

MEDICINE AND SOCIETY

Debra Malina, Ph.D., *Editor***Who Decides When a Patient Can't? Statutes on Alternate Decision Makers**

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Many patients cannot make their own medical decisions, having lost what is called decisional capacity. The estimated prevalence of decisional incapacity approaches 40% among adult medical inpatients and residential hospice patients^{1,2} and exceeds 90% among adults in some intensive care units.^{3,4} Patients who lack capacity may guide decisions regarding their own care through an advance directive, a legal document that records treatment preferences or designates a durable power of attorney for health care, or both. Unfortunately, the rate of completion of advance directives in the general U.S. population hovers around 20 to 29%,⁵⁻⁷ creating uncertainty about who will fill the alternate decision-maker role for many patients.

There is broad ethical consensus that other persons may make life-and-death decisions on behalf of patients who lack decisional capacity. Over the past few decades, many states have enacted legislation designed to delineate decision-making authority for patients who lack advance directives.⁸ Yet the 50 U.S. states and the District of Columbia vary in their procedures for appointing and challenging default surrogates, the attributes they require of such persons, their priority ranking of possible decision makers, and dispute resolution. These differences have important implications for clinicians, patients, and public health.

Patients often reside in one state and receive care in another, and about one fifth of U.S. physicians maintain medical licenses in multiple states.⁹ When faced with variable local statutes, health care systems that cross state lines may struggle to formulate uniform institutional policies regarding medical decision making for patients who lack decisional capacity, especially for

end-of-life care. Clear consensus guidelines focused on life-sustaining interventions also rest in part on assumptions of nationally consistent parameters for decision making, which may not be supported by law.¹⁰ More broadly, examination of the variability in statutes may expose the ways in which patients and medical decisions may be treated differently in different jurisdictions.

We therefore evaluated relevant statutes that we identified in parallel searches using two legal databases: LexisNexis and Fastcase. Search terms included “living will,” “advance directive,” “surrogate,” “health care decisions,” and “health care power of attorney.” Statutes pertaining to health codes, safety, insurance, and probate law were assessed through sequential, independent reviews. All analyzed statutes were effective in their jurisdictions as of March 31, 2016.

DEFINITIONS AND ADJUDICATION

Precise terminology describing persons who exercise decisional authority for an incapacitated patient is essential to elucidating statutory variability. We use “alternate decision maker” to refer to any person participating in decision making for such a patient, regardless of whether he or she was appointed by the court, the patient (in an advance directive), or a default-surrogate statute. A person who assumes decisional authority without having been appointed through the judicial system or prospectively authorized by the patient at a time when he or she had decisional capacity is a “default surrogate.” Legislation regulating default-surrogate consent in many states sets forth a hierarchical priority list of persons to serve as decision makers, which we call a “surrogate ladder.”

We tabulated nomenclature describing the types of alternate decision makers in each state (for the purposes of our discussion, the District of Columbia is considered a state) and searched statutes for language providing for designation of a default surrogate if the patient did not have a durable power of attorney for health care or a judicially appointed guardian. We evaluated all statutes for criteria for appropriateness of an alternate decision maker, characterizing the features highlighted as necessary for someone to serve in that capacity.

We also evaluated the hierarchical treatment of potential alternate decision makers in each state. Laws outlining a surrogacy ladder were identified. If there was such a ladder, we noted the specific circumstances under which it was invoked and evaluated the priority of persons (or classes of persons) it included.

Finally, we searched for statutes' proposed solutions to disputes that arise among surrogates, and we identified states that had a provision for extrajudicial challenge in the event that a health care provider or other interested party questioned the appropriateness of the person appointed through the default-surrogate hierarchy.

DEFINING WHO CAN SERVE

We found that all 50 states and the District of Columbia have laws addressing decision making for incapacitated patients. The statutes, however, use diverse terminology in discussing alternate decision makers (whether court-appointed, patient-designated, or default). Neighboring states may use different terms to refer to decision makers authorized through the judicial system, for instance. Moreover, only a minority of states are internally consistent in the terms they use to describe a given group of decision makers.

Required attributes for alternate decision makers vary substantially among states, and we noted disagreement regarding the need to demonstrate qualities such as decisional capability, availability, willingness to serve, and familiarity with the patient's preferences (Fig. 1, and see the interactive graphic, available at [NEJM.org](http://nejm.org)). Though being an adult is a nearly universal prerequisite (50 of 51 jurisdictions), the age of adulthood is variably defined as 18 years (in 48), 19 years (in 2), and 21 years (in 1). Eight statutes' definitions of "adult" also include mature or

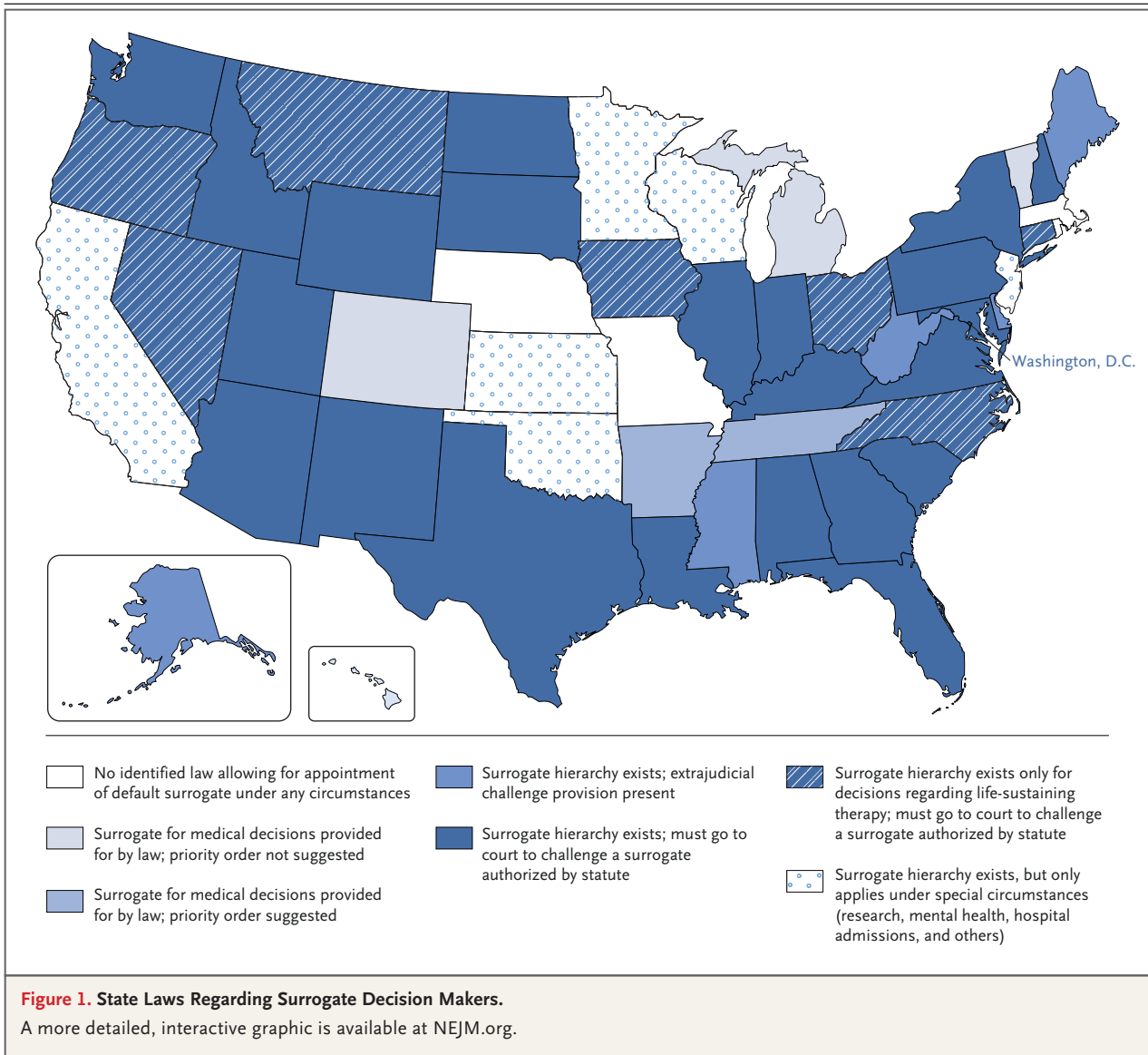
emancipated minors, conceivably providing an avenue for a minor to serve as an alternate decision maker in rare circumstances. Thirty jurisdictions require that alternate decision makers demonstrate the ability to engage in complex medical decision making. However, no state comments on the manner in which a physician would assess such a quality in an alternate decision maker, since that person is not the physician's patient.

Thirty-six states indicate that the alternate decision maker should be "willing to act," though none clarify how "willingness" should be determined. Some statutes list but do not define attributes such as "reasonably available," whereas others include multiple paragraphs outlining requirements such as frequency of contact with the patient before and during the incapacitating illness and availability to meet in person with health care providers. Similarly, "special care and concern" is sometimes listed as a requirement for any alternate decision maker and sometimes applied only to a friend serving in that capacity.

States also outline groups whose ability to serve as decision makers is restricted to cases in which they are related to the incapacitated patient by blood, marriage, or adoption. The group most commonly prohibited from serving as alternate decision makers is health care providers, with 35 states limiting or prohibiting their service in this role.

Of the 51 jurisdictions, 41 have a provision allowing for appointment of a default surrogate for medical decision making in the absence of an agent (Fig. 1). Six states include provisions for default-surrogate decision making without requiring a priority order for persons serving in that capacity, though two of these suggest and outline a descending order of preference. In contrast, 28 have a surrogacy ladder for all medical decisions, while 7 mandate a hierarchy only for decisions about withdrawing or withholding life-sustaining therapies. Six states mandate that default-surrogate ladders be followed only under particular circumstances — most commonly, consent for research participation. Four states are silent on the topic of default-surrogate decision making.

In the 35 states that establish a surrogate hierarchy, the highest-priority classes always include spouse, child, and parent, though 8 states




 An interactive graphic is available at NEJM.org

also insert partner or “chosen adult” on or immediately below the first ladder rung (Fig. 1). There is substantial divergence after the fourth rung and in the classes and number of classes listed. Whereas some ladders recognize institutional mechanisms for decision making (appointing a physician or group of physicians, a social worker, or a hospital ethics committee), others list only family members, sometimes even going so far as to stipulate that surrogates be related within the second (Missouri) or third (Wisconsin) degree of kinship or affinity.

With regard to same-sex relationships, seven states provide for a partner or common-law

spouse to occupy one of the top rungs, displacing first-degree relatives in the priority order, and one state (Arizona) lists unmarried “domestic partner” in fourth priority. One state (Oregon) allows for a “chosen adult” to occupy the second rung if this appointment is agreeable to all remaining persons listed on the default ladder. Twenty-three statutes allow a friend, often defined as an “interested person” (e.g., Arizona) or “an adult who has exhibited special care and concern” (e.g., Alaska) to occupy a low rung.

Twenty-two states have legislated solutions for disputes arising among multiple potential alternate decision makers, with 14 espousing a

“majority rules” approach when equal-priority surrogates disagree and 7 requiring consensus for care decisions to proceed. In the presence of multiple potential surrogates, West Virginia allows “the attending physician or the advanced nurse practitioner [to] . . . select . . . the person who reasonably appears to be best qualified,” theoretically circumventing the need for later conflict resolution. The treating provider may even authorize a person who is “ranked lower in priority if, in his or her judgment, that individual is best qualified . . . to serve as the incapacitated person’s surrogate.”¹¹ In the event of an impasse, some states outline procedures for advanced conflict resolution, such as deferral to the opinion of the physicians or referral to an impartial hospital committee or to probate court.

Grounds for rebutting the authority of a default surrogate vary considerably. Five of 35 states with a mandatory hierarchy outline an extrajudicial procedure for challenging a statutorily derived default surrogate; in the remaining states, such a rebuttal would be within the purview of the court. Illinois includes a provision for replacing a default surrogate who is “not available . . . after reasonable inquiry,” but neither availability nor reasonable inquiry is further defined. Even among states allowing extrajudicial challenges, the courts provide a final pathway for any person to appeal the authority of a default surrogate.

IMPLICATIONS FOR PATIENTS, PHYSICIANS, AND POLICY

Despite widespread ethical agreement on the importance of respect for persons and patient autonomy in making medical decisions, laws governing clinical decision making for incapacitated patients vary widely according to jurisdiction. Current ethical standards for medical care arose from decades of biomedical ethics scholarship and a gradual shift away from paternalism toward a more patient-centered approach.¹²⁻¹⁴ The primacy of patient autonomy extends to patients who cannot participate in decision making, and the proportion of such patients is likely to grow in concert with the aging of the U.S. population, the associated incidence of conditions (e.g., dementia) that limit capacity, and the use of sophisticated life-sustaining technologies. For example, Silveira et al. reported that among elderly de-

cedents for whom a treatment decision had been required in the final days of life, 70% lacked decisional capacity.¹⁵ Lack of consistency even on relatively simple facets of state legislation, such as the language describing essential decision-making roles, poses barriers to ensuring safeguarding of patients’ choices in their most vulnerable moments and to promoting improved quality of care and decisions made at the end of life.

Indeed, advance-directive statutes were adopted in the wake of highly publicized court cases involving patients who survived anoxic brain injury but were left in persistent vegetative states.^{16,17} These cases centered on the decision to withdraw life-sustaining therapy as an expression of self-determination and autonomous choice, exercised through alternate decision makers. Since 1990, health care institutions have been required to ask patients if they have advance directives and inform them of their rights regarding such documents.¹⁸ Yet there is no national standard format valid in all 51 jurisdictions,¹⁹ and state laws historically did not acknowledge anyone’s authority to make decisions for incapacitated patients in the absence of a valid advance directive or judicially appointed guardian.¹⁸ Recognizing the challenges posed by low rates of completion of advance directives, states began drafting default-surrogate statutes in the 1990s.

Accordingly, we found that 41 jurisdictions include a provision for appointment of a default surrogate for at least some health decisions, thereby legally recognizing the decisional authority of default surrogates and providing a safety net for incapacitated patients without advance directives. Yet the considerable variation in relevant state legislation runs counter to calls to support and improve end-of-life care nationwide.

It is unclear whether the heterogeneity we identified truly reflects differences in closely held principles regarding care based on deliberative legislative reflection or simply a failure to achieve — or a lack of interest in building — any national consensus. For example, whether differences in the rigidity, conditions for use, or specific outlines of surrogacy ladders map to defensible ethical or legal principles or merely reflect arbitrary choices of statute authors remains uncertain. Resolving such variability, however, is a prerequisite for essential empirical work regarding decision making for patients without capac-

ity. For example, whether different surrogacy ladders or situation-specific hierarchies (e.g., those applicable to research consent or mental health decisions) align with actual preferences is unknown.²⁰ Harmonization of states' approaches to alternate decision makers may therefore facilitate necessary research while mitigating potential confusion and conflict.

In addition, it remains unclear whether patient care or other outcomes related to decision making for incapacitated patients vary in parallel with state laws. Several key questions need to be examined: the frequency with which surrogate ladders are invoked and to what rung they tend to be pursued; reasons why potential alternate decision makers are rejected in practice; and the prevalence and outcomes of extrajudicial challenges. In-depth answers to these questions and continued theoretical and empirical work elucidating the sources and meaning of state-to-state variability will be important marks of progress.

At a minimum, patients, providers, and health care systems should be aware of the variability in laws, which may impede national efforts to support and research advance care planning and compassionate end-of-life decision making. Working toward consensus definitions and standards will require focused discussion about the roles of federal and state governments in health care regulation and about whether the ethical principles guiding decision making are truly universal and supported as such in the law.

Dr. Mueller reports receiving consulting and lecture fees from Boston Scientific. No other potential conflict of interest relevant to this article was reported.

Disclosure forms provided by the authors are available with the full text of this article at NEJM.org.

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DOI: 10.1056/NEJMs1611497

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