

Peter C. Harman: 'Locked-In' to Their Decisions: Investigating How the States Govern Revocation of Advance Directives and How Three States Make Revocation Impossible for People with Locked-In Syndrome

HASTINGS SCIENCE & TECHNOLOGY LAW JOURNAL

'Locked-In' to Their Decisions: Investigating How the States Govern Revocation of Advance Directives and How Three States Make Revocation Impossible for People with Locked-In Syndrome

PETER C. HARMAN*

CITE AS: 3 Hastings Sci. & Tech. L. J. 193
<http://hstlj.org/content/vol3/iss1/v3i1harman.pdf>

I. Introduction:

On December 28, 1995, Jean-Dominique Bauby woke up in a hospital unable to move, unable to speak.¹ The doctors, nurses—even his loved ones—spoke to each other about him as if he was not there.² His caretakers and family tried to talk to him, but he could not respond. Eventually, they noticed that he was able to blink one eyelid in response.³ Elated, they brought in a specialist to facilitate communication.⁴ “What do you want?” they asked.⁵ His first communication in weeks was a one-word answer: “Death.”⁶

In recent years, much thought has been given to how to best implement the wishes of patients with traumatic brain injuries, like Terri Schiavo.⁷ In some cases, like Schiavo's, the debate is over which family member can make the decisions that best reflect what the patient would have wanted.⁸ Since the late 1970s, most states have enacted laws that allow people to set out their preferences for health care decisions in advance directives, in case the person becomes incapacitated or loses the ability to communicate her preferences.⁹ The advance directive statutes give people the opportunity to make those important choices in advance, while they still have the mental acuity to make well-informed decisions. Importantly, these statutes also allow the declarant to change her mind in the future, either by revoking the advance directive or by modifying her previously expressed preferences. That way, if circumstances change, or if unexpected situations arise, the advance directive documents are flexible. The key to these documents is that when the person loses the ability to make those

decisions, her choices are set so that no other person can make contrary decisions unless they are specifically authorized to do so.

There is, however, one class of people who still have one hundred percent of their mental faculties, but have lost the opportunity to change their minds about their advance directives. People who have locked-in syndrome are catastrophically paralyzed; they often can only communicate by blinking.¹⁰ While each state treats the revocation and modification of advance directives differently, some states make it more difficult than others for locked-in patients to legally change their minds. Some states even make it impossible.

If Mr. Bauby had executed an advance directive requiring the doctors to prolong his life by any means possible, would he have been able to change his directive? More chillingly, if he had requested in his advance directive to have life support removed after several months, and now wanted to continue living by any means possible, could he change his mind then? In the United States, those answers would depend upon the state in which state Mr. Bauby lived.¹¹

Advance directives often enshrine what are literally life-and-death decisions, including when to remove life support. In several states, a locked-in patient would not be able to comport with the formalities required to modify or revoke an advance directive, even if the directive ordered the doctors to halt life-sustaining procedures. The revocation statutes in those states discriminate against people with locked-in syndrome because people who are locked-in are not able to employ normal means of communication. The statutes in those states violate the Americans with Disabilities Act of 1990 and must be changed.¹²

A. Locked-In Syndrome

Locked-in syndrome is a mental state in which a patient is awake and aware of his surroundings, but due to total or near-total paralysis is unable to move or speak.¹³ The condition is usually caused by trauma to the pons area of the brainstem, which acts as a relay for motor signals traveling between the brain and the body.¹⁴

Locked-in syndrome is distinguishable from other states of mental incapacity. Clinicians often categorize severe traumatic brain injury into four subgroups: coma, vegetative state, minimally conscious state, and locked-in syndrome.¹⁵ Comatose individuals are “neither awake nor aware.”¹⁶ Individuals in a vegetative state may exhibit some arousal and responsiveness, but “have no ability to interact with their environment.”¹⁷ A vegetative state is considered persistent if it lasts longer than two months and is considered permanent if it persists for longer than two years.¹⁸ An individual in a minimally conscious state exhibits more environmental interaction than a person in a vegetative state; a minimally conscious individual can “demonstrate[] inconsistent awareness of [himself] and [his] environment.”¹⁹ In contrast to the first three subcategories, patients with locked-in syndrome retain consciousness and self-awareness but are completely paralyzed, sometimes able to move their eyes or digits.²⁰ Thus, a locked-in patient whose mental faculties are intact retains a level of sensory perception and thought of a completely different order of magnitude than a patient in one of the three other categories. The most troubling aspect of locked-in syndrome, though, is the physical similarity of its symptoms to those of the vegetative state and the problems raised in trying to differentiate between vegetative and locked-in patients.²¹

Dr. Adrian Owen described a patient who was the victim of a traffic accident.²² Five months after the accident, the patient remained in a vegetative state according to standardized clinical assessment; the doctors considered her unable to interact with the environment, with

severely limited cognitive ability.²³ In spite of the patient's diagnosis, Dr. Owen attempted to detect awareness in her brain using sophisticated neuroimaging devices.²⁴ Dr. Owen's team was able to document that the patient understood verbal commands and was able to respond to them, even though under standardized diagnostic procedures she was vegetative.²⁵ Dr. Owen concluded that while the patient, to all outward appearances and in line with the standard diagnostic procedures, was in a vegetative state, she in fact exhibited awareness that would put her squarely in the realm of locked-in syndrome. Her mental faculties were worlds beyond what would be expected of someone who actually was vegetative – her cognitive reactions were indistinguishable from a healthy person's.²⁶

This difference in diagnosis changes the patient from a person who cannot make reasoned decisions about her health care to one who can and should, but is simply unable to communicate those decisions to anyone else. Some locked-in patients are able to communicate by blinking or moving an extremity,²⁷ but some, like Dr. Owen's patient, are unable to communicate through any traditional means.

Locked-in syndrome has received significant media attention after the release of a study analyzing the misdiagnosis of patients with disorders of consciousness and recent advances in communication with such patients.²⁸ In the study, attention was brought to Rom Houben, a Belgian man who was diagnosed as vegetative after a car accident in 1983.²⁹ Twenty-three years later, doctors, using neuroimaging devices, were astounded to find that he had been conscious and aware the entire time.³⁰ Unable to communicate with his family or caregivers for over two decades, Houben is now able to "speak" using special computer operated by one finger.³¹

B. New Technology Aids Locked-In Patients

New technology is emerging that radically changes the way that doctors can diagnose and communicate with locked-in patients. New methods are being developed that will allow for more accurate diagnosis of a patient's mental condition.³² The recent media attention given to locked-in syndrome, while focusing on the story of Rom Houben, was sparked by the publication of a study showing that up to four in ten patients diagnosed as vegetative show some signs of consciousness (though most in this group would be classified as minimally conscious).³³ According to the author of the study, these misdiagnoses could lead to "grave consequences, especially in end-of-life decision-making."³⁴

In a 2006 *Science* article, Dr. Adrian Owen, et al., described a new technique using functional brain imaging devices to detect awareness in patients diagnosed as vegetative.³⁵ By looking directly at the brain's energy use, Owen's team was able to detect responses to verbal commands from patients originally diagnosed as vegetative.³⁶ But even this test is not all-encompassing: Dr. Owen made clear that while this type of test can show that a patient is "aware," it cannot prove that a patient is "unaware."³⁷ The groundwork is now in place to use this technology not only to more accurately diagnose disorders of consciousness like locked-in syndrome, but to communicate with patients who otherwise would have no means of communication.³⁸

In a recent *New England Journal of Medicine* article, a team of European doctors successfully used this technology to communicate with a supposedly vegetative patient.³⁹ The patient correctly answered five of six yes or no questions; his answers were adduced by analyzing activity in discrete areas of the brain, as in Dr. Owens' study above.⁴⁰ This new method represents a functional, if rudimentary, way of first double-checking whether a

vegetative diagnosis is accurate and then providing an avenue of communication—one that did not exist even a few years ago.

Advances are also being made using “Brain-Computer Interface,” which allows a locked-in patient to use thoughts to type messages or even turn thoughts directly into computer-generated speech.⁴¹ This new technology allows a locked-in patient, even one who cannot move a digit or his eyes, to make “verbal” statements and also to produce written documents a computer.

C. Advance Directives

An advance directive, or living will, is a document that allows a person (the principal or declarant) to express, in a legally binding fashion, his preferences for medical care should he later become incompetent or unable to communicate; one may also name a surrogate decisionmaker or agent in an advance directive.⁴² State laws regulate advance directives.⁴³ An important aspect of the advance directive document is that it must be able to be modified or revoked if the principal so chooses. A principal may choose to change the named surrogate decisionmaker, he may choose to change his expressed treatment preferences, or he may choose to revoke the document altogether.

Considering that advance directives can be executed without the advice of an attorney or other specialist, the patient executing the advance directive may not take into consideration every possible contingency.⁴⁴ Take, for instance, a person in Bauby’s situation, above. Locked-in syndrome may bring with it a set of circumstances that the patient had not considered when drafting the advance directive. If the subjective experience of the condition was such that the patient could no longer bear the suffering, that patient might wish to modify his advance directive so as to allow the removal of life-sustaining procedures. On the other hand, a patient might, while he is healthy, think that he would not want life-prolonging procedures after a catastrophic accident. The patient, like Bauby eventually did, might decide after the accident that he wants to continue living by any means possible.⁴⁵ This would bring about a nightmarish situation in which the patient wishes to continue living, but has an effective legal document that instructs the physicians to allow him to die. In that situation particularly, it is absolutely imperative that the patient be able to modify or revoke a previously executed advance directive—it is literally a life-or-death situation.⁴⁶

D. The Function of Formalities in Executing Advance Directives

Formalities are necessary for an advance directive to be validly executed; they are what the declarant or others must do to make the document legally effective.⁴⁷ Required formalities can include witnesses, notarization, or other requirements such as a signed writing.⁴⁸ Formalities associated with revoking advance directives serve several purposes.⁴⁹ The purposes of formalities fall into four general categories: (1) ritual/cautionary function, (2) evidentiary function, (3) protective function, and (4) channeling function.⁵⁰

The ritual/cautionary function of formalities seeks to assure that the declarant is aware of the gravity of his action and “preclude[] the possibility that the testator was acting in a casual or haphazard fashion.”⁵¹ The evidentiary function of formalities increases the reliability of proof of the declarant’s intention in executing the document—a written document is a more stable embodiment of the declarant’s intent than an oral statement.⁵² The protective function assures

that there is no coercion or undue influence underpinning the document's execution.⁵³ Finally, the channeling function of formalities serves to standardize the "organization, language, and content" of the documents.⁵⁴

Professor Gregory Gelfand argued that formalities applicable to the execution of advance directives are no less applicable in the revocation or modification of them.⁵⁵ Gelfand contended that in order to avoid the exact pitfalls that formalities of execution serve to prevent, they should be applied equally to revocation and execution.⁵⁶

Formalities do indeed serve important functions in protecting the true intent of the declarant, but they can also serve to hinder that intent. Gulliver and Tilson warn that formalities of execution "surely should not be revered as ends in themselves, enthroning formality over frustrated intent."⁵⁷ Dogmatic adherence to the strictures of formality can easily frustrate the intent of a declarant when his intention is clear and undisputed but some defect in execution injures the validity of the document.⁵⁸ Therefore, while formalities in execution do serve important purposes, their utility decreases dramatically when they serve to frustrate the declarant's intent.

E. The Goal of this Note

A locked-in patient deserves all of the rights and protections available to every mentally competent American.⁵⁹ Misdiagnosis may rob the patient of the opportunity to assert those rights because a patient misdiagnosed as vegetative will be assumed to not have awareness or independent thought. Technology is indeed emerging that would allow a totally paralyzed person to communicate using instruments that analyze brain function,⁶⁰ but in some jurisdictions that sort of communication may not be sufficient for a patient to legally change his advance directive.⁶¹

This paper seeks to analyze how state laws currently dictate whether a locked-in patient may revoke or modify a medical advance directive. Because a locked-in patient is at an extreme end of the spectrum of physical communicative ability, the locked-in state serves as a useful lens through which to analyze how the law treats differently individuals who have some difficulty in communicating with others, even though their mental faculties are fully intact. By analyzing the laws through the viewpoint of one in a locked-in state, a clear light can be shed upon the law's differential treatment of those with communicative disabilities.⁶²

II. Survey of the States

Forty-eight states approve of the use of advance directives by statute.⁶³ The statutes elucidate the procedures required to validly modify or revoke an advance directive.⁶⁴ These statutory procedures can be grouped into three main frameworks: the Majority Approach, the Third Party Approach (which has two subdivisions), and the Principal-Only Approach. There are also two other characteristics of these revocation statutes that the states address differently, but their full analysis is beyond the scope of this paper.

A. The Three Major Frameworks

The most common statutory scheme allows a patient to modify or revoke an advance directive "at any time and in any manner by the declarant"⁶⁵ or "at any time and in any manner that communicates an intent to revoke."⁶⁶ This is the broadest type of language and allows a

wide range of actions by a patient to validly revoke or modify an advance directive. This language is used by a majority of states and is also the framework adopted by the Uniform Health-Care Decisions Act;⁶⁷ it is followed by Alaska, Arizona, Arkansas, California, Connecticut, Delaware, Georgia, Hawaii, Illinois, Iowa, Louisiana,⁶⁸ Maine, Minnesota, Mississippi, Missouri, Montana, Nebraska, Nevada, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Dakota, Vermont, and Wyoming.⁶⁹ This framework is the “Majority Approach.”

The second and third types of governing statutes usually list several ways that an advance directive may be modified or revoked.⁷⁰ The directives are generally revocable orally or in writing or by some physical act that manifests an intention to revoke the document, such as “being canceled, defaced, obliterated, burned, torn or otherwise destroyed.”⁷¹ Seventeen jurisdictions fall under this broad category; there is a very important split within these jurisdictions, though.

Fourteen of these jurisdictions allow a third party, acting at the direction of the declarant, to effect the cancellation or modification of the document. Most of these jurisdictions (Florida, Idaho, Indiana, Kentucky, New Hampshire, South Carolina, Texas, Virginia, Washington, and Wisconsin) require that the third party acting on behalf of the declarant do so “in the presence” of the declarant.⁷² Four states (Alabama, Kansas, Utah, and West Virginia) do not require the third party to perform the revoking act in the principal’s presence, but only require that they act at his “direction.”⁷³ Whether or not they require “presence,” these seventeen jurisdictions are the “Third Party” jurisdictions.

The remaining three states require the canceling act to be performed by the principal to the directive.⁷⁴ Tennessee requires a written statement signed by the principal or an oral statement made by the principal.⁷⁵ Maryland⁷⁶ and Colorado⁷⁷ similarly require oral or written expression and also accept a physical act by the declarant to revoke an advance directive. Colorado, for instance, allows revocation “by the declarant orally, in writing or by burning, tearing, canceling, obliterating, or destroying said declaration.”⁷⁸ This most restrictive approach is the “Principal-Only” approach.

B. Other Jurisdictional Differences

Another jurisdictional split, apart from the above three major frameworks, is that some jurisdictions only allow modification or revocation of a directive if the declarant is competent or not incapacitated, while others allow modification regardless of the principal’s mental state.⁷⁹ Many states do not address capacity in this context.⁸⁰ Of the forty-eight states with statutes governing advance directives, twenty-one⁸¹ allow a declarant to modify or revoke a directive “regardless of the mental or physical condition of the principal.”⁸² Ten of the jurisdictions explicitly require that a declarant have capacity in order to validly modify or revoke an advance directive.⁸³ The remaining seventeen states do not specifically address mental capacity in this context.⁸⁴

A final feature of states’ statutes regarding advance directives is that in many cases there is a different procedure for revoking the designation of an agent or surrogate for health care decisions.⁸⁵ In those cases, the procedure for revoking the designation of a proxy decisionmaker is more circumscribed than the procedure to revoke a directive.⁸⁶ For instance, in Alaska a declarant may revoke an advance directive “in any manner that communicates an intent to revoke,”⁸⁷ but may only revoke the designation of an agent “by a signed writing or by

personally informing the supervising health care provider.”⁸⁸ In other jurisdictions, the same procedure can serve to change an agent’s designation as can be used to modify or revoke the document.⁸⁹

III. Effects of the Three Existing Frameworks in Real-World Settings

Each of the three frameworks of law (the Majority Approach, the Third Party Approach, and the Principal-Only Approach) affects a locked-in patient’s ability to modify or revoke an advance directive differently. The Majority Approach is the most forgiving scheme for a patient with a communicative disability—the language is broad enough so that any means of communication by the patient is sufficient to validly modify an advance directive, but this framework dispenses with the safeguards of the formalities of execution. The Third Party Approach still allows locked-in patients to modify and revoke medical directives, but does not dispense with all of the formalities of execution, though their functions are abrogated. The Principal-Only Approach, on the other hand, keeps in place the formalities to such an extent that a locked-in patient would not be able to change a previously executed advance directive. Full exploration of the capacity and agency jurisdictional splits is beyond the scope of this paper.

A. The Majority Approach

Thirty-one jurisdictions allow a declarant to revoke or modify an advance directive by any means of effectively communicating that intent (the Majority Approach).⁹⁰ By dispensing with most formalities, these jurisdictions allow the broadest range of actions to validly revoke or modify an advance directive. The statute in effect in California is representative of the typical Majority Approach statute; it follows the Uniform Health-Care Decisions Act.⁹¹

California allows revocation “at any time and in any manner that communicates an intent to revoke.”⁹² This exceptionally broad language eliminates any formalities associated with the revocation. The “in any manner” language would allow a patient to revoke an advance directive using any of the methods named in the other statutes: oral or written notification or any of the physical methods because those methods clearly express the intent to revoke. This language also encompasses certain other avenues of communication that are important to locked-in patients, including communication by blinking or communication which utilizes technology, including specialized computers, brain-computer interface, and neuroimaging devices.

The positive impact of this language is that people with communicative disabilities will be able to modify or revoke their advance directives so long as there is some possible method of communication. The continuation or withholding of life-support measures will likely be an important issue for the patient given his precarious state of health and his difficulty in interacting with the world.⁹³ As such, it is important for a locked-in patient to have the legal ability to modify or revoke a previously executed advance directive if that document no longer embodies the patient’s current desires regarding health care.

On the negative side, this type of statute dispenses with practically all of the formalities associated with revoking and modifying advance directives. As discussed above, formalities of execution have important roles to play in assuring that the executed document expresses the declarant’s true intent, free from coercion and duress. Most important in the case of revoking or

modifying an advance directive are the ritual, evidentiary, and protective functions because a locked-in person is in a vulnerable position where being taken advantage of could be a life-or-death situation.⁹⁴

To completely eliminate formalities is to remove important procedural safeguards. Gelfand argues against the loosened formalities associated with this approach.⁹⁵ Gelfand, however, argued this is based on the unfounded (or, looking to new developments in technology, no longer true) assumption that all conscious patients will be able to comply with every state's formalities, given enough time.⁹⁶ While requiring strict formalities in modifying or revoking advance directives serves important interests, those interests are moot if it becomes impossible to comply with the formalities. The Majority Approach, in putting the declarant's intent ahead of adherence to formalities, gives locked-in patients such wide latitude in executing their intent that they lose the protective functions of the formalities.

B. The Third Party Approach

Fourteen jurisdictions allow a declarant to modify or revoke an advance directive by directing a third party to make a written revocation or to physically destroy or cancel the document (the Third Party Approach).⁹⁷ All but four of these jurisdictions require that the third party do so "in the presence of" the principal.⁹⁸

There is long-developed case law that defines "presence" in regards to attestation of wills.⁹⁹ Given the similarities between a witness attesting to a will and a third party acting on a declarant's behalf to revoke an advance directive, case law defining "presence" in the context of will formalities should be illustrative in the context of using a third party to revoke or modify an advance directive. The jurisprudence of the state of Virginia is instructive as a prototype for jurisdictions that require the "presence" of a principal in this situation.

Virginia allows for revocation by a "signed, dated writing" or "an oral expression of intent to revoke."¹⁰⁰ The statute also allows "physical cancellation or destruction" of the document by the declarant or by "another in his presence and at his direction."¹⁰¹ Allowing a third party to act out a locked-in patient's will in changing or revoking a directive gives a severely paralyzed person the ability to abide by the required formalities through a proxy, thus effectuating his intent without dispensing with the formalities. An interesting wrinkle is added, though, because in many states, including Virginia, the person acting at the principal's direction must be "in his presence."¹⁰²

Substantial case law has attempted to precisely define what is meant by "presence."¹⁰³ In Virginia, the Statute of Wills requires "conscious presence"; this is distinguished from mere temporal and physical proximity.¹⁰⁴ Conscious presence is not achieved if the person whose presence is required is asleep or unconscious.¹⁰⁵ The testator must be conscious that the act is occurring *at the time that the act is in progress* to be consciously present.¹⁰⁶ Virginia law does raise a presumption of presence if the act occurs in the same room as the testator, barring evidence of fraud or incapacity.¹⁰⁷

Thus, the conscious presence test established for attestation of wills might be applied in the context of a locked-in patient seeking to revoke an advance directive. An important consideration arises here because it can be very difficult to determine whether a completely locked-in patient is conscious or unconscious without using devices to measure brainwaves.¹⁰⁸ If a patient is absolutely paralyzed, the only way to adduce the mental state of the patient would be through analyzing brain activity¹⁰⁹ or to ask the patient directly whether he was

awake and aware of the proceedings using one of the methods that allows a locked-in patient to communicate. While the conscious presence test poses an added hurdle to the process, it is an important safeguard to assure that the patient's wishes are being accurately fulfilled.

The main strength of the Third Party Approach is that it allows a patient with a severe communicative disability to modify or revoke an advance directive. As with the Majority Approach, so long as there is *some* method by which the patient can communicate with others, that patient may direct another person to revoke or modify the document on his behalf. As discussed above, health care decisions are crucial to a patient with locked-in syndrome and that patient's preferences might change over time. If the patient's wishes no longer comport with the wishes expressed in the document, it is imperative that the patient be able to change or revoke the directive. The Third Party Approach, like the Majority Approach, effectively allows a locked-in patient to modify or revoke an advance directive.

Additionally, the Third Party Approach preserves more of the formalities associated with advance directives than does the Majority Approach, while still allowing patients with communicative disabilities to effect a modification or revocation. On the other hand, the function of some of these formalities may be lost in having a third party, rather than the principal, execute the formalities. The evidentiary function is still fulfilled, because, even if a third party does the action, there will be record of it—either by a signed writing or a physically cancelled document. The ritual function is served somewhat, because an overt act is required of the third party, but the true purpose of the ritual is to impress upon the *declarant* the gravity of the action.¹¹⁰ Filtering ritual formalities through a third party dilutes the effect they would have had upon a declarant had he performed the rituals himself. Finally, the third purpose of formalities, the protective function, is almost completely lost in this situation. Allowing a third party to modify or revoke a person's advance directive opens wide the gates for undue influence and fraud.

The relevant statutes in the Third Party states allow a person to cancel an advance directive so long as he is in the declarant's presence and acting at his direction; four states (Alabama, Kansas, Utah, and West Virginia) do not require that the cancellation occur in the declarant's presence.¹¹¹ These statutes do not even specify how the declarant should signal his "direction."¹¹² A patient with severe communicative disability, like a locked-in patient, would be at the mercy of third parties who could spuriously claim they were acting at the direction of the patient. The protective function of the formalities is entirely lost in Third Party states. Thus, the Third Party Approach allows a locked-in patient to revoke or modify his advance directive without dispensing with the formalities, but in allowing a third party to act at the behest of the principal, the safeguards afforded by some of the formalities are diminished or lost.

C. The Principal-Only Approach

The statutory approach of three jurisdictions could make it impossible for a locked-in patient to modify or terminate a previously executed advance directive.¹¹³ States that employ the Principal-Only approach require that the principal to the advance directive do some physical act, such as speaking or writing, to revoke the document.

Consider a patient whose directive requires that the doctors terminate life support after eighteen months. The directive states that if, at the end of the eighteen months, the patient is still dependent on a respirator or similar devices, life support shall be removed. If this patient was locked-in but was making advances in communicating via fMRI, brain-computer interface,

or even by blinking in code, he may express his desire to keep on living—to revoke his advance directive.

Unfortunately, this patient lives in Tennessee. The patient now wishes to revoke the directive so he can continue living and working toward recovery. He is allowed one of two procedures for the revocation: he may submit to his physician a written, signed, and dated document revoking the directive or he may orally revoke the document to his physician.¹¹⁴ The patient, completely locked-in, can neither hold a pen nor speak. According to the letter of the law in Tennessee, the patient cannot change his advance directive—his doctors would be bound to remove life support at the end of the designated period.

The laws of the Principal-Only jurisdictions—Tennessee, Colorado, and Maryland—are too restrictive. By requiring the declarant to speak, sign his name, or perform some overt action (such as “burning, tearing, . . . or destroying” the document¹¹⁵), these laws do not give completely paralyzed citizens the opportunity to change their minds about previously ratified health care decisions, even when their mental abilities are completely undiminished.¹¹⁶ This most restrictive language takes the requirements of formalities so far as to make them impossible for some people to fulfill.

The only advantage to this approach is that the formalities are undiluted. But such slavish dogmatism goes so far as to make it impossible to fulfill the requirements. Even a highly functioning locked-in patient who can speak with an audible voice using brain-computer interface or who can blink to communicate would be legally unable to modify his advance directive. Such a person could communicate with his physicians, make reasoned decisions—he could even write a book¹¹⁷—but in these states he would not be allowed to change his previously expressed preferences relating to his own medical treatment.

D. The Principal-Only Approach Violates the ADA

These states arbitrarily deprive a class of people of their right to make decisions about health care. The three Principal-Only states’ laws do not allow locked-in patients to revoke or modify advance directives because of their particular difficulties in communication. This violates the Americans with Disabilities Act of 1990 (“ADA”).¹¹⁸ A prima facie case of discrimination under the ADA requires: (1) that the plaintiff has a qualifying disability; (2) “that he is being denied the benefits of services, programs, or activities for which the public entity is responsible, or is otherwise discriminated against by the public entity”; and (3) that the discrimination is founded in the disability.¹¹⁹

A locked-in patient qualifies as disabled under the ADA. Locked-in syndrome qualifies under the “first prong” of ADA disability because the impairment substantially limits “one or more major life activities” and the impairment is a “physiological disorder or condition” that affects the neurological and musculoskeletal systems.¹²⁰ “Major life activities” are defined as “functions such as caring for one’s self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working.”¹²¹ Locked-in patients are clearly disabled under the ADA.

ADA Title II protects disabled citizens from discrimination in “services, programs, and activities” by “public entit[ies].”¹²² Public entities, for the purpose of the ADA, include state governments.¹²³ Exactly what constitutes a “service, program, or activity” is broadly construed.¹²⁴ That language is characterized as “a catch-all phrase that prohibits all discrimination by a public entity, regardless of context.”¹²⁵ Specifically, ADA Title II has been

construed to cover many types of state and local governmental regulation.¹²⁶ Various state and local laws have been scrutinized under the ADA and the Second Circuit advises against “hair-splitting arguments” over what falls within its reach; state statutes governing advance directives are within the reach of ADA Title II.¹²⁷ Therefore, Title II of the ADA clearly prohibits the discriminatory effect of state laws, including those that govern advance directives.

Regulations for ADA Title II hold that “[n]o qualified individual with a disability shall, *on the basis of disability*, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any public entity.”¹²⁸ Specifically,

[a] public entity, in providing any aid, benefit, or service, may not . . . on the basis of disability (i) [d]eny a qualified individual with a disability the opportunity to participate in or benefit from the aid, benefit, or service; . . . [or] (vii) [o]therwise limit a qualified individual with a disability in the enjoyment of any right, privilege, advantage, or opportunity enjoyed by others receiving the aid, benefit, or service.¹²⁹

Thus, because locked-in patients’ extreme paralysis can prevent oral communication as well as make written communication by the patient impossible, these statutes deny locked-in individuals the opportunity to revoke or modify their advance directives. The exclusion of locked-in patients from the benefits of modification and revocation of advance directives is an exclusion based on their disabilities—the communicative disability is what prevents them from validly executing a revocation. As such, the third element of the *prima facie* ADA case is fulfilled.

The wording of the statutes in Tennessee, Colorado, and Maryland prohibit locked-in patients from modifying or revoking previously executed advance directives. The state laws governing advance directives are subject to Title II of the ADA. Locked-in patients are “qualified individual[s] with [] disabilit[ies].”¹³⁰ This discrimination stems from their communicative disabilities. Therefore, the *prima facie* case is fulfilled: These statutes violate the ADA with respect to people with locked-in syndrome.

This unacceptable curtailment of locked-in patients’ rights regarding previously executed advance directives must be remedied. The three states with discriminatory statutes should immediately adopt legislation that conforms to either the Majority or the Third Party Approach in order to halt this illegal discrimination. Any argument that alternative approaches imprudently dispense with formalities should be dismissed as overly dogmatic and as not taking into account the particular needs of people with communicative disabilities.

IV. Conclusion

The statutes governing revocation of advance directives in Colorado, Maryland, and Tennessee discriminate against locked-in patients and must be changed. If those statutes are not changed, a person with locked-in syndrome in one of those states may not be able to legally revoke her advance directive, even if the directive ordered removal of life support. The three Principal-Only states should adopt one of the other two approaches. The Majority Approach dispenses with all of the formalities of execution, but makes it easiest for people with severe communicative disabilities to change or revoke their advance directives. The Third Party Approach allows patients to direct another person to revoke or change the directive; this

approach preserves some of the formalities, but the purposes those formalities serve are mostly lost. Further complicating the Third Party Approach is the question of whether the person acting at the direction of the patient must be “in the presence of” the declarant and how to evaluate “presence” in the context of a locked-in patient.

Given that the value of the formalities is mostly lost when a third party executes them, the framework the discriminatory Principal-Only jurisdictions should adopt is the Majority Approach. The Majority Approach allows a person with severe communicative disability to revoke her directive, without the added difficulty of directing a third party to act for her. Given the rapid advances being made in alternative methods of communication for locked-in patients, allowing revocation by any means of expressing that intent gives the greatest flexibility to the law.

While locked-in syndrome is a rare condition, advances in medical science are promising to make its diagnosis somewhat less uncommon in the future. Coupled with developments in technology that aid in communication with people who have lost the ability to speak, write, or communicate by any traditional method, the more accurate diagnostic procedures bring to light a class of people who can and should be making important health care decisions, but are now hindered only by the law. Colorado, Maryland, and Tennessee should change their laws governing revocation of advance directives before the scenarios described in this paper become a real life-or-death situation for a real person.

* J.D. Candidate, University of California, Hastings College of the Law, 2011; B.A., Psychology, Colorado College, 2005. The author would like to thank the editors and staff of HSTLJ for their continuing dedication and hard work.

1. THE DIVING BELL AND THE BUTTERFLY (Miramax Films 2007).
2. *Id.*
3. *Id.*
4. *Id.*
5. *Id.*
6. *Id.*
7. Schindler v. Schiavo (*In re Schiavo*), 780 So. 2d 176, 180 (Fla. Dist. Ct. App. 2d Dist. 2001).
8. *In re Schiavo*, 780 So. 2d at 178.
9. Gregory Gelfand, *Living Will Statutes: The First Decade*, 1987 WIS. L. REV. 737, 740 n.122 (1987).
10. Steven Laureys et al., *Brain Function in Coma, Vegetative State, and Related Disorders*, 3 LANCET NEUROLOGY, no. 9, 2004 at 537, 539.
11. Mr. Bauby did eventually choose to prolong his life. He wrote a memoir entirely by blinking and he lived for 15 more months, just long enough to see his book published. *Diving Bell*, *supra* note 1.
12. 42 U.S.C. §§ 12101-12213 (2010).
13. LOCKED-IN SYNDROME, MERRIAM-WEBSTER'S MEDICAL DICTIONARY, <http://www.merriam-webster.com/medical/lockedinsyndrome> (last visited Sept. 12, 2010).
14. John B. Oldershaw, et al., *Persistent Vegetative State: Medical, Ethical, Religious, Economic and Legal Perspectives*, 1 DEPAUL J. HEALTH CARE L. 495, 497 (1997); MARK F. BEAR ET AL., NEUROSCIENCE: EXPLORING THE BRAIN 186-87 (2d ed. 2001).
15. Some sources, such as Tovino and Winslade also include akinetic mutism in this group, while others such as Laureys et al. do not. Akinetic mutism is not discussed in this paper for the sake of clarity. Stacey A. Tovino & William J. Winslade, *A Primer on the Law and Ethics of Treatment, Research, and Public Policy In the Context of Severe Traumatic Brain Injury*, 14 ANNALS HEALTH L. 1, 12 (2005); Laureys et al., *supra* note 10, at 539.
16. Tovino & Winslade, *supra* note 15, at 12.
17. *Id.*

-
18. *Id.* at 12–13.
 19. *Id.* at 13.
 20. Tovino & Winslade, *supra* note 15, at 13–14.
 21. Laureys et al., *supra* note 10, at 542 (“EEG and evoked potentials do not reliably distinguish the locked-in syndrome from the vegetative state”).
 22. *RadioLab: After Life* (WNYC radio broadcast July 27, 2009), available at <http://www.radiolab.org/2009/jul/27/>. See also, Adrian Owen, et al., *Detecting Awareness in the Vegetative State*, 313 SCIENCE Sept. 8, 2006 at 1402.
 23. *After Life*, *supra* note 22. See also, Owen, et al., *supra* note 22 (“No evidence of any awareness”).
 24. *After Life*, *supra* note 22. See also, Owen, et al., *supra* note 22.
 25. *After Life*, *supra* note 22. See also, Owen, et al., *supra* note 22.
 26. *After Life*, *supra* note 22. See also, Owen, et al., *supra* note 22.
 27. See, e.g., Tovino & Winslade, *supra* note 15, at 13–14. See also, Kate Holmquist, *Locked-In Syndrome is Like Wearing a Straitjacket*, THE IRISH TIMES, Jan. 2, 2010 at 7. (“Kathleen would look at the ceiling if it was true and close her eyes if it was not. . . . Using one finger on her left hand, she uses predictive text on a DynaVox box like the one used by Stephen Hawking.”).
 28. Caroline Schnakers, et al., *Diagnostic Accuracy of the Vegetative and Minimally Conscious State: Clinical Consensus Versus Standardized Neurobehavioral Assessment*, 9:35 BMC NEUROLOGY *1 (2009). See Malcolm Ritter, *Vegetative Man Communicates Using Thoughts*, HUFFINGTON POST (Feb. 3, 2010), http://www.huffingtonpost.com/2010/02/04/vegetative-man-communicat_n_449044.html. See also, Mark Tutton, *ParalyzedMan ‘Turns Thoughts into Sounds’*, CNN (Dec. 16, 2009), <http://www.cnn.com/2009/HEALTH/12/16/brain.computer.speech/.index.html?iref=allsearch>; Brandon Kleim, *Wireless Brain to Computer Connection Synthesizes Speech*, WIRED, (2009), <http://www.wired.com/wired/science/2009/12/wireless-brain/>.
 29. See Ritter, *supra* note 28.
 30. See *id.*
 31. See *id.*
 32. Owen, et al., *supra* note 22.
 33. Schnakers, et al., *supra* note 28 (Forty-one percent of patients with disorders of consciousness were erroneously assigned a diagnosis of vegetative state).
 34. Schnakers, et al., *supra* note 28.
 35. Owen, et al., *supra* note 22.
 36. The “vegetative” patient was verbally instructed to imagine playing tennis or to imagine walking through her home when prompted. These two tasks activate distinct regions of the brain (the supplemental motor area for the “tennis” prompt and the parahippocampal gyrus, posterior parietal cortex, and lateral premotor cortex for the “house” prompt). The patient’s responses were “indistinguishable” from those of healthy control subjects who were given the same instructions and prompts. Owen, et al., *supra* note 22.
 37. For example, if a patient was deaf, but otherwise mentally intact, a verbal command would not elicit any response if the patient could not hear the command. See *After Life*, *supra* note 22.
 38. Adrian Owen & Martin Coleman, *Using Neuroimaging to Detect Awareness in Disorders of Consciousness*, 23(4) FUNCTIONAL NEUROLOGY 189, 189 (2008). See Martin Monti, et al., *Willfull Modulation of Brain Activity in Disorders of Consciousness*, 362 NEW ENG. J. MED. 579, 579 (2010).
 39. Monti, et al., *supra* note 38.
 40. The one question not answered correctly was not answered incorrectly; rather, the brain activity indicated it was not answered at all. *Id.* at 585.
 41. Tutton, *supra* note 28. See also, Kleim, *supra* note 28.
 42. BLACK’S LAW DICTIONARY, *advance directive* (8th ed. 2004).
 43. See discussion, *infra* Part II.
 44. See, e.g., Office of the Attorney General of California, *Advance Healthcare Directive: What’s Important to You*, (2010), http://www.ag.ca.gov/consumers/general/adv_

hc_dir.php (California attorney general's site containing information to self-execute advance directives, including a "fill-in-the-blank" form).

45. DIVING BELL, *supra* note 1.

46. For the purposes of this paper, statutes that allow a declarant to revoke a directive, those that allow one to modify a directive, and those that allow one to do both are grouped together because both revocation and modification allow a declarant to nullify previously decided upon treatment decisions. Analysis of the issues raised when the patient can revoke, but not modify, a directive is important, but beyond the scope of this paper. To put it succinctly: if a patient is only allowed to revoke a directive, the treatment decisions would revert to statutory defaults after revocation; they may not align with the patient's preferred treatment options but the patient, due to the formalities of execution, would likely not be able to execute a new directive while he or she is locked-in.

47. See Ashbel G. Gulliver & Catherine J. Tilson, *Classification of Gratuitous Transfers*, 51 YALE L. J. 1, 3 (1941).

48. Gelfand, *supra* note 9, at 756; COLO. REV. STAT. § 15-18-109 (2009).

49. Because formalities in the context of wills have been studied more closely than in those relation to advance directives, and they serve the same purposes, looking to the function of formalities in wills will inform their use in advance directives.

50. JESSE DUKEMINIER & STANLEY M. JOHANSON, *WILLS, TRUSTS & ESTATES* 22325 (6th ed. 2000) (quoting Gulliver & Tilson, *supra* note 47, at 5-10; John H. Langbein, *Substantial Compliance with the Wills Act*, 88 HARV. L. REV. 489, 494 (1975)).

51. Gulliver & Tilson, *supra* note 47, at 5-6; Gelfand, *supra* note 9, at 767.

52. Gulliver & Tilson, *supra* note 47, at 6-9; Gelfand, *supra* note 9, at 767.

53. Gulliver & Tilson, *supra* note 47, at 6-13.

54. Langbein, *supra* note 50.

55. Gelfand, *supra* note 9, at 768.

56. *Id.*

57. Gulliver & Tilson, *supra* note 47.

58. For a classic example of frustrated intent because of an admitted technicality, see *Groffman v. Groffman*(1969) 2 ALL E.R. 108 (P.).

59. See U.S. CONST. amend. XIV, § 1.

60. Monti, et al., *supra* note 38; Tutton, *supra* note 28.

61. See COLO. REV. STAT. § 15-18-109 (2009); MD. CODE ANN., HEALTH-GEN. § 5-604 (West 2010); TENN. CODE ANN. § 32-11-106 (2010).

62. For the purposes of this paper, the author defines a communicative disability as one where a person has some degree of difficulty in communicating with others; generally in that they do not have the ability to speak or to write or type, but they have undiminished mental capacity for thought and reason. In other words, locked-in syndrome is the epitome of a condition causing communicative disability, but communicative disabilities may affect others who are not necessarily locked-in.

63. ALA. CODE § 22-8A-5 (2010); ALASKA STAT. § 13.52.020 (2010); ARIZ. REV. STAT. ANN. § 36-3202 (2010); ARK. CODE ANN. § 20-17-204 (2009); CAL. PROB. CODE § 4695 (West 2009); COLO. REV. STAT. § 15-18-109 (2009); CONN. GEN. STAT. § 19a-579a (2008); DEL. CODE ANN. tit. 16, § 2504 (2010); FLA. STAT. § 765.104 (2009); GA. CODE ANN. § 31-32-6 (2009); HAW. REV. STAT. § 327E-4 (2009); IDAHO CODE ANN. § 39-4511 (2009); 755 ILL. COMP. STAT. 35/5 (2010); IND. CODE § 16-36-4-12 (2009); IOWA CODE § 144A.4 (2008); KAN. STAT. ANN. § 65-28,104 (2008); KY. REV. STAT. ANN. § 311.627 (West 2010); LA. REV. STAT. ANN. § 40:1299.58.4 (2010); ME. REV. STAT. ANN. tit. 18-A, § 5-803 (2009); MD. CODE ANN., HEALTH-GEN. § 5-604 (West 2010); MINN. STAT. § 145B.09 (2009); MISS. CODE ANN. § 41-41-207 (2009); MO. REV. STAT. § 459.020 (2009); MONT. CODE ANN. § 50-9-104 (2009); NEB. REV. STAT. § 20-406 (2009); NEV. REV. STAT. § 449.620 (2009); N.H. REV. STAT. ANN. § 137-J:15 (2009); N.J. STAT. ANN. § 26:2H-57 (West 2010); N.M. STAT. ANN. § 24-7A-3 (2009); N.Y. PUB. HEALTH § 2985 (Consol. 2010); N.C. GEN. STAT. § 90-321 (2009); N.D. CENT. CODE § 23-06.5-07 (2009); OHIO REV. CODE ANN. § 2133.04 (West 2010); OKLA. STAT. tit. 63, § 3101.6 (2009); OR. REV. STAT. § 127.545 (2007); 20 PA. CONS. STAT. § 5444 (2009); R.I. GEN. LAWS § 23-4.11-4 (2010); S.C. CODE ANN. § 44-77-80 (2009); S.D. CODIFIED LAWS § 34-12D-8 (2009); TENN. CODE ANN. § 32-11-106 (2010); TEX. HEALTH & SAFETY CODE ANN. § 166.042 (West 2009); UTAH CODE ANN. § 75-2a-114 (2009); VT. STAT. ANN. tit. 18, § 9704 (2010); VA. CODE ANN. § 54.1-2985 (2009); WASH. REV. CODE § 70.122.040 (2010); W. VA. CODE § 16-30-18 (2009); WIS. STAT. § 154.05 (2009); WYO. STAT. ANN. § 35-22-404 (2010). Massachusetts and Michigan do not explicitly authorize advance directives by statute.

64. See *supra* note 63.

65. CONN. GEN. STAT. § 19a-579a(a) (2008).

-
66. CAL. PROB. CODE § 4695(b) (West 2009).
67. UNIF. HEALTH-CARE DECISIONS ACT § 3(b), 9 (1993). The uniform act has been adopted in Alabama, Alaska, California, Delaware, Hawaii, Maine, Mississippi, New Mexico, and Wyoming. U.L.A. HEALTH CARE DEC Refs & Annos (West 2009).
68. Louisiana is included in the majority because revocation can be effected by “nonverbal expression . . . of the intent to revoke.” LA. REV. STAT. ANN. § 40:1299.58.4 (2010).
69. ALASKA STAT. § 13.52.020 (2010); ARIZ. REV. STAT. ANN. § 36-3202 (2010); ARK. CODE ANN. § 20-17-204 (2009); CAL. PROB. CODE § 4695 (West 2009); CONN. GEN. STAT. § 19a-579a (2008); DEL. CODE ANN. tit. 16, § 2504 (2010); GA. CODE ANN. § 31-32-6 (2009); HAW. REV. STAT. § 327E-4 (2009); 755 ILL. COMP. STAT. 35/5 (2010); IOWA CODE § 144A.4 (2008); LA. REV. STAT. ANN. § 40:1299.58.4 (2010); ME. REV. STAT. ANN. tit. 18-A, § 5-803 (2009); MINN. STAT. § 145B.09 (2009); MISS. CODE ANN. § 41-41-207 (2009); MO. REV. STAT. § 459.020 (2009); MONT. CODE ANN. § 50-9-104 (2009); NEB. REV. STAT. § 20-406 (2009); NEV. REV. STAT. § 449.620 (2009); N.J. STAT. ANN. § 26:2H-57 (West 2010); N.M. STAT. ANN. § 24-7A-3 (2009); N.Y. PUB. HEALTH § 2985 (Consol. 2010); N.C. GEN. STAT. § 90-321 (2009); N.D. CENT. CODE § 23-06.5-07 (2009); OHIO REV. CODE ANN. § 2133.04 (West 2010); OKLA. STAT. tit. 63, § 3101.6 (2009); OR. REV. STAT. § 127.545 (2007); 20 PA. CONS. STAT. § 5444 (2009); R.I. GEN. LAWS § 23-4.11-4 (2010); S.D. CODIFIED LAWS § 34-12D-8 (2009); VT. STAT. ANN. tit. 18, § 9704 (2010); WYO. STAT. ANN. § 35-22-404 (2010).
70. See ALA. CODE § 22-8A-5 (2010); COLO. REV. STAT. § 15-18-109 (2009); FLA. STAT. § 765.104 (2009); IDAHO CODE ANN. § 39-4511 (2009); IND. CODE § 16-36-4-12 (2009); KAN. STAT. ANN. § 65-28,104 (2008); KY. REV. STAT. ANN. § 311.627 (West 2010); MD. CODE ANN., HEALTH-GEN. § 5-604 (West 2010); N.H. REV. STAT. ANN. § 137-J:15 (2009); S.C. CODE ANN. § 44-77-80 (2009); TENN. CODE ANN. § 32-11-106 (2010); TEX. HEALTH & SAFETY CODE ANN. § 166.042 (West 2009); UTAH CODE ANN. § 75-2a-114 (2009); VA. CODE ANN. § 54.1-2985 (2009); WASH. REV. CODE § 70.122.040 (2010); W. VA. CODE § 16-30-18 (2009); WIS. STAT. § 154.05 (2009).
71. WIS. STAT. § 154.05 (1)(a) (2009). See also ALA. CODE § 22-8A-5 (2010); COLO. REV. STAT. § 15-18-109 (2009); FLA. STAT. § 765.104 (2009); IDAHO CODE ANN. § 39-4511 (2009); IND. CODE § 16-36-4-12 (2009); KAN. STAT. ANN. § 65-28,104 (2008); KY. REV. STAT. ANN. § 311.627 (West 2010); MD. CODE ANN., HEALTH-GEN. § 5-604 (West 2010); N.H. REV. STAT. ANN. § 137-J:15 (2009); S.C. CODE ANN. § 44-77-80 (2009); TENN. CODE ANN. § 32-11-106 (2010); TEX. HEALTH & SAFETY CODE ANN. § 166.042 (West 2009); UTAH CODE ANN. § 75-2a-114 (2009); VA. CODE ANN. § 54.1-2985 (2009); WASH. REV. CODE § 70.122.040 (2010); W. VA. CODE § 16-30-18 (2009).
72. FLA. STAT. § 765.104 (2009); IDAHO CODE ANN. § 39-4511 (2009); IND. CODE § 16-36-4-12 (2009); KY. REV. STAT. ANN. § 311.627 (West 2010); N.H. REV. STAT. ANN. § 137-J:15 (2009); S.C. CODE ANN. § 44-77-80 (2009); TEX. HEALTH & SAFETY CODE ANN. § 166.042 (West 2009); VA. CODE ANN. § 54.1-2985 (2009); WASH. REV. CODE § 70.122.040 (2010); WIS. STAT. § 154.05 (2009).
73. ALA. CODE § 22-8A-5 (2010); KAN. STAT. ANN. § 65-28,104 (2008); UTAH CODE ANN. § 75-2a-114 (2009); W. VA. CODE § 16-30-18 (2009). West Virginia provides for two means of third party revocation: one requiring presence and the other not. W. VA. CODE § 16-30-18 (2009). Because West Virginia includes the more lenient method, it is grouped with the “no presence required” states.
74. COLO. REV. STAT. § 15-18-109 (2009); MD. CODE ANN., HEALTH-GEN. § 5-604 (West 2010); TENN. CODE ANN. § 32-11-106 (2010).
75. TENN. CODE ANN. § 32-11-106 (2010).
76. MD. CODE ANN., HEALTH-GEN. § 5-604(a) (West 2010).
77. COLO. REV. STAT. § 15-18-109 (2009).
78. Colo. Rev. Stat. § 15-18-109 (2009).
79. Compare CAL. PROB. CODE § 4695(b) (West 2009) (“A patient having capacity may revoke . . .”), with CONN. GEN. STAT. § 19a-579a(a) (2008) (“may be revoked . . . without regard to the declarant’s mental or physical condition”).
80. See, e.g., COLO. REV. STAT. § 15-18-109 (2009); GA. CODE ANN. § 31-32-6 (2009).
81. These states are: Alabama, Arizona, Arkansas, Connecticut, Illinois, Iowa, Louisiana, Minnesota, Missouri, Montana, Nebraska, Nevada, New Jersey, North Carolina; Oklahoma, Pennsylvania, Rhode Island, Tennessee, Texas, Vermont, and Washington. ALA. CODE § 22-8A-5 (2010); ARIZ. REV. STAT. ANN. § 36-3202 (2010); ARK. CODE ANN. § 20-17-204 (2009); CONN. GEN. STAT. § 19a-579a (2008); 755 ILL. COMP. STAT. 35/5 (2010); IOWA CODE § 144A.4 (2008); LA. REV. STAT. ANN. § 40:1299.58.4 (2010); MINN. STAT. § 145B.09 (2009); MO. REV. STAT. § 459.020 (2009); MONT. CODE ANN. § 50-9-104 (2009); NEB. REV. STAT. § 20-406 (2009); NEV. REV. STAT. § 449.620 (2009); N.J. STAT. ANN. § 26:2H-57 (West 2010); N.C. GEN. STAT. § 90-321 (2009); OKLA. STAT. tit. 63, § 3101.6 (2009); 20 PA. CONS. STAT. § 5444 (2009); R.I. GEN. LAWS § 23-4.11-4 (2010); TENN. CODE ANN. § 32-11-106 (2010); TEX. HEALTH & SAFETY CODE ANN. § 166.042 (West 2009); VT. STAT. ANN. tit. 18, § 9704 (2010); WASH. REV. CODE § 70.122.040 (2010).

82. 20 PA. CONS. STAT. § 5444 (2009).

83. These states are: Alaska, California, Delaware, Florida, Maine, New Mexico, New York, Oregon, Virginia, and Wyoming. ALASKA STAT. § 13.52.020 (2010); CAL. PROB. CODE § 4695 (West 2009); DEL. CODE ANN. tit. 16, § 2504 (2010); FLA. STAT. § 765.104 (2009); ME. REV. STAT. ANN. tit. 18-A, § 5-803 (2009); N.M. STAT. ANN. § 24-7A-3 (2009); N.Y. PUB. HEALTH § 2985 (Consol. 2010); OR. REV. STAT. § 127.545 (2007); VA. CODE ANN. § 54.1-2985 (2009); WYO. STAT. ANN. § 35-22-404 (2010).

84. These states are: Colorado, Georgia, Hawaii, Idaho, Indiana, Kansas, Kentucky, Maryland, Mississippi, New Hampshire, North Dakota, Ohio, South Carolina, South Dakota, Utah, West Virginia, and Wisconsin. COLO. REV. STAT. § 15-18-109 (2009); GA. CODE ANN. § 31-32-6 (2009); HAW. REV. STAT. § 327E-4 (2009); IDAHO CODE ANN. § 39-4511 (2009); IND. CODE § 16-36-4-12 (2009); KAN. STAT. ANN. § 65-28,104 (2008); KY. REV. STAT. ANN. § 311.627 (West 2010); MD. CODE ANN., HEALTH-GEN. § 5-604 (West 2010); MISS. CODE ANN. § 41-41-207 (2009); N.H. REV. STAT. ANN. § 137-J:15 (2009); N.D. CENT. CODE § 23-06.5-07 (2009); OHIO REV. CODE ANN. § 2133.04 (West 2010); S.C. CODE ANN. § 44-77-80 (2009); S.D. CODIFIED LAWS § 34-12D-8 (2009); UTAH CODE ANN. § 75-2a-114 (2009); W. VA. CODE § 16-30-18 (2009); WIS. STAT. § 154.05 (2009).

85. *See, e.g.*, CAL. PROB. CODE § 4695(b) (West 2009).

86. *Compare, e.g.*, CAL. PROB. CODE § 4695(a) (West 2009), *with* PROB. § 4695(b).

87. ALASKA STAT. § 13.52.020(b) (2010).

88. ALASKA STAT. § 13.52.020(a) (2010).

89. *See, e.g.*, ARIZ. REV. STAT. ANN. § 36-3202 (2010) (“A person may revoke his own health care directive or disqualify a surrogate by doing any of the following: . . .”).

90. ALASKA STAT. § 13.52.020 (2010); ARIZ. REV. STAT. ANN. § 36-3202 (2010); ARK. CODE ANN. § 20-17-204 (2009); CAL. PROB. CODE § 4695 (West 2009); CONN. GEN. STAT. § 19a-579a (2008); DEL. CODE ANN. tit. 16, § 2504 (2010); GA. CODE ANN. § 31-32-6 (2009); HAW. REV. STAT. § 327E-4 (2009); 755 ILL. COMP. STAT. 35/5 (2010); IOWA CODE § 144A.4 (2008); LA. REV. STAT. ANN. § 40:1299.58.4 (2010); ME. REV. STAT. ANN. tit. 18-A, § 5-803 (2009); MINN. STAT. § 145B.09 (2009); MISS. CODE ANN. § 41-41-207 (2009); MO. REV. STAT. § 459.020 (2009); MONT. CODE ANN. § 50-9-104 (2009); NEB. REV. STAT. § 20-406 (2009); NEV. REV. STAT. § 449.620 (2009); N.J. STAT. ANN. § 26:2H-57 (West 2010); N.M. STAT. ANN. § 24-7A-3 (2009); N.Y. PUB. HEALTH § 2985 (Consol. 2010); N.C. GEN. STAT. § 90-321 (2009); N.D. CENT. CODE § 23-06.5-07 (2009); OHIO REV. CODE ANN. § 2133.04 (West 2010); OKLA. STAT. tit. 63, § 3101.6 (2009); OR. REV. STAT. § 127.545 (2007); 20 PA. CONS. STAT. § 5444 (2009); R.I. GEN. LAWS § 23-4.11-4 (2010); S.D. CODIFIED LAWS § 34-12D-8 (2009); VT. STAT. ANN. tit. 18, § 9704 (2010); WYO. STAT. ANN. § 35-22-404 (2010).

91. U.L.A. HEALTH CARE DEC Refs & Annos (West 2009).

92. CAL. PROB. CODE § 4695(b) (West 2009).

93. *See, e.g.*, DIVING BELL, *supra* note 1 (discussing Bauby’s wish for death and subsequent reversal of that wish).

94. *See* Gelfand, *supra* note 9, at 768.

95. *Id.*

96. Gelfand, *supra* note 9, at 768 n.124 (“In a non-emergency situation, a conscious patient can go through the formalities”).

97. ALA. CODE § 22-8A-5 (2010); FLA. STAT. § 765.104 (2009); IDAHO CODE ANN. § 39-4511 (2009); IND. CODE § 16-36-4-12 (2009); KAN. STAT. ANN. § 65-28,104 (2008); KY. REV. STAT. ANN. § 311.627 (West 2010); N.H. REV. STAT. ANN. § 137-J:15 (2009); S.C. CODE ANN. § 44-77-80 (2009); TEX. HEALTH & SAFETY CODE ANN. § 166.042 (West 2009); UTAH CODE ANN. § 75-2a-114 (2009); VA. CODE ANN. § 54.1-2985 (2009); WASH. REV. CODE § 70.122.040 (2010); W. VA. CODE § 16-30-18 (2009); WIS. STAT. § 154.05 (2009).

98. FLA. STAT. § 765.104 (2009); IDAHO CODE ANN. § 39-4511 (2009); IND. CODE § 16-36-4-12 (2009); KY. REV. STAT. ANN. § 311.627 (West 2010); N.H. REV. STAT. ANN. § 137-J:15 (2009); S.C. CODE ANN. § 44-77-80 (2009); TEX. HEALTH & SAFETY CODE ANN. § 166.042 (Vernon 2009); VA. CODE ANN. § 54.1-2985 (2009); WASH. REV. CODE § 70.122.040 (2010); WIS. STAT. § 154.05 (2009).

99. *See generally* W.W. Allen, *What Constitutes the Presence of the Testator in the Witnessing of his Will*, 75 A.L.R.2d 318 (2009).

100. VA. CODE ANN. § 54.1-2985(A) (2009).

101. VA. CODE ANN. § 54.1-2985(A)(ii) (2009).

102. FLA. STAT. § 765.104 (2009); IDAHO CODE ANN. § 39-4511 (2009); IND. CODE § 16-36-4-12 (2009); KY. REV. STAT. ANN. § 311.627 (West 2010); N.H. REV. STAT. ANN. § 137-J:15 (2009); S.C. CODE ANN. § 44-77-80 (2009); TEX. HEALTH & SAFETY CODE ANN. § 166.042 (Vernon 2009); VA. CODE ANN. § 54.1-2985 (2009); WASH. REV. CODE § 70.122.040 (2010); WIS. STAT. § 154.05 (2009).

-
103. See generally *Allen*, *supra* note 99.
 104. *Tucker v. Sandidge*, 85 Va. 546, 570 (1888).
 105. *Id.*; see also *Baldwin v. Baldwin's Ex'r*, 81 Va. 405, 410 (1886).
 106. *Nock v. Nock's Ex'rs*, 51 Va. 106, 115 (1853); see also *Baldwin*, 81 Va. at 414.
 107. *Nock*, 51 Va. at 119.
 108. Because locked-in patients are severely paralyzed, wakefulness can only be determined through communication, or by observing voluntary eye or digit movement, if possible. However, a lack of communication or movement would not necessarily mean that a patient is not awake. *Monti, et al.*, *supra* note 38, at 585 ("Whether the patient fell asleep during this question, failed to hear it, simply elected not to answer it, or lost consciousness can not be determined.").
 109. *BEAR ET AL.*, *supra* note 14, at 616.
 110. See *Gulliver & Tilson*, *supra* note 47, at 5-6.
 111. VA. CODE ANN. § 54.1-2985(A)(ii) (2009). See ALA. CODE § 22-8A-5 (2010); KAN. STAT. ANN. § 65-28,104 (2008); UTAH CODE ANN. § 75-2a-114 (2009); W. VA. CODE § 16-30-18 (2009).
 112. See ALA. CODE § 22-8A-5; FLA. STAT. § 765.104 (2009); IDAHO CODE ANN. § 39-4511 (2009); IND. CODE § 16-36-4-12 (2009); KAN. STAT. ANN. § 65-28,104; KY. REV. STAT. ANN. § 311.627 (West 2010); N.H. REV. STAT. ANN. § 137-J:15 (2009); S.C. CODE ANN. § 44-77-80 (2009); TEX. HEALTH & SAFETY CODE ANN. § 166.042 (West 2009); UTAH CODE ANN. § 75-2a-114; VA. CODE ANN. § 54.1-2985 (2009); WASH. REV. CODE § 70.122.040 (2010); W. VA. CODE § 16-30-18; WIS. STAT. § 154.05 (2009).
 113. COLO. REV. STAT. § 15-18-109 (2009); MD. CODE ANN., HEALTH-GEN. § 5-604 (West 2010); TENN. CODE ANN. § 32-11-106 (2010).
 114. TENN. CODE ANN. § 32-11-106 (2010).
 115. COLO. REV. STAT. § 15-18-109 (2009).
 116. Colorado actually provides for the possibility that a declarant might not be able to sign a directive to execute it and it provides an alternative means of execution. The law does not provide for such an alternative for revocation. *Id.*
 117. *DIVING BELL*, *supra* note 1.
 118. 42 U.S.C. §§ 12101-12213.
 119. See, e.g., *Melton v. Dallas Area Rapid Transit*, 391 F.3d 669, 671-72 (5th Cir. 2004).
 120. *JOHN PARRY, HANDBOOK ON DISABILITY DISCRIMINATION LAW 10* (2003) (citing 29 CFR § 1630.2(h)(1)).
 121. 28 C.F.R. § 35.104 (2010).
 122. 42 U.S.C. § 12132 (2010).
 123. 28 C.F.R. § 35.104.
 124. *PARRY*, *supra* note 120.
 125. *Innovative Health Sys., Inc. v. City of White Plains*, 117 F.3d 37, 45 (2d Cir. 1997).
 126. Title II covers regulation of leaf burning (See *Heather K. by Anita K. v. City of Mallard*, 946 F. Supp. 1373 (N.D. Iowa 1996)), parking regulations (See *Duprey v. Connecticut*, 28 F. Supp. 2d 702 (D. Conn. 1998)), statutes relating to access to medical records (See *Doe v. Stincer*, 990 F. Supp. 1427 (S.D. Fla. 1997), vacated on other grounds, 175 F.3d 879 (11th Cir. 1999)), and local zoning decisions (*Innovative Health*, 117 F.3d at 45).
 127. *Innovative Health*, 117 F.3d at 45.
 128. 28 C.F.R. § 35.130(a) (2010) (emphasis added).
 129. 28 C.F.R. §§ 35.130(b)(1)(i), 35.130(b)(1)(vii).
 130. 42 U.S.C. § 12132.