

Federal Law on Advance Directives

The Federal Patient Self Determination Actⁱ (enacted in 1990) addresses the rights of health (including mental health) care users to stipulate in advance how they would like to be treated by health care providers when they are incapacitated. These wishes can be articulated by consumers in a specific document (an advance directive) or by appointing someone as a health care agent to speak for them.

The intent of the law is to provide an opportunity for adults to express their desires about medical treatment in advance, and to educate the entire population on advance directives. The law was enacted with the intent to offset a perceived imbalance between health care consumers and providers.ⁱⁱ

The federal law does not grant consumers new rights; those specific rights are spelled out in state law. The federal law requires hospitals and other providers (including psychiatric hospitals and other mental health providers) and health plans to maintain written policies and procedures with respect to advance directives.

Typically under state law, individuals have the right to:

- Accept or refuse medical or surgical treatment
- Have an advance directive and/or appoint a health care agent.

Federal law does not require individuals to complete any form of advance directive (and nor do state laws), and it expressly forbids requiring an advance directive as a requisite for treatment.

Definition of an Advance Directive

Under this federal law, an advance directive is defined as:

“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), relating to the provision of health care when the individual is incapacitated.”ⁱⁱⁱ

Who Must Comply with This Law

Certain provider entities must comply with the law in order to receive Medicare or Medicaid payment from the federal government. However, the requirements of the law apply for all individuals in these facilities (or treated through these providers), not only for people who are on Medicare or Medicaid. Provider entities covered under the law are:

- Hospitals;
- Skilled nursing homes;
- Nursing homes;
- Providers of Medicare and Medicaid home health care;
- Medicaid personal care providers;
- Health maintenance organizations competitive medical plans and health care prepayment plans^{iv};
- hospice programs certified by Medicare or Medicaid.

In addition, state Medicaid agencies have certain obligations under the law.

What Hospitals and Other Institutions Must Do

The law requires that these entities meet certain requirements in order to be paid under Medicare or Medicaid. The entity must:

- Maintain written policies and follow certain procedures with respect to advance directives;
- Document in the patient's medical record whether or not the patient has executed an advance directive (including a psychiatric advance directive);
- Comply with all State laws regarding advance directives (this includes complying with any state law on psychiatric advance directives)^v;
- Not condition the provision of care or otherwise discriminate against an individual based on whether or not the individual has executed an advance directive. This does not mean, however, that a provider is required to provide care that conflicts with an advance directive;
- Inform the individual that complaints concerning implementation of these advance directive requirements may be filed with the state agency that surveys and certifies Medicare and Medicaid providers.
- Provide staff and community education on issues related to advance directives.

How Does This Law Apply to Mental Health

Individuals with mental illness have equal rights under this law with other users of health care. They may establish an advance directive for health care (generally this is used for end-of-life

care), or establish a health care agent for health care.

In addition, this law can be used to establish an advance directive for mental health care, to be used in the event the person becomes incapacitated, and/or to appoint an agent for mental health care.^{vi} Individuals with mental illness are empowered to make advance decisions concerning their health-care needs when they are incapacitated.^{vii}

It is possible under this law and most state laws to combine advance health care decision making and advance mental health care decision making in one document and to appoint a single health care agent to address both health and mental health care issues. It is also possible to use either the federal law, or state law, to establish separate advance directives for health and for mental health care and to have two different agents (one for health and one for mental health).

Information for Consumers

Covered entities must provide adults, as that term is defined in State law, with written information:

- Concerning their right under state law to participate in decisions concerning their medical care;
- On its policy regarding advance directives.

Other entities can be contracted with to furnish this information, but the covered entity is still legally responsible for ensuring that it is shared.

When Providers Can Refuse To Follow an Advance Directive

If permitted under state law, providers can refuse to implement provisions of an advance directive, based on conscience objections. The facility must make clear when instructions of an advance directive would not be followed due to a conscience objection and:

- Provide a clear and precise statement of limitations if the provider cannot implement the advance directive based on conscience;
- Clarify any differences between institution-wide conscience objection and those that may be raised by individual physicians;
- Identify the State legal authority permitting a conscience objection,
- Describe the range of medical conditions or procedures affected by the conscience objection.

This means that it is possible that a specific treatment or specific medication a consumer lists in

their advance directive as being the treatment they prefer may be denied them if the provider, in good conscience, does not feel he/she can authorize it.

Individuals Who Are Incapacitated

When individuals are incapacitated and unable to receive information due to a mental disorder or an incapacitating condition, or if they are unable to articulate whether or not they have an advance directive, the provider may give the information to the family or surrogate instead. However, the information must be given to the individual directly once he/she is no longer incapacitated.

State Medicaid Agency Obligations

The state Medicaid agency (directly or through a contract) must develop a written description of the state's advance directive law to be distributed by Medicaid providers and by health plans. Any revisions to that state law must be incorporated no later than 60 days from when they become effective.

When Medicaid contracts with a managed care plan, it must require the plan to comply with the federal law requirements for maintaining written policies and procedures regarding advance directives. The managed care plan must then meet the requirements of this law (as described in this document).

When Must Institutions Provide Information on Their Policies

Under the law and implementing regulations^{viii}, hospitals, skilled nursing homes and nursing homes must provide the required information to individuals at the time of admission. In the case of managed care health plans, the required information must be provided at the time of enrollment. In the case of hospice programs, information must be provided at the time of initial receipt of care and in the case of home health care or personal care providers, in advance of the individual receiving care.

Community Education

Covered facilities and managed care plans must provide community education regarding advance directives, either directly or in concert with other providers. The education must define an advance directive, emphasize that it is designed to enhance an incapacitated individual's control over medical treatment and describe applicable state law on advance directives. Changes in state law must be incorporated into the managed care plan's materials no later than 90 days after they become effective.

The same written materials do not have to be provided in all settings, but all must define an advance directive, emphasize that it is to enhance an incapacitated individual's control over medical treatment and describe applicable state law.

Federal Role

The Federal Department of Health and Human Services is required to conduct a public education campaign about advance directives, provide technical assistance to States and oversee provider compliance. It is also required to mail information on advance directives to Social Security recipients. In partial fulfillment of these requirements, DHHS has issued a brochure that describes advance directives (see – cite the web link to that page).

Complaints

Individuals may file complaints concerning the advance directive requirements with the state survey and certification agency for Medicare and Medicaid. Health plans and institutions must inform consumers that they have this right.

Impact of the Federal Law

Reviews of the impact of this federal law are mixed. Advance directives are typically more advocated than used, although receiving information on advance directives appears to have an impact on individuals' interest in obtaining a directive. Facilities generally comply with requirements, but few document in the record if the individual has an advance directive. There is little in the way of public education and communication between individuals and doctors falters in this regard.^{ix}

The law was enacted in order to encourage individuals to make advance health care decisions regarding life-sustaining care. It was not until after enactment that the value of advance directives in psychiatric care was seriously considered.

With respect to psychiatric advance directives (PADs), there is considerable interest among individuals at risk of psychiatric crises in creating a psychiatric advance directive, but attitudes of clinicians about PADs are associated with this interest.^x As a result PADs are not yet widely used. However, as PADs become more popular, they could usher in a new era of revolution in medical decision making, greatly increasing patient authority over medical decisions.^{xi}

For further information on PADs, see [Basic Information on PADs \(link here\)](#) and for a discussion of legal issues regarding their use, see [Legal Q&As \(link here\)](#).

This document prepared by the National Resource Center on Psychiatric Advance Directives (www.nrc-pad.org)

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Notes

- i. The Patient Self Determination Act, Pub. L. No. 101-508, §§ 4206 & 4751, 104 Stat. 1388 (codified at 42 USC §§ 1395cc(f), 1396a(w) (1994)).
- ii. Office of Inspector General (1993). *Patient Advance Directives: Early Implementation Experience*. Washington DC: U.S. Department of Health and Human Services (OEI 06-91-01130).
- iii. 42 USC § 1395cc(f)(3).
- iv. Defined in 42 C.F.R. § 417.
- v. State law revisions must be incorporated as soon as possible, but no later than 90 days from the effective date of the revision.
 - ^{vi} For description of types of mental health advance directives currently in use, see Srebnik, Debra, S., & La Fond, John Q.. (July, 1999). *Psychiatric Services* 50:7, 919-925.
 - vii Winick, Bruce, J. (1996). *Advance Directive Instruments for Those with Mental Illness*. University of Miami Law Review. 51:57. 57-95.
 - viii. 42 C.F.R. § 417.
- ix. U.S. Department of Health and Human Services, Office of Inspector General, report OEI-06-91-01130 (August, 1993). PAD: Early Implementation Experience; and General Accounting Office (now the General Accountability Office). GAO/HEHS-95-135. *Implementation and Effectiveness of Advance Directives in Ensuring Patient Self-Determination*.
 - ^x Srebnik, Debra S., Russo, Joan, Sage, Julie, et al. (July, 2003). *Psychiatric Services*. 54:7. 981-986.
 - ^{xi} Hoge, Steven K. (1994). The patient self-determination act and psychiatric care. *The Bulletin of the American Academy of Psychiatry and the Law*. 22:4, 577-586.