

* Currently, information on the option of irrevocable provisions in advance directives is included in the long advance directive form posted by the Department of Health, but is neither consistently nor adequately conveyed, either to individuals receiving medical care or in the form of community education.

Suggested: Address this informational requirement of the Patient Self Determination Act of 1990 and 42 CFR § 489.102 by directing that clear, comprehensive, understandable information be available and affirmatively offered in the manner intended by Congress in 1990.

The federal Patient Self Determination Act requires a written description of state law on advance directives to be developed by the state and distributed by health care providers. It also requires health care providers to distribute written information on the right to accept or refuse medical or surgical treatment.

When it was amended in 2005 Vermont's advance directive law became more comprehensive and nuanced. It also became much more difficult to effectively describe the expanded options in a way that was understandable without being oversimplified. Crafting and conveying this information is nonetheless required by federal law:

<http://www.law.cornell.edu/uscode/text/42/1396a>

42 U.S. Code § 1396a - State plans for medical assistance

(a) Contents

A State plan for medical assistance must—

(57) provide that each hospital, nursing facility, provider of home health care or personal care services, hospice program, or medicaid managed care organization (as defined in section 1396b (m)(1)(A) of this title) receiving funds under the plan shall comply with the requirements of subsection (w) of this section;

(58) provide that **the State, acting through a State agency, association, or other private nonprofit entity, develop a written description of the law of the State (whether statutory or as recognized by the courts of the State) concerning advance directives that would be distributed by providers or organizations** under the requirements of subsection (w) of this section;

The full text of subsection (w) is further below. It's echoed in conditions of participation implementing the PSDA. See 42 CFR §489.102 at <http://www.gpo.gov/fdsys/pkg/CFR-2013-title42-vol5/xml/CFR-2013-title42-vol5-sec489-102.xml>

Requirements for providers include that they:

(1) Provide written information to such individuals concerning—

(i) An individual's rights under State law (whether statutory or recognized by the courts of the State) to make decisions concerning such medical care, **including the right to accept or refuse medical or surgical treatment and the right to formulate, at the individual's option, advance directives. Providers are permitted to contract with other entities to furnish this information but are still legally responsible for ensuring that the requirements of this section are met.** Providers are to update and

disseminate amended information as soon as possible, but no later than 90 days from the effective date of the changes to State law.

Note that

(2) The written information described in paragraph (1)(A) shall be provided to an adult individual—

(A) in the case of a hospital, at the time of the individual's admission as an inpatient,

As clarified in 42 CFR 489.102(b):

(e) If an adult individual is incapacitated at the time of admission or at the start of care and is unable to receive information (due to the incapacitating conditions or a mental disorder) or articulate whether or not he or she has executed an advance directive, then the provider may give advance directive information to the individual's family or surrogate in the same manner that it issues other materials about policies and procedures to the family of the incapacitated individual or to a surrogate or other concerned persons in accordance with State law. The provider is not relieved of its obligation to provide this information to the individual once he or she is no longer incapacitated or unable to receive such information. Follow-up procedures must be in place to provide the information to the individual directly at the appropriate time.

Suggestion:

No later than January 1, 2015, the Agency of Human Services, after consultation with [Disability Rights Vermont, the Long Term Care Ombudsman, Vermont Legal Aid [Elder Law Project, Mental Health Law Project, Disability Law Project, Vermont Ethics Network, Vermont Medical Society, VAHHS, Vermont Coalition for Disability Rights (Coalition of Vermont Elders, DAIL, etc. etc....)] shall issue a comprehensive description of an individual's rights under Vermont law to make decisions concerning medical or surgical care, including the right to accept or refuse such care and to formulate [execute, register, amend, suspend or revoke] advance directives, including the rights and options provided for in Chapter 231 of this title. The Agency shall update the summary within sixty days of the effective date of any change in the law. Written material offered by health care providers, health care facilities and residential care facilities to adults receiving medical care shall incorporate or be consistent with this description and address all matters described therein. Such material shall be amended no later than 90 days from the effective date of changes to state law.

Note that this is a first step, and that there are other informational requirements in subsection (w). **Also note the requirement for community education.**

The regulations implementing the PSDA are at

<http://www.gpo.gov/fdsys/pkg/CFR-2013-title42-vol5/xml/CFR-2013-title42-vol5-sec489-100.xml>

<http://www.gpo.gov/fdsys/pkg/CFR-2013-title42-vol5/xml/CFR-2013-title42-vol5-sec489-102.xml>

<http://www.gpo.gov/fdsys/pkg/CFR-2013-title42-vol5/xml/CFR-2013-title42-vol5-sec489-104.xml>

This is the sole reference to the Patient Self Determination Act in Chapter 231:

§ 9709. Obligations of health care providers, health care facilities, residential care facilities, and health insurers regarding protocols and nondiscrimination

(b) Every health care provider, health care facility, and residential care facility shall develop protocols:

(5) to ensure that the provider or facility complies with its obligations under the Patient Self-Determination Act, 42 U.S.C. § 1395cc(a), and the regulations issued thereunder.

Suggestion: Direct AHS to request and review the protocols and whether they suffice to ensure compliance.

Suggestion:

Add the mental health patient representative to the list of explainers in 18 V.S.A. §9703. Also suggest adding paralegal or staff of state ombudsman program.

* The irrevocable advance directive provision in 18 V.S.A. § 9707(h) requires a named agent and that agent's written acceptance. A person who undertakes the role must be not only willing but capable of acting in this difficult capacity, and finding an agent can be a formidable barrier for isolated or marginalized people who wish to ensure that their advance instructions are not negated by subsequent incapable decisions.

The issue is a general one, but has been raised in the context of court ordered treatment for people in state custody and the possibility of irrevocable advance decision making as a preventive alternative.

Although an agent directing the implementation of an irrevocable provision differs from a guardian the authority and the standards for decision making are similar.

Suggestion:

Direct AHS to study the feasibility of a pilot project with the Office of the Public Guardian serving as agent (or recruiting and training volunteers to serve as agents) for people who wish to execute an irrevocable provision in an advance directive but do not have anyone both suitable and willing to act as agent. This could be limited to irrevocable provisions likely to become activated when a person is in, or at risk of, state custody. It may be that as a part of state government, the Office of the Public Guardian and the guardians it designates would be conflicted in the role. At the least, this part of the OPG's statutory duties might be expanded to include agents carrying out irrevocable

provisions of advance directives:

14 V.S.A. § 3096. Office of public guardian to offer assistance

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(b) The office shall:

(1) Develop public education programs on guardianship and alternatives to guardianship.

(2) Encourage individuals in the private sector to serve as guardians.

(3) Prepare and make available, at no charge, a booklet which describes the duties of a guardian.

(w) Maintenance of written policies and procedures respecting advance directives

(1) For purposes of subsection (a)(57) of this section and sections 1396b (m)(1)(A) and 1396r (c)(2)(E) of this title, the requirement of this subsection is that a provider or organization (as the case may be) maintain written policies and procedures with respect to all adult individuals receiving medical care by or through the provider or organization—

(A) to provide written information to each such individual concerning—

(i) an individual's rights under State law (whether statutory or as recognized by the courts of the State) to make decisions concerning such medical care, including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives (as defined in paragraph (3)), and

(ii) the provider's or organization's written policies respecting the implementation of such rights;

(B) to document in the individual's medical record whether or not the individual has executed an advance directive;

(C) not to condition the provision of care or otherwise discriminate against an individual based on whether or not the individual has executed an advance directive;

(D) to ensure compliance with requirements of State law (whether statutory or as recognized by the courts of the State) respecting advance directives; and

(E) to provide (individually or with others) for education for staff and the community on issues concerning advance directives.

Subparagraph (C) shall not be construed as requiring the provision of care which conflicts with an advance directive.

(2) The written information described in paragraph (1)(A) shall be provided to an adult individual—

(A) in the case of a hospital, at the time of the individual's admission as an inpatient,

(B) in the case of a nursing facility, at the time of the individual's admission as a resident,

(C) in the case of a provider of home health care or personal care services, in advance of the individual coming under the care of the provider,

(D) in the case of a hospice program, at the time of initial receipt of hospice care by the individual from the program, and

(E) in the case of a medicaid managed care organization, at the time of enrollment of the individual with the organization.

(3) Nothing in this section shall be construed to prohibit the application of a State law which allows for an objection on the basis of conscience for any health care provider or any agent of such provider which as a matter of conscience cannot implement an advance directive.

(4) In this subsection, the term “advance directive” means a written instruction, such as a living will or durable power of attorney for health care, recognized under State law (whether statutory or as recognized by the courts of the State) and relating to the provision of such care when the individual is incapacitated.

(5) For construction relating to this subsection, see section 14406 of this title (relating to clarification respecting assisted suicide, euthanasia, and mercy killing).