees. Both models merit further development—and further study.

There are benefits and costs to each approach. Internal mechanisms benefit from maximum access to the patient's medical facts and life situation, as well as the expertise of treating professionals, but raise concerns about conflicts of interest and lack of public scrutiny to ensure that the patient's best interests are protected. External mechanisms can be more objective and insulated from institutional biases, but may lack timeliness,

access to key medical information, appropriate expertise, may be too costly—and too far removed from the patient.

Continued experimentation with both approaches can help refine existing models and test their effectiveness and fairness. In designing these approaches, entities should strive to incorporate aspects of an external model into an internal committee, and vice versa. For example, a hospital or nursing home ethics committee can add greater objectivity and perspective, characteristic of an external body, by ensuring that there are community members on the committee—and that these community members have a substantial role in the process. Outside community members may be less vulnerable to financial concerns, less prone to be influenced by facility administrators and medical leaders, and may bring an empathetic point of view unencumbered by internal professional concerns. Another measure of accountability might be external auditing of selected internal ethics committee decisions.

At the same time, efforts should be made to bring external committee decisions closer to the patient and his/her treatment options. For example, a regional ethics committee formed by several facilities might serve as an external decision-maker with many of the benefits of an internal entity as well. It might bring the requisite medical expertise and understanding of medical decision-making to the case, while adding objectivity and removing economic influences that would be present internally.

8. Facilities should develop, and funders should support, demonstration projects involving ethics committee decision-making on behalf of unbefriended patients.

Our research provided anecdotal evidence that some hospital ethics committees or ad hoc sub-groups of those committees are playing an active role in deciding how to treat incapacitated patients without surrogates. Yet research has shown that only a small percentage of hospitals use their ethics committees for binding, prospective case review. We encountered little discussion of nursing home ethics committees

playing an active, formal role in decision-making on behalf of the unbefriended population. Ad hoc decision-makers in long-term care settings are more likely to be medical directors.

While efforts like those of the Santa Clara County Medical Association and the Hebrew Rehabilitation Center for Aged aim at formalizing some decision-making role for facility ethics committees, more concrete steps are required to test this approach. Facilities could develop written protocols for decision-making by ethics committees. Facility administration as well as external philanthropies could support demonstration projects to test and evaluate the internal ethics committee decision-making model and disseminate the results for replication.

9. States with existing surrogate decision-making committee systems should test their use for the unbefriended elderly population.

The New York and Texas statewide systems of surrogate decision-making for individuals without legal surrogates are limited to individuals with mental retardation or other mental disabilities and the Iowa system is used primarily for that population. Opinions differed on whether these programs could or should be extended and adapted to meet the needs of frail elderly patients in hospitals and long-term care facilities. Clearly, additional funding, as well as changes in committee protocols and training, would be required. Referrals of unbefriended elderly could overwhelm the systems. However, limited demonstration projects could explore the benefits and barriers.

- Existing statewide surrogate decision-making programs should have a thorough and objective evaluation to identify the strengths and weaknesses of current practice, and effect on the lives of patients.
- Using the evaluation as a base, states should initiate and support pilot projects limited in geographic area and timeframe, to include the unbefriended elderly population, and determine the feasibility of making this

population a permanent part of the program. Factors in that evaluation might include: frequency of use, patient support and representation, accommodations to allow for patient participation when possible, needed staff and volunteer training, promptness of decision-making, and cost.

10. State health care consent laws and their practical application to the unbefriended population merit further study.

Close to forty states have health care consent statutes authorizing family members, friends, and others to serve as surrogate decision-makers for incapacitated patients without health care proxies or guardians. As we learned in this study, a handful of those laws specify default surrogates for unbefriended patients lacking relatives or close friends. While we know a great deal about the content of state health care consent laws, we know very little about their implementation. We know of no research on the topic.

Careful study of the implementation of these statutory provisions concerning unbefriended patients could focus on the following key questions:

- To what extent do health care practitioners rely on these statutes?
- Do hospitals and nursing homes take the statutory provisions into account in drafting their policies and procedures? Do institutional ethics committees and hospital counsel rely on the statutes?
- Do these health care consent provisions aid in avoiding guardianships?
- How do these provisions work in practice?
- What groups require education and training on these laws?

The study could include in-depth interviews with facility administrators and health care practitioners in the states with default surrogacy

provisions for the unbefriended. A comprehensive look at this pathway for decision-making would be useful for legislators and policy-makers trying to determine the optimal approach for incapacitated patients with no natural surrogates.

11. States and localities should develop temporary medical treatment guardianship programs.

Over a decade ago, advocates in New Mexico demonstrated a temporary medical treatment guardianship program using trained volunteers and an intensive decisional process with court oversight. They also crafted a Temporary Medical Treatment Guardianship Act. While some states authorize courts to appoint surrogates with the limited purpose of making designated health care decisions, the New Mexico program has not been replicated and the model act has not been adopted by state legislatures.

With the impending growth of the unbefriended elderly population, this model merits attention. It is a tested tool worth looking at, and could be one part of an overall state schema for surrogate decision-making. It might, for instance, be one component of a more broad-based public guardianship program. Some volunteers may be more likely to take on a time-limited responsibility than a full guardianship, and would receive in-depth training in bioethics and surrogate decision-making. In 1990, the director of the New Mexico program observed that “it’s obvious that medical treatment guardianship is an idea whose time has arrived” (Gibson 1990). Instead, sadly the concept has been overlooked.

12. States should support public guardianship programs that are adequately funded and staffed; and research should explore key questions about the quality of care and decision-making in public guardianship programs.

Many states and localities still lack public guardianship programs—the ultimate safety net,

the last resort for incapacitated people who are poor, alone and cannot care for themselves. States that do have programs frequently provide insufficient support in appropriated funds. Respondents interviewed throughout our study generally dismissed guardianship as a mechanism for health care decision-making for the unbefriended elderly—indicating it was too costly, too time-consuming, and overly cumbersome. Indeed, for individuals whose only need is for a health care decision, the other mechanisms named in this report may be preferable.

Undergirding these other mechanisms, however, public guardianship should be there and be readily available for those in need. It is particularly appropriate where: (1) there is a need for ongoing decision-making over time; (2) complex and intertwined health care, financial, and placement decisions are required; or (3) there is a risk of abuse, necessitating court supervision. Therefore:

- States should enact and appropriate funds for public guardianship programs. It is important for policymakers to recognize that while public guardianship costs money, it also can save money—by preventing unnecessary institutional stays or inappropriate medical care, and by securing federal benefits and recovering lost funds for clients (Teaster 2002). Moreover, public guardianship is a moral responsibility of states in carrying out their *parens patriae* duty to care for those unable to care for themselves.
- Public guardianship programs should ensure that staff and volunteers are trained in bioethics and health care decision-making, should develop specific guidelines for making surrogate treatment decisions, should record the rationale for treatment decisions in client files, and regularly should assess the quality of this aspect of the program.
- Research should provide a thorough, updated state-of-the-art review of existing public guardianship programs and identify best practices.

List of References

- Alzheimer's Association. (2003). *Statistics about Alzheimer's disease*. Retrieved in May 2003 from the Alzheimer's Association Web site: <http://www.alz.org/AboutAD/Statistics.htm>.
- American Association of Homes and Services for the Aging. (1993). *Ethics survey*. Washington, D.C.: American Association of Homes and Services for the Aging.
- American Bar Association Commission on the Mentally Disabled & Commission on Legal Problems of the Elderly. (1989). *Guardianship: An agenda for reform*. Washington, D.C.: American Bar Association.
- American Health Care Association. (1999). *Facts and trends*. Retrieved in April 2003 from the American Health Care Association's Web site: <http://www.ahca.org>.
- American Hospital Association. (1988, Dec. 5). *American Hospital Association News*, p. 1, col. 1.
- The Arc. *Introduction to mental retardation*. Retrieved in June 2003 from the Arc of the United States' Web site: <http://www.thearc.org/faqs/mrqa.html>.
- Basta, L.L., M.D. (2001). *Life and death on your own terms*. Amherst, NY: Prometheus Books.
- Beauchamp, T.L. & Childress, J.F. (1983). *Principles of biomedical ethics*, 2d ed. New York: Oxford University Press.
- The Centers for Medicare and Medicaid Services, formerly Health Care Financing Administration. *Statistics*. Retrieved from the Centers for Medicare and Medicaid Services' Web site: <http://www.hcfa.gov/medicaid/msis/2082-4.html>.
- Coleman, C.H. & Petruzzelli, M. (2001). Decision-making for residents without surrogates. In M. Mezey & N.N. Dubler, (Eds.), *Voices of decision in nursing homes: Respecting residents' preferences for end-of-life care*. New York: United Hospital Fund of New York.
- Daar, J.F. (1995). Medical futility and implications for physician autonomy. *American Journal of Law & Medicine*, 21 (2 & 3), 221-240.
- Downing, C. (1988, May). *Temporary medical treatment guardians: Procedural considerations*. Unpublished paper for New Mexico Senior Citizens Law Office.
- Dubler, N.N. & Nimmons, D. (1992). *Ethics on call: Taking charge of life-and-death choices in today's health care system*. New York: Vantage Books.
- The Emergency Exception*. Retrieved in April 2003, from The Medical and Public Health Law Site: <http://biotech.law.lsu.edu/Books/asp/Aspen-THE-11.html>.
- Florida Statewide Public Guardianship Office (2000). *Forgotten faces of Florida* (Interim Report). Tampa, Fla.: Florida Statewide Public Guardianship Office.
- Ford, J.J. (2000). The ABC's of a *Rudow* guardianship. *The best of MBA-CLE*. Boston: Massachusetts Bar Association.
- Freeman, I.C. (1995). One more faulty solution is novelty without progress: A reply to 'Medical decision-making for the unbefriended nursing home resident.' *Journal of Ethics, Law and Aging*, 1(2).
- Furrow, B.R., Greaney, T.L., Jost, T., & Schwartz, R.L. (1995). *Health law*. St. Paul, Minn.: West Publishing Co.
- Gabrel, C.S. (2000, March 1). *An overview of nursing home facilities: Data from the 1997 national nursing home survey*, advance data No. 311. (PHS) 97-1250. Hyattsville, Md.: National Center for Health Statistics.
- Gibson, J.M. (1990, December). Unpublished remarks by the Director of the National Medical Treatment Guardian Program to volunteer trainees, Minnesota Medical Decisions Advocate Project.
- Gillick, M.R. (1995). Medical decision-making for the unbefriended nursing home resident. *Journal of Ethics, Law and Aging*, 1(2).
- Glasser, G., Zweibel, N.R., & Cassel, C.K. (1988). The ethics committee in the nursing home: Results of a national survey. *Journal of the American Geriatric Society*, 36(2), 150-56.

List of References

- Gruber-Baldini, A. L. et al. (2000). The validity of the minimum data set in measuring the cognitive impairment of persons admitted to nursing homes. *Journal of the American Geriatric Society*, 48(2), 1601-1606.
- The Hastings Center. (1987). *Guidelines on the termination of life-sustaining treatment and the care of the dying*. Bloomington, Ind.: Indiana University Press.
- Hebrew Rehabilitation Center on Aging. (1997). *Guidelines for the unbefriended*. Boston: Hebrew Rehabilitation Center on Aging.
- High, D.M. (1990). Old and alone: Surrogate health care decision-making for the elderly without families. *Journal of Aging Studies*, 4(3).
- Hoffmann, D.E., Boyle, P., & Levenson, S.A. (1995). *Handbook for nursing home ethics committees*. Washington, D.C.: American Association of Homes and Services for the Aging.
- Institute of Medicine. (1997). *Approaching death: Improving care at the end of life*. Washington, D.C.: National Academy Press.
- Jennings, B. (2001). Unpublished proposal from the Hastings Center, Garrison, NY.
- Kapp, M. (1995). Surrogate decision-making for the unbefriended: Social and ethical problem, legal solution? (editorial). *Journal of Ethics, Law and Aging*, 1(2).
- Leitzer, E. (1990, January). Unpublished letter transmitting Model Medical Treatment Guardian Statute to the American Bar Association Commission on Legal Problems of the Elderly, Washington, D.C.
- Lipton, L. (2002, January 18). New York program benefits mentally impaired patients. *Psychiatric News*, 37(2), 10.
- McGee, G., Caplan, A.L., Spanogla, J.P., & Asch, D.A. (2001). A national study of ethics committees. *American Journal of Bioethics*, 1(4), 60-65.
- Meisel, A. (1999). *The right to die*, 2d ed. New York: Aspen Publishers.
- Mezey, M., & Dubler, N.N. (Eds.). (2001). *Voices of decision in nursing homes: Respecting residents' preferences for end-of-life care*. New York: United Hospital Fund of New York.
- Mezey, M., Dubler, N.N., Bottrell, M., Milly, E., Ramsey, G., Post, L.F., & Hill, T. (2000). *Guidelines for end-of-life care in nursing homes: Principles and recommendations*. New York: New York University Division of Nursing & The Montefiore Medical Center Division of Bioethics.
- Miller, T.E., Coleman, C.H., & Cugliari, A.M. (1997). Treatment decisions for patients without surrogates: Rethinking policies for a vulnerable population. *Journal of the American Geriatrics Society*, 45, 369-374.
- National Conference of Commissioners on Uniform State Laws (1993). Uniform health care decisions act. Retrieved in March 2003 from the World Wide Web: <http://www.law.upenn.edu/bll/ulc/fnact99/1990s/uhcda93.pdf>.
- National Guardianship Association (1998). *Agency directory*. Tucson, Ariz.: National Guardianship Association.
- New York State Task Force on Life and Law. (1992). *When others must choose: Deciding for patients without capacity*. New York: New York State Task Force on Life and Law.
- New York University Division of Nursing & The Montefiore Medical Center Division of Bioethics. (2000). *Guidelines for end-of-life care in nursing homes: Principles and recommendations*. New York: New York University Division of Nursing & The Montefiore Medical Center Division of Bioethics.
- O'Connor, C.M. (1996, January - February). Statutory surrogate consent provisions: An overview and analysis. *Mental and Physical Disability Law Reporter*, 20(1), 128.
- Sabatino, C. (2002). *State health decisions legislative update-2002*. Retrieved in April 2003 from the American Bar Association Commission on Law and Aging's Web site: <http://www.abanet.org/aging>.
- Santa Clara County Medical Association Ethics Committee. (2001, Unpublished). *Model policy on health care decisions for patients without surrogates*. San Jose, Calif.: Santa Clara County Medical Association.
- Schmidt, W., Miller, K., Bell, W., & New, E. (1981). *Public guardianship and the elderly*. Cambridge, Mass.: Ballinger Publishing Co.

List of References

- Schneiderman, L., Jecker, N., & Jonsen, A. (1996, October). Medical futility: Response to critiques. *Annals of Internal Medicine*, 125, 669-674.
- Select Committee to Study the Statewide System of Providing Substitute Consent for People with Mental Disabilities. (2002). *Report to the governor and the general assembly of Virginia*, House Document No. 37. Richmond, Va.
- Siemon, D., Hurme, S., & Sabatino, C. (1993, October). Public guardianship: Where is it and what does it need? *Clearinghouse Review*, 27(6).
- Silberfeld, M. & Fish, A. (1994). *When the mind fails: A guide to dealing with incompetency*. Toronto: University of Toronto Press.
- Spann, J. (2001, November). Approaches for patients from marginalized groups. *State Initiatives in End-of-Life Care*, (Advance Care Planning-Part I, Issue 12). Community-State Partnerships to Improve End-of-Life Care, Kansas City, Mo.
- Stevenson, D.G., & Studdert, D.M. (2003, March/April). The rise of nursing home litigation: Findings from a national survey of attorneys. *Health Affairs*, 22(2).
- Sundram, C.J. & Stavis, P.F. (1997). The first ten years of New York's surrogate decision-making law: History and development. *Guardianship Practice in New York State*, 2(26). Albany, NY: New York State Bar Association.
- Symposium, Joint Conference on Legal/Ethical Issues in the Progression of Dementia. (2001, Winter). Recommendations of the Joint Conference. *Georgia Law Review*, 35(2).
- Teaster, P.B. & Roberto, K.A. (2002, February). *Virginia public guardian and conservator programs: Summary of the first year evaluation*. Unpublished Report for the Virginia Department for the Aging, Richmond, Va.
- Teno, J.M., Branco, K. J., Mor, V., Phillips, C.D., Hawes, C., Morris, J., & Freis B.E. (1997). Changes in advance care planning in nursing homes before and after the patient self-determination act: Report of a 10-state survey. *Journal of the American Geriatric Society*, 45(3).
- U.S. Administration on Aging. (2003). *Statistics*. Retrieved May 2003 from the U.S. Administration on Aging's Web site: <http://www.aoa.gov/prof/statistics/statistics.asp>.
- U.S. Department of Veterans Affairs, Veterans Health Administration. (2003, January 29). *VHA handbook 10004.1*. Washington, D.C.: U.S. Department of Veterans Affairs.
- Wingspan—The second national guardianship conference. (2002, Spring). *Stetson Law Review*, 31(3).
- Wood, E. (2002). *State adult guardianship legislation: Directions of reform* (an annual review). Retrieved May 2003 from the American Bar Association Commission on Law and Aging's Web site: <http://abanet.org/aging>.

Appendix 1

Recommendation for Establishing Policy on
Health Care Decisions for Incapacitated Patients Without Surrogates

Santa Clara County Medical Association
San Jose, California
February 2001

I. Purpose Statement

To provide procedural mechanisms whereby health care decisions can be made for patients who lack health care decision-making capacity and for whom no surrogate exists.

II. Background

- A. This policy represents a consensus among the medical and legal professionals of the Ethics Committee of the Santa Clara County Medical Association about the most appropriate manner in which to make medical decisions on behalf of incapacitated patients who lack surrogate decision-makers. Despite their incapacity, such patients are entitled to have appropriate medical decisions made on their behalf and to have these decisions made in their best interest, respecting their wishes and values as much as they can be known. The procedures set forth here are intended to meet these goals. This policy is considered necessary since no clear-cut legal guidelines exist that cover these circumstances. As a consequence, unrepresented patients tend to be managed inconsistently and on an ad hoc basis, which often confounds and delays medical decisions. Finally, this policy and its procedural protections were considered especially important for the irreversible decisions to forgo life-sustaining treatment for unrepresented patients.
- B. This policy is procedural in nature and applies to all medical decisions for which informed consent is usually required.
- C. This policy is meant to support the institution's underlying consent policy.
- D. Goals to be achieved

To make and effect health care decisions in accordance with a patient's best interest, taking into consideration the patient's personal values and wishes to the extent that these are known.

Appendix 1: Santa Clara County Medical Association Recommendation

To establish uniform procedures to implement appropriate health care decisions for unrepresented patients. Appropriate health care decisions include both the provision of needed and wanted medical treatment and the avoidance of nonbeneficial or excessively burdensome treatment. Appropriate health care decisions are also those that are based on sound medical advice and made without the influence of material conflicts of interest.

- E. Circumstances where policy is not applicable or is applied only with additional considerations

This policy does not apply in emergency medical situations.

This policy does not apply in situations where, using sound medical judgment, a physician makes a bedside decision to cease attempts at cardio-pulmonary resuscitation of a patient.

If the Public Guardian is appointed, the Public Guardian must be involved in medical decision-making under this policy. Medical circumstances will dictate when medical providers can delay decision-making in order to include the Public Guardian.

Hospital legal counsel should be consulted if a decision to withdraw treatment is likely to result in the death of the patient and the situation arises in any of the following circumstances:

- The patient's condition is the result of an injury that appears to have been inflicted by a criminal act
 - The patient's condition was created or aggravated by a medical accident
 - The patient is pregnant
 - The patient is a parent with sole custody or responsibility for support of a minor child
- F. Application: The patient's age, sex, religion, ethnic or social status, the ability to pay for healthcare services, or avoidance of burden to family or to society shall not be used to bias considerations about the appropriateness of any health care decision under this policy.

III. Who Is An Incapacitated Patient Who Lacks a Surrogate?

- A. The patient has been determined by the primary physician (with assistance from appropriate consulting physicians if necessary) to lack capacity to make health care decisions. Capacity means a patient's ability to understand the nature and consequences of proposed health care, including its significant benefits, risks, and alternatives, and to make and communicate a health care decision.
- B. No agent, conservator, or guardian has been designated to act on behalf of the patient.
- C. No dispositive individual health care instruction is in the patient's medical record.
- D. No surrogate decision-maker can be selected or the surrogate is not reasonably available. For the purpose of this policy, a surrogate can be an adult family member. Also, an individual with a close personal relationship to the patient can serve as a surrogate. Any surrogate needs to have

shown care and concern for the patient's welfare and must have some familiarity with the patient's activities, health, religious beliefs, and values. There must be medical record documentation (such as by a social service worker) that this surrogate has been interviewed and satisfies the above criteria to serve as a surrogate decision-maker.

Efforts to establish whether or not a surrogate is reasonably available should be diligent and can include contacting the facility from which the patient was referred, and contacting public health or social service agencies known to have provided treatment for the patient.

IV. Referral to Ethics Committee

If no surrogate can be located, medical decisions on behalf of incapacitated patients will be made using the following procedures.

A. Medical decisions for which informed consent is required

An ethics consultant (one or more people) will provide advice about the process of medical decision-making. This consultant will come from the facility's Ethics Committee or, if there is none, the consultant will possess appropriate skill and experience in ethical medical decision-making. The consultant will ensure that treatment decisions are made consistent with this policy. In this process, the consultant will make all reasonable efforts to learn about the patient's medical treatment preferences. The consultant should contact others for expanded advice should the circumstances warrant.

B. Medical decisions about withholding or withdrawing life-sustaining treatment

a. The medical team will obtain a second opinion about the decision from an independent physician with relevant medical qualifications.

b. The Chair of the Ethics Committee will appoint a sub-committee to act as surrogate decision-maker and review the proposed decision to ensure that the decision was based on sound medical advice and made in conformity with this policy.

c. **Composition of Sub-Committee:** The sub-committee will consist of multidisciplinary medical personnel capable of independently appreciating the medical consequences of the healthcare decision. At least one non-medical member of the Ethics Committee will be named to the sub-committee. If the patient is in a long-term care facility, the sub-committee will include an ombudsman as a member. All members will be asked whether they have any material conflict of interest, real or apparent, in the matter and, if so, will be excused from the sub-committee.

d. **Conduct and Standards of Review by Sub-Committee:** The sub-committee will advocate on behalf of the patient. The sub-committee will interview the relevant medical treatment providers and anyone else closely involved with the patient. The sub-committee will inquire about the process to determine the decision-making capacity of the patient, the attempts made to learn about the patient's medical preferences and to locate a surrogate decision-maker, the medical basis for the conclusion that medical treatment should be withheld or withdrawn, and about the other available medical options and their likely outcomes. The sub-committee will consider the patient's cultural, ethnic or religious perspectives, if known. If possible, someone of the patient's

cultural, ethnic or religious background should be consulted to determine if it is likely that these factors would influence what treatment the patient would prefer. The sub-committee will also inquire about the likelihood of restoring the patient to an acceptable quality of life. The patient's quality of life will be considered from the perspective of the patient and not from that imposed by any sub-committee member. The sub-committee will weigh and balance all of the above considerations, keeping in mind that the best interest of the patient do not require that life support be continued in all circumstances, such as when the patient is terminally ill and suffering, where there is no hope of recovery of cognitive functions, or where treatment is otherwise nonbeneficial.

e. Decision-Making by Sub-Committee: The sub-committee will assure itself that there were adequate safeguards to confirm the accuracy of the diagnosis and that the medical decision was made in good faith, was based on sound medical advice, and is in the patient's best interest according to this policy. The sub-committee can ask for further medical opinions to verify the primary conclusions. The sub-committee can also ask that further investigations be made about the availability of surrogates, the patient's treatment preferences, or other relevant matters. After this investigation is completed, the sub-committee will then make an independent finding about the proposed decision.

f. Subsequent Action: If the sub-committee is in general agreement about the proposed decision, the decision can be implemented by the primary treating physician. If the sub-committee cannot reach a general agreement or if it disapproves of the medical decision, the Chief of Staff or his/her designee will be included in the decision-making process to assist in resolving any disagreements. In any case where a medical decision to withhold or withdraw life-sustaining treatment will be implemented under this policy, the Chief of Staff must approve of the decision. Irresolvable conflicts can be referred to court for legal resolution with the understanding that a legal remedy should only be sought in extreme circumstances. Any implementation of a decision to withhold or withdraw life-sustaining medical treatment will be the responsibility of the primary treating physician.

V. Record Keeping

Signed and dated medical record progress notes will be written for the following:

- a. The findings used to conclude that the patient lacks medical decision-making capacity,
- b. The finding that there is no durable power of attorney for healthcare, no conservator or guardian, and no medical instructions,
- c. The attempts made to locate surrogate decision-makers and the results of those attempts,
- d. Any interviews of individuals with a close personal relationship to the patient willing to serve as surrogate and facts to substantiate their qualifications under this policy,
- e. The medical bases for the decision to withhold or withdraw life-sustaining treatment and the likely outcome if the decision is implemented, and

Any findings and conclusions by the ethics consultant, the appointed ethics sub-committee, or the Chief of Staff.

VI. References

- (1) Veterans Health Administration, Department of Veterans Affairs, Informed Consent, VHA Directive 1004, February 21, 1996, pages 5-7.
- (2) Kirschner, M. and Michel, V., Guideline Addendum, The April 2, 1990, LACMA Physician Guidelines for Foregoing Life-Sustaining Treatment for Adult Patients. Supplement: Patient's without decision-making capacity who lack surrogates, LACMA Physician, July 12, 1993.
- (3) 22 CCR 70707
- (4) JCAHO Patient Rights and Organizational Ethics, RI.1
- (5) California Probate Code § 3200 *et seq.*
- (6) Health Care Decisions Law (California Probate Code § 4600), specifically, Part 2, Uniform Health Care Decisions Act (California Probate Code §§ 4670, 4735)

Appendix 2

GUIDELINES FOR THE UNBEFRIENDED

May 1997

The Hebrew Rehabilitation Center for Aged is committed to involving residents and families in medical decision-making. Since residents are sometimes temporarily or permanently unable to participate in discussions about treatment alternatives, the HRCA regards identification of a surrogate decision-maker for each resident as essential. In accordance with the federal Patient Self-Determination Act and the Massachusetts Health Care Proxy Act, the HRCA urges all individuals who are capable to appoint a proxy to make decisions for them if they become unable to make decisions for themselves. The following guidelines seek to maximize the likelihood of each resident choosing a surrogate, and to establish a procedure in the event that no family members or proxy have been identified.

1. Prior to admission, family members or a close friend who could serve as a surrogate are identified.
2. At the time of admission, capable residents will be asked to select a health care proxy and an alternate.
3. At regular intervals not to exceed six months, the unit social worker will make sure that the proxy and the alternate are still in communication with the resident or the facility. In the absence of a proxy, the social worker will make sure that a family member is identified as the informal surrogate, with a second family member available as back-up.
4. If at any point during the resident's stay, no family member or proxy is available, the HRCA will appoint an informal surrogate decision-maker. If the resident is decision-capable, the resident will be involved in choosing the surrogate. If the resident is not decision-capable, the HRCA will make the appointment unilaterally. This individual will serve as a patient advocate and as advisor to the primary care team regarding decisions to limit treatment. The informal surrogate will take on the same role as would a family member or proxy vis-à-vis medical decisions. Informal surrogates will be drawn from the ethics committee, but will continue to serve in this role even if they complete their term on the ethics committee. Ethics committee members who are directly involved in the care of a given resident are not eligible to serve as informal surrogate for that resident.

Informal surrogates are not legally recognized: should a resident be transferred to the acute care hospital and should that individual be considered for surgery or invasive procedures, the hospital would need to seek a guardian ad litem for that resident. However, given the difficulties with obtaining guardians through the legal system, the decision to use an informal advisory model is a reasonable alternative. There is a potential for conflict of interest in selecting as a surrogate an individual who works for the HRCA. To guard against this possibility, the surrogates will not be directly involved in the care of the residents whose interests they are

representing. Moreover, their decisions will be subject to review by the Ethics Committee at its monthly meeting.

Informal surrogates will be expected to make decisions regarding limitations of treatment, such as hospitalization. The default response to a cardiac arrest will be DNAR, unless the surrogate suggests otherwise. If a resident is transferred to another unit, he or she will keep the same informal surrogate unless the surrogate is now the primary caregiver. In this event, the responsibilities of the surrogate will be transferred to another member of the Ethics Committee.

The Informal Surrogate System

1. **Appointment:** a member of the HRCA Ethics Committee will be appointed by the chair of the Ethics Committee to serve as an informal surrogate if the team social worker reports that there is no family or designated proxy.
2. **Term:** informal surrogates will carry out their responsibilities for the duration of the resident's stay at the HRCA. Should they become ineligible to serve in this capacity because they are involved in the direct care of the resident or are no longer affiliated with the HRCA, a new surrogate will be appointed.
3. **Resignation:** informal surrogates may resign by writing a letter to the chair of the Ethics Committee, requesting that another surrogate be appointed, should they feel they are incapable of carrying out their responsibilities fairly or should they find the task excessively burdensome.
4. **Responsibilities:** informal surrogates will be asked about treatment decisions in much the way that family members or proxies are involved in decision-making. They will be expected to get to know the resident and to learn about his or her current or previously expressed wishes and personality in order to guide decision-making. Documentation of discussions about preferences should be entered in the Advance Directives section of the medical record. The home telephone number of the informal surrogate will be on record at the resident's nursing stations, as would be the case with a family member or proxy.
5. **Back-up:** the chair of the Ethics Committee will serve as back-up for informal surrogates.
6. **Review:** all decisions in which informal surrogates are involved are subject to review by the Ethics Committee at its regular meeting.
7. **Limits of informal surrogates:** informal surrogates are not empowered legally to make decisions for nursing home residents. Any resident who is transferred to the acute care hospital and in whom decisions about medical treatment must be made will require appointment of a guardian ad litem.