# STATEMENT IN SUPPORT OF H.B. 1323 (FAV) BEFORE THE MARYLAND HOUSE HEALTH COMMITTEE - MARCH 11, 2026

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## Background of Witness

I am a law professor at Mitchell Hamline School of Law in Saint Paul, Minnesota. I have published over 330 articles and two books on healthcare and end-of-life decision making. I write in favor of the bill in my personal capacity.

## Importance of this Bill

The risks to unrepresented patients are significant and well-documented. This alone is sufficient reason to legislate improved decision-making processes. But there are two more reasons to pass this bill. The problems of decision making for unrepresented patients also pose financial risks to hospitals and safety risks to other patients (who are unable to access needed beds). H.B. 1323 offers a process that is more efficient than guardianship yet still offers fairness and substantial procedural due process to unrepresented patients.

## Three Suggested Improvements

While I support this bill, I offer three suggestions.

The first problem concerns the scope of the bill. It limits “unrepresented patient” to hospital patients. This means that the significant advantages of the bill described above will not benefit the significant population of unrepresented individuals in Maryland long-term care facilities.

The second problem is that the bill applies only to patients who do “not have an advance directive.” This makes the definition too narrow. Many unrepresented patients “have” advance directives. But that does not necessarily prevent the patient from being unrepresented. The appointed agents may be unavailable. Or the advance directive’s instructions may be inapplicable to the current situation. The patient is unrepresented when there is no legally authorized decision tool (e.g., advance directive, MOLST, agent, surrogate) available to address the decisions at hand.

The third problem is that the bill does not specify minimum diligent efforts to restore the patient's capacity, to find an available agent, or to find an available surrogate. All these efforts could prevent the patient from being unrepresented and thus avert need to use the surrogate committee. Use of the surrogate committee should be a last resort. The bill should specify the efforts to get a decision made in a preferred path, before turning to the hospital surrogate committee.

## Resources on Healthcare Decision Making for Unrepresented Patients

In case it might aid the committee, I attach four of my articles on unrepresented patients.

Making Medical Treatment Decisions for Unrepresented Patients in the ICU: An Official ATS/AGS Policy Statement, 201(10) AMERICAN JOURNAL OF RESPIRATORY & CRITICAL CARE MEDICINE 1182-1192 (2020) (with multi-professional committee).

Five Things Clinicians Should Know When Caring for Unrepresented Patients, 21(7) AMA JOURNAL OF ETHICS 581-585 (July 2019).

Unbefriended and Unrepresented: Medical Decision Making for Incapacitated Patients without Healthcare Surrogates, 33(4) GEORGIA STATE UNIVERSITY LAW REVIEW 923-1019 (2017).

Procuring Organs from Unrepresented Patients - Amend the Uniform Anatomical Gift Act, 25(9) AMERICAN JOURNAL OF BIOETHICS 57-59 (2025).

AMERICAN THORACIC SOCIETY DOCUMENTS

# Making Medical Treatment Decisions for Unrepresented Patients in the ICU

## An Official American Thoracic Society/American Geriatrics Society Policy Statement

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THIS OFFICIAL POLICY STATEMENT WAS APPROVED BY THE AMERICAN THORACIC SOCIETY FEBRUARY 2020 AND THE AMERICAN GERIATRICS SOCIETY JANUARY 2020

**Background and Rationale**: ICU clinicians regularly care for patients who lack capacity, an applicable advance directive, and an available surrogate decision-maker. Although there is no consensus on terminology, we refer to these patients as "unrepresented." There is considerable controversy about how to make treatment decisions for these patients, and there is significant variability in both law and clinical practice.

**Purpose and Objectives**: This multisociety statement provides clinicians and hospital administrators with recommendations for decision-making on behalf of unrepresented patients in the critical care setting.

**Methods**: An interprofessional, multidisciplinary expert committee developed this policy statement by using an iterative consensus process with a diverse working group representing critical care medicine, palliative care, pediatric medicine, nursing, social work, gerontology, geriatrics, patient advocacy, bioethics, philosophy, elder law, and health law.

**Main Results**: The committee designed its policy recommendations to promote five ethical goals: *1*) to protect highly vulnerable patients, *2*) to demonstrate respect for persons, *3*) to provide appropriate medical care, *4*) to safeguard against unacceptable discrimination, and *5*) to avoid undue influence of competing obligations and conflicting interests. These recommendations also are intended to strike an appropriate balance between excessive and insufficient procedural safeguards. The committee makes the following recommendations: *1*) institutions should offer advance care planning to prevent patients at high risk for becoming unrepresented from meeting this definition; *2*) institutions should implement strategies to determine whether seemingly unrepresented patients are actually unrepresented, including careful capacity assessments and diligent searches for potential surrogates; *3*) institutions should manage decision-making for unrepresented patients using input from a diverse interprofessional, multidisciplinary committee rather than *ad hoc* by treating clinicians; *4*) institutions should use all available information on the patient's preferences and values to guide treatment decisions; *5*) institutions should manage decision-making for unrepresented patients using a fair process that comports with procedural due process; *6*) institutions should employ this fair process even when state law authorizes procedures with less oversight.

**Conclusions**: This multisociety statement provides guidance for clinicians and hospital administrators on medical decision-making for unrepresented patients in the critical care setting.

**Keywords:** substituted judgment; surrogate; unrepresented; adult orphan; patient without advocate

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Endorsed by the Society of Critical Care Medicine on January 24, 2020, and the Neurocritical Care Society on February 13, 2020.

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Am J Respir Crit Care Med Vol 201, Iss 10, pp 1182–1192, May 15, 2020

DOI: 10.1164/rccm.202003-0512ST
Internet address: www.atsjournals.org

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## Overview

ICU clinicians regularly face situations in which an adult patient lacks decision-making capacity, an applicable advance directive, and any available surrogate decision-maker (1–6). For these patients, there is no one with whom the clinician can engage in shared decision-making, which is recommended for important, value-laden decisions in ICUs (7). Available evidence shows that the absence of a decision-maker causes patients to face significant risks of being overtreated, undertreated, or otherwise treated inconsistently with their preferences and values (8–10).

This policy statement refers to these patients as "unrepresented patients." Yet, there is no consensus on which term to use, and others use "unbefriended" or "incapacitated patient without advocate" (11). In addition to terminology, there is considerable controversy over how to make medical treatment decisions for these patients (12). Moreover, in the ICU setting, there is significant variability in how decisions are made and little guidance about how to do so (2).

The committee developed this policy statement to help clinicians and hospital administrators design fair and feasible procedures for making treatment decisions for unrepresented patients in the ICU setting. This policy statement provides *1*) an ethical analysis of medical decision-making for unrepresented patients, *2*) recommended decision-making procedures for unrepresented patients in the critical care setting, and *3*) proposed components of a model institutional policy on decision-making for unrepresented patients in ICUs.

The six recommendations described below have two primary justifications. First, they promote the following five ethical goals: *1*) to protect highly vulnerable patients, *2*) to demonstrate respect for persons, *3*) to provide appropriate medical care, *4*) to safeguard against unacceptable discrimination, and *5*) to avoid the undue influence of competing obligations and conflicting interests. Second, the six recommendations help strike an appropriate balance between excessive and insufficient procedural safeguards. Excessive safeguards may delay providing patients with appropriate medical care and may be too cumbersome for clinicians and institutions. Insufficient safeguards may fail to adequately promote the five ethical goals.

### Recommendation 1

Institutions should promote advance care planning to prevent patients at high risk from becoming unrepresented in the first place, both *1*) by helping adult patients with decision-making capacity to identify a preferred surrogate decision-maker and to record their preferences and values in an advance directive and *2*) by ensuring that such documents are available to clinicians at the point of care.

### Recommendation 2

Institutions should implement strategies to determine whether seemingly unrepresented patients are, in fact, unrepresented by *1*) carefully assessing medical decision-making capacity, *2*) diligently searching for suitable surrogates among the patient's family and friends, and *3*) involving any nonhospital individuals who have shown care and concern for the patient's welfare and are familiar with the patient's values and preferences.

### Recommendation 3

Institutions should manage decision-making for unrepresented patients using collaboration between the clinical team and a diverse interprofessional, multidisciplinary committee rather than *ad hoc* by treating clinicians.

### Recommendation 4

Institutions should use all available information on the patient's preferences and values to guide decisions. If such information is not available, the committee should collaborate with the treatment team to make decisions in the patient's best interest.

### Recommendation 5

Institutions should manage decision-making for unrepresented patients using a fair process that comports with principles of procedural due process, such as transparency, legitimacy, and consistency.

### Recommendation 6

Institutions should employ this fair process even when state law authorizes procedures with less oversight.

## Introduction

ICU clinicians regularly face situations in which an adult patient lacks both decision-making capacity and any available surrogate decision-maker (1–6). For these patients, there is no one with whom the clinician can engage in shared decision-making, which is recommended for important, value-laden decisions in ICUs (7). Available evidence shows that the absence of a decision-maker causes patients to face significant risks of being overtreated, undertreated, or otherwise treated inconsistently with their preferences and values (8–10).

This policy statement refers to these patients as "unrepresented patients." Yet, there is no consensus on which term to use, and others use "unbefriended" or "incapacitated patient without advocate" (11). There is considerable controversy over how to make medical treatment decisions for these patients (11, 12). Moreover, in the ICU setting, there is significant variability in how decisions are made and little guidance about how to do so (2).

Unrepresented patients in the critical care setting are common (5). In 2006, White and colleagues found that 16% of patients admitted to an ICU were unrepresented (1). In 2007, White and colleagues found that 5% of patients who died in the ICU were unrepresented (2). In a more recent survey of critical care clinicians and hospitalists, nearly 50% of respondents reported seeing at least one unrepresented patient per month (3). Other studies measuring the number of unrepresented patients in other healthcare settings corroborate these figures (4, 6, 13).

Incapacitated critically ill patients without an applicable advance directive or a surrogate decision-maker leave clinicians in a quandary. Providers in the United States generally take three different approaches: *1*) providing treatment, *2*) withholding or withdrawing treatment, or *3*) delaying treatment. First, some clinicians might treat the patient without consent. Erring on the side of prolonging life, they may administer improperly prolonged life-sustaining treatment despite limited prospects of benefit, despite burdens on the patient, and even despite evidence of the patient's wishes to avoid such treatment (5, 14). Second, some clinicians might withhold or withdraw treatment because they unilaterally deem it to be potentially inappropriate. Third, other clinicians may delay treatment until the patient regains capacity or a court-appointed surrogate decision-maker is identified.

These inconsistencies are ethically problematic. Furthermore, this variability in care exposes unrepresented patients to three different types of risks: overtreatment, undertreatment, and delayed treatment. In addition, because there is no one to authorize discharge, the unrepresented often have prolonged hospital stays. ICU stays for unrepresented patients are often twice the duration of stays for other patients (9, 10).

Although several professional societies have published policy statements regarding decision-making for unrepresented patients (11, 15, 16), none specifically addresses decision-making for unrepresented patients in the critical care setting. Moreover, these guidelines differ substantially on who may act as a surrogate and authorize treatment decisions on behalf of unrepresented patients (Table 1). State healthcare surrogate laws vary as well (Table 2) (3, 17–19). These conflicting laws and conflicting guidelines from professional societies are problematic. This variability may exacerbate confusion on this topic among clinicians, hospital administrators, and policy makers (15, 20–22).

Both because of these complexities and because clinicians need clear guidance, the American Thoracic Society (ATS) convened a multisociety working group to make recommendations regarding how to make treatment decisions for unrepresented patients in the context of acute critical illness. This ATS/American Geriatrics Society (AGS) policy statement provides clinicians and hospital administrators with guidelines for medical treatment decision-making on behalf of unrepresented patients.

The committee developed this policy statement to help clinicians and hospital administrators design fair and feasible procedures for making treatment decisions for unrepresented patients in the ICU setting. This policy statement provides *1*) an ethical analysis of medical decision-making for unrepresented patients, *2*) recommended decision-making procedures for unrepresented patients in the critical care setting, and *3*) proposed components of a model institutional policy on decision-making for unrepresented patients in ICUs.

This policy statement focuses on decisions regarding life-sustaining treatment for adult patients. It does not address *1*) decision-making for unrepresented patients outside the ICU setting, *2*) decision-making for biomedical research purposes, *3*) decision-making in emergencies, or *4*) decisions regarding organ donation and other postmortem decisions. This policy statement also does not address decisions for minor interventions that are less consequential and may require less process and oversight (e.g., administration of most drugs and vaccines or the performance of minor procedures, such as routine X-rays) (7, 23).

## Methods

An interprofessional, multidisciplinary expert committee developed this policy statement using an iterative process. The ATS Ethics and Conflict of Interest Committee first convened an *ad hoc* working group composed of a subset of members of the ATS Ethics and Conflict of Interest Committee. The committee evaluated the need for additional expertise and invited 20 national experts to join the working group. The full working group was diverse and represented a breadth of disciplines, including critical care medicine, palliative care, pediatric medicine, nursing, social work, gerontology, geriatrics, patient advocacy, bioethics, philosophy, elder law, and health law.

The working group first reviewed known relevant literature, including journals with a focus in medicine, critical care, bioethics, and law. The group deemed this broad approach appropriate because this document is a policy statement that relies heavily on theoretical analysis informed by available research data and is not intended to be considered a practice guideline. The group also reviewed existing policies of other medical organizations. The group then developed the content of this policy through a 3-year iterative discussion–based consensus process consisting of face-to-face meetings, teleconferences, web conferences, and electronic correspondence. A writing committee drafted the policy statement, which the working group members then reviewed on multiple occasions and revised. The policy statement was further modified and ultimately approved by members of the ATS and AGS ethics committees. This statement then underwent a peer review process and ultimately review by both the ATS Board of Directors and the AGS Board of Directors.

## Ethical Goals for Decision-Making for Unrepresented Patients

A review of the literature on unrepresented patients reveals five key reasons why guarded diligence and careful evaluation are required when making treatment decisions for unrepresented patients: *1*) to protect highly vulnerable patients, *2*) to demonstrate respect for persons, *3*) to provide appropriate medical care, *4*) to safeguard against unacceptable discrimination, and *5*) to avoid undue influence of competing obligations and interests (Table 3).

**Table 1.** Existing Policy Statements Pertaining to Unrepresented Patients

| Year | Author/Society | Decision-Maker |
|---|---|---|
| 1992 | New York State Task Force on Life and the Law | Interprofessional, multidisciplinary committee |
| 2003 | American Bar Association | Interprofessional, multidisciplinary committee |
| 2006 | Los Angeles County Medical Association | Interprofessional, multidisciplinary committee |
| 2015 | California Hospital Association | Interprofessional, multidisciplinary committee |
| 2016 | American Medical Association | Hospital ethics committee |
| 2016 | American Geriatrics Society | Institutional committee (e.g., ethics) or healthcare team according to a standardized process |
| 2017 | Veterans Health Administration | Interprofessional, multidisciplinary committee + chief of staff + facility director |
| 2019 | American College of Physicians | Court-appointed guardian |

### Protect Highly Vulnerable Patients

Unrepresented patients in the ICU are extremely vulnerable in several ethically relevant ways (24). First, patients in ICUs cannot advocate for themselves, because they frequently lack decision-making capacity owing to the severity of their illness and/or sedative and pain-relieving medications (7, 25, 26). Second, unrepresented patients lack trusted and reliable friends or family to advocate on their behalf. Third, when admitted to an ICU, patients (including unrepresented patients) usually lack a choice of healthcare clinician. They are completely dependent on the institution and its clinicians. For all these reasons, commentators have described unrepresented ICU patients as "unimaginably helpless" (27), as "highly vulnerable" (11), and as the "most vulnerable" (11).

### Demonstrate Respect for Persons

Although manifesting respect for patient autonomy is a core principle of medical ethics, it is generally not applicable in the context of making decisions regarding life-sustaining treatment for unrepresented patients. This is because respecting a patient's autonomy requires the patient to have expressed an autonomous treatment preference applicable to the clinical situation at hand. By definition, unrepresented patients cannot currently articulate treatment preferences specific to the clinical decision at hand. Most have not done so previously, and even if they have, evidence of those preferences is usually not available (28).

This committee proposes that the broader ethical goal of manifesting respect for persons should be viewed as central to care processes for unrepresented patients. Respect in this context involves both the attitudes one adopts toward the unrepresented patient and the behaviors one manifests. Respect for persons requires an acknowledgment of each person's worth and dignity. The display of respect can take on numerous forms, such as making extensive efforts to learn about and treat the patient as a unique individual, incorporating all that is known about the patient's values into treatment decisions, ensuring serious moral deliberation about decisions, and encouraging others to adopt a demeanor of sincere regard and caring for the person in all interactions.

Learning and incorporating the patient's individuality, values, goals, culture, and previously expressed treatment preferences manifests respect for persons, a core ethical obligation of the medical profession (7, 24). Physical harm is not the only type of risk posed to the unrepresented. Whether overtreated or undertreated, the unrepresented are susceptible to treatment decisions that do not conform to their personal values, morals, or beliefs. This is a serious affront to respect for persons.

The Institute of Medicine observes that patients "who have neither decision-making capacity nor a surrogate decision-maker are at particular risk of not having their wishes known or followed" (8). For instance, several studies report that clinicians often make decisions based on their own idiosyncratic personal preferences. They may not know the patient, or they may not be willing and/or able to take the time to learn the patient's preferences (29, 30). A treatment decision that is not based on a patient's own preferences and values, when ascertainable, is particularly offensive in a society that places a premium on individual self-determination (7).

**Table 2.** State Healthcare Surrogate Decision Laws Pertaining to Unrepresented Patients

| State | Decision-Maker |
|---|---|
| Connecticut, Nebraska, North Carolina, North Dakota, Oregon | Attending alone |
| Arizona, Arkansas, Louisiana, Tennessee, Texas | Attending + second physician |
| Alabama | Attending + ethics committee |
| California | Interdisciplinary team |
| Colorado, Montana | Medical proxy + ethics committee |
| Florida | Independent clinical social worker |
| Texas | Member of clergy |
| New York | Court |

### Provide Appropriate Medical Care

In addition to the risk of disrespect for persons, unrepresented patients face three types of treatment risk: overtreatment, undertreatment, or delayed treatment. In overtreated patients, the absence of an authorized surrogate often results in "maximum medical intervention, whether or not a medical 'full court press' is clinically and ethically warranted" (31). There are several reasons why the unrepresented receive unnecessary or unwanted treatment, including *1*) clinicians' fear of not providing appropriate treatment, *2*) fear of civil liability for failure to treat, *3*) institutional fear of regulatory sanctions, *4*) clinicians' economic incentives to treat, and *5*) clinicians' general interventionist philosophy of medicine.

Most unrepresented patients are overtreated, but some are undertreated. With no surrogate to object, some clinicians may decide that treatment is inappropriate and unilaterally withhold or withdraw it.

**Table 3.** Five Ethical Goals for Safeguards in Decision-Making for Unrepresented Patients

1. Protect highly vulnerable patients
2. Demonstrate respect for persons
3. Provide appropriate medical care
4. Safeguard against unacceptable discrimination
5. Avoid undue influence of competing obligations and conflicting interests

Other clinicians may refuse to provide any type of treatment without informed consent. Consequently, important decisions may be "postponed dangerously [or] forgone altogether" (32, 33).

Some clinicians will wait until an emergency, when consent is implied and therefore there is no need for a surrogate to authorize treatment (3). However, waiting for an emergency may result in longer periods of suffering and indignity, increasing the chance of morbidity or even mortality. The absence of a surrogate can "stymie decision-making and possibly leave . . . patients to linger in pain and discomfort" (34). The Institute of Medicine found it ethically "troublesome" to wait "until the patient's medical condition worsens into an emergency so consent to treat is implied." Such an approach "compromises patient care and prevents any thorough and thoughtful consideration of patient preferences or best interest" (8).

### Safeguard against Unacceptable Discrimination

Clinicians' treatment decisions may be influenced by medically irrelevant characteristics of the patient (e.g., the patient's race, gender, religion, social worth, undocumented immigration status, ethnicity, or sexual orientation) rather than by the nature of the medical service (35–40). It is unacceptable discrimination to treat a class of persons unequally on the basis of medically irrelevant characteristics. Such conduct is unethical and condemned by most health care professions' codes of ethics.

Not only intentional but also implicit biases may go unchecked without a surrogate to whom clinicians must explain and justify their recommendations (41, 42). The risk of unacceptable discrimination is especially germane, because unrepresented patients are often members of groups (e.g., homeless and those with mental illness and substance use disorders) that have been subject to discrimination (43). Furthermore, there is a risk that treatment decisions will be influenced not only by irrelevant patient characteristics but also by irrelevant clinician characteristics, such as their own personal preferences for life-extending care or their religious beliefs (44, 45).

### Avoid Undue Influence of Competing Obligations and Conflicting Interests

Competing obligations occur when clinicians have two or more valid professional responsibilities that conflict. Increasingly, clinicians are perceived to have ethical commitments both to individual patients and to society at large to manage resources in a cost-conscious manner. When clinicians act as decision-makers for their patients, there may be greater likelihood that the patient's interests are not adequately represented, considered, and balanced against the obligation to populations of patients (12, 46).

A related but distinct concern is that clinicians' real or perceived conflicts of interest may compromise their ability to act as decision-maker for an unrepresented patient. At least two types of secondary interests could unduly influence the clinician's professional judgment about the well-being of the unrepresented patient. First, financial interests of the clinician and/or institution could be affected by treatment decisions. For example, potential conflict could lead to overtreatment of patients in fee-for-service reimbursement models and to undertreatment in capitated models. Pressure to make scarce ICU beds available could also lead to undertreatment.

Second, clinicians face nonfinancial conflicts of interest. ICU clinicians generally work as part of an interprofessional, multidisciplinary team. To some degree, their professional satisfaction and advancement depend on good relationships with colleagues. End-of-life care often causes disagreement and moral conflict or distress among staff. Clinicians have an interest in maintaining cordial peer relationships and therefore in making decisions that will keep peace in the ICU. This will push toward overtreatment in some institutions and undertreatment in others.

## Recommendations

Institutions should heed six recommendations outlined below (Table 4). They are designed to promote the five ethical goals. They are also intended to strike an appropriate balance between excessive and insufficient procedural safeguards. Excessive safeguards may unnecessarily delay providing patients appropriate medical care and may be too cumbersome for clinicians and institutions. Insufficient safeguards fail to adequately promote the five ethical goals.

### Recommendation 1

**Institutions should promote advance care planning to prevent patients at high risk for becoming unrepresented from meeting this definition, both *1*) by helping adult patients with decision-making capacity to identify a preferred surrogate decision-maker and to record their preferences and values in an advance directive and *2*) by ensuring that such documents are widely available to clinicians at the point of care.**

Ideally, potentially unrepresented patients would engage in advance care planning in the community in places of worship, homeless shelters, social support agencies, legal aid offices, and primary care offices. Unfortunately, limited time and training constrain these discussions in the clinical environment. However, advance care planning can be effectively implemented in the hospital or ICU. Indeed, this is specifically mandated by the Patient Self Determination Act (47). Several studies found that although most ICU patients lack capacity, at least one-fourth remain involved with their treatment (37, 48). Many patients can name a surrogate after admission but before losing capacity (49).

Moreover, even if patients' capacity is impaired, they might still have capacity to share what they think about death, life, their current living situation, and their hopes for the future. In short, unrepresented patients should participate in making decisions to the extent that they can (50). Given that naming a preferred surrogate may not require as much decisional capacity as creating a living will expressing end-of-life treatment preferences, this "first step" in advance care planning should be encouraged upon admission or during periods of lucidity and documented when possible (23).

**Table 4.** Policy Recommendations for Medical Decision-Making for Unrepresented Patients in Intensive Care Medicine

| | |
|---|---|
| Recommendation 1 | Institutions should promote advance care planning to prevent patients at high risk for becoming unrepresented from meeting this definition, both *1*) by helping adult patients with decision-making capacity to identify a preferred surrogate decision-maker and to record their preferences and values in an advance directive and *2*) by ensuring that such documents are widely available to clinicians at the point of care. |
| Recommendation 2 | Institutions should implement strategies to determine whether seemingly unrepresented patients are, in fact, unrepresented, including *1*) carefully assessing capacity, *2*) diligently searching for potential surrogates among the patient's family and friends, and *3*) involving any nonhospital individuals who have shown care and concern for the patient's welfare and are familiar with the patient's preferences and values. |
| Recommendation 3 | Institutions should manage decision-making for unrepresented patients using collaboration between the clinical team and a diverse interprofessional, multidisciplinary committee rather than *ad hoc* by treating clinicians. |
| Recommendation 4 | Institutions should use all available information on the patient's preferences and values to guide treatment decisions. If such information is not available, the committee should collaborate with the treatment team to make decisions in the patient's best interest. |
| Recommendation 5 | Institutions should manage decision-making for unrepresented patients using a fair process that comports with procedural due process, such as transparency, legitimacy, and consistency. |
| Recommendation 6 | Institutions should employ this fair process even when state law authorizes procedures with less oversight. |

### Recommendation 2

**Institutions should implement strategies to determine whether seemingly unrepresented patients are, in fact, unrepresented, including *1*) carefully assessing capacity, *2*) diligently searching for potential surrogates among the patient's family and friends, and *3*) involving any nonhospital individuals who have shown care and concern for the patient's welfare and are familiar with the patient's values and preferences.**

***Assess capacity carefully.*** The best person to make healthcare decisions for the patient is the patient herself. With support, time, and good communication, some individuals who initially appear to lack capacity in fact may be able to make their own decisions (51). For example, language barriers, sensory deficits, and limited health literacy are sometimes confused with a lack of capacity. Too often, clinicians erroneously assess patients as lacking capacity to make their own treatment decisions.

Second, capacity is not all or nothing; it is decision specific. Several studies found that although most ICU patients lack capacity to make decisions about life-sustaining treatment, approximately one-fourth to one-third still have at least partial capacity (37, 48). For example, although patients may lack the capacity to make complex treatment decisions, they may have sufficient capacity to appoint a surrogate. Moreover, the ability of critically ill patients to participate in decision-making often fluctuates over the course of their illness trajectory (7).

Third, loss of decisional capacity may be transient. Delirium caused by infection, poorly controlled pain, sedating medications, or other substances may temporarily cloud the patient's decisional capacity. These conditions may be superimposed on psychological conditions such as grief, anxiety, or depression or sensory deficits such as hearing or vision loss. When feasible, it is preferable to delay important treatment decisions until reversible causes of impaired capacity are addressed (51).

***Search diligently for potential surrogates.*** For many individuals who are initially thought to be unrepresented, a diligent search often finds an available surrogate. Therefore, before enacting institutional or judicial mechanisms for the unrepresented, many state laws and medical society policy statements first require careful documentation of diligent efforts to locate family or close friend surrogates (52, 53). Processes include examining personal effects, health records, and other social services records (51). Other processes include searching social media, contacting neighbors, and even hiring a private investigator (33).

Family or close friends are preferred over institutional or judicial decision-making. First, they are more likely to know the patient's values and preferences (54). Second, involving family or a trusted friend in medical decisions is a highly valued aspect of community in most societies. Third, most patients want a trusted family member or friend to be involved in their treatment decisions (7). Fourth, most states include these individuals on a statutory hierarchical order of surrogate decision-making. For these reasons, the search for potential surrogates should be aggressive and rigorous (51). Even if a surrogate is not identified, this search process may reveal information about the patient's values and preferences that can guide treatment decisions (and is itself a manifestation of respect for persons).

***Involve individuals who know and care for the patient.*** Clinicians can learn important information about a patient's preferences and values from people who are not willing or permitted to function as a surrogate. These individuals may know and care about the patient and can play a valuable role as "adviser" even if not as "decider." Consulting with these individuals is a way to ensure that all pertinent information about the patient is considered.

Unfortunately, many state laws are narrow and do not formally recognize some potential surrogates who may know and care about the patient (17). Some states recognize only a few types of family members. Some states do not recognize domestic partners or "close friends" to make decisions when no family member is available (55). Nevertheless, nearly 10% of patients select nonrelatives as their healthcare agents (56). Clinicians are often unfamiliar with these laws, which vary considerably from state to state (3, 57–59).

In fact, clinicians may seek the involvement of such nonhospital individuals, even when state law is too narrowly constructed to officially authorize them as surrogates (7). Although this is not specifically authorized, it is not prohibited. Furthermore, clinicians may seek relevant information from individuals who are uncomfortable with formally assuming the role of surrogate decision-maker.

### Recommendation 3

**Institutions should manage decision-making for unrepresented patients using collaboration between the clinical team and a diverse interprofessional, multidisciplinary committee rather than *ad hoc* by treating clinicians.**

***Risks of* ad hoc *decisions by treating clinicians.*** Commonly, treating clinicians assume sole decisional authority when caring for unrepresented ICU patients (6, 12). However, this is problematic for four key reasons. First, there is well-documented variability between clinicians in their judgments about what is appropriate care in such cases, raising the concern of undue variability in treatment decisions (60–65). Second, the perspectives of ICU clinicians about preferences for end-of-life care often differ significantly from the perspectives of patients and their family members (66–70). Third, removing the need for clinicians to justify or explain a treatment plan may eliminate an incentive to carefully consider the plan of care (12). Fourth, giving clinicians unilateral authority risks introducing bias and conflicts of interest. Indeed, most state laws prohibit hospital employees from serving as patient-designated healthcare agents or court-appointed guardians for this very reason (71).

***Advantages of an interprofessional, multidisciplinary process.*** Although entrusting decision-making to a single individual may be efficient, this advantage must be weighed against the plurality of views represented in a larger committee. In nonemergencies, institutional mechanisms are preferred to *ad hoc* strategies by clinicians because they can safeguard key elements of procedural fairness, including transparency, legitimacy, consistency, and the opportunity for appeal and review (72–74).

An interprofessional, multidisciplinary process will improve framing of decisions, putting specific clinical decisions at hand into the broader context of what is known of the patient's values and goals and the likely prognosis relative to the burdens of interventions (e.g., what probability of recovery, to what level of health, in what time period, and with that burdens?). There are communication techniques that are employed with surrogates (e.g., best case, worst case, or most likely case) that can be extrapolated to diverse interprofessional, multidisciplinary committees to ensure that all relevant factors have been considered to explain to other people the clinical situation, the decisions at hand, and the reasoning behind the plan of care (75).

Procedural fairness is especially important, because the cases in question are often ethically controversial, have important interests at stake, and do not have explicit rules that can be mechanically applied (76, 77). Moreover, these cases inherently involve patients who are vulnerable by virtue of critical illness and incapacity and who have little choice regarding their treating clinicians. It is ethically important to incorporate multiple perspectives to minimize the risk that the values of any one individual carry undue weight. Within institutions, a process-based approach may lessen arbitrariness by ensuring broader input, consistency, transparency, and the possibility for continuous institutional learning about how to manage future cases (72, 78, 79).

There are several potential criticisms of institutional interprofessional, multidisciplinary management. Compared with *ad hoc* management by clinicians, institutional management strategies *1*) potentially have a higher administrative burden; *2*) might constrain clinician autonomy; *3*) may require more time; and *4*) could lead to groupthink, such that pressure to agree results in failure to think critically and premature closure (20, 80).

However, these possible disadvantages are mitigated because interprofessional, multidisciplinary management strategies can use existing resources (e.g., the institutional ethics committee) and can be tailored to the capabilities of the individual institution (81, 82). There are techniques to elicit all options and arguments, such as assigning one member to make the case for limiting life-sustaining interventions and another to make the case for continuing them. Furthermore, the possible disadvantages are outweighed by the importance of maintaining procedural fairness and the need to protect particularly vulnerable patients.

***Composition of the interprofessional, multidisciplinary committee.*** To ensure logistical feasibility, institutions should have flexibility in how to form the diverse interprofessional, multidisciplinary committee. For example, it may be desirable to form a subcommittee from a larger standing committee that already has the requisite interprofessional, multidisciplinary representation, such as an ethics committee. Similarly, institutional policies might assign certain processes to one or more members to accommodate local resources and to enhance efficiency. For example, the individual responding to a request for ethics consultation may also initiate convening the interprofessional, multidisciplinary committee and may delegate tasks to committee members.

Whenever possible, the interprofessional, multidisciplinary committee should include three to five members, including a physician, a nurse, and one person who is neither (e.g., a chaplain or social worker). Whenever possible, this committee should include representation from social work, the ethics committee, and the community (83, 84). The committee should not include members of the primary treatment team or its medical consultants (23). Ideally, the committee is diverse in terms of role, gender, and socioeconomic status.

### Recommendation 4

**Institutions should use all available information on the patient's preferences and values to guide treatment decisions. If such information is not available, the committee should collaborate with the treatment team to make decisions in the patient's best interest.**

The diverse interprofessional, multidisciplinary committee and treating clinicians should use all available information on the patient's preferences and values to make the medical decision that is maximally consistent with them under the circumstances. Upon admission, most unrepresented patients do not have a clearly applicable advance directive or Provider Orders for Life-Sustaining Treatment (POLST). Regardless, the interprofessional, multidisciplinary committee should attempt to infer patients' goals, values, or wishes from evidence of the patient's

**Table 5.** Summary of Components of Institutional Policy

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|---|---|
| Component 1 | Early identification of incapacitated and potentially unrepresented patients |
| Component 2 | Interprofessional, multidisciplinary committee confirms that a diligent search was completed and that the patient is unrepresented |
| Component 3 | Interprofessional, multidisciplinary committee diligently gathers information about patient's condition, goals of care, and values |
| Component 4 | Interprofessional, multidisciplinary committee engages with clinical team to deliberate and make treatment decisions |
| Component 5 | Expedited processes for time-pressured nonemergency decisions |
| Component 6 | Periodic retrospective review of cases |
| Component 7 | If applicable, follow recommended processes for potentially inappropriate treatment |
| Component 8 | Guardianship for ongoing cases |

religious, spiritual, personal, cultural, philosophical, and moral beliefs and ethics. Even though the patient is unrepresented, the interprofessional, multidisciplinary committee may still have some evidence of an unrepresented patient's preferences from an advance directive, medical record notes, previous healthcare decisions, or conversations with healthcare workers who previously cared for the patient.

When there is no reliable evidence of the patient's expressed wishes, values, or preferences, the committee should apply the best interest standard. Typically, these seven factors guide application of the best interest standard: *1*) the patient's present level of physical, sensory, emotional, and cognitive functioning; *2*) quality of life, life expectancy, and prognosis for recovery with and without treatment; *3*) the various treatment options and the risks, side effects, and benefits of each; *4*) the nature and degree of physical pain or suffering resulting from the medical condition; *5*) whether the medical treatment being provided is causing or may cause pain, suffering, or serious complications; *6*) the pain or suffering to the patient if the medical treatment is withdrawn or withheld; and *7*) whether any particular treatment would be proportionate or disproportionate in terms of the benefits to be gained by the patient versus the burdens caused to the patient (33).

### Recommendation 5

**Institutions should manage decision-making for unrepresented patients using a fair process that comports with procedural due process such as transparency, legitimacy, and consistency.**

Described below are eight proposed components of due process for a model institutional policy (Table 5). These are broadly informed by the substitute decision-making literature, philosophical conceptions of fairness and procedural justice, and prior professional society guidelines.

***1. Early identification of incapacitated and potentially unrepresented patients.***

Comprehensive efforts should be made by the admitting staff and treatment team early after admission to identify a surrogate for patients lacking decision-making capacity. When it appears that the patient will be unrepresented because a surrogate cannot be found, the interprofessional, multidisciplinary committee should be consulted. This will ensure timely decision-making. If the care team or institution subsequently finds an appropriate surrogate, then that individual assumes decision-making authority.

***2. The interprofessional, multidisciplinary committee convenes to confirm that a diligent search was completed and that the patient is unrepresented.*** Before making treatment decisions on the patient's behalf, the interprofessional, multidisciplinary committee should first confirm that the patient is, in fact, unrepresented. First, the committee should carefully document both prior efforts to determine the patient's capacity and confirm that the patient lacks capacity. Second, the committee should review prior efforts to locate potential surrogates and confirm that there is no available surrogate. After confirming that the patient is unrepresented, the committee should inform the patient (if possible) of how the committee will proceed in the decision-making process.

***3. The interprofessional, multidisciplinary committee diligently gathers information about the patient's condition, goals of care, and values.*** The interprofessional, multidisciplinary committee should meet with the attending clinician and team and ascertain the patient's condition, medical history, social history, and prognosis. The committee should obtain a second opinion from another independent clinician with expertise in the patient's condition, addressing both the patient's prognosis and the recommended treatment plan. Consistent with Recommendations 3 and 4 above, the committee should also gather and review evidence (if any) on the patient's values and preferences, including religious and moral beliefs, and record these in the medical record. Generally, the committee should follow the instructions in an advance directive, POLST, or similar document, if available. However, such information is almost never dispositive of what care should be administered (85). The specific medical circumstances confronting a patient in the ICU and the decisions that need to be made in these circumstances are extremely difficult to anticipate.

***4. The interprofessional, multidisciplinary committee engages with the clinical team to deliberate and make treatment decisions.*** The interprofessional, multidisciplinary committee should engage with the clinical team to deliberate and make treatment decisions. The institutional policy should establish whether the committee is serving as a surrogate in a shared decision-making model with the treatment team (making the treatment decision) or acting in an advisory and oversight role (providing recommendations and ensuring soundness of deliberations). Either way, the committee should explain the basis for its decisions or recommendations, especially how they are consistent with the patient's values and priorities, if they are known. If such information is not available, the committee should explain how the decision promotes the patient's best interest by maximizing benefit and minimizing burden.

The committee should not approve any treatment decision on the basis of the patient's age, race, color, religion, ancestry, national origin, disability, gender, gender identity, gender expression, sexual orientation, or ability to pay, unless such a factor is clearly clinically relevant or is pertinent to the patient's known values, such as a Jehovah's Witnesses patient's wish not to receive blood products. The committee should always advocate for the provision of appropriate pain relief and palliative care.

***5. Expedited processes for time-pressured nonemergency decisions.*** When time pressures (such as a rapidly deteriorating clinical condition) make it infeasible to convene a diverse interprofessional, multidisciplinary committee, clinicians should endeavor to achieve as much procedural oversight as the clinical situation allows. Whenever possible, clinicians should obtain confirmation from a clinical ethics consultant or from an independent clinician that an expedited process is necessary. In situations in which decisions must be made so quickly that no procedural oversight is possible, there should be retrospective review. Clinicians should, to the extent possible, not allow situations to become time pressured. It is ethically "troublesome" to wait "until the patient's medical condition worsens into an emergency so consent to treat is implied" (8).

***6. Periodic retrospective review of cases.*** A mechanism for periodic retrospective review of decisions for unrepresented patients should be a component of an institutional policy. A regular review process, such as a closed session of an unrepresented morbidity and mortality conference, helps to achieve efficient and consistent management of cases and may identify areas for improvement in institutional practices (86).

***7. If applicable, follow recommended processes for potentially inappropriate treatment.*** If the care team believes that the interprofessional, multidisciplinary committee is requesting interventions that are futile or potentially inappropriate, they should refer to the 2015 multiorganization consensus statement on responding to requests for futile or potentially inappropriate interventions in the ICU (86). In these cases, a formal ethics consultation and review by the hospital's ethics committee should be initiated. Both to ensure due diligence and to avoid role confusion, the interprofessional, multidisciplinary committee in this process should not be the same committee promoting procedural fairness on behalf of the unrepresented patient. In cases of persistent disagreement, if feasible on the basis of local laws and resources, the institution should consider initiating the appropriate processes in its jurisdiction to obtain a legal guardian or conservator.

***8. Guardianship for ongoing cases.*** A goal of this document is to identify a process by which clinicians can provide nonemergent medical care for an unrepresented patient without a surrogate's consent. The number and complexity of decisions for unrepresented patients may increase as these patients become sicker. However, sometimes the care team expects an unrepresented patient to remain incapacitated with ongoing healthcare needs for a considerable length of time. In these cases, if feasible on the basis of local laws and resources, the institution should consider initiating the appropriate processes in its jurisdiction to obtain a legal guardian or conservator (11).

### Recommendation 6

**Institutions should employ this fair process even when state law authorizes procedures with less oversight.**

Some state laws authorize clinicians to make treatment decisions on behalf of unrepresented patients with little or no oversight (Table 2) (87–91). Yet, because of the vulnerability of unrepresented patients, hospitals within these jurisdictions should still use a diverse interprofessional, multidisciplinary committee. In these states, attending clinicians may be the officially recognized decision-makers, but they should still consult with an interprofessional, multidisciplinary committee and follow the above due process and institutional policy. To reconcile this policy statement with the law in these states, the committee may function in an advisory and consultative capacity rather than in a decision-making capacity.

## Conclusions

Unrepresented patients in the ICU are particularly vulnerable. Consequently, treatment decisions on their behalf should be evaluated carefully. This policy statement is designed to help clinicians and hospital administrators design fair and practical procedures for making treatment decisions on behalf of unrepresented patients in the ICU setting. ■

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This official policy statement was prepared by an *ad hoc* subcommittee of the American Thoracic Society and the American Geriatrics Society.

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**Author Disclosures:** D.B.W. received author royalties from UpToDate. S.S.C. received research support from BioMarck Pharmaceuticals, Triangle Pharmaceuticals, and United Pharmaceuticals. M.D.S. served as a consultant for Siemens Healthcare; and

received author royalties from UpToDate. R.D.S. served on a data and safety monitoring board for Lyric Pharmaceutical. E.W.W. is a board member of the American Academy of Hospice and Palliative Medicine. T.M.P., J.B., L.C., A.B.C., E.S.D., D.M.G., P.G.-C., M.B.K., B.L., D.C.M., L.F.R., J.L.S., R.L.S., A.J.T., J.D.T., and M.R.W. reported no relationships with relevant commercial interests.

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## References

1. White DB, Curtis JR, Lo B, Luce JM. Decisions to limit life-sustaining treatment for critically ill patients who lack both decision-making capacity and surrogate decision-makers. *Crit Care Med* 2006;34: 2053–2059.
2. White DB, Curtis JR, Wolf LE, Prendergast TJ, Taichman DB, Kuniyoshi G, *et al*. Life support for patients without a surrogate decision maker: who decides? *Ann Intern Med* 2007;147:34–40.
3. Godfrey DM. Health care decision-making during a crisis when nothing is in writing. *NAELA J* 2019;15:e1–e16.
4. Sadovnikoff N, Jurchak M. Substituted judgments in the absence of surrogates. *Crit Care Med* 2007;35:2467–2468.
5. Siegel MD. Alone at life's end: trying to protect the autonomy of patients without surrogates or decision-making capacity. *Crit Care Med* 2006; 34:2238–2239.
6. Karp N, Wood E. Incapacitated and alone: health care decision-making for the unbefriended elderly. Washington, DC: American Bar Association Commission on Law and Aging; July 2003.
7. Kon AA, Davidson JE, Morrison W, Danis M, White DB. Shared decision-making in intensive care units: executive summary of the American College of Critical Care Medicine and American Thoracic Society policy statement. *Am J Respir Crit Care Med* 2016;193:1334–1336.
8. Institute of Medicine, Committee on Approaching Death: Addressing Key End-of-Life Issues. Dying in America: improving quality and honoring individual preferences near the end of life. Washington, DC: National Academies Press; 2015.
9. Pearlman RA. Challenges facing physicians and healthcare institutions caring for patients with mental incapacity. *J Am Geriatr Soc* 1996;44: 994–996.
10. Ricotta DN, Parris JJ, Parris RS, Sontag DN, Mukamal KJ. The burden of guardianship: a matched cohort study. *J Hosp Med* 2018;13:595–601.
11. Farrell TW, Widera E, Rosenberg L, Rubin CD, Naik AD, Braun U, *et al*.; Ethics, Clinical Practice and Models of Care, and Public Policy Committees of the American Geriatrics Society. AGS position statement: making medical treatment decisions for unbefriended older adults. *J Am Geriatr Soc* 2017;65:14–15.
12. White DB, Jonsen A, Lo B. Ethical challenge: when clinicians act as surrogates for unrepresented patients. *Am J Crit Care* 2012;21: 202–207.
13. Royal College of Physicians. End of life care audit – dying in hospital: national report for England, 2016. London: Author; 2016.
14. Sacco J. Incapacitated, alone and treated to death. *New York Times* 2008 October 6;Sect D:5.
15. Sulmasy LS, Bledsoe TA. American College of Physicians Ethics Manual: Seventh Edition. *Ann Intern Med* 2019;170(2 Suppl):S1–S32.
16. American Medical Association (AMA). AMA Code of Medical Ethics Opinion 2.1.2(f) [accessed 2020 Apr 14]. Available from: https://www.ama-assn.org/delivering-care/ethics/decisions-adult-patients-who-lack-capacity.
17. DeMartino ES, Dudzinski DM, Doyle CK, Sperry BP, Gregory SE, Siegler M, *et al*. Who decides when a patient can't? Statutes on alternate decision makers. *N Engl J Med* 2017;376:1478–1482.
18. Hulkower A, Garijo-Garde S, Flicker LS. Should dialysis be stopped for an unrepresented patient with metastatic cancer? *AMA J Ethics* 2019;21:E575–E581.
19. Schweikart SJ. Who makes decisions for incapacitated patients who have no surrogate or advance directive? *AMA J Ethics* 2019;21: E587–E593.
20. Isaacs ED, Brody RV. The unbefriended adult patient: the San Francisco General Hospital approach to ethical dilemmas. *San Franc Med J* 2010;83:25–26.
21. Volpe RL, Steinman D. Peeking inside the black box: one institution's experience developing policy for unrepresented patients. *Hamline Law Rev* 2013;36:265–274.
22. Verma A, Smith AK, Harrison KL, Chodos AH. Ethical challenges in caring for unrepresented adults: a qualitative study of key stakeholders. *J Am Geriatr Soc* 2019;67:1724–1729.
23. Veterans Health Administration, Department of Veterans Affairs. Life-sustaining treatment decisions: eliciting, documenting and honoring patients' values, goals and preferences. VHA Handbook 1004.03. Washington, DC: Department of Veterans Affairs; 2017 Jan 11 [accessed 2020 Apr 14]. Available from: https://www.va.gov/vhapublications/publications.cfm?pub=2.
24. Brown SM, Azoulay E, Benoit D, Butler TP, Folcarelli P, Geller G, *et al*. The practice of respect in the ICU. *Am J Respir Crit Care Med* 2018; 197:1389–1395.
25. Appelbaum PS. Clinical practice: assessment of patients' competence to consent to treatment. *N Engl J Med* 2007;357:1834–1840.
26. Raymont V, Bingley W, Buchanan A, David AS, Hayward P, Wessely S, *et al*. Prevalence of mental incapacity in medical inpatients and associated risk factors: cross-sectional study. *Lancet* 2004;364: 1421–1427.
27. Schmidt WC. Guardianship for vulnerable adults in North Dakota: recommendations regarding unmet needs, statutory efficacy, and cost effectiveness. *N D Law Rev* 2012;89:77–142.
28. Brudney D. Choosing for another: beyond autonomy and best interests. *Hastings Cent Rep* 2009;39:31–37.
29. Anthony DL, Herndon MB, Gallagher PM, Barnato AE, Bynum JP, Gottlieb DJ, *et al*. How much do patients' preferences contribute to resource use? *Health Aff (Millwood)* 2009;28:864–873.
30. Hersh ED, Goldenberg MN. Democratic and Republican physicians provide different care on politicized health issues. *Proc Natl Acad Sci USA* 2016;113:11811–11816.
31. Kapp MB. Editorial—surrogate decision-making for the unbefriended: social and ethical problem, legal solution? *J Ethics Law Aging* 1995; 1:83–85.
32. Kapp MB. The "voluntary" status of nursing facility admissions: legal, practical, and public policy implications. *N Engl J Crim Civ Confin* 1998;24:1–35.
33. Pope TM. Unbefriended and unrepresented: better medical decision-making for incapacitated patients without healthcare surrogates. *Ga State Univ Law Rev* 2017;33:923–1019.
34. Meisel A, Cerminara KL, Pope TM. The right to die: the law of end-of-life decisionmaking, 3rd ed. New York: Aspen; 2020.
35. FitzGerald C, Hurst S. Implicit bias in healthcare professionals: a systematic review. *BMC Med Ethics* 2017;18:19.
36. Zestcott CA, Blair IV, Stone J. Examining the presence, consequences, and reduction of implicit bias in health care: a narrative review. *Group Process Intergroup Relat* 2016;19:528–542.
37. Cook D, Rocker G, Marshall J, Sjokvist J, Dodek P, Griffith L, *et al*. Withdrawal of mechanical ventilation in anticipation of death in the intensive care unit. *New Eng J Med* 2003;349:1123–1132.
38. Danis M. The promise of proactive ethics consultation. *Crit Care Med* 1998;26:203–204.
39. Veatch RM. Assault or homicide: treating and letting die without consent. *Crit Care Med* 2002;30:937–938.
40. Meier DE. Voiceless and vulnerable: dementia patients without surrogates in an era of capitation. *J Am Geriatr Soc* 1997;45: 375–377.
41. Miller TE, Coleman CH, Cugliari AM. Treatment decisions for patients without surrogates: rethinking policies for a vulnerable population. *J Am Geriatr Soc* 1997;45:369–374.
42. Schneiderman LJ, Kaplan RM, Pearlman RA, Teetzel H. Do physicians' own preferences for life-sustaining treatment influence their perceptions of patients' preferences? *J Clin Ethics* 1993;4:28–33.
43. Chamberlain SA, Duggleby W, Teaster P, Estabrooks C. Characteristics and unmet care needs of unbefriended residents in long-term care: a qualitative interview study. *Aging Ment Health* 2020;24:659–667.

44. Chapman EN, Kaatz A, Carnes M. Physicians and implicit bias: how doctors may unwittingly perpetuate health care disparities. *J Gen Intern Med* 2013;28:1504–1510.
45. Christakis NA, Asch DA. Biases in how physicians choose to withdraw life support. *Lancet* 1993;342:642–646.
46. Krutsinger DC, Halpern SD, DeMartino ES. Conflicts of interest in intensive care medicine. *Intensive Care Med* 2018;44:1765–1766.
47. Patient Self Determination Act of 1990, 42 U.S.C. § 1395cc(f).
48. Torke AM, Sachs GA, Helft PR, Montz K, Hui SL, Slaven JE, *et al*. Scope and outcomes of surrogate decision making among hospitalized older adults. *JAMA Intern Med* 2014;174:370–377.
49. Lilley EJ, Morris MA, Sadovnikoff N, Luxford JM, Changoor NR, Bystricky A, *et al*. "Taking over somebody's life": experiences of surrogate decision-makers in the surgical intensive care unit. *Surgery* 2017;162:453–460.
50. Mack JW, Cronin A, Taback N, Huskamp HA, Keating NL, Malin JL, *et al*. End-of-life care discussions among patients with advanced cancer: a cohort study. *Ann Intern Med* 2012;156:204–210.
51. Moye J, Catlin C, Kwak J, Wood E, Teaster PB. Ethical concerns and procedural pathways for patients who are incapacitated and alone: implications from a qualitative study for advancing ethical practice. *HEC Forum* 2017;29:171–189.
52. Proxy decision-makers for medical treatment authorized—definitions. Colo. Rev. Stat. § 15-18.5-103(4)(c).
53. Proxy decisionmakers. Mont. Code Ann. §§ 50-5-1304–1305.
54. Buchanan A, Brock DW. Deciding for others. *Milbank Q* 1986;64:17–94.
55. American Bar Association. Health care decision-making [accessed 2020 Apr 14]. Available from: https://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/.
56. Cohen AB, Trentalange M, Fried T. Patients with next-of-kin relationships outside the nuclear family. *JAMA* 2015;313:1369–1370.
57. Comer AR, Gaffney M, Stone CL, Torke A. Physician understanding and application of surrogate decision-making laws in clinical practice. *AJOB Empir Bioeth* 2017;8:198–204.
58. Comer AR, Gaffney M, Stone CL, Torke A. "What do you mean I cannot consent for my grandmother's medical procedure?" Key issues with state default surrogate decision making laws. *Indiana Health Law Rev* 2017;14:1–29.
59. Comer AR, Slaven JE, Montz A, Burke E, Inger L, Torke A. Nontraditional surrogate decision makers for hospitalized older adults. *Med Care* 2018;56:337–340.
60. Piers RD, Azoulay E, Ricou B, Dekeyser Ganz F, Decruyenaere J, Max A, *et al*.; APPROPRICUS Study Group of the Ethics Section of the ESICM. Perceptions of appropriateness of care among European and Israeli intensive care unit nurses and physicians. *JAMA* 2011; 306:2694–2703.
61. Sprung CL, Cohen SL, Sjokvist P, Baras M, Bulow HH, Hovilehto S, *et al*.; Ethicus Study Group. End-of-life practices in European intensive care units: the Ethicus Study. *JAMA* 2003;290:790–797.
62. Wunsch H, Harrison DA, Harvey S, Rowan K. End-of-life decisions: a cohort study of the withdrawal of all active treatment in intensive care units in the United Kingdom. *Intensive Care Med* 2005;31:823–831.
63. Garland A, Connors AF. Physicians' influence over decisions to forego life support. *J Palliat Med* 2007;10:1298–1305.
64. Curtis JR, Park DR, Krone MR, Pearlman RA. Use of the medical futility rationale in do-not-attempt-resuscitation orders. *JAMA* 1995;273:124–128.
65. Wilkinson DJ, Truog RD. The luck of the draw: physician-related variability in end-of-life decision-making in intensive care. *Intensive Care Med* 2013;39:1128–1132.
66. Gramelspacher GP, Zhou XH, Hanna MP, Tierney WM. Preferences of physicians and their patients for end-of-life care. *J Gen Intern Med* 1997;12:346–351.
67. O'Donnell H, Phillips RS, Wenger N, Teno J, Davis RB, Hamel MB. Preferences for cardiopulmonary resuscitation among patients 80 years or older: the views of patients and their physicians. *J Am Med Dir Assoc* 2003;4:139–144.
68. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000; 284:2476–2482.
69. Norris WM, Nielsen EL, Engelberg RA, Curtis JR. Treatment preferences for resuscitation and critical care among homeless persons. *Chest* 2005;127:2180–2187.
70. Harrison M, Milbers K, Hudson M, Bansback N. Do patients and health care providers have discordant preferences about which aspects of treatments matter most? Evidence from a systematic review of discrete choice experiments. *BMJ Open* 2017; 7: e014719.
71. American Bar Association Commission on Law and Aging. Default surrogate consent statutes. 2019 [accessed 2020 Apr 14]. Available from: http://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/.
72. Daniels N, Sabin J. Limits to health care: fair procedures, democratic deliberation, and the legitimacy problem for insurers. *Philos Public Aff* 1997;26:303–350.
73. Weiss BD, Berman EA, Howe CL, Fleming RB. Medical decision-making for older adults without family. *J Am Geriatr Soc* 2012;60: 2144–2150.
74. Verma A, Smith AK, Harrison KL, Chodos AH. Ethical challenges in caring for unrepresented adults: a qualitative study of key stakeholders. *J Am Geriatr Soc* 2019;67:1724–1729.
75. Taylor LJ, Nabozny MJ, Steffens NM, Tucholka JL, Brasel KJ, Johnson SK, *et al*. A framework to improve surgeon communication in high-stakes surgical decisions: best case/worst case. *JAMA Surg* 2017; 152:531–538.
76. Emanuel EJ. A communal vision of care for incompetent patients. *Hastings Cent Rep* 1987;17:15–20.
77. Misak CJ, White DB, Truog RD. Medical futility: a new look at an old problem. *Chest* 2014;146:1667–1672.
78. Daniels N. Accountability for reasonableness. *BMJ* 2000;321: 1300–1301.
79. Daniels N. Just health: meeting health needs fairly. Cambridge, UK: Cambridge University Press; 2008.
80. Pope TM. Multi-institutional healthcare ethics committees: the procedurally fair internal dispute resolution mechanism. *Campbell Law Rev* 2009;31:257–331.
81. American Academy of Pediatrics, Committee on Bioethics. Institutional ethics committees. *Pediatrics* 2001;107:205–209.
82. American Society for Bioethics and Humanities (ABSH). Core competencies for healthcare ethics consultation, 2nd ed. Glenview, IL: Author; 2011.
83. Griggins C, Blackstone E, McAliley L, Daly B. Making medical decisions for incapacitated patients without proxies: part I. *HEC Forum* 2020; 32:33–45.
84. Blackstone E, Daly BJ, Griggins C. Making medical decisions for incapacitated patients without proxies: part II. *HEC Forum* 2020;32: 47–62.
85. Chiarchiaro J, Ernecoff NC, Scheunemann LP, Hough CL, Carson SS, Peterson MW, *et al*. Physicians rarely elicit critically ill patients' previously expressed treatment preferences in intensive care units. *Am J Respir Crit Care Med* 2017;196:242–245.
86. Bosslet GT, Pope TM, Rubenfeld GD, Lo B, Truog RD, Rushton CH, *et al*.; American Thoracic Society ad hoc Committee on Futile and Potentially Inappropriate Treatment; American Thoracic Society; American Association for Critical Care Nurses; American College of Chest Physicians; European Society for Intensive Care Medicine; Society of Critical Care. An official ATS/AACN/ACCP/ESICM/SCCM policy statement: responding to requests for potentially inappropriate treatments in intensive care units. *Am J Respir Crit Care Med* 2015;191:1318–1330.
87. Procedures for natural death in the absence of a declaration. N.C. Gen. Stat. § 90-322(b).
88. Surrogate; powers; designation of surrogate; priorities; consensus; meeting; continuation of authority; disqualification of surrogate. Neb. Rev. Stat. § 30-604(5)(b)(v).
89. Persons authorized to provide informed consent to health care for incapacitated persons. N.D. Cent. Code § 23-12-13.
90. Liability re removal of life support system of incapacitated patient. Conn. Gen. Stat. § 19a-571(a).
91. Withdrawal of life-sustaining procedures. Or. Rev. Stat. § 127.635(3).

Georgia State University Law Review

Volume 33
Issue 4 *Summer 2017*

Article 3

7-13-2017

# Unbefriended And Unrepresented: Better Medical Decision Making For Incapacitated Patients Without Healthcare Surrogates

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## Recommended Citation

Pope, Thaddeus Mason (2017) "Unbefriended And Unrepresented: Better Medical Decision Making For Incapacitated Patients Without Healthcare Surrogates," *Georgia State University Law Review*: Vol. 33 : Iss. 4 , Article 3.
Available at: http://readingroom.law.gsu.edu/gsulr/vol33/iss4/3

# UNBEFRIENDED AND UNREPRESENTED: BETTER MEDICAL DECISION MAKING FOR INCAPACITATED PATIENTS WITHOUT HEALTHCARE SURROGATES

**Thaddeus Mason Pope**[*]

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## INTRODUCTION

How should we make medical decisions for incapacitated patients who have no available legally-authorized surrogate decision maker? Because these patients lack decision-making capacity, they cannot authorize treatment themselves. Because they lack a surrogate, nobody else can authorize treatment either. Clinicians and researchers have referred to these individuals as "adult orphans" or as "unbefriended," "isolated," or "unrepresented" patients.[1] Clinicians and researchers have also described them as "unimaginably helpless,"[2] "highly vulnerable," and as the "most vulnerable,"[3] because "no one cares deeply if they live or die."[4]

The persistent challenges involved in obtaining consent for medical treatment on behalf of these individuals is an immense problem in ethics and patients' rights. Some commentators describe caring for the unbefriended as "one of the most difficult problems in medical decision making."[5] Others call it the "single greatest category of problems" encountered in bioethics consultations.[6]

Appropriately, this problem is getting more attention. Major policy reports from both legal and medical associations have focused on decision making for the unbefriended.[7] Perhaps most notably, the

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[1] *See infra* Part II.

[2] Winsor C. Schmidt, *Guardianship for Vulnerable Adults in North Dakota: Recommendations Regarding Unmet Needs, Statutory Efficacy, and Cost Effectiveness*, 89 N.D. L. REV. 77, 83 (2013).

[3] Timothy W. Farrell et al., *AGS Position Statement: Making Medical Treatment Decisions for Unbefriended Older Adults,* 65 J. AM. GERIATRICS SOC'Y. 14, 15 (2017).

[4] Naomi Karp & Erica Wood, *Incapacitated and Alone: Healthcare Decision Making for Unbefriended Older People*, 31 HUMAN RIGHTS 20, 21 (2004) [hereinafter Karp & Wood, *Incapacitated and Alone*]. "He's a human being, and a terrible thing is happening to him. So attention must be paid. He's not to be allowed to fall into his grave like an old dog. Attention, attention must be finally paid to such a person." ARTHUR MILLER, DEATH OF A SALESMAN 44 (Taisha Abraham ed. 2011) (1949).

[5] THE HASTINGS CENTER, GUIDELINES ON THE TERMINATION OF LIFE-SUSTAINING TREATMENT AND THE CARE OF THE DYING 24 (David H. Smith & Robert M. Veatch eds., 1987) [hereinafter GUIDELINES ON THE TERMINATION].

[6] Karp & Wood, *Incapacitated and Alone*, *supra* note 4, at 21.

[7] *See, e.g.*, Farrell et al., *supra* note 3; Karp & Wood, *Incapacitated and Alone*, *supra* note 4; N.Y. STATE TASK FORCE ON LIFE AND THE LAW, WHEN OTHERS MUST CHOOSE: DECIDING FOR PATIENTS WITHOUT CAPACITY 161–175 (1992); JESSICA E. BRILL ORTIZ, ADVOCATING FOR THE UNBEFRIENDED ELDERLY: AN INFORMATIONAL BRIEF 3 (2010); CTR. FOR ADVOC. FOR THE RIGHTS AND INTS. OF THE ELDERLY (CARIE), MEETING THE NEEDS OF PERSONS WITH ALZHEIMER'S OR OTHER DEMENTIA WHEN NO INFORMAL SUPPORT IS AVAILABLE 1 (2010); MED. DECISION-MAKING FOR UNKNOWN AND

elite mainstream media has repeatedly covered the problem of the unbefriended in the United States.[8] Decision-making for the unbefriended has also been the primary topic of recent day-long or multi-day conferences,[9] both themed, subject-specific conferences, and individual sessions at several national and regional professional association meetings.[10]

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UNREPRESENTED PATIENTS: A REPORT SUBMITTED TO THE HARV. ETHICS LEADERSHIP GRP. BY THE CMTY. ETHICS COMM. 4 (2016).

[8] *See, e.g.*, Lois Henry, *Need A Worthwhile Project?: Consider This One*, BAKERSFIELD (Oct. 11, 2014), http://www.bakersfield.com/columnists/lois-henry-need-a-worthwhile-project-consider-this-one/article_e954639a-790b-5c32-9fd9-f1bb89c1391f.html; Phyllis Korkki, *Childless And Aging?: Time To Designate A Caregiver*, N.Y. TIMES (Sept. 11, 2012), http://www.nytimes.com/2012/09/12/business/retirementspecial/for-childless-older-people-legal-and-logistical-challenges.html; Tim Lahey, *Voiceless At The End Of Life*, SCI. AM. (Aug. 2, 2013), https://blogs.scientificamerican.com/guest-blog/voiceless-at-the-end-of-life/; Paula Span, *Hiring An End-Of-Life Enforcer*, N.Y. TIMES (Oct. 24, 2013, 12:33 PM), https://newoldage.blogs.nytimes.com/2013/10/24/hiring-an-end-of-life-enforcer/; Paula Span, *When There's No Family*, N.Y. TIMES (Sept. 23, 2013, 12:10 PM), https://newoldage.blogs.nytimes.com/2013/09/23/when-theres-no-family/; Carina Storrs, *The 'Elder Orphans' Of The Baby Boom Generation*, CNN (May 18, 2015), http://www.cnn.com/2015/05/18/health/elder-orphans/.

[9] *See, e.g.*, NorthShore U. Health Sys., *Regional Meeting* (April 17, 2017); Hospice & Palliative Care Assn. of New York, *2017 Annual Interdisciplinary Seminar & Meeting* (Mar. 31, 2017); N.Y. City Health & Hosps. Corp., *The Sixth Annual John Corser Ethics Conference: The Unbefriended* (May 21, 2015); U. of Ark. for Med. Sci., *Intensive Workshop on Healthcare Ethics: Making Decisions for Others* (May 7–8, 2015); David T. Ozar, Professor, Loyola U. Chicago, *The Unbefriended: A New Protected Class of Patients?*, Address at the 2015 Annual Am. Coll. of Legal Med. meeting (Feb. 28, 2015).

[10] *See, e.g.*, Maura George, *The "Unbefriended" Patient – When there is No One to Speak for the Patient*, Georgia Healthcare Ethics Consortium 2017 Annual Conference (Mar. 23, 2017); Jean T. Abbott, Jackie Glover, and Thaddeus M. Pope, *Caring for the "Unrepresented Patient": Strategies to Avoid Moral Distress and Substandard Care,* 12th International Conference on Clinical Ethics Consultation (panel presentation) (May 19-22, 2016); Eric Widera et al., *Unbefriended: Medical Decision Making for the Incapacitated and Alone*, American Academy of Hospice and Palliative Medicine Annual Assembly (March 11, 2016); David Harris and James Shaughnessy, *The Unbefriended Patient: Ethics and Other Considerations,* Tufts Medical Center Medical Grand Rounds (March 23, 2016); Allyson L. Robichaud, *Medical Decision-Making for Patients Without Proxies: The Effect of Personal Experience in the Deliberative Process*, Association for Practical and Professional Ethics 25th Annual International Conference (Feb. 19, 2016); Sharona Hoffman & David Orentlicher, *The Unbefriended Elderly: Making Medical Decisions for Patients without Surrogates* (paper presented at the Annual Meeting of the American Association of Law Schools, Section on Law, Medicine, and Health Care) (Jan. 3, 2015); Joan H. Hellyer, Kathy Meyerle, and Brent Moos, *Decision-Making for the Unbefriended Patient: A Model Approach* (paper presented at the 11th Annual International Conference on Clinical Ethics Consultation) (May 21, 2015); Leslie Kuhnel, *Representing the Voices of Unrepresented Persons* (paper presented at the 10th International Conference on Clinical Ethics Consultation) (April 25, 2014); Janice Fujiwara, Brian Emmert, and Maria T. Carney, *Elder Orphans: Hiding in Plain Sight* (paper presented at the American Geriatrics Society Annual Scientific Meeting) (May 14, 2015); Robert V. Doyle, *The Unbefriended Patient: An Ethical Framework for Decision-Making* (paper presented at the Australasian Association of Bioethics and Health Law Conference) (July 13, 2013); Geri Sprague-Damon and Carol S. Huffman, *Taking the Lead, Seizing Opportunity—LCSW as Health Care Proxy* (paper presented at the Society for Social Work Leadership in Healthcare 45th

Finally, the problem of the unbefriended has received increasing attention not only in the meeting halls of conferences, but also in the pages of academic literature.[11] New articles have been printed in law journals,[12] medical journals,[13] nursing journals,[14] long-term care journals,[15] and bioethics journals.[16] Even the popular media is covering the problem.[17]

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Annual Meeting and Conference) (Nov. 3-6 2010); Thaddeus M. Pope, Martin L. Smith, and Douglas B. White, *The Unbefriended Must Not Be Unprotected: Organizational and Clinical Management of Patients Without Surrogates* (presentation at 17th Annual Meeting of the American Society for Bioethics and Humanities) (Oct. 22, 2015); Karon M. Coleman and Hana Osman, *Incapacitated and Alone: Social Workers as Proxies* (paper presented at the 23rd Annual University of Miami Miller School of Medicine Bioethics Program Conference, Florida Ethics: Debates, Decisions, Solutions) (April 17, 2015); Karen Armstrong, *Making Decisions for Patients without a Surrogate,* Illinois Hospital Association Ethics Training Series Webinar (Aug. 14, 2013); 39th Meeting of the New Hampshire-Vermont Hospital Ethics Committee Network: *If the Patient Can't Decide, then What?* (April 7, 2014); Joan H. Hellyer, *Decision Making for the Unbefriended Patient,* Center for Christian Bioethics Grand Rounds, Loma Linda University (Feb. 26, 2014); Mark Repenshek, *A Patient's Best Interests: How Can Ethical Decisions Be Made without Surrogates?* (paper presented at the 11th Annual Conference on Contemporary Catholic Healthcare Ethics, Clinical Care and Institutional Identity in the Catholic Tradition, Loyola University Chicago Stritch School of Medicine) (March 13-14, 2014); Susan F. Cohn and Margaret H. Reiff, *Care Management Challenges with the 'Unbefriended Elder'* (paper presented at the 18th Annual Jarvie Colloquium: Mindful Aging) (June 20, 2013); Kathryn Beauchamp et al., *Who Will Care about Me?* (paper presented at the Colorado Healthcare Ethics Forum: Quandary of the Unbefriended and Incapacitated) (April 26, 2012); Jessica Evert, *Decision Making for the Unrepresented Patient* (paper presented at the Sutter Health California Pacific Medical Center Annual Summer Workshop in Clinical Ethics, San Francisco) (June 8, 2013). Decision making for the unbefriended was even the subject of a recent Twitter Chat. BioethxChat, *Patients without Surrogates*, TWITTER (April 20, 2015).

[11] *See, e.g.*, Grace Farris, *The Library Card,* 385 LANCET 766 (2015) http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(15)60426-3/fulltext; Megan-Jane Johnstone, *Caring about the Unbefriended Elderly*, 21(9) AUSTRALIAN NURSING & MIDWIFERY J. 20 (2014); Christine Kilgore, *The 'Unbefriended' Challenge PA/LTC*, 15(6) CARING FOR THE AGES 1 (June 2014) http://www.caringfortheages.com/article/S1526-4114(14)00225-X/fulltext; Fred Rincon, *Emergency Management of Acute Ischemic Stroke in Incapacitated Patients Who Have No Surrogate Decision Makers*, 17(6) CONTINUUM LIFELONG LEARNING NEUROLOGY 1335 (2011); Martin L. Smith & Catherine L. Luck, *Desperately Seeking a Surrogate—For a Patient Lacking Decision-Making Capacity*, 4(2) NARRATIVE INQUIRIES IN BIOETHICS 161 (2014) http://muse.jhu.edu/article/552051; Rebecca L. Volpe & Deborah Steinman, *Peeking Inside the Black Box: One Institution's Experience Developing Policy for Unrepresented Patients*, 36(2) HAMLINE L. REV. 265 (2013).

[12] *See, e.g.*, Volpe & Steinman, *supra* note 11.

[13] *See, e.g.*, Farris, *supra* note 11; Rincon, *supra* note 11.

[14] *See, e.g.*, Johnstone, *supra* note 11.

[15] *See, e.g.*, Kilgore, *supra* note 11, at 12.

[16] *See, e.g.*, Smith & Luck, *supra* note 11.

[17] *See, e.g.*, Paul C. McLean, *The Loneliest Patients: When They Can't Make Decisions, Who Will?*, WBUR COMMONHEALTH (Oct. 19, 2016), http://www.wbur.org/commonhealth/2016/10/19/unbefriendedpatientspaulmclean; Encarnacion Pyle, *More 'Elder Orphans' without Family Nearby Needing Help*, COLUMBUS DISPATCH (Nov. 13, 2016).

But while the problem has been increasingly recognized and acknowledged, it has not yet been adequately mitigated or resolved. In 1987, the Hastings Center released *Guidelines on the Termination of Life-Sustaining Treatment and Care of the Dying.*[18] The eminent bioethics think tank observed 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."[19]

Nearly thirty years later, far too little has changed. There is still no consensus on the proper solution. Across the United States, few jurisdictions have developed laws or policies that adequately protect this most vulnerable population.[20] "Existing mechanisms to address the issue of decision-making for the unbefriended are scant and not uniform."[21] Most facilities are "muddling through on an ad hoc basis."[22]

In 2015, the Institute of Medicine made substantially the same pessimistic observations in its own comprehensive report on end-of-life care.[23] And in 2016, American Geriatrics Society updated its earlier 1996 position statement.[24] The AGS identified "significant state-to-state variability in legal approaches to unbefriended

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[18] GUIDELINES ON THE TERMINATION, *supra* note 5.

[19] *Id.* at 25.

[20] Am. Med. Dirs. Ass'n, *White Paper on Surrogate Decision-Making and Advance Care Planning in Long-Term Care*, SOC'Y FOR POST-ACUTE & LONG-TERM CARE MED. (Mar. 1, 2003), http://www.paltc.org/amda-white-papers-and-resolution-position-statements/white-paper-surrogate-decision-making-and ("Only a few states specify a procedure . . . [for a] patient without a surrogate."); Joseph Sacco, *Incapacitated, Alone, and Treated to Death*, N.Y. TIMES (Oct. 6, 2008), http://www.nytimes.com/2008/10/07/health/views/07case.html.

[21] MARY JOY QUINN, GUARDIANSHIPS OF ADULTS: ACHIEVING AUTONOMY, JUSTICE, AND SAFETY 112 (2005). I have collected examples of institutional policies on decision making for the unbefriended at http://thaddeuspope.com/consent/unbefriended.html.

[22] Marshall B. Kapp, *The 'Voluntary' Status of Nursing Facility Admissions: Legal, Practical, and Public Policy Implications*, 24(1) CRIM. & CIVIL CONFINEMENT 1, 12 (April 1997) [hereinafter *The 'Voluntary' Status of Nursing Facility Admissions*]; Marshall B. Kapp, *Editorial—Surrogate Decision-Making for the Unbefriended: Social and Ethical Problem, Legal Solution?* 1(2) J. ETHICS, L. & AGING 83 (1995) [hereinafter *Surrogate Decision-Making*].

[23] *See* COMM. ON APPROACHING DEATH, INST. OF MED., DYING IN AMERICA: IMPROVING QUALITY AND HONORING INDIVIDUAL PREFERENCES NEAR THE END OF LIFE 24–25 (2015) [hereinafter DYING IN AMERICA].

[24] Farrell, *supra* note 3.

patients."[25] And it concluded that these variations "create confusion for health care providers," resulting in "harms including treatment delays or prolongation of potentially burdensome treatments."[26]

The purpose of this Article is to help improve the quality of healthcare decision making for the unbefriended. I hope that this comprehensive and systematic explanation of both the problem and the available solutions will empower both public and clinical policymakers to develop more informed and more circumspect policies and procedures.

In Section I, I review traditional mechanisms to protect prospective autonomy. The law has devised several tools, such as advance directives and surrogates, that permit individuals to control their future medical treatment in the event that they lose decision-making capacity.[27] Unfortunately, none of these tools are available for the unbefriended.[28] In Section II, I more carefully define "unbefriended patient," assess the size of the unbefriended population, and examine demographics and causal factors.

In Section III, I describe four risks and patient safety problems arising from being unbefriended in the U.S. healthcare system. Unbefriended patients are exposed to overtreatment, undertreatment, and placement in an inappropriate setting.[29] In addition to these physical risks, they are likely to receive healthcare discordant with their values and preferences.[30]

The best way to avoid these risks is to avoid becoming unbefriended in the first place. So, in Sections IV and V, I examine key means of prevention. Section IV mechanisms can be employed by clinicians without legal change: (1) vigilant and ultra-careful capacity assessment, (2) more advance care planning, and (3) diligent

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[25] *Id.*

[26] *Id.*

[27] Thaddeus M. Pope, *Legal Fundamentals of Surrogate Decision Making,* 141(4) CHEST 1074, 1074 (2012) [hereinafter Pope, *Legal Fundamentals*].

[28] *Id.* at 1077.

[29] Volunteers of America—Minnesota, Unbefriended Elders: Matching Values with Decisions, Presentation at Minnesota Gerontological Society (April 30 2010), *http://www.mngero.org/downloads/UnbefriendedElders.pdf.*

[30] *Id.*

searching for surrogates. Section V mechanisms require legislation to authorize longer or more flexible default surrogate lists. If more people are authorized to make healthcare decisions, it is less likely the patient will be unbefriended.

Unfortunately, prevention is not always successful.[31] Some patients are "unavoidably" unbefriended.[32] In Section VI, I describe the main officially available solution: guardianship. But guardianship is rarely the right solution. First, there is a broad consensus that guardianship should be only a last resort.[33] Second, the process is too slow and cumbersome to be responsive to the patient's medical needs.[34]

Consequently, both legislatures and individual health systems or facilities have developed other more accessible mechanisms on their own.[35] But these mechanisms vary in how they balance speed and fairness.[36] In Section VII, I examine mechanisms that lack adequate due process.[37] These include having the healthcare decision authorized: (1) by the attending physician herself, (2) by a second physician, or (3) by an "interdisciplinary team."[38] Finally, in Section VIII, I describe solutions that are more accessible than guardianship, yet still afford adequate procedural due process.[39] These often include tiered approaches that correlate the amount of oversight to the gravity of the decision at hand.[40] These solutions typically require

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[31] *See* Farrell et al., *supra* note 3, at 15.

[32] *See id.*

[33] AM. BAR ASS'N, PRACTICAL TOOL FOR LAWYERS: STEPS IN SUPPORTED DECISION MAKING 6 (2016), http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html.

[34] ALAN MEISEL, KATHY L. CERMINARA & THADDEUS M. POPE, THE RIGHT TO DIE: THE LAW OF END OF LIFE DECISIONMAKING 3-118 to 3-120 (3rd ed. & 2017 Supp.) [hereinafter THE RIGHT TO DIE].

[35] *See* AM. BAR ASS'N COMM'N ON LAW AND AGING, STATE GUARDIANSHIP LEGISLATION: DIRECTIONS FOR REFORM 1 (2011), http://www.americanbar.org/content/dam/aba/uncategorized/2011/2011_aging_ gship_elss _2010.authcheckdam.pdf.

[36] *See id.* at 1; Farrell et al., *supra* note 3.

[37] *See infra* Part VII.

[38] T.E. Miller, C.H. Coleman & A.M. Cugliari, *Treatment Decisions for Patients without Surrogates: Rethinking Policies for a Vulnerable Population*, 45(3) J. AM. GERIATRICS SOC'Y 369, 371 (1997).

[39] *See infra* Part VIII.

[40] Mathew Varughese et al., *Ethics and Clinical Practice Guided by the Family Health Care Decisions Act*, 16(1) NYSBA HEALTH L.J. 75, 80 (2011).

consent either from the ethics committee or from an external and independent committee.[41]

Ultimately, we must balance speed and fairness. On the one hand, we want a decision-making process that is accessible, quick, convenient, and cost-effective. On the other hand, we want a process that provides the important safeguards of expertise, neutrality, and careful deliberation. This Article offers a comprehensive organization and framing of various models that are specified in law or implemented at the institutional level. My intent is to that this examination will help public and institutional policymakers determine where to best strike the balance.

## *I. Traditional Mechanisms to Protect Prospective Autonomy*

Patient autonomy is highly valued in the United States.[42] Patients with decision-making capacity can make their own healthcare decisions.[43] Moreover, patients retain the right of self-determination even when they lose the capacity to make healthcare decisions for themselves.[44] Our society's individualistic norms place "such a strong emphasis on the voice of the patient" that medical decisions should "continue to be guided by that voice as much as possible."[45] For example, in the seminal *In re Quinlan* case, the New Jersey Supreme Court ruled that Karen did not lose her right to choose when she lost capacity.[46] That right could be exercised on her behalf by her family.[47]

The law has devised three main tools to promote "prospective autonomy," the right to control one's future medical treatment in the event that one loses decision-making capacity.[48] The first mechanism

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[41] THE RIGHT TO DIE, *supra* note 34, at 3-101 to 3-102.

[42] Pope, *Legal Fundamentals*, *supra* note 27, at 1074. A fourth mechanism is guardianship. *See infra* Section VI.

[43] *See id.*

[44] *Id.*

[45] Bruce Jennings, *Ethical Dilemmas in Surrogate Decision Making, in* LIVING WITH GRIEF: ETHICAL DILEMMAS AT THE END OF LIFE 158 (K.J. Doka ed., Hospice Foundation of America 2005).

[46] *See In re* Quinlan, 355 A.2d 647, 671–72 (N.J. 1976).

[47] *See id.*

[48] Pope, *Legal Fundamentals*, *supra* note 27, at 1074.

is the instructional advance directive or living will.[49] But most of us do not write such directives.[50] The second mechanism is the proxy directive or durable power of attorney for healthcare, designating another person, a surrogate, to direct the course of our medical treatment upon our incapacity.[51] But most of us do not appoint surrogates either.[52] Therefore, the third mechanism by which our prospective autonomy is protected and promoted is the most common: through the informal selection of surrogates based on statutory priority lists.[53]

Essentially, the issue is one of consent. Clinicians need consent to administer treatment or diagnostic interventions.[54] Two situations are relatively straightforward. First, if the patient has capacity, then she can provide or refuse that consent herself.[55] Second, in emergency situations, even if the patient lacks capacity, her consent is implied.[56] So, there is no need for patient or surrogate consent in emergencies. But outside these two situations, clinicians need consent through some vehicle of prospective autonomy.[57] Our focus is on consent mechanisms for incapacitated patients in non-emergency situations.

### *A. Decision Making Capacity*

Essential to an understanding of prospective autonomy is an understanding of decision-making capacity. If the patient has capacity, then there is no need for either advance directives or surrogates.[58] Adult patients—both those 18 years of age or older and emancipated minors—are presumed to have capacity until determined otherwise.[59]

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[49] *Id.*

[50] *Id.*

[51] *Id.*

[52] *Id.*

[53] *Id.*

[54] *See* Paul S. Appelbaum, *Assessment of Patients' Competence to Consent to Treatment*, 357 NEW ENG. J. MED. 1834, 1834 (2007).

[55] *See* Pope, *Legal Fundamentals*, *supra* note 27, at 1074.

[56] RESTATEMENT (SECOND) TORTS § 892D(a) (AM. LAW. INST. 1979).

[57] *See* Appelbaum, *supra* note 54, at 1834.

[58] Pope, *Legal Fundamentals*, *supra* note 27, at 1075.

[59] *Id.*

This presumption is rebutted only after the attending physician, often with confirmation from a second physician, determines that the patient lacks one or more of the three essential attributes of capacity.[60] First, the patient must possess the ability to understand both her own condition and the treatment's significant benefits, burdens, risks, and reasonable alternatives.[61] Second, the patient must be able to reason and deliberate about her treatment choices.[62] Third, the patient must be able to make and communicate a decision.[63]

Capacity is decision specific. This means that a patient lacking capacity to make a complex decision might still have capacity to make other decisions.[64] It also means that incapacity is not a status-based judgment.[65] Being elderly or diagnosed with dementia does not automatically make one incapacitated.[66]

In 2017, the Idaho Legislature found that many individuals with developmental disabilities are erroneously presumed to lack capacity.[67]

> The term developmental disability covers a wide range of conditions, many of which do not impair the ability of the person to make competent medical decisions. However, this right has been often denied to such persons, with a demand that the person have a guardian. This is not only a denial of the fundamental rights of the person, it can lead to expensive and unneeded court proceedings.[68]

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[60] *Id.*

[61] *Id.*

[62] *Id.*

[63] *Id.*

[64] Pope, *Legal Fundamentals*, *supra* note 27, at 1075.

[65] *Id.*

[66] *Id.*

[67] S.B. 1090, 64th Leg., Reg. Sess. (Idaho 2017), codified at IDAHO CODE § 39-4503.

[68] S.B. 1090, 64th Leg., Reg. Sess. (Idaho 2017) (Statement of Purpose), https://legislature.idaho.gov/wp-content/uploads/sessioninfo/2017/legislation/S1090SOP.pdf.

Accordingly, Idaho enacted a statute that provides even individuals who are "developmentally disabled" may have capacity and thus may consent to their own care.[69]

### *B. Emergency Exception and Implied Consent*

In emergency situations, healthcare decision making for the unbefriended is reasonably straightforward. The patient lacks capacity to consent and there is no reasonably available surrogate.[70] Clinicians cannot get "actual" consent for needed treatment. But this is not problematic. There is no need to obtain patient or surrogate consent, because consent to treatment is implied.[71] The emergency makes it necessary, or apparently necessary, for providers to act *before* there is opportunity to obtain consent.[72]

Emergency situations are typically defined as those in which, "according to competent medical judgment, the proposed surgical or medical treatment or procedures are reasonably necessary" and a "delay in treatment could reasonably be expected to jeopardize the life or health of the person affected or could reasonably result in disfigurement or impaired faculties."[73]

For example, a 2011 Missouri bill provided that healthcare may be provided to an unbefriended patient without consent if:

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[69] S.B. 1090, 64th Leg., Reg. Sess. (Idaho 2017), codified at IDAHO CODE § 39-4503.

[70] *See id.*

[71] *See, e.g.*, ARIZ. REV. STAT. ANN. § 36-512 (2016); CAL. BUS. & PROF. CODE § 2397(a)((2)–(3)) (West 2016); CAL. HEALTH & SAFETY CODE § 1418.8(h) (West 2016); CAL. PROB. CODE § 3210(b) (West 2016); COLO. REV. STAT. § 15-18.6-104(3) (2016); DEL. CODE ANN. tit. 16, § 2510(a)(4) (2016); IDAHO CODE § 39-4504(i) (2016); IND. CODE § 16-36-3-3 (2016); MISS. CODE ANN. § 41-41-7(2017); MO. REV. STAT. § 27- 431.063 (2017); N.C. GEN. STAT. § 90-21.13(c)(1) (2016); N.Y. PUB. HEALTH LAW § 2994-q(2) (McKinney 2017); S.C. CODE ANN. § 44-66-40(A) (2016) ("Health care may be provided without consent to a patient who is unable to consent if no person authorized . . . is available immediately, and in the reasonable medical judgment of the attending physician or other health care professional responsible for the care of the patient, the delay occasioned by attempting to locate an authorized person, or by continuing to attempt to locate an authorized person, presents a substantial risk of death, serious permanent disfigurement, or loss or impairment of the functioning of a bodily member or organ, or other serious threat to the health of the patient.").

[72] RESTATEMENT (SECOND) TORTS § 892D(a) (AM. LAW. INST. 1979); Stewart-Graves v. Vaughn, 170 P.3d 1151, 1155 (Wash. 2007); Miller v. HCA, Inc., 118 S.W.3d 758, 772 (Tex. 2003). The emergency exception might be characterized for addressing urgent healthcare decision making on behalf of the temporarily unbefriended.

[73] *See, e.g.*, O.C.G.A. § 31-9-3(a) (2016). *See also* 42 U.S.C. § 1395dd(e)(1) (2012).

> [I]n the reasonable medical judgment of the attending physician or other healthcare professional responsible for the care of the patient, the delay occasioned by attempting to locate an authorized person or by continuing to attempt to locate an authorized person presents a substantial risk of death, serious permanent disfigurement, or loss or impairment of the functioning of a bodily member or organ, or other serious threat to the health of the patient.[74]

The law in every other state is substantially similar.[75]

In short, the law concerning treatment decisions in emergency situations is reasonably well settled. Therefore, the challenges confronting healthcare providers for the unbefriended primarily concern non-emergency treatment. The remaining decision-making mechanisms focus on how treatment decisions are made for incapacitated patients in non-emergency situations.[76]

### *C. Advance Directives and POLST*

Arguably, if patients left sufficiently clear and complete instructional advance directives (living wills), there would be no need for surrogates. Providers could simply consult the patient's own *ex ante* instructions for guidance.[77]

But more than three decades of experience shows that it is difficult to effectively implement this form of "directed decision-making."[78] Most individuals do not complete advance directives.[79] Most of those that are completed are not available when needed.[80] And, even when completed and available, instructional advance directives are often

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[74] H.B. 392, 96th Gen. Assemb., 1st Reg. Sess. (Mo. 2011).

[75] *E.g.*, O.C.G.A. § 31-9-3(b) (2016) ("In addition to any instances in which a consent is excused or implied at law, a consent to surgical or medical treatment or procedures suggested, recommended, prescribed, or directed by a duly licensed physician will be implied where an emergency exists.").

[76] On the other hand, some have argued for expanding the scope of the emergency exception to cover some of these other cases. J. Bernstein, *Presumed Consent: Licenses and Limits Inferred from the Case of Geriatric Hip Fractures*, 18(1) BMC MED. ADD PERIOD? ETHICS 17 (2017).

[77] Pope, *Legal Fundamentals*, *supra* note 27, at 1075.

[78] *Id.*

[79] *Id.*

[80] *Id.*

insufficiently clear and detailed to obviously apply to the patient's current situation.[81] Accordingly, prospective autonomy is usually promoted not through instructional advance directives but through substitute decision-makers collectively known as "surrogates."[82]

### *D. Agents and Durable Powers of Attorney for Healthcare*

Every state has established a process that allows competent individuals to appoint an agent to decide about healthcare when they become unable to decide for themselves.[83] While terminology varies from state to state, this type of surrogate is normally referred to as a "proxy," an "agent," a "healthcare representative," or an "attorney-in-fact."[84]

This appointment can be made through a legal form typically referred to as an advance directive or a durable power of attorney for healthcare (DPAHC).[85] While short and simple, these appointment forms require the strict observation of certain formalities.[86] For example, the individual must often sign the form in the presence of two witnesses who are neither related to the individual nor employed at a facility where the individual is a patient or resident.[87]

The agent's power is often referred to as "springing" because it is triggered when the patient loses capacity; and it vanishes when the

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[81] *Id.* In contrast, POLST forms overcome some of the obstacles of advance directives. Thaddeus M. Pope, *Controlling the Misuse of CPR with Certified Patient Decision Aids and POLST*, 17(2) AM. J. BIOETHICS 35 (2017); Thaddeus M. Pope & Melinda Hexum, *Legal Briefing: POLST (Physician Orders for Life-Sustaining Treatment),* 23(4) J. CLINICAL ETHICS 353 (2012).

[82] *Id.*

[83] Pope, *Legal Fundamentals*, *supra* note 27, at 1075.

[84] *Id.*; AM. BAR ASS'N COMM'N ON LAW AND AGING, SUBSTITUTE DECISION-MAKER TERMINOLOGY UNDER STATE LAW (July 2016), http://www.americanbar.org/content/dam/aba/administrative/law_aging/SubstituteDecision-MakingTerminology.authcheckdam.pdf.

[85] *Id.*

[86] *Id. See also* Joshua A. rolnick et al., *Delegalizing Advance Directives – Facilitating Advance Care Planning*, 376 NEW ENG. J. MED. 2106 (2017). For some individuals, like long-term care residents, it may be difficult to comply with the mandatory execution formalities. These individuals are surrounded by facility employees who can neither serve as agent nor witness an appointment. But, in many states, these residents and patients can still designate a surrogate informally. *See, e.g.*, DEL. CODE ANN. tit. 16, § 2507(b)(1) (2016). The individual makes the designation directly to the supervising provider in the presence of a witness. *Id.* The provider then confirms the designation on the medical record and has that signed by the witness. *Id.*

[87] THE RIGHT TO DIE, *supra* note 34, § 7.05, at 7-69, 7-71, 7-74 to 7-78.

patient regains capacity.[88] Whenever authorized to act, the agent typically has the right to make all healthcare decisions that the patient could have made for herself, unless the patient has explicitly limited the agent's authority.[89] And providers must comply with decisions made in good faith by an agent to the same extent they would have to comply with decisions made by the patient herself.[90]

### *E. Default Surrogates and Proxies*

If there is no advance directive, no court-appointed guardian, and no patient-appointed agent, then the healthcare provider can select the surrogate.[91] This is sometimes referred to as "devolved decision-making."[92] The provider makes the designation pursuant to default surrogate statutes in almost every state.[93]

Because most individuals have neither completed nor effectively implemented advance directives appointing healthcare agents, most states have enacted "default statutes."[94] These laws specify a hierarchy of surrogates to consent to medical treatment on behalf of incapacitated individuals.[95] These surrogates are automatically designated based on their familial, or otherwise defined, relationship to the incapacitated individual.[96]

These statutes specify a priority list of individuals whom the physician should or must designate.[97] Typically, at the top of this hierarchy are the patient's spouse, adult child, parent, and adult sibling.[98] The hierarchy prioritizes those relatives who are typically more likely to know the convictions and beliefs of the patient and more likely to be concerned for the patient.[99] Default surrogates are

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[88] Pope, *Legal Fundamentals*, *supra* note 27, at 1075.

[89] *Id.*

[90] *Id.*

[91] *Id.*

[92] *Id.*; *see also* Karp & Wood, *Incapacitated and Alone, supra* note 4, at 21.

[93] Pope, *Legal Fundamentals*, *supra* note 27, at 1076.

[94] *Id.* at 1074. *See also infra* Section V.

[95] Pope, *Legal Fundamentals*, *supra* note 27, at 1074.

[96] *Id.* at 1076.

[97] *Id.*

[98] *Id.*

[99] *Id.*

the most numerous type of surrogate.[100] Therefore, the sequence and manner in which they are designated from the list has great significance. But there are material differences among the states.[101]

### *F. Guardians and Conservators*

In cases of conflict among potential surrogates or when no surrogate is reasonably available, it is sometimes necessary to petition a court to appoint a surrogate.[102] A court-appointed surrogate is typically referred to as a "guardian" or "conservator."[103] The petition is usually filed by a relative or by the administrator of a healthcare facility where the patient resides.[104] The court-appointed guardian may be a family member, a friend, a disinterested stranger, a non-profit or for-profit agency, or a public program.[105] Since the appointment is usually not directed by the patient herself, judicial appointment is sometimes referred to as "displaced decision-making."[106]

After the appointment, the court is supposed to supervise and monitor the guardian's choices on behalf of the patient to ensure that the patient is getting appropriate medical care.[107] Because this entire process can be cumbersome and expensive, comparatively few surrogates are guardians.[108] Moreover, the guardianship system is currently the subject of significant scrutiny and reform.[109]

For example, while capacity is decision-specific, guardianship is typically all-or-nothing. Once the patient is assessed as "incompetent," the guardian has full power to make most, if not all,

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[100] *Id.*

[101] *See infra* Section V. *See also* Erin S. DeMartino et al., *Who Decides When a Patient Can't? Statutes on Alternate Decision Makers,* 376(15) NEW ENG. J. MED. 1478 (2017).

[102] Pope, *Legal Fundamentals*, *supra* note 27, at 1076.

[103] *Id.*

[104] *Id.*

[105] *Id.*

[106] *Id.*; *see also* Karp & Wood, *Incapacitated and Alone, supra* note 4, at 21.

[107] Pope, *Legal Fundamentals*, *supra* note 27, at 1076; *see also* Naomi Karp & Erica F. Wood, *Guardianship Monitoring: A National Survey of Court Practices,* 37 STETSON L. REV. 143, 146 (2007).

[108] Pope, *Legal Fundamentals*, *supra* note 27, at 1076.

[109] *Id.*; *see also* U.S. GOV'T ACCOUNTABILITY OFF., GAO-11-678, INCAPACITATED ADULTS: OVERSIGHT OF FEDERAL FIDUCIARIES AND COURT-APPOINTED GUARDIANS NEEDS IMPROVEMENT 8 (2011).

decisions for the patient, even if the patient retains capacity to make some decisions or even all decisions some of the time.[110] Policymakers are working to encourage the use of less restrictive alternatives; more limited, tailored guardianship orders; and more procedural due process protections.[111]

### *G. Decision Making Standards*

Through whichever of these mechanisms treatment decisions are made for an unbefriended patient, the decision-making standards are approximately the same. These standards are usually specified in state statutes in the U.S., and there is substantial uniformity across the country.[112]

A surrogate is an "extension of the patient"[113] and stands in the shoes of the patient. Accordingly, the surrogate is "obligated to suppress his or her own judgment in favor of 'channeling' what the [patient] would have done."[114] The surrogate "must make the medical choice that the patient, if competent, would have made and not one that the surrogate might make for himself or herself."[115] There is generally a two-step hierarchy; surrogates should apply these standards sequentially: (1) substituted judgment and then (2) best interest.[116]

Under the substituted judgment standard, surrogates must engage in some speculation and "infer" patients' wishes from their prior statements and conduct.[117] Laws across several states are substantially similar. Alabama, for example, provides that a surrogate must make decisions "that conform as closely as possible to what the

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[110] Pope, *Legal Fundamentals*, *supra* note 27, at 1076.

[111] *Id. See also* ABA Commission on Law and Aging, *Guardianship and Supported Decision-Making Law and Practice*, https://www.americanbar.org/groups/law_aging/resources/ guardianship_law_practice.htm.

[112] *Id.* at 1077.

[113] AMA, CODE OF MEDICAL ETHICS, Opinion 8.081.

[114] *See* Lawrence A. Frolik, *Is a Guardian the Alter Ego of the Ward?*, 37 STETSON L. REV. 53, 65 (2007).

[115] *In re* Guardianship of Browning, 568 So. 2d 4, 13 (Fla. 1990). Added period and space after so.

[116] Pope, *Legal Fundamentals*, *supra* note 27, at 1076.

[117] *Id.*

patient would have done or intended under the circumstances."[118] A surrogate must take into account "any evidence of the patient's religious, spiritual, personal, philosophical, and moral beliefs and ethics."[119]

There is often no reliable evidence of the unbefriended patient's expressed wishes, values, or preferences. When this is the case, surrogates cannot apply the substituted judgment standard, and therefore must apply the best interest standard.[120] Surrogates must shift focus from the patient's autonomy to the patient's welfare.[121] In the absence of subjective evidence about a patient's wishes, a surrogate must rely on more objective grounds, on an outcome that best promotes the patient's well-being.[122]

Typically, these seven factors are used to guide the application of the best interest standard: (1) the patient's present level of physical, sensory, emotional, and cognitive functioning; (2) quality of life, life expectancy, and prognosis for recovery with and without treatment; (3) the various treatment options and the risks, side-effects, and benefits of each; (4) the nature and degree of physical pain or suffering resulting from the medical condition; (5) whether the medical treatment being provided is causing or may cause pain, suffering, or serious complications; (6) the pain or suffering to the patient if the medical treatment is withdrawn; and (7) whether any particular treatment would be proportionate or disproportionate in terms of the benefits to be gained by the patient versus the burdens caused to the patient.[123]

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[118] *Id.*

[119] *Id.*; *see also* ALA. CODE § 22-8A-11(c) (2016).

[120] Pope, *Legal Fundamentals*, *supra* note 27, at 1077; *In re* YP, 2015 INT 129 (D.C. Sup. Ct. Prob. Div. Apr. 10, 2017), http://www.thaddeuspope.com/images/In_re_YP_DC_Prob_2017_best_interest_stop_LST_.pdf.

[121] Pope, *Legal Fundamentals*, *supra* note 27, at 1077.

[122] *Id.* at 1077–78.

[123] Thaddeus M. Pope, *The Best Interest Standard: Both Guide and Limit to Medical Decision Making on Behalf of Incapacitated Patients*, 22 J. CLINICAL ETHICS 134, 136 (2011).

## *II. Who Are Unbefriended and Unrepresented Patients?*

The mechanisms directed at protecting prospective autonomy that are described in the last section help most incapacitated individuals. But none are available to protect the unbefriended. In this Section, I define the "unbefriended patient" and describe some competing terminology. I then assess the size of the unbefriended population, its demographics, and its causal factors. Importantly, the number of unbefriended patients continues to grow significantly.

### *A. Definition of "Unbefriended Patient"*

The unbefriended are incapacitated individuals who cannot be helped by any of the standard legal mechanisms that protect and promote prospective autonomy. First, they have not left an instructional advance directive (a living will). Or, even if they have an instructional advance directive and it is available, it does not address the relevant clinical circumstances.[124] Second, the unbefriended have not appointed a healthcare agent (power of attorney). Or, if they have appointed an agent, none is reasonably available. Third, they have no court-appointed guardian.

This is normally the point at which default decision making mechanisms would be useful. But the unbefriended have no available friends or family to make medical decisions as "default" surrogates.[125] Unbefriended patients may have outlived, lost contact with, or been abandoned by family members. Or they may be loners who have spent much of their lives disconnected and in social isolation.

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[124] Pope, *Legal Fundamentals*, *supra* note 27, at 1075. While most unbefriended patients are individuals who have lost decision-making capacity, there are two other categories (1) individuals such as the mentally disabled who never had capacity, and (2) minors who have not yet acquired capacity. *See id.* at 1075.

[125] Pope, *Legal Fundamentals*, *supra* note 27, at 1074. Sometimes, a patient's unbefriended status is a factor not so much due to the *non-existence* of a surrogate, but to the *unavailability* of a surrogate, at the relevant time. For example, an unbefriended patient might have relatives, but those relatives may be unresponsive, uninvolved, or incapable of making treatment decisions for the patient. *Id.* at 1077.

### *B. Competing Terminology*

Many different terms have been used to describe the unbefriended. Here are just eight words and phrases: "adult orphans,"[126] "friendless patients,"[127] "unrepresented patients,"[128] "patients alone,"[129] "solo citizens,"[130] "patients without a surrogate decision maker,"[131] "patients without proxies,"[132] "patients for whom no surrogate is identified as reasonably available, willing, or competent to act."[133]

The Reader has already seen that I employ the term "unbefriended." Some commentators have criticized this term, because of its negative connotation. It arguably stigmatizes, insults, and demeans this population. And it signals to the young that their lives are not valuable. I am sympathetic to these concerns. But I continue to use the term "unbefriended," because it seems to have the most currency in the bioethics, medical, and legal literature.[134]

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[126] Farrell et al., *supra* note 3, at 14.

[127] Casey Frank, *Surrogate Decision-Making for 'Friendless' Patients*, 34 COLO. LAW. 71, 71 (April 2005); CAL. LAW. REV. COMM'N, MEMORANDUM 98-63: HEALTH CARE DECISIONS: COMMENTS ON TENTATIVE RECOMMENDATION 9 (Sept. 18, 1998).

[128] VIKI KIND, THE CAREGIVER'S PATH TO COMPASSIONATE DECISION MAKING 46–48 (2010).

[129] LINDA FARBER POST, JEFFREY BLUSTEIN & NANCY N. DUBLER, HANDBOOK FOR HEALTHCARE ETHICS COMMITTEES 205–08 (2007); *See* American Health Decisions, *The Patient Alone: Making Health Care Choices for Patients without Surrogates* (May 6-7, 2008).

[130] See Karp & Wood, *Incapacitated and Alone*, *supra* note 4, at 31.

[131] *See generally* Douglas B. White et al., *Life Support for Patients without a Surrogate Decision Maker: Who Decides?* 147 ANNALS OF INTERNAL MED. 34 (2007) [hereinafter *Who Decides?*]; Douglas B. White et al., *Decisions to Limit Life-Sustaining Treatment for Critically Ill Patients Who Lack Both Decision-Making Capacity and Surrogate Decision-Makers*, 34(8) CRITICAL CARE MED. 2053 (2006) [hereinafter *Decisions to Limit Life-Sustaining Treatment*]; Steven J. Baumrucker et al., *A Cognitively Impaired Patient without a Surrogate: Who Makes the Decision?* 28 AM. J. HOSPICE & PALLIATIVE MED. 583 (2011); Am. Med. Dirs. Ass'n., *supra* note 20.

[132] *See generally Patients without Proxies: What's Happening in Other States?* MID-ATLANTIC ETHICS COMMITTEE NEWSLETTER (L. & Health Care Program, U. of Md. Sch. of L. and the Md. Health Care Ethics Committee Network), Summer 2010, at 7; A. Robichaud & C. Griggins, *Patients without Proxies: Medical Decision-Making for Patients without Advocates*, PowerPoint presentation for Cleveland State University (Nov. 18, 2010), http://wapps.csuohio.edu/campusmailbag/forum_posts.asp?TID=6308.

[133] *See generally* S. Res. 4098, 214th Gen. Assemb., Reg. Sess. (N.J. 2011).

[134] *See, e.g.*, Eric D. Isaacs and Robert V. Brody, *The Unbefriended Adult Patient*, 83(6) SAN FRANCISCO MED. 25, 25 (July-August 2010); Varughese et al., *supra* note 40; Robert M. Gibson, *How Do We Address the Unbefriended Patient's Needs?*, CAL. ASS'N OF LONG-TERM CARE MED. (2015), http://www.caltcm.org/index.php?option=com_content&view=article&id=194:how-do-we-address-the-unbefriended-patient-s-needs-&catid=22:news&Itemid=111; CHARLIE P. SABATINO, ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING: LEGAL AND POLICY ISSUES 18 (Washington, D.C.: U.S. Department of Health and Human Services, 2007), http://aspe.hhs.gov/daltcp/reports/2007/

Moreover, it is the term used by the American Bar Association.[135] Most recently, the American Geriatrics Society used the term "unbefriended" in its 2016 Position Statement, "Making Medical Treatment Decisions for Unbefriended Older Adults."[136]

Nevertheless, it is useful to distinguish two related though distinct concepts: "unbefriended" and "unrepresented." One might limit the term "unbefriended" to describe individuals who have no available and willing friends or family. In contrast, one might limit the term "unrepresented" to describe individuals who have no legally authorized decision maker.

There are four possible relationships between being "unbefriended" and being "unrepresented":

| | |
|---|---|
| Unbefriended<br>Unrepresented | Not unbefriended<br>Unrepresented |
| Unbefriended<br>Not unrepresented | Not unbefriended<br>Not unrepresented |

In category 1, the individual is both unbefriended and unrepresented. She has no family or friends who are available and willing to serve as surrogate. Nor does she have a court-appointed guardian. In category 2, the individual is not unbefriended. She has available friends or family. Or perhaps she has care-providers at her long-term care facility. Nevertheless, she is unrepresented, because her friends, family, or professional care-providers are not legally authorized decision makers. In category 3, the individual is unbefriended, because she lacks available friends or family. But, she is not unrepresented because she has a guardian or other decision

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adacplpi.pdf.; Martin J. Gorbien & Amy R. Eisenstein, *Elder Abuse and Neglect: An Overview,* 21(2) CLINICS IN GERIATRIC MED. 279, 288 (2005); Marshall B. Kapp, *Medical Decision Making for Older Adults in Institutional Settings: Is Beneficence Dead in an Age of Risk Management?*, 11(1) ISSUES IN L. & MED. 29, 34 (1995); Michael A. Williams, *Unbefriended*, 67(11) NEUROLOGY 2088, 2088 (2006). The term "unbefriended" was apparently coined in a symposium, 1(2) J. ETHICS, L. & AGING (1995). One article attributes the term to Joanne Lynn. T.E. Finucane, R.D. Elon, J.M. Keenan, *The Medical Director in Non-Institutional Long-Term Care Programs*, 11(3) CLINICS IN GERIATRIC MED. 391 (1995).

[135] Karp & Wood, *Incapacitated and Alone, supra* note 4, at 21.

[136] Farrell et al., *supra* note 3.

maker. Finally, in category 4, the individual is neither unbefriended nor unrepresented. It would be better to use these separate terms with narrower and more precise meanings. But that is not common usage.

### *C. Size of the Unbefriended Patient Population*

There are more than 70,000 unbefriended patients and long-term care residents in the United States.[137] The majority of the unbefriended are believed to live in hospitals and long-term care facilities. There are two significant hospital studies. One found that 16 percent of patients admitted to an intensive care unit (ICU) were unbefriended.[138] The other found that 5 percent of patients who died in the ICU were unbefriended.[139] There is one key long term care study.[140] It estimated that these individuals make up about 3 to 4 percent of the nursing home population.[141]

These are the three studies most often cited to substantiate the size of the unbefriended population.[142] Still, other studies corroborate these estimates.[143] For example, a British study of hospitals found an unbefriended rate of 4 percent.[144] While clinicians usually discuss a

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[137] I computed this by adding 45,500 (3.5 percent of the 1.3 million in long-term care) and 25,000 (5 percent of the 500,000 in intensive care units).

[138] *Decisions to Limit Life-Sustaining Treatment*, *supra* note 131, at 2053.

[139] *Who Decides?*, *supra* note 131, at 34.

[140] *See* Karp & Wood, *Incapacitated and Alone, supra* note 4, at 20; Muriel R Gillick, *Medical Decision-Making for the Unbefriended Nursing Home Resident*, 1(2) J. ETHICS, L. & AGING 87, 88 (1995); T. Miller & A.M. Cugliari, *Withholding and Withdrawing Treatment: Policies in Long-Term Care Facilities*, 30(4) GERONTOLOGIST 462 (1990).

[141] *See* Karp & Wood, *Incapacitated and Alone, supra* note 4, at 20; Gillick, *supra* note 140, at 88; Miller & Cugliari, *supra* note 140.

[142] Decision making for this population also comprises a significant percentage of ethics consults. Keith M. Swetz et al., *Report of 255 Clinical Ethics Consultations and Review of Literature,* 82(6) MAYO CLINIC PROCEEDINGS 686, 690 (2007). But almost no retrospective reports on ethics consults break out unbefriended as a separate category.

[143] *See, e.g.*, Jennifer Moye et al., *Ethical Concerns and Procedural Pathways for Patients Who are Incapacitated and Alone: Implications from a Qualitative Study for Advancing Ethical Practice*, 29 HEC FORUM 171 (2017), DOI 10.1007/s10730-016-9317-9 (collecting citations); Combined Respondents' and Cross Appellants' Opening Brief at 28, California Advocates for Nursing Home Reform (CANHR) v. Chapman, No. A147987 (Cal. App. Jan. 17, 2017) (estimating 6000 to 12,000 in California); *but see* Andrew M. Courtwright et al., *The Role of a Hospital Ethics Consultation Service in Decision-Making for Unrepresented Patients,* 14 BIOETHICAL INQUIRY (2017), DOI:10.1007/s11673-017-9773-1 (reporting only 25 cases for unrepresented patients between 2007 and 2013).

[144] ROYAL COLLEGE OF PHYSICIANS, END OF LIFE CARE AUDIT – DYING IN HOSPITAL NATIONAL REPORT FOR ENGLAND 2016 31 tbl.14 (2016) [hereinafter END OF LIFE CARE AUDIT]

do not resuscitate order with the patient's surrogate, 4 percent of respondents explained that they were unable to do that either because "there was no nominated person important to the patient" or because "attempts . . . to contact the nominated person were unsuccessful."[145] Similarly, a study conducted by the American Bar Association, the Society of Critical Care Medicine, and the Society of Hospital Medicine surveyed 45,000 physicians; nearly 50 percent of respondents reported seeing at least one unbefriended patient per month.[146]

Some state specific studies also confirm the size of the problem. A North Dakota study estimated there are 300 to 700 unbefriended individuals in that state.[147] If that figure were extrapolated nationwide, there would be 129,000 unbefriended.[148] A Massachusetts study estimates around 3200 to 3800 unbefriended in that state.[149] A Minnesota nursing facility survey identified an unbefriended rate of just under 2 percent.[150] Social services staff from Minnesota Volunteers of America estimated they handle approximately 250 calls per year regarding end-of-life decisions about people who have impaired decision-making capacity with no legally designated decision maker.[151]

### *D. Demographics and Causal Factors*

These are significant numbers, and they continue to grow. While (a) the elderly is the largest group of unbefriended, they are not the

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[145] *Id.*

[146] , Am. Bar Ass'n, Comm'n on Law and Aging, *Background Briefing: Health Care Decision Making Round Table: Who Decides If The Patient Cannot And There Is No Advance Directive: Research And Recommendations on Clinical Practice, Law and Policy,* (March 17, 2017).

[147] Schmidt, *supra* note 2 at 84.

[148] North Dakota's population is 740,000 and the U.S. population is 320,000,000. U.S. CENSUS BUREAU, https://www.census.gov/quickfacts (last visited Mar. 2, 2017).

[149] JENNIFER MOYE ET AL., EXAMINING THE NEED FOR A PUBLIC GUARDIAN IN MASSACHUSETTS: PHASE 1 15 (2016), http://guardianship.institute/pdf/ExaminingtheNeedforaPublicGuardianinMassachusetts.pdf (last visited May 4, 2017).

[150] Douglas Silverman, St. Program Admin. Principle, Minn. Dep't. of Hum. Serv., PowerPoint Presentation at 2011 Minnesota Age & Disabilities Odyssey: Serving the Unbefriended Elder Population: Trends, Challenges, and Successes (June 21, 2011) (citing a study by Andrea Palumbo, Elder Justice Scholar, William Mitchell College of Law), http://www.mnodyssey.org.

[151] Karp & Wood, *Incapacitated and Alone, supra* note 4, at 13.

only group who may be adversely affected by a lack of a surrogate—or a "reasonably available" surrogate.[152] There are five other key populations of unbefriended individuals: (b) minors, (c) the homeless, (d) the mentally disabled, (e) individuals in same-sex relationships, and (f) individuals who have family or friends but who are nevertheless unbefriended due to a plethora of legal and other reasons.[153] I group these various populations into three categories: (1) permanently unbefriended, (2) legally unbefriended, and (3) temporarily unbefriended.

### *1. Permanently Unbefriended*

Incapacitated patients without surrogates in four populations are properly described as "permanently unbefriended." These four populations are: (1) the elderly, (2) the homeless, (3) the mentally ill, and (4) patients whose potential surrogates are unwilling or unable to serve.[154] These individuals literally have no one to make treatment decisions on their behalf. No available surrogate even exists.

#### *a. The Elderly*

Most of the unbefriended are elderly. For example, take Great-Aunt Sue, who "outlived her husband, never had any children, and has survived all of her siblings and their children."[155] The 2010 U.S. Census indicates there were approximately 40,000,000 people over the age of 65 living in the U.S., 13 percent of the total population.[156] This is a 15 percent increase in that age group since 2000.[157] It is one

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[152] *See generally* Silverman, *supra* note 150.

[153] *See* QUINN, *supra* note 21, at 111; Rupal M. Parekh & Gail Adorno, *Health Care Decision Making for Unbefriended, Incapacitated Adults: A Value-Committed Policy Transfer Analysis,* J. POL'Y PRACT., Sept. 8, 2016, DOI: 10.1080/15588742.2016.1222925.

[154] Parekh & Adorno, *supra* note 153, at 2. One study flags the prevalence of transgender individuals among the unrepresented. Courtwright et al., *supra* note 143.

[155] Mandy Moye, *From the Bench and Bar: Helping Great-Aunt Sue, an Unbefriended Elder,* CHEROKEE TRIBUNE & LEDGER NEWS (Feb. 5, 2017), http://www.tribuneledgernews.com/opinion/from-the-bench-and-bar-helping-great-aunt-sue-an/article_72bb10e2-eb60-11e6-b097-934032e642ac.html.

[156] LINDSAY M. HOWDEN & JULIE A. MEYER, U.S. CENSUS BUREAU, AGE AND SEX COMPOSITION: 2010 2 (May 2011), *http://www.census.gov/prod/cen2010/briefs/c2010br-03.pdf.*

[157] *Id.*

of the fastest growing age groups.[158] Moreover, the 65 and older age group will continue to grow at unprecedented rates because the boomer generation, born between 1946 and 1964, is one of the largest generations in U.S. history.[159]

Because of a lower marriage rate, a higher divorce rate, and fewer children, among other factors, many in this growing population are aging alone.[160] Nearly one-half of those 75+ and 30 percent of those 65+ live alone.[161] Social isolation is a significant and growing problem among the elderly and especially among the extreme elderly.[162] This negatively affects the health of these individuals while they still have capacity.[163] And it causes them to become unbefriended when they lose capacity.

### *b. The Homeless*

The homeless are another group who are likely to be permanently unbefriended. Often, it is difficult or impossible even to identify homeless patients.[164] Obviously, when the patient cannot be identified, it is difficult, even impossible, to identify her or his surrogate. Moreover, even when clinicians can identify the person,

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[158] *Id.*

[159] Karp & Wood, *supra* note 107, at 149.

[160] Sharon Jayson, *Alone and Aging: Creating A Safety Net for Isolated Seniors*, KAISER HEALTH NEWS (Nov. 28, 2016), http://khn.org/news/alone-and-aging-creating-a-safety-net-for-isolated-seniors/; Katie Hafner, *Researchers Confront an Epidemic of Loneliness,* N.Y. TIMES (Sept. 15, 2016), https://www.nytimes.com/2016/09/06/health/lonliness-aging-health-effects.html?_r=0; Carol Marak, *Senior Isolation – Ranking the 50 States,* SENIORCARE.COM (Mar. 10, 2017), http://seniorcare.com/resources.

[161] U.S. ADMIN. ON AGING, A PROFILE OF OLDER AMERICANS (2016), https://aoa.acl.gov/aging_statistics/profile/index.aspx.

[162] *See* U.S. Senate Special Committee on Aging, *Hearing: Aging Without Community: The Consequences of Isolation and Loneliness* (April 27, 2017); Harry Owen Taylor et al., *Social Isolation, Depression, and Psychological Distress Among Older Adults,* J. AGING & HEALTH, Oct. 17, 2016, DOI:10.1177/0898264316673511.

[163] *See, e.g.*, NAT'L ACADS. OF SCIS., ENG'G, AND MED, FAMILIES CARING FOR AN AGING AMERICA 73-122 (2016); Jennifer L. Wolff et al., *Supporting Family Caregivers of Older Americans* 375(26) NEW ENG. J. MED. 2513 (2016); Elizabeth Simpson, *For Want of a Ride, Norfolk Man Delays Eye Treatment*, VIRGINIA PILOT (Jan. 13, 2017), http://pilotonline.com/news/local/health/your-health-for-want-of-a-ride-norfolk-man-delays/article_dc163f25-5374-5eb6-b228-8a681e8b9fae.html.

[164] *See* QUINN, *supra* note 21, at 111.

many homeless individuals do not have family or friends who are willing and able to make decisions on their behalves.[165]

For example, Michelle Bateman, a 43-year-old woman, remained unconscious in the Hospital of the University of Pennsylvania for four months before she was identified and her family located.[166] She went into cardiac arrest on August 13, 2010, and was brought to an area hospital and later transferred to Penn, but never regained consciousness.[167] Because no one could determine her identify and no family members were immediately present, the hospital was left to absorb all costs of treatment and presumably all decisions relating to that treatment.[168] Meanwhile, her family placed missing person reports and made phone calls, and the hospital ran nationwide fingerprint checks and asked for help from local TV stations and newspapers, but to no avail.[169] Finally, four months later, in December 2010, a friend recognized her picture in the newspaper and contacted her family.[170]

### *c. Mentally Disabled*

A third category of permanently unbefriended are those with mental disabilities. This category typically includes two populations: (1) developmentally disabled: people with conditions such as mental retardation, autism, cerebral palsy, or epilepsy, and (2) people who are mentally ill: people with conditions such as schizophrenia, manic-depressive disorder, and serious depression. Although these populations often overlap significantly with the homeless population, many others are served by special institutions.[171] Because mentally

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[165] James J. O'Connell, *Raging Against the Night: Dying Homeless and Alone*, 16(3) J. CLINICAL ETHICS 262, 263 (Fall 2005); John Song, Edward R. Ratner, & Diane M. Bartels, *Dying While Homeless: Is It a Concern When Life Itself Is Such a Struggle?"* 16(3) J. CLINICAL ETHICS 251, 251 (Fall 2005); Wendi M. Norris et al., *Treatment Preferences for Resuscitation and Critical Care among Homeless Persons*, 127(6) CHEST 2180, 2181 (2005).

[166] Don Sapatkin, *Unconscious Woman is ID'd: Relatives Say They Filed Missing-Person Report in Aug.*, PHILADELPHIA INQUIRER, Dec. 14, 2010, at A1.

[167] *Id.*

[168] *Id.*

[169] *Id.*

[170] *Id.*

[171] Seena Fazel, Vivek Khosla, Helen Doll & John Geddes, *The Prevalence of Mental Disorders*

disabled patients are often easily identifiable and are especially vulnerable, many laws and programs have been developed specifically for their benefit and protection.[172]

#### *d. Unwilling or Unable*

Finally, some patients are unbefriended despite the *existence* of family or friends. Although family or friends may exist, they are *unavailable* to make treatment decisions.[173] They might not be found or reachable by healthcare providers.[174] They may be unwilling to participate because of time constraints, physical location, or a poor relationship with the patient.[175] Other times, even if the potential surrogate is willing to participate, they may be unable to participate because of their own capacity issues or because the patient herself did not want them to serve.[176]

### *2. Legally Unbefriended*

In contrast to the permanently unbefriended, the "legally unbefriended" have someone available and willing to make treatment decisions on their behalf. But because of legalities, these patients may still become unbefriended. There are two key populations of legally unbefriended patients: (1) patients in same sex relationships, and (2) patients in other non-traditional relationships.

#### *a. Same Sex Couples*

Before June 26, 2013, only a minority of states legally recognized same-sex marriages.[177] Consequently, same-sex partners were often

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*among the Homeless in Western Countries: Systematic Review and Meta-Regression Analysis*, 5(12) PUB. LIBR. SCI. MED. 1670, 1675–76 (2008).

[172] *See infra* Part VIII.

[173] MD. CODE ANN., HEALTH–GEN § 5-605(a) (West 2016) (providing four definitions of "unavailable").

[174] *Id.*

[175] *Id.*

[176] *Id.*

[177] *Same Sex Marriage Laws*, NAT'L CONF. OF STATE LEGIS. (June 26, 2016), http://www.ncsl.org/research/human-services/same-sex-marriage-laws.aspx.

not recognized as a patient's "spouse" for purposes of healthcare decision-making, unless the spouse had been appointed a surrogate in an advance directive.[178] This barrier was removed when the U.S. Supreme Court held that the Fourteenth Amendment requires every state to license a marriage between two people of the same sex and to recognize same-sex marriages lawfully licensed and performed out-of-state.[179]

### *b. Non-Traditional Relationships*

Other non-traditional relationships are also at risk of being unbefriended. A recent study of over 100,000 patients found that only 93 percent identified a member of their nuclear family as next of kin.[180] Four percent selected friends or relatives outside their nuclear family as surrogates, including "baby momma," "common law spouse," and "live-in soul mate."[181] One percent chose unrelated individuals to whom they had a different social tie, including "landlady," "priest," "roommate," or "sponsor."[182] While those in the study had capacity to identify and nominate these non-nuclear family surrogates—if they had not already done so in an advance directive—, incapacitated individuals have no such opportunity. Because many states do not recognize these relationships as authorizing healthcare decision-making, these patients may become legally unbefriended.

Alternatively, one might say that patients in same-sex relationships are not "unbefriended." After all, they have close friends available to serve as surrogates. Yet, these patients remain "unrepresented," because their friends are not legally authorized or recognized to serve as substitute decision makers.

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[178] MATTHEW STIFF, HUMAN RIGHTS CAMPAIGN FOUND., BREAKING DOWN BARRIERS: AN ADMINISTRATOR'S GUIDE TO STATE LAW AND BEST POLICY PRACTICE FOR LGBT HEALTHCARE ACCESS 8, 9 (2009).

[179] *See generally* Obergefell v. Hodges, 135 S. Ct. 2584 (2015).

[180] Andrew B. Cohen, Mark Trentalange & Terri Fried, *Patients with Next of Kin Relationships Outside the Nuclear Family*, 313(13) JAMA 1369, 1369 (2015).

[181] *Id.* at 1370. *See also* Colleen Galambos et al., *Analysis of Advance Directive Documentation to Support Palliative Care Activities in Nursing Homes,* 41 HEALTH & SOCIAL WORK 228, 231 (2016) (finding in a study of 1900 nursing home residents that 14 percent designated "other relative," 2 percent designated "friend," and 8 percent designated an "unknown" individual).

[182] Cohen, Trentalange & Fried, *supra* note 180, at 1370.

### *3. Temporarily Unbefriended*

The permanently unbefriended have no available surrogate. The legally unbefriended have a willing and available surrogate, but that person is not authorized to serve as surrogate. In contrast, the temporarily unbefriended "have" a surrogate that is legally authorized and willing to serve. But the surrogate is not available within the relevant timeframe for healthcare decision-making. There are two main populations of temporarily unbefriended patients: (1) minors and (2) those with momentarily unreachable surrogates.

#### *a. Minors*

With a few limited exceptions, individuals under the age of majority, typically 18, may not legally consent to medical treatment.[183] Consent must be given by a parent, guardian, or other legally authorized adult.[184] Typically, a parent will attend doctors' appointments with minor children, but children often present to a medical facility without an adult.[185] In the absence of an adult who can legally consent, physicians are urged to refrain from treating minors in non-emergency situations.[186] Physicians who provide care without proper consent may be subject to civil liability.[187]

There are many reasons why parents or guardians might not be available. First, family living arrangements vary greatly, and many children reside with an adult who is not a legal guardian, such as a grandparent, aunt, uncle, or stepparent.[188] Second, children may be brought to medical facilities by a childcare provider.[189] It is increasingly common for both parents to work, resulting in children

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[183] American Academy of Pediatrics, Committee on Pediatric Emergency Medicine & Committee on Bioethics, *Consent for Emergency Medical Services for Children and Adolescents*, 128(2) PEDIATRICS 427 (2011) [hereinafter *Consent for Emergency*].

[184] *Id.*

[185] *Id.*

[186] *Id.* at 428.

[187] *Id.*

[188] Jan Ellen Berger & Comm. on Med. Liability, American Acad. of Pediatrics, *Consent by Proxy for Nonurgent Pediatric Care*, 112(5) PEDIATRICS 1186, 1189 (2003).

[189] *Id.*

spending large amounts of time with childcare providers.[190] Such providers are not legal guardians, and, therefore, do not have legal authority to consent to treatment.[191] Third, children may be traveling out-of-state without a parent when a need for treatment arises.[192] In certain states, noncustodial parents may not consent to medical treatment.[193] Or the parents may go on vacation, leaving their minor child at home.[194] Fourth, many children live in foster homes, and often no one has asked the court to appoint a legal guardian.[195]

These challenges may seem surprising given the enhanced communication available in today's culture.[196] But many hospitals and emergency personnel find it difficult or impossible to achieve real-time contact with parents or guardians, as many facilities do not have adequate systems in place to achieve this.[197] Some states have expanded the ability of individuals to appoint proxies and agents.[198] For example, in 2015, Florida enacted legislation permitting parents or guardians to appoint an agent who can authorize non-emergency medical treatment for a minor.[199]

### *b. Momentarily Unreachable Surrogates*

Just as parents may be momentarily unreachable to make healthcare decisions for their children, other types of surrogates may also be temporarily unreachable. One study found that 45 percent of incapacitated patients' next-of-kin could not be reached to make treatment decisions.[200]

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[190] *Id.* at 1189.

[191] *Id.*

[192] *Id.* at 1190.

[193] *Id.*

[194] Berger, *supra* note 188, at 1194.

[195] *Id.* at 1190.

[196] *See Consent for Emergency*, *supra* note 183, at 430–31.

[197] *Id.*

[198] H.B. 889, 2015 Leg., Reg. Sess. (Fla. 2015) (codified at FLA. STAT. ANN. § 765.2035 (West 2016)).

[199] *Id.*

[200] Andrew M. Fader, Steven R. Gambert, Maureen Nash & Krishan L. Gupta, *Implementing a "Do-Not-Resuscitate" (DNR) Policy in a Nursing Home*, 37(6) J. AM. GERIATRICS SOC'Y 544, 547 (1989).

## *III. Risks and Patient Safety Problems*

Unbefriended patients are vulnerable to many undesirable, and possibly dangerous or life-threatening, situations. They often have multiple chronic conditions such as Alzheimer's disease, cancer, heart problems, diabetes, and kidney failure.[201] With no available formal decision-making mechanism, their healthcare providers are left in a quandary.[202]

On the one hand, they might treat the patient without consent. On the other hand, providers might refuse to treat until they can obtain valid consent. Providers in the U.S. take both approaches, exposing the patients to two different types of risks: overtreatment and undertreatment.[203] In addition, because there is no one to authorize discharge, the unbefriended often remain in inappropriate healthcare settings.[204] Finally, apart from physical risks, the unbefriended are likely to receive treatment that is discordant with their preferences and values.[205]

### *A. Physical Risks from Overtreatment*

The unbefriended are often overtreated. The absence of an authorized surrogate often results in "maximum medical intervention, whether or not a medical 'full court press' is clinically and ethically warranted."[206] The unbefriended receive unnecessary or unwanted treatment for various reasons, including physicians' fear of civil liability for failure to treat, institutional fear of regulatory sanctions, physicians' economic incentives to treat, and physicians' general interventionistic philosophy of medicine.[207]

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[201] Karp & Wood, *Incapacitated and Alone*, *supra* note 4, at 12.

[202] *Id.* at 20–21.

[203] Robert N. Swidler, *New York's Family Health Care Decisions Act: The Legal and Political Background, Key Provisions, and Emerging Issues*, N.Y. STATE BAR ASS'N HEALTH L.J., June 2010, at 20.

[204] *Id.* at 19–20.

[205] *Id.*

[206] *Surrogate Decision-Making*, *supra* note 22, at 22.

[207] *Unbefriended Elders: Matching Values with Decisions,* VOLUNTEERS OF AM.–MINN. (April 30 2010), http://www.mngero.org/downloads/UnbefriendedElders.pdf [hereinafter *Unbefriended Elders*].

### *B. Physical Risks from Undertreatment*

Not only are the unbefriended overtreated, they are also undertreated. Many physicians refuse to provide any type of treatment without informed consent.[208] Consequently, important decisions may be "postponed dangerously, [or] forgone altogether."[209] Some physicians will wait until an emergency, and then consent is implied, and therefore, there is no need for a surrogate to authorize treatment.[210]

However, delaying treatment while waiting for emergency situations may result in longer periods of suffering and indignity, and increases the chance of morbidity to the patient.[211] The absence of a surrogate can "stymie decision-making and possibly leave . . . patients to linger in pain and discomfort."[212] The Institute of Medicine found it ethically "troublesome" to wait "until the patient's medical condition worsens into an emergency so consent to treat is implied."[213] Such an approach "compromises patient care and prevents any thorough and thoughtful consideration of patient preferences or best interests."[214]

### *C. Physical Risks from Inappropriate Setting*

Unable to secure consent for discharge, the unbefriended patient often remains at the wrong healthcare setting, such as a hospital, for too long.[215] The delay lengthens the patient's stay and the risk of nosocomial infections.[216] Whether through interacting with other

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[208] *Id.*

[209] *The 'Voluntary' Status of Nursing Facility Admissions*, *supra* note 22, at 12.

[210] *See supra* Section I.B.

[211] *Surrogate Decision-Making*, *supra* note 22, at 18; *Unbefriended Elders*, *supra* note 207.

[212] THE RIGHT TO DIE, *supra* note 34, § 3.16[F].

[213] DYING IN AMERICA, *supra* note 23, at 146 (internal quotations omitted).

[214] *Id.* at 147.

[215] Rosalind Abdool et al., *Difficult Healthcare Transitions: Ethical Analysis and Policy Recommendations for Unrepresented Patients*, 23(7) NURSING ETHICS 770 (2016); Moye et al., *supra* note 143.

[216] Mary F. Marshall, *Editorial: Improving Guardianship Processes for Unrepresented Adult Patients Who Lack Decisional Capacity: An Ethical and Institutional Imperative*, 40(9) JOINT COMMISSION JOURNAL ON QUALITY & PATIENT SAFETY 387, 387 (2014); CAL. SENATE RULES COMM., OFFICE OF SENATE FLOOR ANALYSIS, SENATE FLOOR ANALYSIS, S.B. 481, 2017-18 Leg., Reg. Sess., at

patients or just being in the hospital environment, 10 perecent to 20 percent of patients develop urinary tract infections, pneumonia, or other hospital-acquired infections.[217] The longer the stay, the higher the risk. Furthermore, the unbefriended patient may be deprived of needed care such as the benefits of hospice.[218] Or they might progressively lose their ability for rehabilitation.[219]

### *D. Risks to Patient Autonomy*

Physical harm is not the only type of risk posed to the unbefriended. A serious affront to individual self-determination is also a threat. Whether overtreated or undertreated, the unbefriended are susceptible to treatment decisions that do not conform to their personal values, morals, or beliefs.[220] The Institute of Medicine observes: "'Unbefriended' patients who have neither decision-making capacity nor a surrogate decision maker are at particular risk of not having their wishes known or followed."[221]

For instance, several studies report that physicians often make decisions based upon their own preferences.[222] They may not know the patient, or they may not be willing or able to take the time to learn the patient's preference. A treatment decision that is not based upon a patient's own preferences and values is particularly offensive in a society that places a premium on personal autonomy. To the extent that a patient's preferences and values can be ascertained, treatment decisions should be determined through substituted

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6 (2017), file:///Users/landonreed/Downloads/201720180SB481_Senate%20Floor%20Analyses-.pdf (quoting California Hospital Association).

[217] CTR. FOR DISEASE CONTROL, PREVENTING HEALTHCARE-ASSOCIATED INFECTIONS 1 (2016).

[218] Timothy W. Kirk & Nancy Neveloff Dubler, *Let Hospice Be Available to Everyone*, TIMES UNION (June 11, 2015, 6:35 PM), http://www.timesunion.com/tuplus-opinion/article/Let-Hospice-be-available-to-everyone-6322179.php.

[219] MOYE ET AL., supra note 149, at 28. Of course, the lack of a surrogate may not be the only obstacle to discharge. *See, e.g.*, Jennifer L. Herbst, *Permanent Patients: Hospital Discharge Planning Meets Housing Insecurity*, 47(1) HASTINGS CENTER REP. 6 (Jan.-Feb. 2017).

[220] *See* DYING IN AMERICA , *supra* note 23, at 147-52.

[221] *Id.* at 146.

[222] Miller, Coleman & Cugliari, *supra* note 38, at 370 ("Without a surrogate, decisions may be less open, less clearly articulated, and more susceptible to judgments about the patient's social and individual worth."); *see* Norris et al., *supra* note 165, at 2185.

judgment; otherwise, they should be consistent with the patient's best interests.

## *IV. Prevention Is the Best Solution*

Before examining "special" decision-making mechanisms for the unbefriended, it is important to first examine ways to prevent a patient from becoming unbefriended in the first place. Using established autonomy-protective strategies can often preclude the need to resort to "alternative" decision-making mechanisms. Three key preventative strategies are: (1) vigilant and ultracareful capacity assessments, (2) more and better advance care planning, and (3) diligent searching for surrogates.

### *A. Vigilant and Ultracareful Capacity Assessment*

Obviously, the best person to make healthcare decisions for the patient is the patient herself. With support, time, and good communication, seemingly unbefriended individuals may be able to make decisions that at first blush appear not to be possible. The individuals might not actually be unbefriended. But for a diagnostic or assessment error, clinicians would assess them as still having capacity to make their own treatment decisions.[223]

Many bioethicists are concerned that unbefriended individuals are more likely to be the victim of an incorrect determination of incapacity by a physician.[224] Indeed, patients often present to a hospital with an initial appearance of incapacity that later "dissipates under scrutiny."[225] For example, in one reported case, an elderly woman who entered Massachusetts General Hospital for a heart

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[223] *See* Michael Church & Sarah Watts, *Assessment of Mental Capacity: A Flow Chart Guide,* 31 The Psychiatrist 304, 304–306 (2007) (reviewing "properly supported processes" sufficient to enable the patient to make the decision in question, such as: multiple learning trials with corrected feedback and enhanced structure using computer-based presentations); Norris et al., *supra* note 165, at 2185.

[224] M.S. Chin & V.A. Brown, *The Dilemma of Capacity: Respecting Patient Wishes and Preferences and Decision Making Ability*, 2(1) J. HOSPITAL ETHICS (2010).

[225] Cristina Papanikos, *Establishing the Guardianship*, 8 FLA. GUARD. PRAC. § 12.16; Lesley Charles et al., *Physician Education on Decision-Making Capacity Assessment,* 63 CANADIAN FAMILY PHYSICIAN e21 (2017) (finding that physians are poorly trained and vary in their approaches to assessing capacity).

condition found herself just days later declared mentally ill and transferred involuntarily to a nursing home.[226] Her hearing in Suffolk Probate Court lasted about two minutes.[227] A subsequent, more detailed evaluation convinced the original judge to void the guardianship and restore her freedom.[228]

Capacity is not all-or-nothing. While nearly half of long-term-care residents may lack capacity, a quarter still had partial capacity.[229] For example, although patients may lack the capacity to make complex treatment decisions, they may have sufficient capacity to appoint a surrogate.[230] The Volunteers of America-Minnesota program found that even though half its clients had a cognitive impairment, they still had sufficient capacity to complete an advance directive.[231] An unbefriended patient might still have capacity to share what she thinks "about death, life, her current living situation, and her hopes for the future."[232] In short, the unbefriended should be allowed to participate in making decisions to the extent that they can.[233]

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[226] *Old, Sick, and Unbefriended,* BOS. GLOBE (Jan. 18, 2008), http://archive.boston.com/bostonglobe/editorial_opinion/editorials/articles/2008/01/18/old_sick_and_unbefriended/.

[227] *Id.*

[228] *Id.*

[229] Miller, Coleman & Cugliari, *supra* note 38, at 369.

[230] *See* Gillick, *supra* note 140, at 87; AMERICAN BAR ASS'N COMM'N ON LAW AND AGING & AMERICAN PSYCHOLOGICAL ASS'N, ASSESSMENT OF OLDER ADULTS WITH DIMINISHED CAPACITY: A HANDBOOK FOR PSYCHOLOGISTS 52 (2008); Scott Y. H. Kim and Paul S. Appelbaum, *The Capacity to Appoint a Proxy and the Possibility of Concurrent Proxy Directives,* 24 BEHAVIORAL SCI. & L. 469 (2006).

[231] ORTIZ, *supra* note 7, at 8.

[232] *See* Baumrucker et al., *supra* note 131, at 587. The concept of the "least restrictive alternative" is a centerpiece of guardianship reform. *See* MENTAL HEALTH LEGAL ADVISORS COMM., THE HANDBOOK ON GUARDIANSHIP AND THE ALTERNATIVES 6 (2007).

[233] UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES art.12 (2008). In states that utilize the traditional process, substantial efforts are underway to develop practical alternatives and guardian prevention methods. Darlene Payne Smith & Sharon B. Gardner, *Complex Family Matters in Guardianship, Advanced Elder Law and Advanced Guardianship, in* ADVANCED GUARDIANSHIP COURSE 2009 ch.11 at 1 (Houston, TX: State Bar of Texas, 2009). For instance, the Texas legislature recently mandated the development of an additional program to assist those individuals with mental disabilities and no guardian in making decisions. H.B. 1454, 2009 Leg., 81st Sess. (Tx. 2009). The statute requires the Health and Human Services Commission to develop and evaluate two Volunteer Supported Decision-Making Advocate Programs. *Id.*; The programs will assist these individuals in making life decisions such as where to live and with whom and where to work. *Id.*; *See Volunteer Supported Decision-Making*, TX. COUNCIL FOR DEVELOPMENTAL DISABILITIES, http://www.tcdd.texas.gov/projects/grants-completed-projects/the-arc-of-san-angelo/ (last visited Mar. 6, 2017).

Particularly encouraging is the growth of "supported decision making." [234] This is a process in which adults who need assistance with decision making—for example, some people with intellectual or developmental disabilities—receive the help they need and want to understand the situations and choices they face—so they can make life decisions for themselves—without the need for a substitute decision maker.[235]

Perhaps the patient really does lack capacity. Even then, that may not be a necessary or permanent condition. Perhaps the incapacity is caused by medical conditions such as infections, dehydration, delirium, malnutrition, pain, or medication side effects. Perhaps it is caused by sensory deficits such as hearing or vision loss. Perhaps incapacity is caused by psychological conditions such as stress, grief, or depression. Many of these conditions can be treated. Thereby, the patient's capacity could be restored.[236]

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[234] G. Davidson et al., *Supported Decision Making: A Review of the International Literature*, 38 INT'L J. L. & PSYCH. 61, 61 (2015); Nina A. Kohn et al., *Supported Decision-Making: A Viable Alternative to Guardianship?*, 177(4) PENN. STATE L. REV. 1111, 1113 (2013). In 2014, the U.S. Department of Health and Human Services, Administration for Community Living, awarded a grant to Quality Trust for Individuals with Disabilities to create a Supported Decision Making Technical Assistance and Resource Center. *National Resource Center for Supported Decision-Making is Accepting Applications for the Second Year of State Grant Program*, NAT'L RES. CTR. FOR SUPPORTED DECISION MAKING (Aug. 17, 2016), http://www.supporteddecisionmaking.org/news/national-resource-center-supported-decision-making-accepting-applications-second-year-our-state. Relatedly, Nevada created a special advance directive for adults with intellectual disabilities. Assemb. B. 128, 2015 Leg., 78th Sess. (Nev. 2015) (enacted as Chapter 337).

[235] Danielle Ofri, *Documenting My Patient's Next of Kin*, N.Y. TIMES (May 21, 2015, 10:06 AM), https://well.blogs.nytimes.com/2015/05/21/documenting-my-patients-next-of-kin/?_r=0; Chris Serres, *Minnesota Nonprofits Seek to Overhaul Legal Guardianship System for Vulnerable Adults*, STAR TRIBUNE (Dec. 12, 2016, 5:57 AM), http://www.startribune.com/minn-nonprofits-seek-to-overhaul-legal-guardianship-system-for-vulnerable-adults/405955396/. Notably, we utilize something akin to supported decision making to communicate with horses and dolphins. Helen Briggs, *Horses Can Communicate with Us Scientists*, BBC NEWS (Sept. 24, 2016), http://www.bbc.com/news/science-environment-37450952. So, we definitely should use it to communicate with patients when possible.

[236] MOYE ET AL., *supra* note 149, at 21 (reporting in some cases "a clinical intervention improves capacity (e.g. delirium clears or medication enhances acuity)" and emphasizing "attention to enhancing and restoring capacity"); Moye et al., *supra* note 143 (offering checklists on how to enhance capacity); Courtwright et al., *supra* note 143 (finding 20% of unrepresented patients had "fluctuating" capacity); AM. BAR ASS'N, PRACTICAL TOOL, *supra* note 33, at 6 (2016).

## *B. More and Better Advance Care Planning*

Better capacity assessment can reduce the number of unbefriended patients. Some can make treatment decisions for themselves. Others can at least nominate an agent or surrogate to make treatment decisions on their behalf. But these are limited solutions. Many unbefriended are permanently unconscious or otherwise "definitely" incapacitated.[237] Yet, even for many of these patients, prevention can help. But it must come earlier.

If patients leave adequate guidance about their post-capacity treatment, then they can avoid the risks of being unbefriended. All individuals are strongly encouraged to engage in advance care planning.[238] Even isolated individuals who are unable to appoint a family member might still be able to appoint a friend or a "professional" surrogate.[239]

A Minnesota program nicely illustrates the use of advance care planning to prevent at-risk individuals from becoming unbefriended.[240] From 2008 to 2011, supported in part by a grant from the Minnesota Department of Human Services, the Volunteers of America-Minnesota (VOAMN) ran a program called "The Unbefriended Elders: Matching Values with Decisions."[241] The program served elderly residents of certain counties who had no written healthcare directive on file and who were at risk of guardianship proceedings because of the absence of any available default surrogate.[242] The program consisted of local volunteers who were trained to identify and work with the unbefriended before they became incapacitated.[243] The volunteers helped the at-risk elderly to complete healthcare directives and identify, locate, and support potential surrogate decision makers.[244] Evaluations of the project

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[237] *See* Gillick, *supra* note 140, at 87.

[238] END OF LIFE CARE AUDIT, *supra* note 144 at 10; Farrell et al., *supra* note 3.

[239] *See* Gillick, *supra* note 140, at 90.

[240] ORTIZ, *supra* note 7, at 8.

[241] *Id.* at 8–9.

[242] *Id.*

[243] *Id.*

[244] *Id.*

indicate 62.5 percent of those served completed healthcare directives and 80 percent named an agent.[245]

The program evaluators concluded that it is very feasible to serve this vulnerable population, and that there is a growing need for training and education regarding their unmet needs.[246] The grant that funded the VOAMN project expired and the program has formally ended.[247] But the Care Management and Consultation branch of the VOAMN still provides assistance for the unbefriended and those caring for them.[248]

Even if a patient has not engaged in advance care planning before admission to a hospital or long-term care facility, it still may not be too late. Clinicians should, at least at that point, clarify the patient's preferences about who should serve as surrogate in the event the patient loses capacity. Indeed, these very inquiries are legally mandated both by state law[249] and by the Patient Self Determination Act.[250]

Furthermore, some have suggested that electronic physician orders for life sustaining treatment registries can help track the wishes of the unbefriended.[251] Several additional states have enacted Provider

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[245] Douglas Silverman, Minn. Dep't Health and Human Servs., Serving the Unbefriended Elder Population 40 (June 21, 2011), http://mn.gov/web/prod/static/odyssey/live/2011/PowerPoint/Monday/McDonnell-B/9-30am/SilvermanOdysseyFinal.pptx.

[246] *Id.* at 42.

[247] ORTIZ, *supra* note 7, at 9.

[248] VOLUNTEERS OF AM.: MINN. & WIS., CARE MANAGEMENT & CONSULTATION 2, https://www.voamnwi.org/pdf_files/care-management-brochure.

[249] For example, a New York Statute mandates the following:

> Within a reasonable time after admission as an inpatient to the hospital of each adult patient, the hospital shall make reasonable efforts to determine if the patient has appointed a health care agent or has a guardian. . . . With respect to a patient who lacks capacity, if no such health care agent, guardian or potential surrogate is identified, the hospital shall identify, to the extent reasonably possible, the patient's wishes and preferences, including the patient's religious and moral beliefs, about pending health care decisions, and shall record its findings in the patient's medical record.

N.Y. PUB. HEALTH § 2994-g(1) (2015).

[250] 42 U.S.C. § 1395cc(f)(1) (2012); 42 C.F.R. § 482.13(b)(3) (2012); 42 C.F.R. § 489.102(a)(4) (2017).

[251] Jeffrey Duncan et al., *Electronic End-of-Life Care Registry: the Utah ePOLST Initiative*, 2013 AIMA ANN. SYMP. PROC. 345, 352 (2013), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3900183/pdf/amia_2013_symposium_345.pdf.

Orders for Life-Sustaining Treatment (POLST) legislation.[252] In just the past several years, these include: Delaware, Indiana, and Nevada.[253] While limited to a certain set of life-sustaining treatments for seriously ill patients, POLST permits individuals to create clear, actionable, transferable orders for their post-capacity treatment, so to better avoid some of the risks of being unbefriended.

The promise of advance care planning may be even greater today. The Centers for Medicare & Medicaid Services (CMS) included advance care planning in the 2016 Medicare Physician Fee Schedule.[254] There are now two new current procedural technology (CPT) codes for these services: 99497 and 99498.[255] The former covers "advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified healthcare professional; first 30 minutes, face-to-face with the patient, family member(s), and/or surrogate."[256] The latter covers the same for "each additional 30 minutes."[257]

In short, these new CPT codes address one of the most significant barriers to advance care planning: inadequate Medicare reimbursement. If physicians are paid to explore end-of-life options, then these discussions will occur more often.[258] Indeed, the evidence supports this. Nearly 14,000 providers billed almost $35 million for advance care planning conversations for about 223,000 patients from January through June 2016.[259]

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[252] Other states have tried to enact POLST legislation. *See, e.g.*, S.B. 165, 131st Gen Assemb., Reg. Sess. (Ohio 2016); H.B. 385, 2013 Leg., Reg. Sess. (Ky. 2013).

[253] DEL CODE ANN. tit. 16 §§ 2501–2520 (2015); IND. CODE §§ 16-36-6-1–16-36-6-20 (2013); NEV. REV. STAT. §§ 449.691–449.697 (2013).

[254] Thaddeus M. Pope, *Legal Briefing: Medicare Coverage of Advance Care Planning,* 26 J. CLINICAL ETHICS 362, 366 n.12 (2015).

[255] *Id.* at 366 n.13.

[256] *Id.*

[257] *Id.*

[258] Thaddeus M. Pope, *Legal Briefing: The New Patient Self Determination Act,* 24 J. CLINICAL ETHICS 156, 161 (2013); Thaddeus M. Pope, *Legal Briefing: Advance Care Planning*, 20 J. CLINICAL ETHICS 362, 366 (2009) [hereinafter *Advance Care Planning*].

[259] JoNel Aleccia, *Docs Bill Medicare for End-of-Life Advice as 'Death Panel' Fears Reemerge*, USA TODAY (Feb. 9, 2017, 6:06 PM), http://www.usatoday.com/story/news/2017/02/09/kaiser-docs-bill-medicare-end -of-life-advice-death-panel-fears-reemerge/97715784/.

While more advance care planning can help limit the number of unbefriended, it will never be a complete solution. Among other obstacles, homeless, institutionalized, or migratory individuals may lack access to appropriate witnesses or notaries to complete an advance directive.[260]

### *C. Diligent Search for Surrogates*

Better capacity assessment and more advance care planning are two proven prevention strategies.[261] A third is diligent searching.[262] For many individuals who are initially thought to be unbefriended, a diligent search often turns up an available surrogate.[263] The search should be, and is often legally required to be, aggressive and rigorous.[264] Before reverting to "special" mechanisms for the unbefriended, many states first require a very careful documentation of efforts to locate "natural" surrogates.[265]

For example, facility staff should contact nursing homes, neighbors, and relevant service agencies.[266] They should attempt to legally gain access to a patient's home or apartment.[267] They should construct a genogram (a graphic of a person's family relationships and medical history) and an eco-map (a graphic of the systems at play in a person's life).[268] Staff should examine patients' personal effects, health records, social media, and other records such as

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[260] L.S. Castillo et al., *Lost in Translation: The Unintended Consequences of Advance Directive Law on Clinical Care*, 154 ANNALS INTERNAL MED. 121, 121–22, 124 (2011).

[261] *See Advance Care Planning*, *supra* note 258, at 362, 367 n.1.

[262] *See* Sapatkin, *supra* note 166; Farrell et al., *supra* note 3.

[263] *See id.*

[264] *See, e.g.*, TEX. HEALTH & SAFETY CODE § 313.005(b) (stating the "attending physicians shall make a reasonably diligent effort to contact . . . persons eligible to serve as surrogate decision-makers").

[265] *See* FLA. STAT. § 765.401(h) (2016).

[266] L.M. Peterson, *Clinical Decision Making for the Unbefriended Patient*, 17 LAHEY CLINIC J. MED. ETHICS 1, 3 (2010).

[267] *Id.*

[268] S.F. Cohn and M.H. Rieff, Assoc. Dir. & Exec. Dir. Jarvie Commonwealth Serv., 18th Annual Jarvie Colloquium: Care Management Challenges in Serving Un-Befriended Older Adults with Compromised Cognitive Capacity (Apr. 29, 2011), http://www.jarvie.org/docs/Unbefriended_Elder_with_Cogn_Impairment_presentation.pdf.

benefits and pension plans.[269] In this way, surrogates were found for nearly half of those who were initially thought to be unbefriended.[270]

Of course, there is not always time to engage in all these efforts. But even if the identification of a surrogate is not possible, prior healthcare providers and others may have information about a patient's history, past relationships, wishes, values, or priorities.[271] Even if a surrogate cannot be found, providers may still be able to gather "scattered bits and pieces of information, clues from a patient's past."[272] In short, even an unsuccessful search can be valuable, because clinicians may gather evidence that clarifies a patient's values relating to healthcare, and preferences regarding treatment under different circumstances.[273]

This is important, because whoever makes the treatment decision should exercise substituted judgment to the extent possible.[274] Decision making on other grounds is illegitimate.[275] For example, a 2012 decision of the Appeals Court of Massachusetts reversed a lower court's order authorizing an abortion and sterilization of a 32-year-old mentally ill woman.[276] While incapacitated, the woman clearly and consistently had expressed her opposition to an abortion.[277] Similarly, a lawsuit in Washington, D.C., alleged that the D.C. government consented to elective surgeries for mentally disabled residents without considering their wishes.[278] Only if

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[269] *See* Peterson, *supra* note 266, at 8.; MOYE ET AL., *supra* note 149, at 41–42; Moye et al., *supra* note 143 (including detailed checklists on how to locate friends and family).

[270] *See* Robichaud & Griggins, *supra* note 132, at 8. On the other hand, social work resources are limited. Resources devoted to extensive searching are resources that cannot benefit other patients.

[271] *Id.* at 7.

[272] *See* Karp & Wood, *Incapacitated and Alone*, *supra* note 4, at 18.

[273] M. Jurchak, ASBH Ninth Annual Meeting, *Creating a Voice for Absent or Inadequate Surrogates*, AM. SOC'Y BIOETHICS & HUMANITIES, http://asbh.confex.com/asbh/2007/techprogram/P6154.HTM (last visited Feb. 21, 2017). The policy at Brigham and Women's Hospital (in Boston) suggests that "weaving these fragments of experience and knowledge together produces a 'synthetic judgment' of the patient's preferences." *Id.*

[274] *In re* Guardianship of Moe, 81 Mass. App. Ct. 136, 140 (2012).

[275] *Id.*

[276] *Id.* at 141.

[277] *Id.* at 137.

[278] Does v. District of Columbia, No. 01-2398 (HHK) (D.D.C. Sept. 30, 2011) (order granting motion to file second amended complaint).

evidence of patient wishes is not available should surrogates make healthcare decisions on the grounds of objective best interests.

## *V. Prevention with Better Default Surrogate Lists*

Healthcare providers can and should take measures to help prevent individuals from becoming unbefriended. But lawmakers can help too. If the statutory list of authorized surrogates were longer or broader, then it is more likely that a surrogate will be found. Similarly, if the list allowed clinicians more flexibility in nominating a surrogate, then it would be more likely that a surrogate will be found.[279]

### *A. Longer Default Surrogate Lists*

Most individuals have either not completed, or at least not effectively implemented, advance directives appointing healthcare agents or durable powers of attorney.[280] In response, most states have enacted "default statutes," which specify a hierarchy of surrogates to consent to medical treatment on behalf of incapacitated individuals.[281] These surrogates do not need to be designated or appointed by the patient or by a court.[282] Instead, they are automatically designated, based on their familial, or otherwise defined, relationship to the incapacitated individual.[283] U.S. statues normally provide a list in order of priority.[284] Most give spouses the

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[279] Farrell et al., *supra* note 3. Clinicians in states without any default lists whatsoever have already developed *ad hoc* and flexible processes. C.L. Brigman, *How Long Can Michigan Tread Water without a Family Consent Law?*, 93 MICH. BAR. J. 32, 35 (2014).

[280] Charles P. Sabatino, *The Evolution of Health Care Advance Planning Law and Policy*, 88(2) MILBANK Q. 211, 221–22 (2010).

[281] *Id.* at 215–16.

[282] *Id.*

[283] *Id.* In most states, the surrogate is authorized solely because of her familial relationship to the patient. But some, like North Dakota, add a condition that the family member must have "maintained significant contacts with the incapacitated person." N.D. CENT. CODE § 23-12-13 (2017).

[284] ALASKA STAT. § 13.52.030(d) (2016); ARIZ. REV. STAT. § 36-3231(A)(6) (2016); DEL. CODE ANN. tit. 16, § 2507 (2016); D.C. CODE § 21-2210 (2017); FLA. STAT. § 765.401(g) (2016); O.C.G.A § 31-9-2(7) (2016); 755 ILL. COMP. STAT. § 40/25(a)(7) (2016); ME. STAT. tit. 18-A, § 5-805 (2016); MD. HEALTH-GEN. CODE ANN. § 5-605(a)(2) (2016); N.M. STAT. ANN. § 24-7A-5 (2017); N.Y. PUB. HEALTH LAW § 2994-d(1)(f) (2016); N.C. GEN. STAT. § 90-322 (2016); N.D. CENT. CODE § 23-12-13 (2017); OR. REV. STAT. § 127.635(2)(g) (2016); 20 PA. CONS. STAT. § 5461 (2016); TENN. CODE ANN.

highest priority and typically also include, in various sequences, parents, siblings, adult children, and grandparents.[285]

With a broader and longer statutory list of authorized surrogates, it is more likely that a surrogate can be found, and, thus, less likely that a patient will be unbefriended.[286] After all, one catches more fish with a bigger net.[287] Recently, several states expanded their default surrogate lists.[288] In addition, some states' default priority lists are now broader because of unrelated legislation. For example, the term "spouse" in all surrogate lists now includes same-sex partners.[289] Most notable among these surrogate list amendments is that many states have amended their laws to allow "close friends," or some variation of "interested adult," to make decisions when no family member is available.[290]

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§ 68-11-1806(c)(3) (2016); VA. CODE ANN. § 54.1-2986(A)(7) (2016); W. VA. CODE § 16-30-8 (2016); WIS. STAT. § 50.06 (2015); WYO. STAT. ANN. § 35-22-406 (2016).

[285] ALASKA STAT. § 13.52.030(d); ARIZ. REV. STAT. § 36-3231(A)(6); DEL. CODE ANN. tit. 16, § 2507; D.C. CODE § 21-2210; FLA. STAT. § 765.401(g); O.C.G.A § 31-9-2(7); 755 ILL. COMP. STAT. § 40/25(a)(7); ME. STAT. tit. 18-A, § 5-805; MD. HEALTH-GEN. CODE ANN. § 5-605(a)(2); N.M. STAT. ANN. § 24-7A-5; N.Y. PUB. HEALTH LAW § 2994-d(1)(f); N.C. GEN. STAT. § 90-322; N.D. CENT. CODE § 23-12-13; OR. REV. STAT. § 127.635(2)(g); 20 PA. CONS. STAT. § 5461; TENN. CODE ANN. § 68-11-1806(c)(3); VA. CODE ANN. § 54.1-2986(A)(7); W. VA. CODE § 16-30-8; WIS. STAT. § 50.06; WYO. STAT. ANN. § 35-22-406.

[286] MOYE ET AL., *supra* note 149, at 20 (reporting that 95% of interviewees "believe that a Default Consent provision would decrease the number of guardianships overall . . . reserving public guardianship as truly a last resort function"). My own informal interviews revealed that clinicians in Indiana and Minnesota push families to seek guardianship when the default surrogate list does not clearly recognize their authority. Some states, like Delaware, also have comparatively shorter lists of eligible relatives. DEL. CODE ANN. tit. 16, § 2507. In contrast, other states include, near the bottom of the list, "nearest living relative" or "close adult relative." *See, e.g.*, D.C. CODE ANN. tit. § 21-2210; FLA. STAT. § 765.401. The shorter the list of surrogates, the more likely it is that patients will be unbefriended. On the other hand, the variations in statutory lists may be mitigated by the fact that "overwhelmingly . . . clinical practice is to talk with everyone who is present and demonstrating knowledge . . . concern for the patient." David Godfrey, *Clinical Realities in Healthcare Decision Making,* 38(4) BIFOCAL 57, 57 (April 2017).

[287] *Cf.* Am. Pelagic Fishing Co. v. United States, 55 Fed. Cl. 575, 575 n.2, 581 n.9 (2003). On the other hand, while a longer surrogate list helps prevent patients from becoming unbefriended, this may not necessarily improve the quality of healthcare decision making. Some default surrogate lists recognize surrogates who may not perform well.

[288] *See, e.g.*, S.B. 302, 2014 Leg., Reg. Sess. (La. 2014).

[289] *See* Obergefell v. Hodges, 135 S. Ct. 2584, 2604 (2015).

[290] ALASKA STAT. § 13.52.030(d) (2016); ARIZ. REV. STAT. § 36-3231(A)(6) (2016); COLO. REV. STAT. § 19a-571 (2016); D.C. CODE § 21-2210 (2017); FLA. STAT. § 765.401(g) (2016); O.C.G.A § 31-9-2(7) (2016); IDAHO CODE § 39-4503 (2016); 755 ILL. COMP. STAT. § 40/25(a)(7) (2016); ME. STAT. tit. 18-A, § 5-805 (2016); MD. HEALTH-GEN. CODE ANN. § 5-605(a)(2) (2016); N.M. STAT. ANN. § 24-7A-5 (2017); N.Y. PUB. HEALTH LAW § 2994-d(1)(f) (2016); N.C. GEN. STAT. § 90-322 (2016); N.D.

For example, New Mexico permits "an adult who has exhibited special care and concern for the patient, who is familiar with the patient's personal values and who is reasonably available" to act as a surrogate when no family member listed in the statutory hierarchy is available.[291] Similarly, Pennsylvania allows "an adult who has knowledge of the principal's preferences and values, including, but not limited to, religious and moral beliefs, to assess how the principal would make healthcare decisions."[292] The Veterans Health Administration also includes "close friend" in its default surrogate list.[293]

The Delaware Health Care Decisions Act purports to include close friends as default surrogates.[294] When no family member is available, the statute authorizes "an adult who has exhibited special care and concern for the patient, who is familiar with the patient's personal values and who is reasonably available" to make medical treatments.[295] But the statute awkwardly authorizes a close friend only if the chancery court appoints that person as a guardian.[296] Commentators often write that Delaware includes close friends as default surrogates,[297] but since providers cannot informally designate close friends, close friends are not really part of Delaware's default priority list.

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CENT. CODE § 23-12-13 (2017); ORE. REV. STAT. § 127.635(2)(g) (2016); 20 PA. CONS. STAT. § 5461 (2016); S.D. CODIFIED LAWS § 34-12C-1 (2016); TENN. CODE ANN. § 68-11-1806(c)(3) (2016); VA. CODE § 54.1-2986(A)(7) (2016); W. VA. CODE § 16-30-8 (2016); WIS. STAT. § 50.06 (2015); WYO. STAT. ANN. § 35-22-406 (2016). Delaware includes "close friend," but only if appointed as guardian. DEL. CODE ANN. 16, § 2507 (2016).

[291] N.M. STAT. ANN. § 24-7A-5(c) (West 1997). However, the statute further dictates that a surrogate "may not be an owner, operator or employee of a health-care institution at which the patient is receiving care." *Id.* § 24-7A-5(j).

[292] 20 PA. STAT. AND CONS. STAT. ANN. § 5461 (West 2006).

[293] 38 C.F.R. § 17.32(e)(4) (2009); VETERANS HEALTH ADMIN., HANDBOOK 1004.01, INFORMED CONSENT FOR CLINICAL TREATMENTS AND PROCEDURES 1 (2009) [hereinafter VHA HANDBOOK].

[294] 16 DEL. CODE ANN. tit. 16, § 2507(b)(3)(a) (West 2016).

[295] *Id.* § 2507(b)(2–3).

[296] *Id.* § 2507(b)(4–5).

[297] AM. BAR ASS'N COMM'N ON LAW AND AGING, DEFAULT SURROGATE CONSENT STATUTES 3 (2014), http://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_default_surrogate_consent_statutes.authcheckdam.pdf; *Healthcare Equality Index: Default Surrogate Selection Laws*, HUM. RTS. CAMPAIGN (Nov. 14, 2014), http://www.hrc.org/resources/healthcare-equality-index-default-surrogate-selection-laws.

Over the past several years, several additional states have added "close friends" as authorized surrogates in their default statutes.[298] For example, in 2010, a Georgia bill added "adult friends" to its list of default surrogates.[299] This new category includes an "adult who has exhibited special care and concern for the patient, who is generally familiar with the patient's health care views and desires, and who is willing and able to become involved in the patient's health care decisions and to act in the patient's best interest."[300]

In 2010, New York also added "close friend" as its ultimate default surrogate or decision-maker of last resort.[301] Under the New York Family Health Care Decisions Act, "close friend" includes an individual "who has maintained such regular contact with the patient as to be familiar with the patient's activities, health, and religious or moral beliefs, and who presents a signed statement to that effect to the attending physician."[302] In 2011, New Jersey introduced legislation, closely patterned after the New York act, which would have authorized the patient's close friend as the ultimate default surrogate.[303]

In 2014, Louisiana added "adult friend" to the end of its priority list.[304] An adult friend is one "who has exhibited special care and concern for the patient, who is generally familiar with the patient's health care views and desires, and who is willing and able to become involved in the patient's health care decisions and to act in the patient's best interest."[305] The statute requires the adult friend to sign

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[298] *See, e.g.*, *infra* note 299. Close friends are also included in healthcare decisions statutes of many foreign jurisdictions. *See*, *e.g.*, *Guardianship Act of 1987* (NSW) cl 3E (Austl.).

[299] O.C.G.A. § 31-9-2 (2010).

[300] S.B. 367, 150th Leg., Reg. Sess. (Ga. 2010).

[301] N.Y. PUB. HEALTH LAW § 2994-d(1)(f) (McKinney 2017). Like most state statutes, New York's contains certain restrictions on who may serve as a surrogate, even if the individual would otherwise qualify as a close friend. *Id.* § 2994-d(2). Notably, healthcare providers typically cannot qualify as close friends. *Id.*

[302] N.Y. PUB. HEALTH LAW § 2994-a(4) (McKinney 2017).

[303] A4098, 214th Legis., 2011 Sess. (N.J. 2011). The bill was reintroduced in the next legislative session. A1835, 215th Legis., 2012 Sess. (N.J. 2012).

[304] S.B. 302, 2014 Leg., 40th Reg. Sess. (La. 2014).

[305] *Id.*

an "acknowledgment form . . . certifying that he or she meets such criteria."[306]

### *B. More Flexible Default Surrogate Lists*

Instead of making the default list longer, some states have given healthcare providers more flexibility and discretion.[307] Instead of specifying a strict sequence in hierarchical priority, these lists allow the providers to select the individual they judge will make the best surrogate.[308]

Tennessee has an interesting variation on the statutory default priority list that places the physician in a powerful position. A recent Tennessee court case held that despite existing custom, a patient's next of kin is *not* automatically authorized to make healthcare decisions upon the patient's incapacity.[309] If a patient has not appointed an agent and a court has not appointed a guardian, then the treating physician is authorized to appoint a decision maker.[310] The statutory default list is not a mandate but only a guideline. The physician does not mechanically follow the sequence in the statute.

Instead, the physician must choose "an adult who has exhibited special care and concern for the patient, who is familiar with the patient's personal values, who is reasonably available, and who is willing to serve."[311] Physicians may consider family members or next of kin, but are not bound to do so.[312] They may choose any adult, so long as that person satisfies the listed criteria.[313]

Like Tennessee, West Virginia similarly gives an attending physician or advanced nurse practitioner discretion to select the best

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[306] *Id.*

[307] *See, e.g.,* TENN. CODE ANN. § 68-11-1806(c) (2016).

[308] *Id.*

[309] Barbee v. Kindred Healthcare Operating Inc., No. W2007-00517-COA-R3-CV, 2008 WL 4615858, at *10 (Tenn. Ct. App. Oct. 20, 2008).

[310] TENN. CODE ANN. § 68-11-1806(c). The Tennessee Department of Health provides an "*Appointment of Surrogate Form*." TENN. DEP'T OF HEALTH, DIV. OF HEALTH LICENSURE AND REGULATION, PROVIDER IDENTIFICATION OF SURROGATE, https://tn.gov/assets/entities/health/attachments/PH-4269.pdf.

[311] TENN. CODE ANN. § 68-11-1806(c)(2).

[312] *See e.g.*, *id.*

[313] TENN. CODE ANN. § 68-11-1806(c)(3).

qualified surrogate, even if that person would be lower in a common ranking of surrogates.[314]

Colorado and Hawaii have similar variations on the default priority list, but which leave the physician with some discretion, though less than in Tennessee and West Virginia.[315] After determining that a patient is incapacitated, the attending physician may initiate proceedings to nominate a surrogate decision maker to act on behalf of the patient.[316] The physician seeks out as many interested persons as possible, including the patient's spouse, family, and close friends[317]. There is no automatic hierarchy.[318] Instead, all interested parties must meet and decide amongst themselves who will be the decision maker.[319]

Hopefully, the group will choose the person who is most familiar with and most likely to honor the patient's wishes and values. The nominated individual is then legally authorized to make decisions for the patient, and should make decisions based on the substituted judgment or best interest standard.[320]

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[314] W. VA. CODE § 16-30-8(b)(2016). The West Virginia Center for End-of-Life Care has developed a useful "Checklist for Surrogate Selection." WEST VIRGINIA CENTER FOR END-OF-LIFE CARE, CHECKLIST FOR SURROGATE SELECTION, http://wvendoflife.org/media/1024/surrogate-selection.pdf.

[315] COLO. REV. STAT. ANN. § 15-18.5-103(3) (West 2016); HAW. REV. STAT. ANN. § 327E-5(c)-(d) (West 2016). A 2006 roundtable meeting of the Elder Law Section of the Colorado Bar addressed that this statute needs to be amended to provide for an isolated individual with no close family or friends. ELDER LAW SECTION, COLO. BAR ASS'N, MEETING OF ELDER LAW SECTION OF THE CBA 7 (2006), http://www.mentoredforgood.net/repository/Inside_Bar/Elder/ELS%20Minutes%20January%202016.pdf.

[316] COLO. REV. STAT. ANN. § 15-18.5-103(3); HAW. REV. STAT. ANN. § 327E-5(b).

[317] COLO. REV. STAT. ANN.§ 15-18.5-103(1.5)(a); HAW. REV. STAT. ANN. § 327E-5(b).

[318] COLO. REV. STAT. ANN. § 15-18.5-103(4)(a); HAW. REV. STAT. ANN. § 327E-5(d).

[319] COLO. REV. STAT. ANN. § 15-18.5-103(4)(a); HAW. REV. STAT. ANN. § 327E-5(d).

[320] COLO. REV. STAT. ANN. § 15-18.5-103(4)(c)(V); HAW. REV. STAT. ANN. § 327E-5(g). The nominated Colorado surrogate, like default surrogates in several other states, may elect to withhold or withdraw artificial nourishment or hydration only under certain conditions. COLO. REV. STAT. ANN. § 15-18.5-103(6)(a). Two physicians—the attending and a second, independent physician—must certify that such care is only "prolonging the act of dying and is unlikely to result in the restoration of the patient to independent neurological functioning." *Id.* The statute requires that the healthcare facility provide the assistance of its medical ethics committee to any surrogate decision maker who is deciding to withhold or withdraw medical treatment. *Id.* § 15-18.5-103(6.5).

### *C. First Time Default Surrogate List*

While a number of states have recently amended already existing priority lists, more than a half dozen other states considered adding completely new default surrogate lists for the first time.[321] For example, seeking a mechanism for medical decision making that would "minimize extraneous delay," Massachusetts considered enacting a default surrogate list.[322] The proposed priority included: (1) guardian, (2) spouse, (3) adult child, (4) parent, (5) adult sibling, (6) adult grandchild, and (7) close friend.[323]

In 2014, New Hampshire enacted legislation that created a strict priority list of default surrogates.[324] The statute provides that if there is no reasonably available agent or guardian, a physician or an advanced practice registered nurse (APRN) may identify a surrogate.[325] The list includes: the patient's (1) spouse or civil union partner, unless there is a divorce proceeding, separation agreement, or restraining order limiting that person's relationship with the patient; (2) adult child; (3) parent; (4) adult sibling; (5) adult grandchild; (6) close friend; (7) agent with financial power of attorney; and (8) guardian of the estate.[326]

In 2014, New Jersey considered legislation that would have created a strict priority list of default surrogates.[327] "A health care facility shall designate one person from the following list, as applicable, from the class highest in priority when persons in prior classes are not reasonably available, willing, and competent to act, to serve as surrogate for an adult patient who is determined to lack decision-making capacity."[328] The list included the patient's: (1) spouse, partner in a civil union couple, or domestic partner, if not

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[321] AM. BAR ASS'N Comm'n on Law and Aging, *supra* note 84, at 3.

[322] S.B. 853, 2015 Leg., 189th Sess. (Mass. 2015).

[323] *Id.*

[324] H.B. 1434, 2014 Leg., 163d Reg. Sess. (N.H. 2014).

[325] *Id.*

[326] *Id.*

[327] S.B. 1233, 216th Leg., 2014 Sess. (N.J. 2014); Assemb. B. 1934, 216th Leg., 2014 Sess. (N.J. 2014).

[328] Assemb. B. 1934, 216th Leg., 2014 Sess. (N.J. 2014).

legally separated from the patient; (2) adult child; (3) parent; (4) adult sibling; and (5) close friend.[329]

In 2015, Vermont considered legislation that would have authorized "surrogates."[330] But unlike other states, these surrogates could make decisions only about DNR (do-not-resuscitate) orders or COLST (clinician orders for life sustaining treatment).[331] The bill defined "surrogate" to include the patient's: (1) spouse, (2) adult child, (3) adult sibling, (4) adult grandchild, and (5) clergy person.[332] It also included an "interested person" who has "exhibited special care and concern for the patient" and who is personally familiar with the patient's values.[333]

In 2017, Nebraska and Massachusetts considered default surrogate legislation. The Nebraska bill would have established a strict sequence: (1) spouse unless legally separated, (2) adult child, (3) parent, (4) adult brother or sister, and (5) "an adult who has exhibited special care and concern for the patient, who is familiar with the patient's personal values."[334] In contrast, the Massachusetts bill was more flexible, allowing the physician to "select a proposed surrogate who is ranked lower in priority if, in his or her judgment, that individual is best qualified."[335]

In 2017, both Oklahoma and Montana successfully enacted default surrogate legislation. The Oklahoma statute provides a strict sequence: (1) guardian, (2) healthcare proxy, (3) attorney-in-fact, (4) spouse, (5) adult children, (6) parents, (7) adult siblings, (8) other adult relatives of the patient in order of kinship, and (9) close friends.[336] But none of these individuals may act if they were "convicted of, pled guilty to, or pled no contest" to specified crimes,

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[329] *Id.*

[330] S.B. 62, 2015–16 Gen. Assemb., Reg. Sess. (Vt. 2015).

[331] *Id.*

[332] *Id.*

[333] *Id.*

[334] Legis. B. 104, 105th Leg., Reg. Sess. (Neb. 2017).

[335] S.B. 783, 190th Gen. Ct., 2017 Sess. (Mass. 2017).

[336] H.B. 1894, 56th Leg., Reg. Sess. (Okla. 2017) (to be codified at OKLA. STAT. tit. 63 § 3102.4 (effective Nov. 1,2017)).

or if they were "found to have committed abuse, verbal abuse or exploitation."[337]

In contrast, Montana adopted a more flexible approach like Colorado. The attending clinician shall make reasonable efforts to locate and notify as many interested persons as practicable. These are the patient's spouse, parents, adult children, siblings, grandchildren, and close friends. The clinician informs the "interested persons" of the patient's lack of decisional capacity and asks that they select a lay proxy decision-maker. Those interested persons—and others they invited—must make reasonable efforts to reach a consensus as to who among them will make medical treatment decisions on behalf of the patient.[338]

### *D. Limitations of Default Surrogate Laws*

Expanded or more flexible default surrogate laws offer protection to the unbefriended by expanding the categories of individuals who qualify as authorized healthcare decision makers. For example, even those patients who have no available family may still have a close friend.

But expanding default surrogate lists remains only a limited solution. Even close friend laws are of little value to patients who do not have any known or reasonably available close friends. Many times, such patients have had meaningful interactions only with healthcare providers. But providers are almost always prohibited from serving as surrogates, even if they would otherwise qualify as close friends.[339]

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[337] H.B. 1894, 56th Leg., Reg. Sess. (Okla. 2017) (to be codified at OKLA. STAT. tit. 63 § 3102.5 (effective Nov. 1,2017)).

[338] S.B. 92, 65th Leg., Reg. Sess., 2017 Mont. Laws Ch. 285.

[339] *E.g.*, N.M. STAT. ANN. § 24-7A-5(C) (West 2017); N.Y. PUB. HEALTH LAW § 2994-d(2) (McKinney 2017) ("An operator, administrator, or employee of a hospital or a mental hygiene facility from which the patient was transferred, or a physician who has privileges at the hospital or a health care provider under contract with the hospital may not serve as the surrogate for any adult who is a patient of such hospital, unless such individual is related to the patient by blood, marriage, domestic partnership, or adoption, or is a close friend of the patient whose friendship with the patient preceded the patient's admission to the facility.").

Perhaps the most vivid example of the limitations of default surrogate lists comes from Colorado.[340] That state already had a flexible default list.[341] But clinicians still confronted significant numbers of unbefriended patients. So, policymakers found it necessary to develop a special decision making mechanism for the unbefriended.[342]

## *VI. Guardianship Is Rarely a Good Solution*

Default surrogate laws are preventative.[343] They help assure that an individual who knows and cares about the patient will be a legally authorized decision maker.[344] But even longer or more flexible default surrogate lists cannot help everyone. For that subset of individuals there is one more standard solution: guardianship. Indeed, in most states, guardianship remains the only officially recognized mechanism by which treatment decisions can be made on behalf of the unbefriended.[345]

But guardianship is neither a preferred nor an adequate solution.[346] Commentators have overwhelmingly concluded that the disadvantages of guardianship significantly outweigh the advantages.[347] Consequently, guardianship is generally considered to be a last resort option, to be used only after all other less restrictive alternatives have been exhausted.[348] Even then, providers are often unable to obtain a guardian or at least obtain one soon enough to make the healthcare decisions at hand.[349]

In this Section, I first (a) summarize why guardianship is not seen as a good solution. I then look at four specific types of guardians: (b)

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[340] COLO. REV. STAT. ANN. § 15-18.5-104(3) (West 2017).

[341] *Id.*

[342] *See infra* Section VIII.

[343] *See supra* Section V.

[344] *See supra* Section V.

[345] *See* A. KIMBERLEY DAYTON ET AL., 3 ADVISING THE ELDERLY CLIENT § 34:10 (2016).

[346] *See infra* Section VI.A.

[347] AM. BAR ASS'N, PRACTICAL TOOL, *supra* note 33, at 6.

[348] *Id.*

[349] Robin J. Bandy et al., *Medical Decision-making During the Guardianship Process for Incapacitated, Hospitalized Adults: A Descriptive Cohort Study*, 25 J. GEN. INTERNAL MED. 1003, 1006 (2010).

private guardians, (c) volunteer guardians, (d) public guardians, and (e) temporary and emergency guardians.

### *A. Problems with Guardianship*

Guardianship is a legal relationship that is created by state courts when a judge determines that individuals are incapacitated and unable to make decisions on their own behalf.[350] The court creates a relationship in which the guardian is given legal authority to make decisions for an incapacitated individual—referred to as the *ward*—regarding that person or that person's property, or both.[351] Every state provides for guardianship.[352] Indeed, most states provide no other healthcare decision-making mechanism for the unbefriended.[353] So, especially for the unbefriended, "there might be no alternative to a guardianship if such an adult becomes incompetent without executing appropriate planning documents."[354]

On the surface, this might appear to be entirely appropriate and adequate.[355] The formal judicial process helps to assure neutrality, impartiality, and public accountability.[356] The procedural due process afforded by the courts helps to assure that all perspectives and alternatives are aggressively pursued, and it provides important protections against improper decision making.[357] While the courts may lack expertise in healthcare decision making, they can draw on the advice and recommendations of treating and independent clinicians.[358] Consequently, guardianship might appear to be a mechanism ideally suited to protecting vulnerable unbefriended

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[350] Utah Law Review, *Third National Guardianship Summit Standards and Recommendations*, 2012 UTAH L. REV. 1191, 1191 (2012).

[351] *Id.*

[352] Karp & Wood, *Incapacitated and Alone*, *supra* note 4, at 10.

[353] *Id.*

[354] DAYTON ET AL., *supra* note 345, at § 34:10.

[355] *See id.*

[356] *See id.*; THE RIGHT TO DIE, *supra* note 34, at § 3.26[A][2].

[357] THE RIGHT TO DIE, *supra* note 34, at § 3.26[A][2]; Lou-Anne M. Beauregard, *Ethics in Electrophysiology: Who Speaks for this Man*?, 35 PACING & ELECTROPHYSIOLOGY 564, 566 (2012).

[358] THE RIGHT TO DIE, *supra* note 34, at § 3.26[D].

patients.[359] Indeed, the American College of Physicians posits that a court-appointed guardian should be utilized in every case.[360]

Nevertheless, despite the widespread utilization of the guardianship procedure, commentators generally believe that the disadvantages of guardianship significantly outweigh the advantages.[361] The five main deficiencies are: (1) slow speed, (2) high cost, (3) limited competence, (4) low availability, and (5) restricted authority.

### *1. Too Slow.*

Perhaps the most frequently mentioned criticism of guardianship is the time

that it takes.[362] In terms of *speed*, court proceedings are problematic, because they are very time consuming, and, in these situations, time is of the essence.[363] Guardianship proceedings regularly take at least six to eight weeks,[364] and they frequently take much longer than that.[365]

Medical decisions must be made in the interim, because the patient will need diagnostic and therapeutic interventions.[366] A 2010 study noted the lack of data describing how decisions are made for patients while they are awaiting a court-appointed guardian.[367] The study

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[359] DAYTON, *supra* note 345, at § 34:10.

[360] Lois Snyder, *American College of Physicians Ethics Manual: Sixth Edition*, 156 ANNALS OF INTERNAL MED. 73, 78 (2012).

[361] See Moye et al., *supra* note 143; QUINN, *supra* note 21, at 112; Edward J. Larson & Thomas A. Eaton, *Limits of Advance Directives: A History and Assessment of the Patient Self Determination Act,* 32 WAKE FOREST L. REV. 249, 290 (1997).

[362] J.J. Chen et al., *Barriers Beyond Clinical Control Affecting Timely Hospital Discharge for a Patient Requiring Guardianship*, 56 PSYCHOSOMATICS 206, 206 (2015).

[363] THE RIGHT TO DIE, *supra* note 34, at § 3.26[C]. *Cf.* Jenny Kitzinger & Celia Kitzinger, *Causes and Consequences of Delays in Treatment Withdrawal from PVS Patients: A Case Study of* Cumbria NHS Clinical Commissioning Group v. Miss S and Ors *[2016] EWCOP 32*, J. MED. ETHICS (2016), DOI: 10.1136/medethics-2016-103853.

[364] THE RIGHT TO DIE, *supra* note 34, at § 3.26[C]; Rains v. Belshe, 38 Cal. Rptr. 2d 185, 189 (Cal. Ct. App. 1995) (seven-month delay in obtaining judicial decision authorizing treatment).

[365] Jean Callahan et al., *Guardianship Proceedings in New York State: Findings and Recommendations*, 37 BIFOCAL 83, 84 (2016); Deb Bennett-Woods, Jean Abbott & Jackie Glover, *Giving Voice to the Voiceless: The Colorado Response to Unrepresented Patients* (2017).

[366] Smith & Luck, *supra* note 11, at 167; S. Brown, "Medical Decision Making for the Unbefriended: Who Will Decide?"

[367] PAMELA B. TEASTER ET AL., PUBLIC GUARDIANSHIP: IN THE BEST INTEREST OF INCAPACITATED

revealed that, in many cases, a treatment decision was necessary prior to the appointment of a guardian.[368] Many commentators charge that it is "morally untenable and clinically unconscionable" for a patient to wait.[369]

To some degree, the waiting period problem can be mitigated. For example, to speed up the process, the Dartmouth-Hitchcock Medical Center in New Hampshire has coordinated its efforts with the court.[370] For example, hearings are now held by teleconference, and the social work staff prepares petitions in just the way that the court needs.[371] But courts in many jurisdictions will be unable to move faster.

### *2. Too Expensive*

Not only are guardianship procedures too slow but they are also too expensive. In terms of *cost,* guardianship proceedings require a significant investment.[372] A facility must pay medical experts to assess the patient's capacity, and must pay an attorney to prepare and argue the petition.[373] It must often pay for a guardian *ad litem*, another attorney or an independent evaluator, to represent the interests of the ward,[374] and the facility must pay filing fees and other court costs.[375] All these expenses will likely total $5,000 to $8,000.[376]

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PEOPLE? 4 (ABC-CLIO, 2010).

[368] *Id.* at 21.

[369] J.J. Chen et al., *supra* note 362, at 207.

[370] J.J. Chen et al., *A Clinical Pathway for Guardianship at Dartmouth-Hitchcock Medical Center,* 40 JOINT COMMISSION J. ON QUALITY & PATIENT SAFETY 389, 390 (2014).

[371] *Id.* at 390, 394.

[372] *See The 'Voluntary' Status of Nursing Facility Admissions*, *supra* note 22, at 10; Larry A. Frolik, *How to Avoid Guardianship*, 23 EXPERIENCE 26, 26 (2013); THE RIGHT TO DIE, *supra* note 34, at § 3.26[F].

[373] L.A. FROLIK & R.L KAPLAN, ELDER LAW IN A NUTSHELL 251 (5th ed., West, 2010).

[374] *Id.* at 251–52.

[375] *See id.*

[376] *See, e.g.*, Bernard A. Krooks, *How Much Does It Cost to Appoint a Guardian?*, LITTMAN KROOKS, LLP (June 2, 2015), http://www.specialneedsnewyork.com/2015/06/how-much-does-it-cost-to-get-a-guardian-appointed/. Recently proposed legislation would provide a tax credit for legal expenses paid with respect to establishing guardianship. H.R. 878, 112th Cong. ( 2011).

### *3. Too Unavailable*

Even if guardianship worked in terms of time and costs, there is often no guardian for the court to appoint. In terms of *availability,* an appointed guardian is typically and ideally a willing family member or friend.[377] Companies also provide professional guardianship services for families who can afford them.[378] However, neither of these options is viable for unbefriended individuals without family, friends, or resources. Courts are forced to find other alternatives, such volunteer guardians and public guardians;[379] unfortunately, even these resources are usually inadequate to meet the need.[380]

### *4. Too Incompetent*

Even if guardianship were more accessible in terms of time, cost, and availability, it is unclear what caliber of decision-making guardians can provide. In terms of *competence,* in most guardian situations, the guardian does not know the patient and is unable to make decisions based on the patient's morals and values.[381] Moreover, most states have no provision for guardian licensing, certification, or registration. Guardians are poorly trained, and, given very high caseloads, they are often unable to properly supervise their wards.[382] In short, it is unclear whether guardians can or do make

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[377] QUINN, *supra* note 21, at 73.

[378] *Id.* at 86–89; Ellen Waldman, *No Family? Resources Still Available for Aging Seniors,* ASHLAND DAILY TIDING (Feb 22, 2017, 2:00 AM), http://www.dailytidings.com/news/20170222/no-family-resources-still-available-for-aging-seniors

[379] QUINN, *supra* note 21, at 95, 99, 104.

[380] *Id.* at 104.

[381] N.Y. STATE TASK FORCE ON LIFE AND THE LAW, *supra* note 7, at 52–53.

[382] Jeff Kelly, Maggie Kowalski & Candice Novak, *Courts Strip Elders of their Independence*, BOSTON GLOBE (Jan. 13, 2008), http://archive.boston.com/news/local/articles/2008/01/13/courts_strip_elders_of_their_independence/. The Boston Globe published an article discussing the dire guardianship situation in Massachusetts, and noted that there are no prerequisite training requirements to become a guardian. *Id.* The article discusses how "guardianship businesses" open up, but the compensation is so low that, in order to survive, the businesses take on too many wards to adequately monitor all of them; the wards become neglected and ignored, some receiving only two visits a year from their guardian. *Id.* The article notes that courts are too overburdened to properly monitor the guardians and fail to demand the filing of required paperwork. *Id.* For instance, guardians in Massachusetts are required to file an inventory of property and an annual accounting. *Id.* But in one county, 262 of the 308 guardian cases in the probate court had no filing at all. *Id. See also* U.S. GAO, THE EXTENT OF ABUSE BY GUARDIANS IS UNKNOWN, BUT SOME MEASURES EXIST TO HELP PROTECT

better decisions for unbefriended patients than other potential surrogates, such as attending physicians and ethics committees.[383]

Encouragingly, efforts to improve the guardianship system are ongoing. For example, in the U.S. in 2011, at least 27 states passed new adult guardianship legislation.[384] The Third National Guardianship Summit, convened by 10 national organizations in October 2011, resulted in 43 standards for the performance of guardians and 21 recommendations for court and legislative action.[385] At the federal level, legislation like the Guardian Accountability and Senior Protection Act would provide funding for state courts to assess and improve handling of adult guardianship proceedings.[386]

But, even if enacted tomorrow, the impact of reform remains years away. The current guardianship situation is not generally perceived as effective for the unbefriended.[387] It is encumbered with "onerous formalities"[388] that are "untenable most of the time."[389] Consequently, guardianship is generally viewed as an option of last resort.[390]

### *5. Limited Authority*

Finally, assuming one were able to navigate the time, costs, availability, and competence obstacles, one more obstacle remains.

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OLDER ADULTS (2016).

[383] N.Y. STATE TASK FORCE ON LIFE AND THE LAW, *supra* note 7, at 53.

[384] *State Adult Guardianship Legislation: Directions of Reform – 2011,* AM. BAR ASS'N COMM'N ON LAW & AGING, http://www.americanbar.org/content/dam/aba/administrative/law_aging/2011/2011_aging_gship_reform_12.authcheckdam.pdf. (last visited Feb. 28, 2017).

[385] *Third National Guardianship Summit Standards and Recommendations*, *supra* note 350, at 1191; *Third National Guardianship Summit Standards and Recommendations,* AM. BAR ASS'N (Aug. 6–7, 2012), http://www.americanbar.org/content/dam/aba/publishing/rpte_ereport/2012/5_october/te_alert.authcheckdam.pdf.

[386] S.1744, 112th Cong. (2011).

[387] QUINN, *supra* note 21, at 104.

[388] Frank, *supra* note 127, at 75.

[389] Cynthia Griggins, *Patients without Proxies: What's Happening in Other States?* MID-ATLANTIC ETHICS COMM. NEWSL.,(Univ. of Md. Francis King Carey School of Law, Baltimore, Md.), Summer 2010, at 7.

[390] Lisa Nerenberg, *Unbefriended Elders Receive Court Protection in California*, 27(3) AGING TODAY 10 (2006); CAL. PROB. CODE § 4650 (2016) ("[A] court is normally not the proper forum in which to make healthcare decisions, including decisions regarding life-sustaining treatment."); QUINN, *supra* note 21, at 99.

Guardians often lack—or perceive that they lack—authority to make certain treatment decisions.[391] For example, in Georgia, an appellate court affirmed the dismissal of a hospital's petition for an "emergency guardian."[392] St. Joseph's/Candler Health System wanted an emergency guardian to authorize the discharge of its patient, Claudine Tapley Farr.[393] But the court denied the request, because there was no "emergency," no "immediate and substantial risk of death or serious physical injury, illness, or disease."[394] When courts apply similar rules, hospitals may be relegated to serving as de facto homeless shelters.

Although Georgia narrowed the role of guardians, other states expanded their role.[395] Minnesota and Michigan now permit guardians to make end-of-life decisions.[396] In 2014, the Minnesota Supreme Court confirmed that guardians have the authority to consent to the withholding or withdrawal of life-sustaining treatment, without court approval, when "all interested parties agree that removal is in the ward's best interest."[397] In 2013, Michigan enacted legislation that permits guardians to consent to a DNR order.[398]

### *B. Private Guardians*

Even if a treating facility engages in the cumbersome, lengthy guardianship process for an unbefriended patient, there is often yet another obstacle: a shortage of available guardians.[399] Most guardians are family or friends.[400] But these are obviously unavailable to the

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[391] Karna Sandler, *A Guardian's Health Care Decision-Making Authority: Statutory Restrictions,* 35(4) BIFOCAL 106 (Apr. 2014); J. Freeman, *End-of-Life Care Decisions—Challenges for Patients under Guardianship*, 104(1) IOWA MED. 14 (2014).

[392] *In re* Farr, 743 S.E.2d 615, 615 (Ga. App. 2013).

[393] *Id.*

[394] *Id.* at 616.

[395] *See* H.B. 4382, 97th Leg., Reg. Sess., (Mich. 2013); *In re* Tschumy, 853 N.W.2d 728, 747 (Minn. 2014).

[396] H.B. 4382, 97th Leg., Reg. Sess., (Mich. 2013); *In re Tschumy*, 853 N.W.2d at 747.

[397] *In re Tschumy*, 853 N.W.2d at 747.

[398] H.B. 4382, 97th Leg., Reg. Sess., (Mich. 2013).

[399] *See* GEORGIA APPLESEED, CARING FOR GEORGIA'S UNBEFRIENDED ELDERS: VIEWS FROM THE PROBATE BENCH ON THE 2010 AMENDMENTS TO THE SURGICAL AND MEDICAL CONSENT STATUTE 6 (Alston & Bird LLP, 2013).

[400] *Id.* at 5.

unbefriended. Professional guardians are willing to serve only if they will be compensated and compensation usually comes from the patient's estate.[401] But since the unbefriended are often indigent, professional guardians are usually unavailable.[402] Frequently, there is nobody else. In short, it is often difficult to find individuals willing to serve as guardians for the unbefriended.[403]

### *C. Volunteer Guardians*

In response to the challenges with obtaining private guardians, some states have developed volunteer programs. For example, in Akron, Ohio, under the leadership of Probate Judge Elinore Marsh Stormer, Jewish Family Service recruits, screens, and trains volunteer guardians to serve as surrogate decision makers.[404]

Similarly, the Colorado Guardianship Alliance (the Alliance) developed a program to recruit volunteers to serve as court appointed guardians for the unbefriended.[405] It screens all potential guardians and requires them to go through a training program, free of charge.[406] When a medical facility or nursing home has an incapacitated patient, it calls the Alliance, which provides a volunteer guardian, when possible.[407] The guardian may determine where the ward should live, make medical treatment decisions, and see that daily needs such food, clothing, and shelter are met.[408] The guardian provides annual reporting to the Alliance as well as to the court.[409]

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[401] Karp & Wood, *Incapacitated and Alone supra* note 4, at 9–10.

[402] *Id.* at 14.

[403] GEORGIA APPLESEED, *supra* note 399, at 6.

[404] Ed Meye, *Volunteer Guardian Program Set Up by Summit County Probate Court,* AKRON BEACON J. (June 18, 2014, 7:07 PM), http://www.ohio.com/news/local/volunteer-guardian-program-set-up-by-summit-county-probate-court-1.496799; *Volunteer Guardians,* JEWISH FAMILY SERVICE OF AKRON https://jfsakron.org/volunteer-guardians (last visited June 16, 2017).

[405] *Guardianship Alliance Programs and Services,* ABILITY CONNECTION COLO., http://www.abilityconnectioncolorado.org/guardianshipallianceofcolorado/volunteer-guardian-program/ (last visited Feb. 28, 2017). This program may be superseded by 2016 legislation in Colorado that provides an intramural mechanism for healthcare decision making on behalf of the unbefriended. *See infra* Section VIII.

[406] *Guardianship Alliance Programs and Services*, *supra* note 405.

[407] *Id.*

[408] *Id.*

[409] *Id.*

As in Akron and Colorado, citizens in Indiana forged a statewide initiative to create and fund volunteer guardianship programs.[410] The Indiana Adult Guardianship Services Project (IAGSP) was formed in 2008 and is heavily involved in this initiative.[411] Its stated purpose is to "build a framework of community-based adult guardianship services projects/programs across the state."[412] IAGSP sponsors research projects to further explore the ethics, standards, and regulations surrounding guardianships.[413] As of 2014, IAGSP was working to implement pilot guardianship programs in six counties across the state.[414] It convened a multidisciplinary task force to support development of these programs.[415]

Importantly, Indiana law provides that the court may appoint a volunteer advocate for a senior or incapacitated adult.[416] These guardians may consent to medical care or other treatment needs for an incapacitated adult.[417] As a result of the statewide initiative, Wishard Health Services began funding the Wishard Volunteer Advocates Program. There are dozens of trained volunteers who have served as court-appointed guardians of more than 300 unbefriended patients in Marion County, Indiana hospitals and nursing homes.[418]

The program has experienced significant success.[419] Program consultants report seeing fewer unbefriended patients re-admitted, and greater Medicaid reimbursement to hospitals, due to the

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[410] *Advance Directives Resource Center*, IND. STATE DEP'T OF HEALTH, http://www.in.gov/isdh/25880.htm (last visited Feb. 28, 2017).

[411] *Id.*

[412] *Id.*

[413] IND. ADULT GUARDIANSHIP SERVS. PROJECT, WHO'S OVERSEEING THE OVERSEERS? A REPORT ON THE STATE OF ADULT GUARDIANSHIP IN INDIANA 9 (2012), http://www.in.gov/judiciary/admin/files/ad-guard-2012-full-report.pdf.

[414] *Id.* at 12.

[415] *Id.* at 1. The task force consists of various organizations and state agencies, including the Indiana State Guardianship Association (ISGA). *Id.* at 4. The ISGA is a non-profit organization formed to strengthen guardianship and related services through networking, education, and tracking, and commenting on legislation. *Id.* at 10. The 2012 report appears to be the last one available.

[416] IND. CODE § 29-3-8.5-1 (2016).

[417] IND. CODE § 29-3-8.5-4(a)(1) (2016).

[418] *See id.*

[419] Robin Bandy et al., *Wishard Volunteer Advocates Program: An Intervention for At-risk, Incapacitated, Unbefriended Adults*, 62 J. AM. GERIATRICS SOC'Y 2171, 2172 (2014).

guardians who assist patients with the application process.[420] In short, the volunteer program trained enough volunteers to create an effective and quality mechanism. In 2011, the Center for At Risk Elders assumed the responsibilities of the Wishard program, now known as the CARE Volunteer Advocates Program.[421]

### *D. Public Guardians*

Recognizing that the general guardianship situation is poor, most U.S. states have implemented variations of traditional guardianships.[422] Notable among these variations are "public guardianship" programs.[423] These programs follow four different models.[424] Most public guardians are either publicly funded social service organizations or county government public officials.[425]

For instance, Mr. Yeager was an unbefriended individual in Colorado.[426] His physician concluded that attempting resuscitation would be futile.[427] The court affirmed the right of the Morgan County Department of Human Services to authorize a do-not-resuscitate (DNR) order and granted the Department unlimited authority to make medical decisions on behalf of Yeager.[428] A minority of states have taken a different approach, instead establishing public guardians as either officials of the court or as employees of an independent state office within the executive branch of government.[429]

Unfortunately, in whatever form they have been established, public guardianship services suffer from three serious problems. First, the programs are generally overburdened, understaffed, and

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[420] *Id.* at 2171.

[421] *What We Do*, *About Care*, CENTER FOR AT RISK ELDERS, http://indianacare.org/what-we-do (last visited June 16, 2017). Similar programs have been launched in Central Indiana. *See, e.g.*, No One Dies Alone (NODA), ESKENAZI HEALTH, http://www.eskenazihealth.edu/programs/noda.

[422] *See* TEASTER ET AL., *supra* note 367, at 16.

[423] *Id.*

[424] *Id.* at 17.

[425] PAMELA B. TEASTER ET AL., WARDS OF THE STATE: A NATIONAL STUDY OF PUBLIC GUARDIANSHIP 1 (2005).

[426] *See In re* Yeager, 93 P.3d 589, 591 (Colo. App. 2004).

[427] *Id.* at 592–93.

[428] *Id.* at 595.

[429] *See* TEASTER ET AL., *supra* note 367, at 23.

underfunded.[430] Consequently, most states have significant unmet needs for public guardianship.[431] At the same time, some jurisdictions give guardians ridiculously high numbers of clients, far above the recommended 1:20 ratio.[432] Second, education and training requirements vary considerably. Only 15 states have licensing, certification, or regulation systems.[433] Third, public guardians often have—or at least perceive that they have—limited authority regarding decisions surrounding life-sustaining treatment.[434] Sometimes, they decline to exercise their authority, because they assume that patients are 'safe" as long as they are in the hospital.

Some states have moved to develop new or better public guardianship programs. For example, in Oregon, individual counties have long been permitted to fund and establish their own public guardian programs.[435] But almost none of the counties could sustain their programs.[436] So, in 2009 the state convened a task force and renewed it in 2011.[437] The task force estimated that between 1,500 and 3,000 Oregon adults needed public guardianship services.[438] Following the task force's recommendations, in 2014, the legislature authorized the Oregon Office of the Long-Term Care Ombudsman, an independent state agency, to appoint a public guardian.[439] The first

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[430] *See* Karp & Wood, *Incapacitated and Alone*, *supra* note 4, at 28–29; PAMELA B. TEASTER, ERICA F. WOOD, WINSOR C. SCHMIDT, JR. & SUSAN A. LAWRENCE, PUBLIC GUARDIANSHIP AFTER 25 YEARS: IN THE BEST INTERESTS OF INCAPACITATED PEOPLE 94 (A.B.A. 2007), http://www.americanbar.org/content/dam/aba/administrative/law_aging/PublicGuardianshipAfter25YearsIntheBestInterestofIncapacitatedPeople.authcheckdam.pdf.

[431] TEASTER, WOOD, SCHMIDT & LAWRENCE, *supra* note 430, at 93.

[432] *Id.* at 101, 197.

[433] *Id.*

[434] *E.g.*, MINN. R. 9525.3055(2) (2017); *In re* Shirey, No. 98005210-DD (Mich. Prob. Ct., Montgomery Cty., 17 Oct. 2005).

[435] *See* Yuxing Zheng, *Oregon Public Guardian, Conservator Program Could be Created by Lawmakers*, THE OREGONIAN (Dec. 18, 2013), http://www.oregonlive.com/politics/index.ssf/2013/12/oregon_public_guardian_conserv.html.

[436] *See id.*

[437] ORE. JOINT INTERIM TASK FORCE ON PUB. GUARDIAN AND CONSERVATOR, JOINT INTERIM TASK FORCE ON PUBLIC GUARDIAN AND CONSERVATOR (HB 2237) REPORT 2 (Dec. 2011).

[438] S. Travis Wall, *Oregon's New Public Guardian Program*, LUND REPORT (Mar. 12, 2015), https://www.thelundreport.org/content/oregon%E2%80%99s-new-public-guardianship-program.

[439] S.B. 1553, 77th Leg. Assemb., Reg. Sess. (Ore. 2014) (codified at ORE. REV. STAT. §§ 125.675 to 125.730 (West 2017)).

public guardian was appointed in late 2014.[440] The program has begun to provide services but is still being developed.[441]

Nebraska also recognized that its "present system of obtaining a guardian . . . for an individual which often depends on volunteers is inadequate."[442] So, like Oregon, Nebraska established the public guardian as a decision maker of last resort.[443] In January 2015, the state started to develop processes, guidelines, and personnel policies to implement the law.[444] The Nebraska public guardian program is now in operation and has handled more than 100 cases.[445]

Most recently, Colorado has also been considering a public guardian program.[446] In 2013, a multi-disciplinary collaborative prepared a white paper that colorfully illustrates the problems of the unbefriended.[447] For example, the white paper reports how the unbefriended remain in acute care with disproportionately burdensome treatment.[448] But for the lack of an authorized decision maker, they could be moved to a more appropriate, less restrictive, and less costly setting.[449]

Among other examples, the Colorado Collaborative for Unrepresented Patients described a patient who had dry gangrene that

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[440] ORE. LEG. COMM. SERVS., GUARDIANSHIPS & OREGON PUBLIC GUARDIAN AND CONSERVATOR 3 (Sept. 2011).

[441] Wall, *supra* note 438; Oregon Long Term Care Ombudsperson, *Public Guardian*, OREGON.GOV, https://www.oregon.gov/LTCO/Pages/Oregon-Public-Guardian.aspx. Notably, the Oregon Public Guardian and Conservator Program (OPG) prioritizes cases into three levels of priorities. *Public Guardian*, *supra*. Healthcare decisions fall into the third category. *Id.* Because of the OPG's "limited capacity" to provide services, it is "only serving individuals who fall into the highest of these priorities." *Id.*

[442] L.B. 920, 103d Leg., 2d Reg. Sess. (Neb. 2014) (codified at NEB. REV. STAT. §§ 30-4101 to 4118 (West 2017)).

[443] *Id.*

[444] *Office of the Public Guardian*, NEB. JUDICIAL BRANCH, https://supremecourt.nebraska.gov/print/11541 (last visited Mar. 1, 2017).

[445] Michalle Chaffee, *Introduction to the Nebraska Office of Public Guardian,* NEB. LAW. 41, Nov.-Dec. 2015, at 41; NEBRASKA OFFICE OF PUBLIC GUARDIAN, 2016 REPORT, https://supremecourt.nebraska.gov/20885/2016-report-nebraska-office-public-guardian.

[446] *See generally*, COLO. COLLABORATIVE FOR UNREPRESENTED PATIENTS, ADDRESSING GAPS IN HEALTHCARE DECISION MAKING FOR UNREPRESENTED ADULTS: A PROPOSAL FOR THE INCLUSION OF A PUBLIC HEALTHCARE GUARDIAN IN THE OFFICE OF PUBLIC GUARDIANSHIP (2013), https://www.courts.state.co.us/Courts/Supreme_Court/Committees/Committee.cfm?Committee_ID=41

[447] *See generally*, *id.*

[448] *Id.* at 7.

[449] *See id.* at 7.

was not causing sepsis.[450] Since this was not an emergency, clinicians could not act on the basis of implied consent.[451] Since there was no authorized decision maker, clinicians had to wait until the condition deteriorated.[452] In 2014, the Chief Justice of the Colorado Supreme Court appointed a task force that recommended a pilot public guardianship program.[453] But unlike Oregon and Nebraska, no bills have been introduced.

### *E. Temporary and Emergency Guardians*

Yet another variation on traditional guardianship is to allow for temporary and emergency guardianships.[454] Such petitions are filed with the court when there is no time to conduct normal "plenary" or full guardianship hearings, which may take several weeks or months.[455] These procedures are neither as cumbersome nor as expensive as full guardianship.[456]

Temporary and emergency guardians are authorized to make one or a series of decisions, but do not have unlimited or ongoing decision-making powers.[457] They are appointed to make the immediate treatment decisions only and then their authorization ends.[458] For instance, Indiana provides for emergency guardian appointments when an adult needs immediate attention and there is no known person who can consent to treatment.[459] A temporary

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[450] *Id.* at 8.

[451] *Id.* at 8.

[452] COLO. COLLABORATIVE FOR UNREPRESENTED PATIENTS, *supra* note 446, at 8.

[453] COLO. PUB. GUARDIANSHIP ADVISORY COMM., THE PUBLIC GUARDIANSHIP ADVISORY COMMITTEE'S REPORT TO THE CHIEF JUSTICE OF THE COLORADO SUPREME COURT 7 (2014), https://www.courts.state.co.us/userfiles/file/Court_Probation/Supreme_Court/Committees/Public_Guardian/2014_OfficeofPublicGuardianship-FinalReport%282%29.pdf.

[454] Related to these are "single court transactions," where the judge directly makes the treatment decision. See QUINN, *supra* note 21, at 112; VA. CODE ANN. § 37.2-1101 (West 2016), *amended by* S.B. 371, 2012 Gen. Assemb., Reg. Sess. (Va. 2012).

[455] *E.g.*, CAL. PROB. CODE § 3208 (West 2016); FLA. PROB. RULE 5.900 (2017); O.C.G.A. § 31-36A-7 (2016) (placement only); IND. CODE § 16-36-1-8 (2016); N.J. CT. RULE 4:86-12 (2016) (special medical guardian); S.D. CODIFIED LAWS. § 34-12C-4 (2016); VA CODE ANN. § 37.2-1101(B) (West 2016), *amended by* S.B. 371, 2012 Gen. Assemb., Reg. Sess. (Va. 2012).

[456] *See* Karp & Wood, *Incapacitated and Alone*, *supra* note 4, at 29.

[457] *Id.*

[458] *Id.*

[459] IND. CODE § 29-3-3-4 (2017).

guardian is appointed for a maximum of 90 days, or until a permanent guardian is appointed.[460]

In 2010, Georgia gave hospitals and other healthcare facilities the right to petition the court for expedited appointment of a temporary guardian to make medical decisions.[461] The statute provides: "In the absence, after reasonable inquiry, of any [other surrogate] to consent for the patient, a hospital or other healthcare facility or any interested person may initiate proceedings for expedited judicial intervention to appoint a temporary medical consent guardian."[462] But the law restricts the guardian from withdrawing life-sustaining procedures unless specifically authorized by the court.[463]

### *VIII. Mechanisms Lacking Adequate Due Process*

If we cannot prevent the individual from becoming unbefriended through better capacity assessment, advance care planning, or expanded default surrogate lists, and if guardianship is not a reasonable option; then we need some mechanism by which to authorize treatment decisions.[464]

Fortunately, the laboratories of the states are busy experimenting with solutions.[465] Nevertheless, the dominant approach is the "solo" physician model in which the attending physician alone makes the

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[460] *Id.*

[461] O.C.G.A. § 31-9-2(a.1) (2017).

[462] *Id.* Sample petition forms for the appointment of a temporary medical consent guardian are available at http://www.gaprobate.org/forms/forms10/pdf/11GPCSF% 2036.pdf. The implementation of this act is being studied. *Safeguarding Seniors: Informed End of Life Decision Making*, SEEDS OF JUSTICE (Ga. Appleseed Ctr. for Law & Justice, Atlanta, Ga.), 2012, https://gaappleseed.org/media/docs/newsletter_2011-12.pdf.

[463] O.C.G.A. § 29-4-18(i) (2017).

[464] This briefing does not address some related issues. First, it does not address decision-making mechanisms for special and extraordinary medical situations such as sterilization and the administration of psychotropic medication. Additional protections are usually required in such situations. *See* FLA. STAT. ANN. § 765.113 (West 2016). Second, this briefing does not address the situation in which the incapacitated unbefriended patient "objects" to treatment. Third, while this briefing focuses on healthcare decision making, such decisions are often intertwined with those concerning finances. For example, it might be necessary to authorize someone to sell a patient's property so that she or he can qualify for Medicaid and long-term care placement. Fourth, this briefing does not address the participation of the unbefriended in biomedical research.

[465] Godfrey, *supra* note 286, at 58 ("Fourteen states have developed nine different statutory models.").

healthcare decision herself.[466] But that approach affords little oversight and protection. Consequently, many commentators argue that more is needed. But "how much" of a second opinion is required?[467] In this Section, I describe models which afford too little procedural due process: (a) solo physician unilateral authority, (b) second physician confirmation, (c) California interdisciplinary teams, and (d) California prison healthcare.

### *A. Solo Physician Unilateral Authority*

There is significant disagreement about how to handle healthcare decision making for the unbefriended. But the dominant approach is for the attending physician to make the healthcare decision herself.[468]

Sometimes, this approach is explicitly authorized by state law.[469] For example, in South Carolina, healthcare services may be provided without the consent of the patient or surrogate if, "in the reasonable judgment of the attending physician or other healthcare professional, the healthcare is necessary for the relief of suffering or restoration of

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[466] Thaddeus M. Pope, *Legal Briefing: Adult Orphans and the Unbefriended: Making Medical Decisions for Unrepresented Patients without Surrogates*, 26(2) J. CLINICAL ETHICS 180, 182 (2015) [hereinafter Pope, *Adult Orphans and the Unbefriended*].

[467] I owe this phrasing to Paul McLean, vice president of the nonprofit Community Voices in Medical Ethics and blogger and social network coordinator for the affiliate Community Ethics Committee. I have recently outlined basic notions of procedural due process. Thaddeus M. Pope, *Procedural Due Process and Intramural Hospital Dispute Resolution Mechanisms: The Texas Advance Directives Act*, 10 ST. LOUIS U. J. HEALTH L. & POL'Y 93 (2017) [hereinafter Pope, *Procedural Due Process*]. Theories of procedural fairness can also be found outside constitutional law. *See, e.g.*, NORMAN DANIELS & JAMES E. SABIN, SETTING LIMITS FAIRLY: CAN WE LEARN TO SHARE MEDICAL RESOURCES? (2002); Jocelyn Downie et al., *Next Up: A Proposal for Values-Based Law Reform on Unilateral Withholding and Withdrawal of Potentially Life-Sustaining Treatment*, 54(3) ALBERTA L. REV. 803 (2017).

[468] *See* Pope, *Adult Orphans and the Unbefriended*, *supra* note 466, at 182. On the other hand, only 11 percent of respondents in a recent survey conducted by the ABA Commission on Law and Aging, the Society for Hospital Medicine, and the Society for Critical Care Medicine reported that they would "make a decision yourself, abiding by professional ethics and standards." David Godfrey, *Older Adults and Healthcare Decision Making in Clinical Settings*, JUSTICE IN AGING ISSUE BRIEF (Mar. 2017), at 2–3, http://www.justiceinaging.org/wp-content/uploads/2017/03/Older-Adults-and-Health-Care-Decision-Making-in-Clinical-Settings-Issue-Brief.pdf. Nearly 50% would consult a second physician, risk management, or an ethics committee. *Id.* Around 40% would seek a guardian. *Id.*

[469] *See* CONN. GEN. STAT. § 19a-571(a) (2016). Sometimes physicians are given far narrower roles with respect to the unbefriended. *See* UTAH ADMIN. CODE § R432-31-11(3) (2017). For example, in Utah, physicians may "complete and sign new Life with Dignity Orders for individuals with prior forms who no longer have capacity to complete new orders, and who do not have a surrogate/guardian to authorize the new order." *Id.*

bodily function or to preserve the life, health, or bodily integrity of the patient."[470] The healthcare provider is not liable for providing, in good faith, healthcare without consent unless the provision of care is negligent.[471] A 2011 Missouri bill was virtually identical.[472]

With respect to life-sustaining treatment, North Carolina provides: "If none of the [surrogates] is reasonably available then at the discretion of the attending physician the life-prolonging measures may be withheld or discontinued upon the direction and under the supervision of the attending physician."[473] Oregon's law is virtually identical.[474] Connecticut law oddly provides that the physician need only "consider" the patient's wishes and need only "consult" the surrogate.[475]

While only a handful of states authorize clinicians to treat without consent, some commentators have suggested including healthcare providers on the statutory priority list of authorized surrogates.[476] After all, even when there is no available family member or close friend, there is almost always an available physician. Indeed, there is evidence that some patients prefer physicians over guardians as surrogate decision makers.[477] In short, there is some legal authorization and even broader clinical practice of physicians making healthcare decisions for their unbefriended patients.

Nevertheless, many are uncomfortable with this status quo. Some have charged it with "unacceptable ethical arbitrariness."[478] The Institute of Medicine warns that "having a single health professional

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[470] S.C. CODE ANN. § 44-66-50 (2016).

[471] S.C. CODE ANN. § 44-66-70(D) (2016).

[472] Adult Health Care Consent Act, H.B. 392, 96th Gen. Assemb., 1st Reg. Sess. (Mo. 2011).

[473] N.C. GEN. STAT. § 90-322(b) (2016).

[474] OR. REV. STAT. § 127.635(3) (2016).

[475] CONN. GEN. STAT. § 19a-571(a) (2016).

[476] Etienne Phipps & Richard Allman, *Potential Impact of Advance Directive Law Act 169 on Decisions and Care for Patients at End of Life: Reflections of Ethics Consultants* 20 POPULATION HEALTH MATTERS NO. 2, 2–3 (2007), http://jdc.jefferson.edu/hpn/vol20/iss2/8/.

[477] Norris et al., *supra* note 165, at 2184. Many states specifically prohibit healthcare providers or employees of a facility to which a patient has been admitted from serving as a patient's surrogate unless they are related to the patient or are a close friend whose friendship preceded the patient's admission. *See* DEL. CODE ANN. tit. 16, § 2503(h) (2016).

[478] *See* Ozar, *supra* note 9. Ozar also argues that having a physician as surrogate is problematic because of the regular rotation of hospitalists, physicians who specialize in hospital-based medicine. *Id.* The patient needs a "longtitudinal partner." *Id.*

make unilateral decisions for an unbefriended patient is ethically unsatisfactory in terms of protecting patient autonomy and establishing transparency."[479]

Notably, 38 states and the District of Colombia expressly prohibit a patient's providers from serving as their own patient's surrogate or court appointed guardian.[480] Commentators have increasingly challenged the basis for this widespread prohibition.[481] But its persistence is a powerful statement that public policy disfavors clinicians serving as surrogates for their patients even with their consent.

There are three main concerns. First, there are long-standing and well-grounded concerns that giving physicians unilateral authority to make treatment decisions is risky due to conflicts of interest.[482] When the treating physician is the decision maker, she suffers from a conflict of interest, given both her own and her facility's financial incentives. For example, The Greater New York Hospital Association lost $13 million in nine months awaiting appointment of guardians for 400 undischarged patients.[483] Similar studies across the field show that hospitals have a strong financial incentive to have an

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[479] DYING IN AMERICA, *supra* note 23, at 146.

[480] AM. BAR ASS'N COMM'N ON LAW AND AGING, DEFAULT SURROGATE CONSENT STATUTES (2016), http://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_default_surrogate_consent_statutes.authcheckdam.pdf (identifying AL, AK, CA, CT, DE, DC, GA, HI, ID, IL, IA, KS, KY, ME, MD, MA, MN, MS, NE, NV, NH, NJ, NY, NC, ND, OH, OR, PA, RI, SC, TX, VT, WA, WV, WI and WY). *See, e.g.*, N.D. CENT. CODE §§ 23-06.5-04, 30.1-28-11 (2012).

[481] *See, e.g.*, Philip M. Rosoff & Kelly M. Leong, *An Ethical and Legal Framework for Physicians as Surrogate Decision-Makers for Their Patients,* 43(4) J. L. MED. & ETHICS 857 (2015).

[482] *See* Larson & Eaton, *supra* note 361, at 290; *Who Decides?, supra* note 131, at 38.

[483] Winsor C. Schmidt, *Public Guardianship Issues for New York: Insights from Research*, 6(3) ELDER L. ATTY. 31 (Fall 1996); Winsor C. Schmidt, Endowed Chair and Distinguished Scholar in Urban Health Policy, Uni. of Louisville Sch. of Medicine, Presentation at Third National Guardianship Summit, slide 63 (Oct. 12, 2011). *See also* Winsor C. Schmidt, *Development and Trends in the Status of Public Guardianship: Highlights of the 2007 National Public Guardianship Study,* 33(5) MENTAL & PHYSICAL DISABILITY L. REP. 728 (Sept.-Oct. 2009) (reporting that Florida saved $3.9 million in health care costs in one year with appropriate public guardian services for 2,208 individuals); PAMELA B. TEASTER & KAREN A. ROBERTO, VIRGINIA PUBLIC GUARDIAN AND CONSERVATOR PROGRAMS: A PROFILE OF PROGRAMS, REPORT TO THE VIRGINIA DEPARTMENT FOR THE AGING (2003) (finding that Virginia saved $5.6 million in health care costs with public guardian services for 85 patients); VERA INSTITUTE OF JUSTICE, GUARDIANSHIP PRACTICE: A SIX-YEAR PERSPECTIVE 7 (Dec. 2011) (reporting their New York City guardianship project saved Medicaid $2.5 million for 111 clients).

expeditious mechanism to make healthcare decisions for unbefriended patients.[484]

Second, when the treating physician is the decision maker, the decision may be too influenced by the physician's *own* personal values and biases.[485] Non-clinician surrogates regularly make decisions guided by their own values, rather than the patient's values.[486] The evidence of such physician biases is too voluminous even to digest here. Examples include the impact of the physician's race on treatment[487] and the incentive to make decisions that comport with the interests of hospital management.[488] The risk is especially high, because the unbefriended—physically disabled, homeless, racial minorities—are often the targets of negative assumptions.[489]

Third, this "solo" decision making may result in less carefully considered treatment plans. When physicians need not reduce the result of their thought processes and justify their treatment recommendation, they may not think through the plan as carefully.[490] Clinicians "will give more careful consideration . . . if they are

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[484] Schmidt, *supra* note 2, at 95–96 (collecting studies); *see also* Parekh & Adorno, *supra* note 153, at 14; MASSACHUSETTS GUARDIANSHIP POLICY INSTITUTE, 2017 REPORT 1 (2017), http://guardianship.institute/pdf/2017+Report+With+Meetings.pdf (finding public guardianship could save $10 million); Courtwright et al., *supra* note 143 ("Compared to the general inpatient population, a greater percentage of unrepresented patients were underinsured (15.6 per cent versus 64 per cent)"); Nina Bernstein, *To Collect Debts, Nursing Homes Are Seizing Control Over Patients,* N.Y. TIMES (Jan. 25, 2015), https://www.nytimes.com/2015/01/26/nyregion/to-collect-debts-nursing-home-seizing-control-over-patients.html?_r=0 (reporting that nursing homes seek guardianship when the healthcare agent fails to pay).

[485] *See* Pope, *Adult Orphans and the Unbefriended*, *supra* note 466, at 182.

[486] *Cf.* Phillip M. Rosoff, *Licensing Surrogate Decision-Makers*, 29(2) HEC FORUM 145 (2017).

[487] S.C. Modi et al., *Influence of Patient and Physician Characteristics on Percutaneous Endoscopic Gastrostomy Tube Decision-making*, 10(2) J. PALLIATIVE MED. 359 (2007).

[488] David L. Williamson et al., *Incapacitated and Surrogateless Patients: Decision Making for the Surrogateless Patient: An Attempt to Improve Decision Making*, 16(2) AM. J. BIOETHICS 83 (2016); Morten Magelssen et al., *Sources of Bias in Clinical Ethics Case Deliberation*, 40(10) J. MED. ETHICS 678 (2014); Thaddeus M. Pope, *Multi-Institutional Healthcare Ethics Committees: The Procedurally Fair Internal Dispute Resolution Mechanism*, 31 CAMPBELL L. REV. 257, 274-99 (2009).

[489] Bennett-Woods, Abbott, & Glover, supra note 365; Ruqaiijah Yearby, *Breaking the Cycle of 'Unequal Treatment' with Health Care Reform: Acknowledging and Addressing the Continuation of Racial Bias*, 44(4) CONN. L. REV. 1281 (2012).

[490] *See* Pope, *Procedural Due Process*, *supra* note 467, at 140-42 (arguing that decisions are better when the decision maker must state not only the end result but also the process by which they reached it); Volpe & Steinman, *supra* note 11.

required to state not only the end result of their inquiry but the process by which they reached it."[491]

### *B. Second Physician Confirmation*

While the solo physician approach is the most common in practice, it is only explicitly authorized in fewer than five states.[492] Another approximately ten states authorize attending physicians to make treatment decisions on behalf of the unbefriended only with some confirmation or "double-check" on their clinical decision making.[493]

This additional review is widely perceived as an important safeguard.[494] The Ethics Committee of the American Geriatrics Society maintains that the patient's team of treating providers should make a decision.[495] Second physician confirmation normally takes one of three forms: (1) concurrence of a second physician, (2) concurrence of an institutional committee, or (3) concurrence of an external committee. The first model is described here, and the second two are described in following sections.

For example, in Tennessee, if no family or close friend is reasonably available, the treating physician is then authorized to make medical decisions, but only after obtaining concurrence from a second independent physician.[496] Texas law similarly provides: "if none of the [surrogates] is available, then treatment decisions 'must be concurred in by another physician who is not involved in the

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[491] United States v. Merz, 376 U.S. 192, 199 (1964); *cf.* FRANK M. COFFIN, THE WAYS OF A JUDGE: REFLECTIONS FROM THE FEDERAL APPELLATE BENCH 57 (Houghton Mifflin Company Boston 1980).

[492] See e.g., Bonnie Booth, *Doctor's Request to End Patient's Care Denied*, AM. MED. NEWS (June 12, 2006); John Agar, *Judge Rules Lawton Woman's Life Must Be Preserved*, KALAMAZOO GAZETTE, 25 April 2006. Several years ago, in Michigan, a physician was treating 97-year-old Hazel Wagner, a heart attack victim with no chance of recovery. Agar, *supra*. The patient was screaming to the physician, "Help me Jesus!" *Id.* The physician petitioned the court to end life support efforts, but the court denied the petition. *Id.* The court ruled that the petition would have to come from the patient's guardian and that a physician's role was not to advocate, but simply to advise. *Id.*

[493] THE RIGHT TO DIE, *supra* note 34, at § 3.25[A][3][a].

[494] Miller, Coleman & Cugliari, *supra* note 38, at 371; Farrell et al., *supra* note 3.

[495] Ethics Committee of the Am. Geriatrics Soc'y, *Making Treatment Decisions for Incapacitated Older Adults without Advance Directives*, 44(8) J. AM. GERIATRICS SOC'Y 986, 986 (1996).

[496] TENN. CODE ANN. § 68-11-1806(c)(5) (2016) (alternatively allowing confirmation from an ethics committee).

treatment of the patient or who is a member of an ethics or medical committee of the healthcare facility.'"[497]

Likewise, in North Carolina, "the patient's attending physician, in the attending physician's discretion, may provide healthcare treatment without the consent of the patient or other person authorized to consent for the patient if there is confirmation by a physician other than the patient's attending physician of the patient's condition and the necessity for treatment."[498] Arizona similarly provides: "If the health care provider cannot locate any of the [surrogates], the patient's attending physician may make health care treatment decisions for the patient after the physician consults with . . . a second physician who concurs with the physician's decision."[499]

In 2014, Louisiana proposed making the attending physician the surrogate of last resort.[500] The bill provided that if no other decision maker is reasonably available, then the patient's attending physician "shall have the discretion to provide or perform any surgical or medical treatment or procedures . . . and may also make decisions regarding continued services needed by the patient, including but not limited to approving the placement or transfer of the patient to another facility."[501] But the bill would have required that "prior to taking such action, the attending physician shall obtain confirmation from another physician of the patient's condition and the medical necessity for such action."[502]

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[497] TEX. HEALTH & SAFETY CODE ANN. §§ 166.039(e),166.088(f) ("If there is not a qualified relative available . . . an out-of-hospital DNR order must be concurred in by another physician who is not involved in the treatment of the patient or who is a representative of the ethics or medical committee of the health care facility in which the person is a patient.").

[498] N.C. GEN. STAT. ANN § 90-21.13(c1) (2016).

[499] ARIZ. REV. STAT. § 36-3231(B) (2016). The statute prefers that the attending physician consult with and obtain the recommendations of an institutional ethics committee. *Id.* But if this is not possible, then concurrence of second physician is sufficient. *Id.*

[500] S. Res. 302, 2014 Leg., Reg. Sess. (La. 2014) (proposed section § 40:1299.53 (D)).

[501] *Id.* Similarly, Article 7 of Taiwan's new Hospice and Palliative Care Law authorizes the palliative care team to act as sole decision makers on behalf of an incompetent, terminally ill patient's best interests if no family member is available. Yi-Chen Su, *When Ethical Reform Became Law: The Constitutional Concerns Raised by Recent Legislation in Taiwan*, 40(7) J. MED. ETHICS 484, 484 (2014).

[502] S. Res. 302, 2014 Leg., Reg. Sess. (La. 2014) (proposed section § 40:1299.53 (D)).

Since 1993, Oregon has had a mechanism for making life-sustaining treatment decisions for the unbefriended.[503] But it has had no mechanism for making decisions regarding major medical treatment.[504] So, in 2011, Oregon enacted a new law permitting a hospital "to appoint a health care provider . . . who has received training in health care ethics."[505] If the appointed provider is the patient's attending physician, then that individual must obtain a second opinion from another healthcare provider.[506]

In Mississippi:

> [C]onsent may be given by an owner, operator or employee of a residential long-term health-care institution at which the patient is a resident if there is no advance health-care directive to the contrary and a licensed physician who is not an owner, operator or employee of the residential long-term health-care institution at which the patient is a resident has determined that the patient is in need of health care."[507]

But this power to consent is limited to those healthcare services determined necessary by the physician.[508] And it does not include the power to consent to "withholding or discontinuing any life support, nutrition, hydration or other treatment, care or support."[509]

In West Virginia, the surrogate of last resort can include "any other person or entity, including, but not limited to, public agencies, public guardians, public officials, public and private corporations and other persons or entities which the Department of Health and Human

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[503] OR. REV. STAT. ANN. § 127.635(3) (West 2016) ("If none of the persons described in subsection (2) of this section is available, then life-sustaining procedures may be withheld or withdrawn upon the direction and under the supervision of the attending physician.").

[504] Jeffrey M. Cheyne, *Legislative Update for Estate Planners*, OR. ST. B. ELDER L. NEWSL. (Or. State Bar, Tigard, Or.), Oct. 2011, at 5.

[505] S.B. 579 § 2(a), 76th Leg., Reg. Sess. (Or. 2011). I thank Barbara Glidwell, the longtime patient advocate at Oregon Health Sciences University, for her generous telephone interview (Sept. 27, 2011).

[506] S.B. 579 § 2(a), 76th Leg., Reg. Sess. (Or. 2011).

[507] MISS. CODE ANN. § 41-41-215(9) (2017).

[508] *Id.*

[509] *Id.*

Resources [DHHR] may from time to time designate."[510] In a 2003 regulation, the DHHR designated three categories of individuals and entities as eligible surrogates for patients in DHHR facilities: (1) any organization authorized under state or federal laws, or under contract with the DHHR, to advocate for individuals in DHHR facilities; (2) any organization authorized under federal or state laws, or under contract with DHHR, to provide surrogacy, guardianship, or conservator services for persons in DHHR facilities; and (3) any DHHR employee not otherwise precluded from serving as a surrogate.[511]

### *C. California Interdisciplinary Teams*

A second physician confirmation entails more robust vetting than a solo physician approach. Similarly, slightly more robust than second physician confirmation is a special decision-making mechanism for the unbefriended in California long-term care facilities. A 1992 statute authorizes these facilities to establish interdisciplinary teams (IDTs), sometimes known as Epple committees,[512] to make decisions for unbefriended residents.[513]

An IDT must include at least two to four members: "the resident's attending physician, a registered professional nurse with responsibility for the resident, other appropriate staff in disciplines as determined by the resident's needs, and, where practicable, a patient representative, in accordance with applicable federal and state requirements."[514]

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[510] W. VA. CODE ANN. § 16-30-8(a)(7) (West 2016).

[511] W. VA. CODE. R. § 64-86-4 (2016).

[512] IDTs are sometimes known as "Epple Committees" because they are named after the California State Assemblyman, Bob Epple, who sponsored the legislation that created them. *See* H.D., 3209, 1991–92 Leg., Reg. Sess. (Cal. 1992).

[513] Robert M. Gibson, *Decision-Making in Long Term Care: A Poster Presented at the 40th CALTCM Annual Meeting*, CALIFORNIA ASSOCIATION OF LONG-TERM CARE MEDICINE (Dec. 2011), http://www.caltcm.org/index.php?option=com_content&view=article&id=232:decision-making-in-long-term-care—a-poster-presented-at-the-40th-caltcm-annual-meeting&catid=22:news&Itemid=111.

[514] CAL. HEALTH & SAFETY CODE § 1418.8(e) (2016). Rains v. Belshe, 38 Cal. Rptr. 2d 185, 187 (Cal. Ct. App. 1995).

IDTs are widely recognized as "the best solution to a troubling problem."[515] Indeed, looking to this IDT model, California considered a "surrogate committee" for other, non-long-term-care patients.[516] But none was enacted as part of the 1999 Health Care Decisions Act.[517] So, the IDT model is not officially available for California hospitals.

Despite two decades of apparently successful use, in 2013, California Advocates for Nursing Home Reform (CANHR) filed a lawsuit in Alameda County Superior Court challenging the constitutionality of the IDT statute.[518] Finally, nearly two years later, in February 2015, Judge Evelio Grillo issued a tentative ruling in two parts. First, he rejected CANHR's several claims that the IDT statute was "facially" unconstitutional, because a California appellate court had already upheld its constitutionality 20 years ago.[519] Second, Judge Grillo asked the parties to address CANHR's "as applied" challenges.[520]

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[515] Robert M. Gibson & James G. Boyd, *Medical Decision-Making in California Long-Term Care Facilities: Health and Safety Code section 1418.8, a Mandated Alternative to Conservatorship*, 19(1) CAL. TRUSTS & ESTATES Q. 5, 10 (2013), http://www.pltcweb.org/uploads/documents/Gibson_&_Boyd,_2013.pdf.; Robert M. Gibson, *How Do We Address the Unbefriended Patient's Needs?*, CALIFORNIA ASSOCIATION OF LONG TERM CARE MEDICINE, http://www.caltcm.org/index.php?option=com_content&view=article&id=194:how-do-we-address-the-unbefriended-patient-s-needs-&catid=22:news&Itemid=111 (last visited June 16, 2017); Robert M. Gibson & Rebecca Ferrini, *More Challenges to California's IDT Decision-Making Statute*, CALIFORNIA ASSOCIATION OF LONG TERM CARE MEDICINE, http://www.caltcm.org/index.php?option= com_content&view=article&id=189: more-challenges-to-california-s-idt-decision-making-statute&catid=22:news&Itemid=111 (last visited June 16, 2017).

[516] CAL. L. REV. COMM'N, MEMO 99-39, 1 (Oct. 6, 1999), http://www.clrc.ca.gov/pub/1999/M99-39.pdf.

[517] The original bill, A.B. 891 (1999) (Alquist), proposed new Probate Code sections 4720 to 4725, which would have addressed decision making for the unbefriended. Indeed, the problem of the unbefriended was an original and key motivation for the entire Health Care Decisions Act. But, these provisions were politically controversial. They were removed so that the rest of the bill could move forward. CAL. L. REV. COMM'N., MEMO 99-39, 1 (Oct. 6, 1999), http://www.clrc.ca.gov/pub/1999/M99-39.pdf; CAL. L. REV. COMM'N., 2000 HEALTH CARE DECISIONS LAW AND REVISED POWER OF ATTORNEY LAW 31 (2000), http://www.clrc.ca.gov/pub/Printed-Reports/Pub208.pdf.

[518] Complaint for Declaratory and Injunctive Relief, California Advocates for Nursing Home Reform v. Chapman, No. CGC-13-528046 (Cal. Super. Ct., Jan. 10, 2013). Disability Rights California reported on a similar case: Pamila Lew & Leslie Morrison, *The Deadly Failure of a Hospital to Follow a Patient's Decisions about his Medical Care*, 7026.01 DISABILITY RTS. CAL. 1, 8 (2013), http://www.disabilityrightsca.org/pubs/702601.pdf.

[519] Rains v. Belshe, 38 Cal. Rptr. 2d 185, 189 (Cal. Ct. App. 1995).

[520] Order Grating Petition for Writ of Mandate in Part and Denying in Part, California Advocates for Nursing Home Reform v. Chapman, No. RG13700100 (Alameda Cty. Super. Court, Cal. 22 Oct. 2013).

CANHR made three "as applied" challenges to the IDT statute. First, CANHR argued that the IDT statute is unconstitutional because there is no absolute requirement that a "patient representative" be present.[521] CANHR alleged that many long-term care facilities regularly fail to include a patient representative.[522] Second, CANHR contended that IDTs lack authority to prescribe anti-psychotics.[523] Third, CANHR contended that IDTs lack authority to make end-of-life decisions, for example, complete a POLST or refer to hospice.[524]

In his tentative ruling, Judge Grillo suggested that since the IDT statute specifically requires that there be a patient representative "where practicable," CANHR might prevail, if it can demonstrate that long-term care facilities regularly and customarily fail to include patient representatives."[525] Indeed, the leading case on the IDT statute held:

> While there may be exigent circumstances in which the participation of such a representative is not practicable, due to temporary unavailability, illness, or similar causes, the Legislature clearly required the routine and ongoing participation of a patient representative in such medical care decisions to ensure that nothing is over-looked from the patient's perspective.[526]

On the other hand, it is unclear who counts as a "patient representative."[527] For example, social workers often serve as advocates for patients.[528] But it is unclear whether they are disqualified as "patient representatives" because they are employed by the facility.

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[521] *Id.* at 21.

[522] *Id.* at 23.

[523] *Id.* at 25.

[524] *Id.* at 33.

[525] *Id.* at 24.

[526] Rains v. Belshe, 38 Cal. Rptr. 2d 185, 189 (Cal. Ct. App. 1995).

[527] L. Schwartz, *Is There an Advocate in the House? The Role of Health Care Professionals in Patient Advocacy*, 28 J. MED. ETHICS 37, 37 (2002).

[528] Ellen L. Csikai & Shadi S. Martin, *Bereaved Hospice Caregivers' Views of the Transition to Hospice*, 49(5) SOC. WORK IN HEALTH CARE 387, 398 (2010).

Judge Grillo also indicated the need for further litigation on CANHR's other two arguments.[529] He suggested that IDTs may lack authority to make treatment decisions regarding either anti-psychotics or end-of-life care.[530] Judge Grillo observed that the leading case construing the IDT statute had determined that the law "by its own terms applies only to the relatively nonintrusive and routine, ongoing medical intervention, which may be afforded by physicians in nursing homes; it does not purport to grant blanket authority for more severe medical interventions."[531]

Judge Grillo entered a final judgment in January 2016.[532] Both parties cross-appealed the order and it remains stayed pending appeal.[533] While a ruling for CANHR might make the process better comport with procedural due process, that would entail some serious risks. Restricting the authority of IDTs to make end-of-life decisions consigns the unbefriended to the prospect of a prolonged and potentially unnecessarily painful death. Restricting the authority of IDTs to prescribe antipsychotics leaves the unbefriended unplaceable in nursing facilities, which may result in unnecessary decompensation and hospitalization.[534]

Pending the outcome of the litigation, the California Legislature has been considering bills that would amend the IDT statute. A 2016 bill would have required that IDTs include "independent" medical consultants and "independent" patient advocates.[535] CANHR objected that these individuals would not be sufficiently independent since they would still be hired and "paid" by the long-term care facility.

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[529] *See generally* Brief for Petitioner, California Advocates for Nursing Home Reform v. Chapman, No. RG13700100 (Cal. Super. Ct., 2015).

[530] *Id.* at 32, 40.

[531] *Id.* at 25.

[532] California Advocates for Nursing Home Reform v. Chapman, No. RG13700100 (Cal. Super. Ct., Jan. 27, 2016) (Judgment), http://thaddeuspope.com/images/CANHR_v_Chapman.pdf.

[533] Appellant Reply Brief, California Advocates for Nursing Home Reform (CANHR) v. Chapman, No. A147987 (Cal. App. May 22, 2017); Combined Reply and Respondent's Brief, California Advocates for Nursing Home Reform (CANHR) v. Chapman, No. A147987 (Cal. App. June 13, 2017).

[534] I thank Robert Gibson for helping me appreciate the significance of this case.

[535] S.B 503, 2015-16 Leg., Reg. Sess. (Cal. 2016).

A 2017 bill would have added notice requirements to the IDT statute.[536] It would have required the facility to communicate to the resident orally and in writing that: (1) the attending physician determined the resident lacks capacity, (2) the facility was unable to locate a surrogate, (3) the medical intervention recommended, (4) the role of the IDT, and (4) the right of the resident to challenge the determinations. CANHR objected that this notice comes too late. Coming after the capacity determination and IDT meeting, it "does not give the resident a reasonable opportunity to participate in the team-decision process."[537]

### *D. California Prison Healthcare*

Just as the challenges to the IDT statute were heating up in 2015, California enacted a statute authorizing healthcare decisions for unbefriended prisoners.[538] Under this law, the prison physician or dentist files a petition with the Office of Administrative Hearings to request appointment of a surrogate decisionmaker. But despite the procedural due process protections afforded by a formal proceeding, the law includes an odd loophole.

On the one hand, the statute provides that "an employee of the Department of Corrections and Rehabilitation, or other peace officer, shall not be appointed surrogate decisionmaker for health care for any inmate patient."[539] On the other hand, the statute includes a broad exception for staff not engaged in direct care of the inmate.

> The individual is a health care staff member in a managerial position and does not provide direct care to the inmate patient. A surrogate decisionmaker appointed under this subparagraph may be specified by his or her functional role at the institution, such as "Chief Physician and

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[536] S.B. 481, 2017-18 Leg., Reg. Sess. (Cal. 2017).

[537] CAL. SENATE JUDICIARY COMM., S.B. 481, 2017-18 Leg., Reg. Sess., at 7 (2017), file:///Users/landonreed/Downloads/201720180SB481_Senate%20Judiciary-.pdf.

[538] A.B. 1423, 2015-16 Leg., Reg. Sess. (Cal. 2015), codified at CAL. PENAL CODE § 2604 (West 2017).

[539] CAL. PENAL CODE § 2604(q)(2).

> Surgeon" or "Chief Medical Executive" to provide clarity as to the active decisionmaker at the institution where the inmate patient is housed, and to anticipate potential personnel changes.[540]

This hardly seems sufficient to mitigate bias and conflict of interests that healthcare management will have with respect to inmate patients.

## *VIII. Mechanisms with Sufficient Due Process*

In the last section, I argued that several prominent approaches lack adequate due process: (1) solo physician unilateral authority, (2) second physician confirmation, (3) California IDT, and (4) California prison healthcare. In contrast, other approaches are sufficiently fair. These include: (a) tiered approaches correlating the amount of oversight to the gravity of the decision at hand, (b) approaches requiring ethics committee consent, (c) approaches requiring external consent, and (d) approaches for discharge and transfer.

### *A. Tiered Approaches Correlating Oversight to Gravity*

At first glance, New York's 2010 Family Health Care Decisions Act (FHCDA) looks like it authorizes the solo physician approach. But on closer examination, it becomes clear that the discretion of the attending physician narrows as the invasiveness or burden of the treatment rises.[541] Specifically, the FHCDA divides treatment into three categories: (1) routine medical treatment, (2) major medical treatment, and (3) life-sustaining treatment.[542]

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[540] CAL. PENAL CODE § 2604(q)(2)(B). There is also an exception if the DOCR employee is a "family member or relative of the inmate patient." *Id.* § 2604(q)(2)(A).

[541] Varughese et al., *supra* note 40, at 80.

[542] A fourth category of medical treatment is emergency treatment. *See supra* Section I.B. For decision-making purposes, some even identify a fifth category: futile treatment. *See* Karp & Wood, *Incapacitated and Alone*, *supra* note 4, at 17; *also Application of Justice Health; re a Patient* (2011) 80 NSWLR 354, 354 (Austl.).

### *1. Routine Medical Treatment*

Routine medical treatment includes those treatments, services, and procedures for which providers do not ordinarily seek specific consent. Examples of such treatment include drawing blood for tests or providing medication for high blood pressure. These interventions involve little or no risk to patients and are clearly beneficial.[543] An attending physician is authorized to unilaterally decide about the provision of routine medical treatment for unbefriended patients.[544]

### *2. Major Medical Treatment*

Major medical treatment includes those treatments, services, and procedures that involve the use of general anesthesia; any significant risk to the patient; or any significant invasion of bodily integrity requiring an incision, producing significant pain, or having a significant recovery period. Examples of such treatment include lumbar puncture, colonoscopy, and hernia repair.

These types of decisions carry greater risks and burdens and incorporate important nonmedical considerations. Accordingly, the decision-making process is more extensive. First, the attending physician must consult with the staff directly responsible for the patient's care, including nurses, social workers, nurse aids.[545] Second, the attending physician must obtain an independent concurring determination from a second physician.[546]

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[543] The New York State Health Facilities Association has developed model forms that help assure compliance with the statute. N.Y. STATE BAR ASS'N, NEW YORK'S FAMILY HEALTH CARE DECISIONS ACT, MODEL NURSING HOME FORMS FOR THE FAMILY HEALTH CARE DECISIONS ACT, www.nyshfa.org/files/2014/01/FHCDA_Forms2.doc.

[544] N.Y. PUB. HEALTH LAW § 2994-g(3)(B) (McKinney 2011); Assemb. B. 4098 § 3(a)(1), 214th Leg., Reg. Sess. (N.J. 2011). In these cases, pursuant to its institutional policy that is not expressly authorized by Ohio law, the Cleveland Clinic also requires a "social work consultation" to locate surrogates, to assess whether guardianship is appropriate, and to confirm that the patient's best interests are being served. *Cleveland Clinic Policy on Medical Decision-Making for Patients Lacking Decision-Making Capacity Who Do Not Have a Surrogate Decision-Maker*, CLEVELAND CLINIC (Apr. 20, 2009), http://my.clevelandclinic.org/Documents/Bioethics/Policy_on_Patients_without_Surrogates.pdf [hereinafter *Policy on Decision-Making*].

[545] N.Y. PUB. HEALTH LAW § 2994-g(4)(B)(i) (McKinney 2011).

[546] N.Y. PUB. HEALTH LAW § 2994-g(4)(B)(ii) (McKinney 2011); *see also* Assemb. B. 4098 § 2(b)(2), 214th Leg., Reg. Sess. (N.J. 2011). In facilities other than general hospitals, the medical director shall make the independent determination that the recommendation is appropriate. Assemb. B.

### *3. Life-sustaining Treatment*

Life-sustaining treatment includes the use of any medical device or procedure to sustain a vital bodily function. Typical treatments include cardiopulmonary resuscitation, mechanical ventilation, dialysis, and clinically assisted nutrition and hydration.[547]

Because of the life and death stakes, decisions to withhold or withdraw life-sustaining treatment are subject to the closest scrutiny. An attending physician may make such decisions only if she or he determines, with the concurrence of an independent physician, that the treatment either "would violate accepted medical standards" or "offers the patient no medical benefit because the patient will die imminently, even if the treatment is provided."[548] Otherwise, withholding or withdrawing life-sustaining treatment requires judicial approval.[549]

The Veterans Health Administration (VHA) follows a process very similar to that outlined in the New York FHCDA. For those treatments or procedures that involve minimal risk, practitioners can make a decision after attempting to explain the nature and purpose of the proposed treatment to the patient.[550] In contrast, for procedures that require signature consent, both the attending physician and the

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4098 § 3(a)(2)(c), 214th Leg., Reg. Sess. (N.J. 2011). In these cases, the Cleveland Clinic also requires a "social work consultation" and a "consultation by the ethics consult service." *See* CLEVELAND CLINIC *supra* note 544.

[547] N.Y. PUB. HEALTH LAW §§ 2994-a(19), 2994-g(3)(A)–(4)(A) (McKinney 2011); Assemb. B. 4098 § 1, 214th Leg. Reg. Sess. (N.J. 2011).

[548] N.Y. PUB. HEALTH LAW § 2994-g(5)(b) (McKinney 2011); Assemb. B. 4098 § 3(b)(2), 214th Leg., Reg. Sess. (N.J. 2011).

[549] N.Y. PUB. HEALTH LAW § 2994-g(5) (McKinney 2011); Assemb. B. 4098 § 3(b), 214th Leg., Reg. Sess. (N.J. 2011). The Cleveland Clinic does not have a substantive rule like New York. Instead, it requires both a "concurring medical opinion" and approval of a "multidisciplinary subcommittee of the ethics committee." *See Policy on Medical Decision-Making*, *supra* note 544. Before the June 2010 enactment of the FHCDA, New York authorized attending physicians to write DNR orders for unbefriended patients when resuscitation would be medically futile. N.Y. PUB. HEALTH LAW § 2966(1)(a) (McKinney 2010).

[550] 38 C.F.R. § 17.32(f) (2017); VHA HANDBOOK, *supra* note 293, at 1004.01(14)(c). Still, treatment must not be provided indefinitely without review of the treatment plan at least every six months by the attending practitioner of record and the service chief, or designee, to ensure that clinical objectives are being met and the treatment plan is in the best interests of the patient. *Id.*

chief of service or his or her designee must indicate approval of the treatment decision in writing.[551]

In the VHA, as in New York, decisions to withhold or withdraw life-sustaining treatment require a more elaborate process. They must be reviewed by a multidisciplinary committee appointed by the facility director.[552] The committee functions as the patient's advocate and may not include members of the treatment team.[553] The committee must submit its findings and recommendations in a written report to the chief of staff, who must note his or her approval of the report in writing.[554] After reviewing the record, the facility director may concur with the decision to withhold or withdraw life support or request further review by regional counsel.[555]

A new Colorado statute also authorizes a tiered approach.[556] For routine treatments and procedures that are "low-risk and within broadly accepted standards of medical practice," the attending physician may make health care treatment decisions.[557] For treatments that otherwise require a "written, informed consent, such as treatments involving anesthesia, treatments involving a significant risk of complication, or invasive procedures," the attending physician shall obtain the written consent of the surrogate—another physician—and a consensus with the medical ethics committee.[558] For end-of-life treatment that is nonbeneficial and involves withholding or withdrawing specific medical treatments, the attending physician shall obtain an independent concurring opinion from a physician other than the surrogate, and obtain a consensus with the medical ethics committee.[559] In 2017, Montana enacted a virtually identical statute.[560]

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[551] VHA HANDBOOK, *supra* note 293, at 1004.01(14)(c)(2).

[552] *Id.* at 1004.01(14)(c)(3)(b).

[553] *Id.*

[554] *Id.*

[555] *Id.* at 1004.01(14)(c)(3)(d).

[556] COLO. REV. STAT. § 15-185-103(4)(c)(V) (West 2017).

[557] COLO. REV. STAT. § 15-185-103(4)(c)(V)(A).

[558] COLO. REV. STAT. § 15-185-103(4)(c)(V)(B).

[559] COLO. REV. STAT. § 15-185-103(4)(c)(V)(C). The statutory rules are elaborated upon in informal guidance. Colorado Collaborative for Unrepresented Patients (CCUP), *Decision Making for Unrepresented Patients Who Lack Capacity: Guidelines for Health Care Facilities in Colorado* (Nov. 4,

Like New York, the VHA, Colorado, and Montana, some foreign jurisdictions also follow a tiered approach. In New South Wales, for example, medical treatment for unbefriended patients may be carried out without consent so long as it is "minor."[561] But for "major" treatment, consent must be obtained from a Guardianship Tribunal.[562]

### *B. Approaches Requiring Ethics Committees*

Whether or not authorized by law, many treatment decisions for the unbefriended are made by physicians without institutional or judicial review, and even without the concurring opinion of another physician.[563] In other words, much decision making is informal and *ad hoc.* As discussed above, many commentators and policy makers have expressed concern with leaving treatment decisions solely in the hands of individual physicians or other facility employees.

To address these concerns, the American Medical Association, among others, has recommended a more thorough process to better ensure accountability, objectivity, and independence. Specifically, the AMA recommended consulting "an ethics committee to aid in identifying a surrogate decision-maker or to facilitate sound decision-making."[564] Below, I review the advantages of ethics committees. I then review laws both requiring and recommending ethics committee review. Finally, I look at institutional policies requiring ethics committee consent even when not legally mandated.

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2016). These rules work fine for inpatients. But, a guardian is still needed for patients with permanent incapacity who will need continuity of services.

[560] S.B. 92, 65th Leg., Reg. Sess., 2017 Mont. Laws Ch. 285. .

[561] *Guardianship Act 1987* (NSW) s 37 (2)–(3) (Austl.).

[562] *Guardianship Act 1987* (NSW) s 36(1)(b) (Austl.).

[563] *See supra* note 468 and accompanying text.

[564] CODE OF MEDICAL ETHICS § 8.081 (A. MED. ASS'N 2015); AMA COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS, SELECTION OF HEALTH CARE DECISION-MAKING SURROGATES, CEJA Report 3-A-04. The AMA recently revised its code. It now provides "Consult an ethics committee or other institutional resource when . . . no surrogate is available." CODE OF MEDICAL ETHICS § 2.1.2(f) (A. MED. ASS'N 2016), https://www.ama-assn.org/delivering-care/ama-code-medical-ethics.

### *1. Advantages of Ethics Committees*

A committee has some advantages over a single decision maker.[565] With an individual decision maker, there is always a concern that the decision will be based upon financial incentives or upon the peculiar biases of that person.[566] A committee, on the other hand, can better offer various perspectives and can utilize a multifaceted array of both medical and ethical considerations.[567] A committee is more likely to view a patient as an individual, considering, in addition to the medical benefits and burdens, any known moral or personal values and the nature of a patient's previous lifestyle.[568] At the same time, committees provide quicker, more accessible, and more personalized decisions than the court system.

On the other hand, committees are sometimes impractical because of the necessary logistics. First, it often takes too much time: (1) to convene a committee, (2) to thoroughly evaluate patients and their treatment options, (3) to collectively deliberate, and (4) to issue a decision.

Patients in need of medical care often do not have this much time. Decisions must be made quickly. Many facilities deal with this by

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[565] Just as a committee may offer more perspectives and greater deliberation than an individual decision maker, some jurisdictions require the involvement of additional individuals. While not authorized as surrogates, these individuals do provide some oversight of and support for those making the treatment decisions. *See* Karp & Wood, *Incapacitated and Alone*, *supra* note 4, at 37–38. One example is the long-term care ombudsperson or patient advocate. *Id.* at 35. Another is the "independent mental capacity advocate" required by the U.K. Mental Capacity Act of 2005. *See* Mental Capacity Act 2005, c.9 (UK), http://www.legislation.gov.uk/ukpga/2005/9.

[566] Diane E. Meier, *Voiceless and Vulnerable: Dementia Patients without Surrogates in an Era of Capitation*, 45(3) J. AM. GERIATRICS SOC'Y 375, 375 (1997).

[567] *See generally* Insoo Hyun et al., *When Patients Do Not Have a Proxy: A Procedure for Medical Decision Making When There is No One to Speak for the Patient,* 17(4) J. CLINICAL ETHICS 323 (2006); Moye et al., *supra* note 143.

[568] Hyun et al., *supra* note 567, at 327–328. This article cites two case examples of patients without a surrogate. *Id.* Mr. T was an older gentleman; his physician recommended that a feeding tube be inserted, due in part to Mr. T's poor nutrition. *Id.* A committee was convened, and after discussion with the patient and the nursing home where he had been living, the committee advised against the tube. *Id.* They noted that eating was one of his only remaining pleasures, and the life-extending benefits to Mr. T were unimpressive. *Id.* In contrast, Mr. A's physician also recommended a feeding tube, due to Mr. A's poor nutrition. *Id.* But Mr. A was much younger and had better prospect for an improved quality of life. Hyun et al., *supra* note 567, at 327–328. The committee noted that the feeding tube was very effective for short-term nutrition, and recommended the tube for Mr. A. *Id.* These decisions exemplify how committees can evaluate medical decisions subjectively, based on the individual characteristics of each patient, as opposed to simply the objective medical benefits. *Id.* at 328.

having treatment decisions for the unbefriended reviewed by just a subgroup, which is more easily convened.[569] A second practical obstacle is that these committees are usually burdened with under-funding, understaffing, and under-trained members.

### *2. Laws Requiring Ethics Committee Consent*

Not only are ethics committees used in many states without any specific mandate or authority, but several states have enacted statutes allowing institutional committees to guide decision making for the unbefriended.[570] The New York approach is described above. This approach is widely supported.

In Alabama, for example, decisions may be made by "a committee composed of the patient's primary treating physician and the ethics committee of the facility where the patient is undergoing treatment or receiving care, acting unanimously."[571] If there is no ethics committee, then decisions can instead be made:

> [B]y unanimous consent of a committee appointed by the chief of medical staff or chief executive officer of the facility and consisting of at least the following: (i) the primary treating physician; (ii) the chief of medical staff or his or her designee; (iii) the patient's clergyman, if known and available, or a member of the clergy who is associated with, but not employed by or an independent contractor of the facility, or a social worker associated with but neither employed by nor an independent contractor of the facility.[572]

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[569] *See* Griggins, *supra* note 389, at 8.

[570] *See, e.g.*, ALA. CODE § 22-8A-11 (2016); O.C.G.A. § 31-39-4(e) (2017).

[571] ALA. CODE § 22-8A-11(d)(7) (2016). "In the event a surrogate decision is being made by an ethics committee or appointed committee of the facility where the patient is undergoing treatment or receiving care, the facility shall notify the Alabama Department of Human Resources for the purpose of allowing the department to participate in the review of the matter." *Id.*

[572] *Id.*

In Georgia, with respect to DNR orders, "an attending physician may issue an order not to resuscitate" for a patient, provided three conditions are satisfied.[573] First, the physician must determine with the concurrence of a second physician, in writing in the patient's medical record, that such patient is a candidate for non-resuscitation.[574] Second, "an ethics committee or similar panel" must concur in the opinion of the attending physician and the concurring physician that the patient is a candidate for non-resuscitation.[575] Third, the patient must be receiving inpatient or outpatient treatment from, or is a resident of, a healthcare facility other than a hospice or a home health agency.[576]

As discussed above, many states authorize attending physicians to make decisions regarding routine medical treatment. But safeguards typically increase proportionately with the gravity of the treatment. These safeguards often include the approval of an ethics committee.[577] For example, in the VHA, ethics committees are utilized for decisions involving withholding or withdrawal of life-sustaining treatment.[578] Such decisions by an ethics committee must be approved by a multidisciplinary committee acting as the patient's advocate.[579]

Most recently, Colorado and Montana adopted approaches requiring ethics committee consent.[580] Effective in late 2016, a Colorado attending physician "may designate another willing physician to make health care treatment decisions as a patient's proxy

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[573] O.C.G.A. § 31-39-4(e).

[574] O.C.G.A. § 31-39-4(e)(1).

[575] O.C.G.A. § 31-39-4(e)(2).

[576] O.C.G.A. § 31-39-4(e)(3).

[577] DeKalb Med. Ctr., Inc. v. Hawkins, 655 S.E.2d 823, 824 (Ga Ct. App. 2007); GUIDELINES ON THE TERMINATION, *supra* note 5, at 40.

[578] VHA HANDBOOK, *supra* note 293, at 16.

[579] 38 C.F.R. § 17.32(f)(2) (2017); VHA HANDBOOK, *supra* note 293, at 15. The chief of staff and the facility director must approve the withdrawal of any life sustaining treatment. *Id.* The patient's record must be documented accordingly. *Id.* The treating physician is not permitted to be a member of the committee. *Id.* The committee must use the substituted judgment standard, if possible, and, if not, must decide based on the best interest of the patient. *Id.* The committee should seek input from the patient's religious, ethnic, or cultural groups. *Id.*

[580] H.B. 1101, 70th Gen. Assemb, 2d Reg. Sess. (Colo. 2016); S.B. 92, 65th Leg., Reg. Sess. (Mont. 2017).

decision-maker."[581] But the attending must first (1) obtain the "independent determination of the patient's lack of decisional capacity,"[582] and (2) "consult[] with and obtain[] a consensus on the proxy designation with the medical ethics committee."[583] If the health care facility does not have a medical ethics committee, the facility can use the medical ethics committee at another health care facility."[584] In 2017, Montana enacted a virtually identical statute.[585]

### *3. Laws Recommending Ethics Committee Consent*

Some states prefer, but do not strictly require, ethics committee review. In Arizona, for example, an attending physician may make a treatment decision after consulting and obtaining the recommendation of an institutional ethics committee.[586] But the statute recognizes that may not always be possible. If it is not possible, the statute alternatively allows a physician to make the treatment decision after consulting with and obtaining the concurrence of a second physician.[587]

Similarly, Arkansas provides that if none of the specified individuals eligible to act as a surrogate are reasonably available, then the "designated physician may make healthcare decisions for the principal" after she "consults with and obtains the recommendations of an institution's ethics officers."[588] Alternatively, the designated physician may "obtain concurrence from a second physician" who is "not directly involved" in the patient's health care and independent of the designated physician.[589]

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[581] COLO. REV. STAT. § 15-18.5-103(4)(c)(I) (West 2017).

[582] COLO. REV. STAT. § 15-18.5-103(4)(c)(I)(B).

[583] COLO. REV. STAT. § 15-18.5-103(4)(c)(I)(D).

[584] COLO. REV. STAT. § 15-18.5-103(4)(c)(II). The statutory rules are elaborated upon in informal guidance. Colorado Collaborative for Unrepresented Patients (CCUP), *Decision Making for Unrepresented Patients Who Lack Capacity: Guidelines for Health Care Facilities in Colorado* (Nov. 4, 2016).

[585] S.B. 92, 65th Leg., Reg. Sess. (Mont. 2017). Montana also allows an advanced practice registered nurse to be a surrogate. *Id.*

[586] ARIZ. REV. STAT. ANN. § 36-3231(B) (2016).

[587] *Id.*

[588] Arkansas Health Care Decisions Act, 2017 Arkansas Laws Act 974.

[589] Arkansas Health Care Decisions Act, 2017 Arkansas Laws Act 974. "Independent" means the second physician: (1) Does not serve in a capacity of decision making, influence, or responsibility over

Finally, even when not given a formal decision-making role, ethics committees are often given at least a consulting role in treatment decisions for the unbefriended. For example, a 2011 Oregon statute expressly provides that a healthcare facility may appoint an ethics committee to "participate in making decisions."[590]

### *4. Institutional Policies Requiring Ethics Committee Consent*

In addition to these decision-making processes specifically authorized by state or federal law, it is important to note that many facilities in other U.S. states authorize institutional committees to make treatment decisions for the unbefriended even though not expressly authorized by law.[591] Such innovation is important in the absence of explicit authorizing law.[592] "[T]he legal risk of not pursuing a guardianship (which would provide clear legal authority for any decision made) is generally considered quite low, and the benefits of not requiring an extensive legal proceeding . . . quite high."[593]

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the designated physician; and (2) Does not serve in a capacity under the authority of the designated physician's decision making, influence, or responsibility. *Id.*

[590] S.B. 579 § 2(b), 2011 Leg., 76th Sess. (Or. 2011).

[591] Eric D. Isaacs & Robert V. Brody, *The Unbefriended Adult Patient: The San Francisco General Hospital Approach to Ethical Dilemmas*, 83(6) S.F. MED. 1, 25 (2010 (describing the process at San Francisco General Hospital); *Who Decides?*, *supra* note 131. This is what Karp and Wood refer to as "flying below the radar screen." *See* Karp & Wood, *Incapacitated and Alone*, *supra* note 4, at 38–40; Kapp, *supra* note 22, at 12 (noting physicians act as "de facto surrogates . . . covertly and with hesitation"). Isaacs and Brody argue that it is unclear that a more elaborate process does or would produce better results. Isaacs & Brody, *supra*. For example, judges usually follow the medical recommendation. Because the New York SDMC votes to go forward with the medical procedure in 96 percent of cases, some have observed that this review "may not substantially improve decisions." *See* Miller, Coleman & Cugliari, *supra* note 38, at 371; *In re* Guardianship of Browning, 543 So. 2d 258, 271 (Fla. Dist. Ct. App. 1989) ("Until we see evidence of some abuse by an informal forum, we believe its advantages outweigh its disadvantages."); Karp & Wood, *Incapacitated and Alone*, *supra* note 4, at 41 (describing concerns about "the due processization of medical decision-making"); Kapp, *supra* note 22, at 34 (arguing that requiring legally authorized surrogates may reduce beneficent behavior on the part of facility staff who often "functioned in essence in the role of family for the resident who had no one else"). On the other hand, the prospect of accountability matters. Thaddeus M. Pope, *Multi-Institutional Healthcare Ethics Committees: The Procedurally Fair Internal Dispute Resolution Mechanism*, 31 CAMPBELL L. REV. 257, 323 (2009); *Who Decides?*, *supra* note 131.

[592] Lauren Sydney Flicker, *A Patient (Not) Alone*, 28(2) J. CLINICAL ETHICS 102 (2017); Matthew Wynia, *Civic Obligations in Medicine: Does "Professional" Civil Disobedience Tear, or Repair, the Basic Fabric of Society?,* 6(1) AMA J. ETHICS (Jan. 2004), http://journalofethics.ama-assn.org/2004/01/pfor1-0401.html.

[593] Courtwright et al., *supra* note 143.

For example, the California Health Care Decisions Act fails to address medical decision making for the unbefriended. Nevertheless, the Santa Clara County Medical Association wanted a less cumbersome and more immediately responsive decision-making process than guardianship.[594] So, in 2001, it developed a model policy for facilities in the county.[595] It has since been adopted not only by institutions in Santa Clara, but also by institutions in other parts of California.[596]

One hospital that adopted the model Santa Clara policy noted that it wanted to make "appropriate healthcare decisions" for unbefriended patients in "a timely and transparent manner."[597] Here, basically, is how it works. Once a patient is determined to be unbefriended, the policy calls for the physician of record to ask the chair of the ethics committee to appoint and chair a "multidisciplinary committee" to make treatment decisions.[598] The policy recommends, but does not require, that a community member and a representative of the patient's cultural, ethnic, or religious community serve on the committee.[599] The attending physician is a nonvoting member of the committee.[600] Consensus is required, and in cases of withholding and withdrawing treatment, the approval of the hospital's medical director is also required.[601]

### *C. Approaches Requiring Independent External Consent*

Review by an institutional committee provides more accountability than review by an attending physician alone.[602] But some are

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[594] *See* Karp & Wood, *Incapacitated and Alone*, *supra* note 4, at 35–36. While not specifically authorized in California law, the Santa Clara policy has received judicial endorsement and deference. *Id.*

[595] *Ethics Subcommittee Surrogate for Patients*, AHC MEDIA (Sept. 1, 2004), RRPope - GA ST U L REV (Author Review) TMP 05-07-17.dochttps://www.ahcmedia.com/articles/3979-ethics-subcommittee-surrogate-for-patients.

[596] *See* Karp & Wood, *Incapacitated and Alone*, *supra* note 4, at 35–36.

[597] SANTA CLARA VALLEY MED. CTR., VMC 301.14, ADMINISTRATIVE POLICIES AND PROCEDURES MANUAL: HEALTH CARE DECISIONS FOR INCAPACITATED PATIENTS WITHOUT SURROGATES 1 (2011).

[598] *Id.* at 2.

[599] *Id.* at 3.

[600] *Id.*

[601] *Id.* at 4.

[602] *See* Pope, *supra* note 591, at 321.

concerned that such a process is still too much of an "inside job."[603] Ethics committees are, after all, primarily comprised of individuals who are economically dependent upon the facility.[604]

Responsive to this concern, New York, Texas, and Iowa have enacted statutes that authorize extra-institutional, "external" surrogate committees to make treatment decisions for certain unbefriended persons.[605] While the Iowa committees serve all unbefriended patients, the New York and Texas committees serve only certain current and former residents of facilities for the mentally disabled.[606] In contrast, Florida authorizes independent social workers to make treatment decisions for any unbefriended person.[607]

### *1. New York Surrogate Decision Making Committee*

In 1985, the New York legislature determined that the judicial process to appoint a guardian was not meeting the needs of its mentally disabled citizens.[608] So, it enacted legislation establishing a "statewide quasi-judicial surrogate decision-making process."[609] At the heart of this process is the Surrogate Decision Making Committee (SDMC).

The SDMC consists of volunteers appointed by the state Commission on Quality of Care and Advocacy.[610] These volunteers

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[603] Abdool et al., *supra* note 215, at 777; Iris C. Freeman, *One More Faulty Solution Is Novelty without Progress: A Reply to "Medical Decision-Making for the Unbefriended Nursing Home Resident*, 1 J. ETHICS, L. & AGING 93 (1995).

[604] *See* Pope, *supra* note 591, at 277–78. In addition, intramural mechanisms are of little use for the chronically ill who will present across multiple care settings.

[605] IOWA CODE § 135.29(1) (2010); N.Y. MENTAL HYG. LAW § 80.05(c)(i) (McKinney 2009); TEX. HEALTH & SAFETY CODE ANN. § 597.042(a) (West 1999).

[606] IOWA CODE § 135.29(2); N.Y. MENTAL HYG. LAW § 80.03(b) (McKinney 2011); TEX. HEALTH & SAFETY CODE ANN. § 597.001(2) (West 2015).

[607] FLA. STAT. ANN. § 765.401(1)(h) (2016).

[608] Clarence J. Sundram et al., *The First Ten Years of New York's Surrogate Decision-Making Law: History of Development*, in REPRESENTING PEOPLE WITH DISABILITIES (Peter Danziger et al. eds., 3d ed. 2007); Stanley S. Herr & Barbara L. Hopkins, *Health Care Decision Making for Persons with Disabilities: An Alternative to Guardianship,* 271(13) JAMA 1017, 1018 (1994); Clarence J. Sundram, *Informed Consent for Major Medical Treatment of Mentally Disabled People: A New Approach*, 318 NEW ENG. J. MED. 1368, 1369 (1988); Robert S. Olick & K. Faber-Langendoen, *Caring for Patients Without Surrogates Under the Family Health Care Decisions Act*, BIOETHICS IN BRIEF (Upstate Med. Univ., New York, N.Y.), Mar. 1, 2011, at 1.

[609] N.Y. MENTAL HYG. LAW § 80.01 (McKinney 2009).

[610] *Id.* § 80.05(b).

come from four distinct categories: (1) physicians, nurses, psychologists, or other healthcare professionals; (2) family or advocates of a mentally disabled person; (3) New York attorneys; and (4) other individuals with "recognized expertise" in the treatment of mentally disabled persons.[611] Sitting in panels of four, these volunteers make treatment decisions for the unbefriended patient.[612]

A SDMC must first determine, through clear and convincing evidence, that a patient lacks capacity.[613] The committee then decides whether the proposed treatment is in the best interest of the patient.[614] In making its decision, the SDMC fully considers any evidence of the patient's previously expressed desires.[615] A decision by an SDMC is legally valid consent, as if the person had made a capacitated decision on her or his own behalf.[616] But, the SDMC's decision is valid only for the specifically proposed treatment presented, not for any future medical care.[617] And certain designated individuals, including staff at the patient's residential facility, may appeal the decision to court.[618] The use of SDMCs became statewide in 2001.[619]

The program boasts that it is superior to judicially appointed guardians because it is inexpensive, expeditious, and ethical.[620] First, there is no cost for training or hearings.[621] There are no court costs or attorneys' fees.[622] Second, an average decision takes only 14 days,

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[611] *Id.* § 80.05(c)(i).

[612] *Id.* § 80.05(f).

[613] *Id.* § 80.07(e).

[614] *Id.* § 80.07(f).

[615] N.Y. MENTAL HYG. LAW § 80.07(f) (McKinney 2009).

[616] *Id.*

[617] *Id.*

[618] *Id.* § 80.07(h).

[619] George E. Pataki, *Improving Lives, Protecting Rights*, COMMISSION ACTIVITIES (N.Y. St. Commission on Quality of Care for the Mentally Disabled, Schenectady, N.Y.), 2001, at 14.

[620] N.Y. JUSTICE CTR. FOR THE PROT. OF PEOPLE WITH SPECIAL NEEDS, SURROGATE DECISION MAKING COMMITTEE PROGRAM: PANEL MEMBER HANDBOOK (March 2017), HTTPS://WWW.JUSTICECENTER.NY.GOV/SITES/DEFAULT/FILES/DOCUMENTS/SDMA-PANEL-MEMBER-HANDBOOK.PDF; *Frequently Asked Questions – Information for Prospective Volunteer Panelists*, JUSTICE CTR FOR THE PROT. OF PEOPLE WITH SPECIAL NEEDS, https://www.justicecenter.ny.gov/faq/61 (last visited Mar. 6, 2017).

[621] *Frequently Asked Questions – Information for Prospective Volunteer Panelists, supra* note 620 ("The Surrogate Decision-Making Committee (SDMC) program is . . . cost-free.").

[622] *See id.*

and expedited hearings are available.[623] Hearings are held statewide at the convenience of the individuals involved.[624] Third, the committees utilize a person-centered approach to medical decision making.[625]

In 2009, the regulations governing SDMCs were amended to conform the program to statutory amendments that expanded the jurisdiction of the program.[626] SDMCs are now available to a wider range of individuals served by the New York Office for People with Developmental Disabilities. For example, individuals who receive home or community based care, or who are only provided with case management or service coordination services, are now eligible for SDMC services.[627] Similarly, individuals who have been discharged from mental hygiene facilities into nursing homes or the community are now eligible to have SDMC decisions made on their behalf.[628] Lastly, the SDMCs are now authorized, subject to very specific safeguards, to make decisions to withhold or withdraw life-sustaining treatment.[629]

### *2. Texas Mental Retardation Committees*

Like New York, Texas has also implemented a surrogate decision-making committee program to make decisions on behalf of its unbefriended citizens who suffer from mental retardation and related conditions.[630] The committees are appointed by the Texas Department of Aging and Disability Services and consist of three to

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[623] Pataki, *supra* note 619, at 14.

[624] *Id.*

[625] *Surrogate Decision Making Committee (SDMC)*, EAC NETWORK, http://eac-network.org/surrogate-decision-making-committee/ (last visited Mar. 6, 2017).

[626] XXXI N.Y. Reg. 13 (Mar. 11, 2009), available at https://docs.dos.ny.gov/info/register/2009/mar11/pdfs/rules.pdf. *See also* NEW YORK TASK FORCE ON LIFE AND THE LAW, SPECIAL ADVISORY COMMITTEE, RECOMMENDATIONS FOR AMENDING THE FAMILY HEALTH CARE DECISIONS ACT TO INCLUDE HEALTH CARE DECISIONS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES AND PATIENTS IN OR TRANSFERRED FROM MENTAL HEALTH FACILITIES (June 21, 2016).

[627] XXXI N.Y. Reg. 13 (Mar. 11, 2009), available at https://docs.dos.ny.gov/info/register/2009/mar11/pdfs/rules.pdf.

[628] *Id.*

[629] *Id.*

[630] TEX. HEALTH & SAFETY CODE ANN. § 597.042 (West 1999); 40 TEX. ADMIN. CODE §§ 9.281–9.295 (2016).

five volunteers.[631] Volunteers must attend a four-hour training.[632] When a committee is convened, it reviews written documentation as well as oral testimony from the patient, the provider, and any other interested person.[633] It then decides if the proposed treatment is in the best interest of the individual.[634]

In 1999, proposed Texas legislation would have authorized similar "surrogate decision making committees" for patients in hospitals and nursing homes.[635] The bill called for the Texas Board of Human Services to adopt rules regarding the appointment of such committees to, among other things, "ensure the independence of each committee member" and "govern the minimum number" of members.[636] Unfortunately, the bill died in committee.[637]

### *3. Iowa Office of the Substitute Decision Maker*

Iowa also has external surrogate committees.[638] But in contrast to the external committees in New York and Texas, external committees in Iowa are not limited to any specific population of unbefriended patient.[639] Iowa law provides that individual counties may establish "local substitute medical decision-making boards."[640]

These 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."[641] But they may not consent to stopping life-sustaining treatment.[642] Agency regulations

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[631] 40 TEX. ADMIN. CODE § 9.290 (2016).

[632] *SDM Program: Becoming a Member of a Surrogate Consent Committee*, TEX. HEALTH & HUMAN SERV., https://hhs.texas.gov/laws-regulations/legal-information/surrogate-decision-making-program/sdm-program-become-a-member-a-surrogate-consent-committee (last visited Mar. 6, 2017).

[633] *Id.*

[634] *Id.*

[635] H.B. 1270, 1999 Leg., 76th Sess. (Tex. 1999).

[636] *Id.*

[637] *See H.B. 1270, 76th Regular Session*, LEGISLATIVE REFERENCE LIBRARY OF TEX., http://www.lrl.state.tx.us/legis/billsearch/actions.cfm?legSession=76-0&billtypeDetail=HB&billNumberDetail=1270&billSuffixDetail=&startRow=1&IDlist=&unClicklist=&number=100 (last visited Mar. 6, 2017).

[638] IOWA CODE § 135.29(1) (2010).

[639] *Id.* § 135.29(2).

[640] *Id.* § 135.29(1).

[641] *Id.* § 135.29(2).

[642] IOWA ADMIN. CODE r. 641-85.2(5) (2012).

require that local substitute medical decision-making boards include one or more members from three categories: (1) physicians, nurses, or psychologists; (2) attorneys or social workers; and (3) other individuals with "recognized expertise or interest in" the unbefriended.[643]

In March 2012, the Iowa Department of Public Health adopted amendments to the requirements and procedures for local substitute medical decision-making boards.[644] The changes remove references to a "statewide" substitute medical decision-making board that was repealed by the legislature in 2010.[645] Unfortunately, the local committees have not fared much better. Since 1989, only seven of 99 Iowa counties ever developed committees.[646] While state regulations still authorize any Iowa county to establish a committee, there has not been a local committee for more than ten years.[647] Consequently, 2017 legislation eliminates the authorizing statute because the program is "unfunded or outdated."[648]

Most recently, Iowa revived its state Office of the Substitute Decision Maker.[649] First established in 2005, the OSDM is an analog of public guardianship programs in other states.[650] The OSDM is available to be appointed by the court as a substitute decision maker of last resort.

### *4. Florida Independent Social Workers*

While professional decision making for the unbefriended is usually vested primarily with physicians, it is sometimes vested with other

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[643] IOWA ADMIN. CODE r. 641-85.3(1) (2012).

[644] IOWA STATE BD. OF HEALTH, AGENDA (2012), http://www.idph.state.ia.us/IDPHChannelsService/file.ashx?file=21EFBB4A-221C-46E0-8F3B-98414FF2C08E (last visited Mar. 6, 2017).

[645] *Id.* at 1.

[646] Correspondence from Diana Nicholls-Blomme, Iowa Department of Public Health (May 4, 2012).

[647] *Id.*

[648] H.F. 393 § 24, 87th Gen. Assemb., Reg. Sess. (Iowa 2017) (enacted, effective July 1, 2017).

[649] IOWAN DEPT. ON AGING, OFFICE OF SUBSTITUTE DECISION MAKER 1–2, https://dhs.iowa.gov/sites/default/files/Office-of-Substitute-Decision-Maker-Handout.pdf

[650] IOWA CODE § 231E.4(1) (2016).

clinicians, individuals, and entities.[651] In Florida, for example, the ultimate surrogate in the default priority list is "a clinical social worker . . . selected by the provider's bioethics committee and . . . [not] employed by the provider."[652] While these social workers have the authority to consent to major medical treatment, "decisions to withhold or withdraw life-prolonging procedures will be reviewed by the facility's bioethics committee."[653] Some Florida social workers have formed companies to serve these surrogate functions.[654]

In 2015, South Carolina considered similar legislation.[655] Following Florida's lead, South Carolina also proposed adding "clinical social worker" to the very end of its priority list, for those individuals without even close friends.[656] As in Florida, such a surrogate must be selected by the healthcare facility's bioethics committee and must not be employed by the facility.[657] And social workers cannot make decisions to withhold or withdraw life-prolonging procedures without review by the healthcare facility's bioethics committee.[658]

Relatedly, in Texas, if no other surrogate is reasonably available and willing to consent to treatment on behalf of a patient, treatment decisions may be made by "a member of the clergy."[659] In 2011, Texas extended this surrogate decision-making process not only to

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[651] *See, e.g.*, FLA. STAT. ANN. § 765.401(1)(h) (West 2016).

[652] FLA. STAT. ANN. § 765.401(1)(h).

[653] *Id.*

[654] *See* Karp & Wood, *supra* note 107, at 150 (noting that a "burgeoning number of not-for-profit and for-profit agencies . . . has developed to serve the at-risk, 'unbefriended' population"). It is increasingly important to carefully examine the qualification and incentives of these and other professional guardians. Parekh & Adorno, *supra* note 153. I thank Carol S. Huffman, owner of a Florida-based surrogate service, Social Work Advantage, for a telephone interview (Jan. 12, 2012). They thank Ken Goodman for a telephone interview (Feb. 3, 2012).

[655] *See generally* H.B. 3999, 121st Gen. Assemb., Reg. Sess. (S.C. 2015).

[656] *Id.*

[657] *Id.*

[658] *Id.*

[659] TEX. HEALTH & SAFETY CODE ANN. § 313.004(a)(5) (West 2015). The original Consent to Medical Treatment Act was limited to patients in a nursing facility or hospital. TEX. HEALTH & SAFETY CODE ANN. § 313.002(8) (West 2007) (amended 2011). In 2007, the legislature added "home and community support services agency." H.B. 3473, 80th Leg., Reg. Sess. (Tex. 2007). The scope of consent does not include life-sustaining treatment. TEX. HEALTH & SAFETY CODE ANN. § 313.003(b) (West 2015).

patients in hospitals, nursing homes, and home care, but also to inmates in county or municipal jails.[660] Several other states authorize clergy as "surrogates of last resort," but these states require that the clergy know the patient.[661] A recent report recommended using certified chaplains.[662]

### *D. Discharge and Transfer Decisions*

One particular challenge with unbefriended patients is authorizing discharge from an acute care hospital to some other more appropriate care setting.[663] This challenge often goes unmet. Many of the mechanisms described above—for example, intramural ethics committees—help only when the unbefriended individual remains a patient at that same facility. But some states have addressed the discharge and transfer problem.[664] For example, both New Jersey and Tennessee recently considered special mechanisms for this type of decision.[665]

New Jersey proposed the creation of "transition authorization panels."[666] These panels would be comprised of three persons to "authorize the transition of an eligible patient from a participating hospital to a specific post-acute care provider, and to make transition-related financial arrangements."[667] The panel members would be drawn from three classes of persons: (1) those designated by the hospital, (2) those designated by the director of the county social

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[660] H.B. 1128, 82nd Leg., Reg. Sess. (Tex. 2011).

[661] D.C. CODE ANN. § 21-2210(a)(5a) (West 2017); IND. CODE § 16-36-1-5(a)(3) (2016); IND. CODE § 16-36-4-13(g)(7) (2016); TEX. HEALTH & SAFETY CODE ANN. § 313.004(a)(5) (West 2015).

[662] Harvard Community Ethics Committee, *Medical Decision-Making for Unknown and Unrepresented Patients* (Mar. 2016) (report submitted to the Harvard Ethics Leadership Group. The Board of Chaplaincy Certification Inc. certifies professional chaplains according to established national qualifications. BCCI Certification, BOARD OF CHAPLAINCY CERTIFICATION INC., http://www.professionalchaplains.org/ (last visited June 16, 2017).

[663] *See, e.g.*, Walter F. Roche, Jr., *Last Minute Change in Law Lets Hospitals Drop Patients*, TENNESSEAN (Apr. 21, 2014, 7:27 PM), http://www.tennessean.com/story/news/politics/2014/04/21/last-minute-change-law-hospitals-drop-patients/7987061/.

[664] *See, e.g.*, O.C.G.A. §§ 31-36A-1 to 31-36A-7 (Temporary Health Care Placement Decision Maker for an Adult).

[665] TENN. CODE ANN. § 34-1-133 (2016); S.B. 1233, 216th Leg., Reg. Sess. (N.J. 2014).

[666] S.B. 1233, 216th Leg., Reg. Sess. (N.J. 2014).

[667] *Id.*

services agency of the county in which the hospital is located, and (3) those designated by the State of New Jersey Office of the Ombudsman for the Institutionalized Elderly.[668]

While the New Jersey legislation failed, the Tennessee legislation succeeded. Tennessee amended its conservatorship statute to permit hospitals to petition the court to appoint an "expedited limited healthcare fiduciary" to make decisions about discharging an unbefriended patient who no longer needs hospital care.[669] The authority of this "limited healthcare fiduciary" lasts for only 60 days and is for the "limited purpose of consenting to discharge, transfer, and admission and consenting to any financial arrangements or medical care necessary to affect such discharge, transfer or admission to another healthcare facility."[670]

New York, unlike New Jersey and Tennessee, has, since 2010, had an elaborate mechanism by which decisions can be made for unbefriended patients.[671] But there were still some gaps. One of those is the ability of the decision maker for unbefriended patients to authorize discharge to hospice.[672] The problem was that these decisions did not comfortably fall within the three then-existing statutory categories: (1) routine medical treatment, (2) major medical treatment, and (3) the withholding or withdrawal of life-sustaining treatment.[673] Consequently, potential hospice patients could not get the type and level of care that best served their interests. They were deprived of the comfort and benefit of hospice care.[674]

To fill this gap, New York legislators introduced bills in both 2014 and 2015 that would expressly create a means to elect hospice on

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[668] *Id.*

[669] TENN. CODE ANN. § 34-1-133 (2016); Roche, Jr., *supra* note 663.

[670] TENN. CODE ANN. § 34-1-133 (2016).

[671] Andem Effiong & Stephanie Harman, *Patients Who Lack Capacity and Lack Surrogates: Can They Enroll in Hospice?*, 48(4) J. PAIN & SYMPTOM MGMT. 745, 748 (2014). The program is now housed in the New York Justice Center for the Protection of People with Special Needs. *Surrogate Decision-Making Committee*, JUST. CTR. FOR PROTECTION PEOPLE WITH SPECIAL NEEDS, http://www.justicecenter.ny.gov/services-supports/sdmc (last visited Mar. 3, 2017).

[672] Effiong & Harman, *supra* note 671, at 747; Kirk & Dubler, *supra* note 218.

[673] *See* Karp & Wood, *Incapacitated and Alone*, *supra* note 4, at 20.

[674] Kirk & Dubler, *supra* note 218.

behalf of hospice-eligible unbefriended patients.[675] Basically, the attending physician must make the recommendation in accordance with standard surrogate decision-making standards.[676] The attending physician must then obtain both a concurring opinion by another physician and approval by the facility's ethics committee.[677] The bill passed the assembly and is now codified.[678] Many other states continue to struggle with discharges and transfers, because intramural mechanisms are insufficient.

## CONCLUSION

Most authors addressing the strengths and weaknesses of existing healthcare decision-making mechanisms for the unbefriended invoke the language of balance and equilibrium.[679] Muriel Gillick, for example, writes that "a balance must be struck between the need to protect [the unbefriended] from caregiver bias and institutional self-interest, on the one hand, and a stranger's excessive distance on the other."[680] Diane Meier writes that the decision maker must be responsive yet independent.[681]

This is an appropriate way to frame the question. On the one hand, we want a decision-making process that is accessible, quick, convenient, and cost-effective. On the other hand, we want a process that provides the important safeguards of expertise, neutrality, and careful deliberation.[682] The attending physician may be too close and the court appointed guardian may be too far. In striking the balance, we can take guidance from the sliding-scale approach taken in New York and in the VHA that provides oversight proportionate to consequences of the decision.

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[675] N.Y. PUB. HEALTH LAW § 2994-g (2016).

[676] *See id.*

[677] *Id.*

[678] *Id.*

[679] *See, e.g.*, Gillick, *supra* note 140, at 91; Meier, *supra* note 566, at 376.

[680] *See* Gillick, *supra* note 140, at 91.

[681] Meier, *supra* note 566, at 376.

[682] *See* Karp & Wood, *Incapacitated and Alone*, *supra* note 4, at 47–48; Hyun et al., *supra* note 567, at 5.

We must gather and review data to assess how these and other currently implemented processes are working. The status quo is unacceptable. The majority of states must legally authorize workable decision-making mechanisms. Failing that, facilities should follow the model of facilities in Santa Clara and Cleveland, and seriously consider adopting policies and processes on their own.

**AMA Journal of Ethics®**

**July 2019, Volume 21, Number 7: E582-586**

**HEALTH LAW**

# Five Things Clinicians Should Know When Caring for Unrepresented Patients

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## Abstract

Increasingly, clinicians confront patients who are incapacitated and have no available surrogate. Such unrepresented patients cannot consent to proposed health care, and nobody else is available who is authorized to consent on their behalf. Despite the challenge of decision making for unrepresented patients, few laws or professional organization policy statements offer a solution. This article helps fill this void by describing the top 5 things clinicians should know when they are caring for unrepresented patients: (1) realize that these patients are highly vulnerable; (2) confirm that the patient is incapacitated; (3) confirm that the patient is unrepresented; (4) appreciate variability among state law decision-making processes for unrepresented patients; (5) use guardianship only as a last resort.

## Five Things Clinicians Should Know

If a patient in a health care organization is incapacitated and has no available surrogate, this means that the patient cannot consent to proposed health care and that nobody else is available who is authorized to consent on the patient's behalf. Decision making for such unrepresented patients is a common challenge in the United States. Nevertheless, few laws or professional organization policy statements address either who should make treatment decisions for unrepresented patients or according to which criteria treatment decisions should be made.[1-3]

To provide actionable recommendations in the absence of formal guidance, this article describes the top 5 things that clinicians should know when caring for unrepresented patients. First, clinicians should realize that unrepresented patients are highly vulnerable. Second, clinicians must confirm that the patient is, in fact, incapacitated. Third, clinicians must confirm that the patient is, in fact, unrepresented. Fourth, clinicians should appreciate that state law decision-making processes for unrepresented patients are highly variable. Fifth, clinicians should use guardianship and conservatorship only as a last resort.

## Unrepresented Patients Are Highly Vulnerable

Unrepresented patients are extremely vulnerable. They not only are unable to advocate for themselves but also lack trusted and reliable friends or family to advocate for them. As such, clinicians and institutions should carefully evaluate treatment decisions made on their behalf.[3] Unrepresented patients face 3 types of treatment risks: overtreatment, undertreatment, and delayed treatment.

*Overtreatment*. The absence of an authorized surrogate often results in maximum medical intervention whether clinically and ethically warranted.[3] There are several reasons why unrepresented patients receive unnecessary or unwanted treatment, including: (1) clinicians' fear of not providing appropriate treatment, (2) clinicians' fear of civil liability for failure to treat, (3) institutional fear of regulatory sanctions, (4) clinicians' economic incentives to treat, and (5) clinicians' general interventionist philosophy of medicine.[3]

*Undertreatment*. Whereas most unrepresented patients are overtreated, some are undertreated. With no surrogate to object, some clinicians may decide that treatment is inappropriate and unilaterally withhold or withdraw it. Other clinicians may refuse to provide any type of treatment without informed consent. Consequently, important decisions may be postponed or forgone altogether.[3]

*Delayed treatment*. Finally, some clinicians will wait until an emergency when consent is implied and there is no need for a surrogate to authorize treatment. However, waiting for an emergency may result in longer periods of suffering and indignity, increasing the chance of patient morbidity or mortality. Addressing the issue of unrepresented patients, the Institute of Medicine found it ethically "troublesome" to wait "until the patient's medical condition worsens into an emergency so consent to treat is implied."[4]

In short, available evidence suggests that, in the absence of a surrogate, there is a risk that incapacitated patients will receive treatment inconsistent with their preferences or best interests. Being aware of these risks should help clinicians be more vigilant in guarding against them.

## Confirm That the Patient Is, in Fact, Incapacitated

The core challenge in decision making for an unrepresented patient is identifying who can make health care decisions for the patient when she cannot make them for herself. As long as the patient retains decision-making capacity, she can make her own health care decisions. And as long as the patient can understand the significant benefits, risks, and alternatives and can make and communicate a decision about proposed health care, there is no need for a surrogate. Unfortunately, clinicians might too quickly (and erroneously) conclude that a patient lacks capacity.

Three tips should help mitigate such errors in determining capacity. First, all patients are presumed to have capacity. Therefore, it is not the clinician's job to *prove* that the patient has capacity. Instead, it is the clinician's job to rebut the presumption and prove that the patient lacks capacity. Second, capacity is a decision-specific determination. Just because the patient lacks capacity to make more complex decisions (like surgery) does not necessarily mean that the patient also lacks capacity to make simpler decisions. Importantly, the patient may retain the ability to designate a surrogate. Third, decision-making capacity is often not a fixed state. It may fluctuate over time, such that the patient has capacity in the morning but not in the afternoon. Moreover, even if the patient lacks decision-making capacity, clinicians should restore it to the extent possible (for example, by trying alternative pain management medications).[5]

In short, clinicians should always assess capacity carefully. Except in cases of obvious and complete incapacity, clinicians should always attempt to ascertain the patient's ability to participate in the decision-making process.[6,7] The best decision maker for the patient is the patient herself. Clinicians should not turn to substitutes and alternatives unless necessary.

### Confirm That the Patient Is, in Fact, Unrepresented

If the patient is, in fact, incapacitated, then a surrogate must make health care decisions on the patient's behalf. Unfortunately, just as clinicians might too quickly conclude that patients lack capacity, they might also too quickly (and erroneously) conclude that patients lack available surrogates. Patients who appear to be unrepresented are often not, in fact, unrepresented.[3]

Three tips should help mitigate errors in determining whether patients are unrepresented. First, clinicians should make diligent efforts to ascertain if the patient has an advance directive or physician order for life-sustaining treatment. If the patient has written wishes, instructions, or orders, then those documents should guide health care decisions. In rare cases, these documents may be sufficiently clear and applicable to preclude the need for a surrogate. Second, clinicians should make diligent efforts to locate available surrogates. Social workers have a rich toolkit of strategies that often prove successful; a thorough search will usually locate a surrogate.[5] Third, clinicians should take a broad and flexible view of who can serve as the patient's surrogate. Many state default surrogate statutes specify a short, limited list of surrogate categories, usually in a priority sequence (eg, spouse, adult child, adult sibling).[3] If nobody on this list is available, clinicians should consider consulting people who know and care about the patient, even if they do not fit into categories on the statutory list.

### State Laws on Unrepresented Patients Are Highly Variable

While only a dozen states have formally specified decision-making processes for unrepresented patients, those state processes are highly variable.[3] For example, in the absence of an available surrogate, Nebraska and North Carolina permit the attending physician to make life-sustaining treatment decisions on the patient's behalf.[3] In contrast, other states require various levels of vetting and oversight for these decisions. For example, Arkansas and Tennessee require consultation with or concurrence from a second independent physician; Florida requires an independent clinical social worker for decisions about major medical treatment; and Colorado and Montana require the approval of a medical ethics committee for end-of-life treatment decisions.[3]

Clinicians should view these laws as a floor rather than as a ceiling. Because of the vulnerability of unrepresented patients, institutions in these and other jurisdictions should manage decision making through a fair process even when state law authorizes procedures with less oversight. Typically, more oversight is warranted as the invasiveness or burden of the treatment increases. Some hospital policies divide treatment into 3 categories: (1) routine medical treatment, (2) major medical treatment, and (3) life-sustaining treatment.[8-10] At least with respect to life-sustaining treatment, clinicians should consult a multidisciplinary committee even if not required by law.

## Use Guardianship and Conservatorship Only as a Last Resort

As I have written elsewhere, "Guardianship is a legal relationship that is created by state courts when a judge determines that the patient is incapacitated and unable to make decisions on their own behalf. The court creates a relationship in which the guardian is given legal authority to make decisions for an incapacitated individual."[3] In most states, guardianship (also known as conservatorship) remains the only officially recognized mechanism by which treatment decisions can be made on behalf of the unrepresented.

At first, guardianship looks like a good solution. The formal judicial process helps ensure neutrality, impartiality, and public accountability. But, as I have written elsewhere, guardianship is generally considered "neither a preferred nor an adequate solution."[3] Both legal and medical commentators "have overwhelmingly concluded that the disadvantages of guardianship significantly outweigh the advantages."[3] The process is slow and expensive. And it is often ineffective, either because a guardian cannot be found or because the guardian has real or perceived constraints on his or her ability to make decisions in the patient's best interest. "Consequently, guardianship is generally considered to be a last resort option, to be used only after all other less restrictive alternatives have been exhausted."[3]

## Conclusion

While the challenge of decision making for unrepresented patients has been documented for decades, there is still no consensus on the proper solution. Few legislatures, regulators, or professional societies have developed laws or policies to adequately protect this vulnerable population. Worse, the few laws and policies that exist are inconsistent and variable in terms of the oversight required for treatment decisions. Therefore, the main contribution of guidelines is likely to be at the institutional level.

## References

1. Pope TM. Making medical decisions for patients without surrogates. *N Engl J Med*. 2013;369(21):1976-1978.
2. Pope TM. Legal fundamentals of surrogate decision making. *Chest*. 2012;141(4):1074-1081.
3. Pope TM. Unbefriended and unrepresented: medical decision making for incapacitated patients without healthcare surrogates. *Ga State Univ Law Rev*. 2017;33(4):923-1019.
4. Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: National Academies Press; 2015.

5. Moye J, Catlin C, Kwak J, Wood E, Teaster PB. Ethical concerns and procedural pathways for patients who are incapacitated and alone: implications from a qualitative study for advancing ethical practice. *HEC Forum*. 2017;29(2):171-189.
6. Miller TE, Coleman CH, Cugliari AM. Treatment decisions for patients without surrogates: rethinking policies for a vulnerable population. *J Am Geriatr Soc*. 1997;45(3):369-374.
7. Farrell TW, Widera E, Rosenberg L, et al; Ethics, Clinical Practice and Models of Care, and Public Policy Committees of the American Geriatrics Society. AGS Position statement: making medical treatment decisions for unbefriended older adults. *J Am Geriatr Soc*. 2017;65(1):14-15.
8. Decision-making for unrepresented patients. Thaddeuspope.com. http://thaddeuspope.com/images/Unrepresented-Patients-1_SOCAL_BIOETHICS.pdf. Accessed May 22, 2019.
9. Cleveland Clinic policy on medical decision-making for patients lacking decision making capacity who do not have a surrogate decision-maker. Thaddeuspope.com. http://thaddeuspope.com/images/CLEVELAND_CLINIC_Policy_on_Patients_without_Surrogates_a.pdf. Published April 20, 2009. Accessed May 22, 2019.
10. Stanford Hospital and Clinics. Health care decisions for patients who lack capacity and lack surrogates. Thaddeuspope.com. http://thaddeuspope.com/images/Stanford_Health_Care_Decisions_For_Patients_Who_Lack_Capacity_and_Surrogates_7_09.pdf. Published July 2009. Accessed May 22, 2019.

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**Citation**
*AMA J Ethics*. 2019;21(7):E582-586.

**DOI**
10.1001/amajethics.2019.582.

**Conflict of Interest Disclosure**
The author(s) had no conflicts of interest to disclose.

**ISSN 2376-6980**

THE AMERICAN JOURNAL OF BIOETHICS
2025, VOL. 25, NO. 9, 57–59
https://doi.org/10.1080/15265161.2025.2529944

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OPEN PEER COMMENTARIES

# Procuring Organs from Unrepresented Patients: Amend the Uniform Anatomical Gift Act

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Shea rightly calls for "more reflection and debate" about how we treat unrepresented patients, the most vulnerable members of society (Shea 2025). I have called for the same thing in a long series of articles and presentations, many of which Shea cites and quotes. Because the stakes are comparatively more substantial, Shea focuses on those cases when a choice must be made regarding whether the patient should receive life-sustaining treatment. In that context, he argues for the superiority of the "medical futility standard" over the traditional best interest standard. While I disagree with Shea's conclusions, I sympathize with his quest for more "stringent" and more "demanding" decision-making standards. Shea is correct that we should afford unrepresented patients "greater moral protection" (Shea 2025). Shea is also correct that we must "change current policies and practices" regarding unrepresented patients.

In this Article, rather than focus on decisions regarding life-sustaining treatment, I focus on another comparatively neglected situation: organ procurement. A new Uniform Law Commission Study Committee has just begun considering changes to the Uniform Anatomical Gift Act (UAGA). Guided by Shea's strong protectionist principles, I propose three amendments that can better protect unrepresented patients.

## ORGAN PROCUREMENT FROM UNREPRESENTED PATIENTS

The Uniform Law Commission first approved the UAGA in 1968. By 1972, it was adopted by all U.S. jurisdictions. While its 1987 amendments were less widely adopted, the Uniform Law Commission's most recent amendments, in 2006, were adopted by 48 states. So, today, the UAGA provides rules and standards for organ procurement almost everywhere in the United States (UAGA 2006).

Under the UAGA, if an individual made a choice in their lifetime and left either first-person authorization or first-person refusal, that choice is dispositive and binding (UAGA § 8). But when there is no such evidence of the individual's wishes, OPOs seek authorization from other persons. The UAGA provides nine categories of persons who can provide this authorization and make anatomical gifts: (1) agent, (2) spouse, (3) adult child, (4) parent, (5) adult sibling, (6) adult grandchild, (7) grandparent, (8) adult who exhibited special care and concern for the decedent, and (9) guardian (UAGA 2006 § 9(a)). The OPOs must proceed in a hierarchical sequence, seeking authorization from persons at the top of the list and moving down the list only when persons in higher categories are not reasonably available (UAGA 2006 §§ 9(a), 14(g)).

For three reasons, some individuals are unrepresented because they have nobody on this list. First, the individual may be unidentified. We cannot find a family member if we do not even know who the patient is. Second, the individual may have nobody on this list, for example because they have outlived all members of their family. Third, even if the people on this list exist, they may not be reasonably available at the time an anatomical gift decision must be made. Moreover, because substitute decision making rules are not identical either from state-to-state or even within a given state, some patients might be unrepresented for health care decisions yet not for anatomical gifts. Other patients might be unrepresented for anatomical gifts yet not for healthcare decisions.

For those patients unrepresented for anatomical gifts the UAGA provides a tenth category of authorized people: "any other person having the authority to dispose of the decedent's body" (UAGA § 9(a)(10)). This person is typically a coroner, medical examiner, or hospital administrator. And their authorization of organ procurement is often called "administrative

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consent" (Anaya v. City of New York 2024). This is the UAGA provision on unrepresented patients that the new Uniform Law Commission Study Committee is examining.

While nearly 20 years old, the UAGA administrative consent rules have come under growing criticism and scrutiny (Anaya v. City of New York 2024; Raho 2020; Raho et al. 2019). So, in 2025, the Uniform Law Commission appointed the *Study Committee on Postmortem Retrieval of Gametes, Safeguards for the Acquisition and Use of Anatomical Material by Non-Transplant Anatomical Organizations, and Protections for Unrepresented Donors* (Uniform Law Commission 2025). This Committee is exploring the need and feasibility of amending the UAGA regarding organ procurement from unrepresented patients.

## EXPAND CATEGORIES OF PERSONS WHO CAN MAKE ANATOMICAL GIFTS

I am unsurprisingly pleased that Shea so extensively employs my scholarship on decision making for unrepresented patients (Shea 2025). A core lesson of those articles and position statements is that we should never determine an individual is unrepresented unless we have already first exhausted avenues for finding a decision maker who knew the individual in their lifetime. The UAGA espouses this principle of "last resort" by offering nine categories of persons who can make anatomical gifts on behalf of an individual. And it requires OPOs to make a "reasonable search" for these persons (Uniform Law Commission 2006, § 14(g)). Only when none of these people is reasonably available, can the individual be considered unrepresented such that a coroner, medical examiner, or hospital administrator can act.

But the UAGA can and should focus more on prevention. It should require OPOs to take more measures to forestall the individual from being considered unrepresented. The UAGA's nine-category list is twenty years old and fails to include categories of decision makers now included on other esteemed lists of healthcare decision makers.

Highlighting the UAGA's obsolescence, in 2023, the Uniform Law Commission updated its list of default surrogates in the Uniform Health Care Decisions Act (Uniform Law Commission 2023). To reflect a "broad array of families and support systems," that list now includes, for example, not only spouse but also "domestic partner." It also includes the individual's adult stepchild "whom the individual actively parented during the stepchild's minor years and with whom the individual has an ongoing relationship." Evidence-based reasons for revising the UHCDA list apply equally to the UAGA list. So, categories of persons authorized to make anatomical gifts under the UAGA should mirror categories of persons authorized to make treatment decisions under the UHCDA.

## SPECIFY DILIGENCE TO IDENTIFY INDIVIDUALS AND FIND AUTHORIZED PERSONS

Expanding the list of persons authorized to make anatomical gifts is necessary but not sufficient. We must also ensure OPOs make diligent efforts to contact these persons. While the UAGA requires OPOs to make a "reasonable search," it remains silent on what exactly is required (UAGA §§ 2(23) 9(a), 14(g)). What makes a search "reasonable"?

Recent high-profile court cases suggest that guidance is needed. These cases suggest that OPOs sometimes move too quickly to conclude the individual is unrepresented. In one case, New York facilities gave administrative authorization for organ procurement after determining the individual was unrepresented because they could not identify her. But a court ruled that the family credibly alleged the individual was readily identifiable from her personal belongings (Anaya v. City of New York 2024). In another case, a California OPO determined a patient's father was not reasonably available even though he was easily contacted (O'Connor v. Fresno Community Hospital 2023).

Major guidance documents from leading medical societies like the American Geriatrics Society and the American Thoracic Society place a strong emphasis on prevention (Dixon et al. 2025). The UAGA should better specify both the duration and scope of the required "reasonable search." For example, California law requires a search "for at least 12 hours" (Jacobsen v. Marin General Hospital 1999). And it requires "a check of local police missing persons records, examination of personal effects, and the questioning of any persons visiting the decedent before his or her death or in the hospital, accompanying the decedent's body, or reporting the death."

## CONSIDER THE UNREPRESENTED PATIENT'S PREFERENCES

Finally, in addition to the foregoing procedural issues, we must heed Shea's argument and also attend to substantive standards (Shea 2025). The UAGA includes nine categories of persons authorized to make anatomical gifts because that helps assure the individual's "personal preferences" are considered. But the UAGA fails to assure the same thing for unrepresented patients. While uncommon, clinicians sometimes have evidence of unrepresented patients' preferences and values. In these cases, those giving administrative authorization for anatomical gifts should consider this evidence. The UAGA should follow states like New Jersey and require this consideration.

## CONCLUSION

I applaud the Uniform Law Commission for reconsidering the manner of organ procurement from unrepresented patients. The Study Committee should recommend appointment of a Drafting Committee because: (1) the UAGA list of persons authorized to make anatomical gifts should align to the UHCDA list of default surrogates, (2) the UAGA should better define the diligence required to identify individuals and contact persons authorized to make anatomical gifts, and (3) the UAGA should require those giving administrative consent to consider available evidence of the patient's preferences and values.

## DISCLOSURE STATEMENT

Professor Pope was a paid expert witness in California state court litigation concerning identification of persons authorized to consent to anatomical gifts. O'Connor v. Fresno Community Hospital, No. 18CECG01184 (Fresno County Superior Court, Cal. 2023).

## FUNDING

The author(s) reported there is no funding associated with the work featured in this article.

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## REFERENCES

Anaya v. City of New York. 2024. New York County Supreme Court, NY No. 154130/2023.

Dixon, J. D., A. V. Josyula, N. M. Javier, Y. Zweig, M. Singh, L. Kim, N. Thothala, and T. W. Farrell.,. 2025. American Geriatrics Society position statement: Making medical treatment decisions for unrepresented older adults. *Journal of the American Geriatrics Society* 73 (5):1353–64. doi:10.1111/jgs.19288.

Jacobsen v. Marin General Hospital 1999. No. 97-16139 (9th Cir. Sept. 15, 1999), affirming, 963 F. Supp. 866 (N.D. Cal. 1997) (citing Cal. Health & Safety Code § 7154.40(a)(10)).

O'Connor v. Fresno Community Hospital. 2023. No. 18CEC G01184 (Fresno County Superior Court, Cal. 2023) (settlement).

Raho, J. A. 2020. Should unrepresented homeless persons become deceased organ donors? *Clinical Transplantation* 34 (3):e13788. doi:10.1111/ctr.13788.

Raho, J. A., K. Brown-Saltzman, S. G. Korenman, F. Weiss, D. Orentlicher, J. A. Lin, E. A. Moreno, K. Nuri-Robins, A. Stein, K. E. Schnell, et al. 2019. Ethics of organ procurement from the unrepresented patient population. *Journal of Medical Ethics* 45 (11):751–4. doi:10.1136/medethics-2019-105584.

Shea, M. 2025. The ethical standard for end-of-life decisions for unrepresented patients. *The American Journal of Bioethics* 25 (9):72–83. doi:10.1080/15265161.2024.2416122.

Uniform Law Commission 2006. Uniform Anatomical Gift Act. https://www.uniformlaws.org/viewdocument/final-act-19?CommunityKey=015e18ad-4806-4dff-b011-8e1ebc0d1d0f&tab=librarydocuments.

Uniform Law Commission 2023. Uniform Health Care Decisions Act. https://www.uniformlaws.org/committees/community-home?CommunityKey=3df274d6-776b-4780-8e4e-018a850ef44e.

Uniform Law Commission 2025. Study Committee on Post-Mortem Retrieval of Gametes, Safeguards for the Acquisition and Use of Anatomical Material by Non-Transplant Anatomical Organizations, and Protections for Unrepresented Donors. https://www.uniformlaws.org/committees/community-home?CommunityKey=f89709fe-1905-452b-9ffe-019355699e8a.