



MENTAL RETARDATION BULLETIN

COMMONWEALTH OF PENNSYLVANIA • DEPARTMENT OF PUBLIC WELFARE

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SUBJECT

**PROCEDURES FOR SUBSTITUTE
HEALTH CARE DECISION MAKING**

BY

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SCOPE

COUNTY MENTAL HEALTH/MENTAL RETARDATION ADMINISTRATORS
BASE SERVICE UNIT DIRECTORS
COMMUNITY RESIDENTIAL MENTAL RETARDATION FACILITY DIRECTORS
STATE ICF/MR DIRECTORS
NON-STATE ICF/MR DIRECTORS

PURPOSE

State law and general standards of practice establish minimum standards of health care to which all individuals are entitled without discrimination. Persons with mental retardation have the right to receive the same health- and life-sustaining treatment as offered to non-disabled persons.

The purpose of this bulletin is to establish the procedures within which persons with mental retardation who are 18 years of age or older will make health care decisions or when such decisions must be made for them. It is expected that health care providers will rely on this bulletin and respect the decisions of substitute decision makers appointed according to the process detailed herein.

BACKGROUND

The autonomy of persons who have the capacity to make particular health care decisions as they arise must be respected. In the event that a health care decision becomes necessary, a reasonable effort must be made to explain the proposed course of action and its risks and benefits to the individual prior to instituting that course of action. However, situations may arise where a health care decision is necessary and the individual, whether adjudicated incompetent or not, does not have the capacity to make that decision. In such cases, a decision must then be made on that individual's behalf.

REFER COMMENTS AND QUESTIONS TO:

Appropriate Regional Program Manager

DEFINITIONS

"Acts 28/26 facility" means a nursing home, personal care home, domiciliary care home, community residential facility, state operated intermediate care facility for the mentally retarded, privately operated intermediate care facility for the mentally retarded, adult daily living center, home health agency or home health service provider whether licensed or not.¹

"Advance Directive" means a signed and witnessed document which is a valid declaration under the Advance Directive for Health Care Act.² An Advance Directive becomes effective only when the attending physician has certified that the individual is incompetent and has a terminal condition or is permanently unconscious and has obtained a physical examination and confirmation of a second physician.²

"Incompetent" means the lack of sufficient capacity for a person to make or communicate decisions concerning himself/herself.² Even when an individual has not been adjudicated incapacitated or incompetent he/she may still be incompetent to make a particular health care decision. An individual who is determined to be incapacitated or incompetent by a doctor at any given point in time may have the capacity to make a decision at a later date, if there has been no court adjudication of incompetence. Only a court may modify or reverse court determined incompetence or competence.

"Do not resuscitate order" or "DNR Order" means an order in the individual's medical record that Cardiopulmonary Resuscitation (CPR) or other specified life-sustaining measures or treatments should not be provided to the individual.

"Facility Director" means the administrative head of a facility.³ In facilities licensed under 55 Pa. Code Ch. 6400, "facility director" means the Chief Executive Officer under 55 Pa. Code § 6400.43. In facilities licensed under 55 Pa. Code Ch. 6500, "facility director" means the Chief Executive Officer under 55 Pa. Code § 6500.42. In intermediate care facilities for persons with mental retardation, the "facility director" means the administrator appointed under 42 C.F.R. § 483.410(a)(3).

"Next of kin" means a close family member.

"Permanently unconscious" means a medical condition that has been diagnosed in accordance with currently accepted medical standards and with reasonable medical certainty as total and irreversible loss of consciousness and capacity for interaction with the environment. The term includes, without limitation, a persistent vegetative state or irreversible coma.²

"Terminal condition" means an incurable or irreversible medical condition in an advanced state caused by injury, disease or physical illness which will, in the opinion of the attending physician, to a reasonable degree of medical certainty, result in death regardless of the continued application of life-sustaining treatment.²

DISCUSSION

The health care or end of life decisions of an individual who is competent should be honored. Competence should be determined according to the best professional judgment of the medical provider. Competent individuals may also execute Advance Directives and name health care proxies in accordance with the Advance Directives for Health Care Act.² An Advance Directive becomes effective only when the individual's attending physician has certified in writing that the individual is incompetent and has a terminal condition or is permanently unconscious. The attending physician's certification must be confirmed by a second physician. The current decision of a competent individual will supersede any prior Advance Directive that was made. Competent individuals should be encouraged to make Advance Directives which will become effective should they lose competency for any reason. Advance Directives should be reviewed and updated in writing periodically. Competent individuals may revoke their Advance Directives at any time utilizing any form of communication to the attending physician or health care provider.²

If an individual is not competent to make a particular health care or end of life decision, another person must make that decision on the individual's behalf. An individual need not be adjudicated incompetent or incapacitated to lack competence to make a particular decision. Consent is implied in law for emergencies and there is no need to seek a substitute decision maker before providing emergency medical treatment.^{4,8}

The following principles should guide the decisions of a substitute decision maker to assure that the best interests of the individual are served:

- **Individuals with disabilities are entitled to all appropriate medical care that non-disabled individuals would receive, including comprehensive hospice services.⁵**
- **Substitute decision makers should place high value on preserving the life of the individual.**
- **Substitute decisions should effectuate, as much as possible, the decision the individual would make for himself/herself.⁷**
- **Individuals with disabilities should be accommodated to the extent necessary so that they can participate as fully as possible in all decisions which affect**

- them. Accommodations shall include: communication devices, interpreters and physical assistance.
- Substitute decision makers should give due consideration to all information, including the recommendations of other interested and involved persons.
- Treatment that would be medically futile is not required.^{7,9} A judgment of futility of treatment should not be prejudiced by the serious disability of the individual or the notion of what the quality of life is for the person with the disability.
- The ideal substitute decision embodies a consensus of all interested/involved parties.

When necessary, substitute decision makers should be chosen in the following order:

1. **A health care proxy or attorney in fact for health care decisions.**¹⁰ If the individual, while competent, has designated a person to make health care decisions on the individual's behalf, *that person the individual chose should make health care decisions for the individual.*
2. **A guardian of the individual's person.** If, pursuant to Pennsylvania's guardianship statute,⁶ a court has already designated a person to make decisions on the individual's behalf, that person should make health care decisions for the individual. *Where there is intractable conflict between interested parties with respect to a particular health care or end of life decision, it is advisable to request a court to appoint a guardian. Medical treatment to preserve life should be provided until the conflict can be resolved.*
3. **Next of kin.** If no one has been designated by a court or by the individual, *the following next of kin in order of priority and as available and willing, should make health care decisions for the individual: the spouse, an adult son or daughter, either parent, or an adult brother or sister.*⁷
4. **The facility director.** In the absence of any other appointed decision maker or willing next of kin, the facility director becomes the decision maker pursuant to the Mental Health and Mental Retardation Act of 1966 (MH/MR Act).³ *Section 417 (c) of the MH/MR Act specifies that the facility director may authorize elective surgery,*³ but the facility director's authority also encompasses the range of health care options that have become available since the MH/MR Act was passed.

Where the facility director becomes the substitute decision maker for an individual who has a terminal condition or is permanently unconscious, the director must first review the individual's annual plan and all relevant medical records, including a lifetime medical history to help identify the individual's medical status historically and immediately prior to needing a substitute decision. *The facility director may authorize treatment only with the written agreement of two physicians not employed by the facility.*³ The facility director must be informed of the interdisciplinary team's consensus regarding the decision to be made, based upon team members' direct knowledge of and familiarity with the individual, so the facility director will have sufficient information to make a decision that the individual would make if able to do so. Even where another substitute decision maker is identified, the facility director should continue to monitor the situation to ensure that the law is followed and that decisions are made with the best interest[s] of the individual as the paramount concern. Unresolved conflicts arising from lack of consensus or the perceived violation of the law, may be pursued through the courts, by any party.

There are limits on a substitute decision maker's authority. They are:

- **An Act 28/26 facility may not withhold treatment, care, goods, and services provided by such a facility in the absence of authorization from a health care proxy, an attorney-in-fact, a durable power of attorney, an advance directive or a written document signed by the person while competent.**
- **No substitute decision maker may execute an Advance Directive or name a health care proxy on behalf of an incompetent individual.**
- **No substitute decision maker may authorize a DNR Order or otherwise withhold life-sustaining care unless the individual has a terminal condition or is permanently unconscious.**^{7,8}
- **A substitute decision maker may authorize termination of life-sustaining treatment for an individual who has a terminal condition or is permanently unconscious without a court order, providing the individual's condition has been confirmed in writing by two physicians.**^{2,7}

Substitute decision makers may withhold treatment that would only extend the process of dying.⁷ Palliative care that may have the unintended effect of hastening the death of an individual with a terminal condition may be allowed.⁹

OBSOLETE BULLETIN:

This bulletin replaces and supersedes MR Bulletin 00-90-02.

¹ Acts 28/26, 18 Pa.C.S. § 2713.

² Advance Directive for Health Care Act, 20 Pa.C.S. §§ 5401 et seq.

³ Mental Health and Mental Retardation Act of 1966, 50 P.S. §§ 4101 et seq.

⁴ Health Care Services Malpractice Act, 40 P.S. §§ 1301.101 et seq.

⁵ Americans with Disabilities Act, 42 U.S.C. §§ 12101 et seq.

⁶ Probate, Estates and Fiduciaries Code, Chapter 55, relating to Incapacitated Persons, 20 Pa.C.S. §§ 5501 et seq.

⁷ In re Fiori, 673 A.2d 905 (Pa. 1996).

⁸ In re Dorone, 534 A.2d 452 (Pa. 1987).

⁹ See, e.g., Vacco v. Quill, 117 S. Ct. 2293 (1997).

¹⁰ Probate, Estates and Fiduciaries Code, Chapter 56, relating to Powers of Attorney, 20 Pa.C.S. §§ 5601 et seq.