

**ANNEX A**

**TITLE 55: PUBLIC WELFARE**

**PART VIII. MENTAL RETARDATION MANUAL**

**SUBPART A. STATEMENTS OF POLICY**

**CHAPTER 6000. STATEMENTS OF POLICY**

**OFFICE OF DEVELOPMENTAL PROGRAMS**

**Subchapter R. PROCEDURES FOR SURROGATE HEALTH CARE  
DECISION MAKING**

**GENERAL PROVISIONS**

**§ 6000.1001. Scope.**

Administrative entity administrators and directors, county Mental Health/Mental Retardation administrators, supports coordination organization directors and providers of mental retardation services may consider this statement of policy with respect to the decisions of surrogate health care decision makers identified under Pennsylvania law.

**§ 6000.1002. Purpose.**

The purpose of this statement of policy is to clarify surrogate health care decision-making procedures applicable to individuals with mental retardation who are 18 years of age or older in light of Act 169 and other applicable law.

**§ 6000.1003. Definitions.**

The following words and terms, when used in this subchapter, have the following meanings, unless the context clearly indicates otherwise.

*Act 169* — Act 2006 - 169, which added 20 Pa.C.S. Chapter 54 (relating to health care).

*Act 28 facility* — 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. See 18 Pa.C.S. § 2713 (relating to neglect of care-dependent person).

*Advance health care directive* — The term as defined in 20 Pa.C.S. § 5422 (relating to definitions). An advance health care directive is a signed and witnessed document which directs health care in the event that the individual (the principal) is incompetent and has an end-stage medical condition or is permanently unconscious. It also may designate a person to carry out the individual's wishes regarding health care at the end of life.

*CPR — Cardiopulmonary Resuscitation* — The term as defined in 20 Pa.C.S. § 5422.

*Competent* — The term as defined in 20 Pa.C.S. § 5422. Under Act 169, the attending physician determines competency.

*DNR Order—Do not resuscitate order* — An order in the individual’s medical record that CPR should not be provided to the individual.

*End stage medical condition* — The term as defined in 20 Pa.C.S. § 5422.

*Facility director* —

- (i) For those facilities that are MR facilities as defined in MH/MR Act, the facility director is the administrative head of a facility.
- (ii) In facilities licensed under 55 Pa.Code Ch. 6400 (relating to community homes for individuals with mental retardation), the term means the Chief Executive Officer as per § 6400.43 (relating to chief executive officer).
- (iii) In facilities licensed under 55 Pa.Code Ch. 6500 (relating to family living homes), the term means the Chief Executive Officer as § 6500.42 (relating to chief executive officer).
- (iv) In intermediate care facilities for persons with mental retardation, the term means the administrator appointed under 42

C.F.R. § 483.410(a)(3) (relating to condition of participation: governing body and management).

- (v) In facilities licensed under 55 Pa.Code Ch. 5310 (relating to community residential rehabilitation services for the mentally ill), the term means the director selected under § 5310.11 (relating to governing body).
- (vi) In facilities licensed 55 Pa.Code Ch. 5320 (relating to requirements for long-term structured residence licensure), the term means the program director selected under § 5320.22 (relating to governing body).

*Health care* — The term as defined in 20 Pa.C.S. § 5422.

*Health care agent* — The term as defined in 20 Pa.C.S. § 5422.

*Health care decision* — The term as defined in 20 Pa.C.S. § 5422.

*Health care power of attorney* — The term as defined in 20 Pa.C.S. § 5422. A health care power of attorney is the actual document declaring an individual to make health care decisions for the principal. The person designated in a health care power of attorney is sometimes referred to as the “health care agent”.

*Health care provider* — The term as defined in 20 Pa.C.S. § 5422.

*Health care representative* — The term as defined in 20 Pa.C.S. § 5422. In addition, Act 169 specifies the following limitation on designation of the health care representative: Unless related by blood, marriage or adoption, a health care representative may not be the principal’s attending physician or other health care provider, not an owner, operator or employee of a health care provider in which the principal receives care.

*Incompetent* — The term as defined in 20 Pa.C.S. § 5422.

*Living will* — The term as defined in 20 Pa.C.S. § 5422.

*MH/MR Act* — The Mental Health and Mental Retardation Act of 1966 (50 P.S. §§ 4101-4704).

*MH* — Mental health.

*MR* — Mental retardation.

*Mental health advance directive* — A document that directs MH services and supports that an individual might want to receive during a crisis if the individual is unable to make decisions because of the individual’s mental illness. This is a separate document from an advance health care directive. See 20 Pa.C.S. Chapter 58 (relating to mental health care).

*Permanently unconscious* — The term as defined in 20 Pa.C.S. § 5422.

*Person* — The term as defined in 1 Pa.C.S. § 1991 (relating to definitions).

*Principal* — The term as defined in 20 Pa.C.S. § 5422. The principal is at least 18 years of age, has graduated from high school, has married, or is an emancipated minor.

*Surrogate health care decision maker* — A person that makes health care decisions for another individual.

## **HEALTH CARE DECISION MAKING**

### **§ 6000.1011. Competent Individuals.**

- (a) The health care or end of life decisions of an individual who is competent should be honored.
- (b) Competent individuals may also execute advance health care directives in accordance with 20 Pa.C.S. Chapter 54 (relating to health care).
- (c) Competent individuals should be encouraged to make advance health care directives which will become operative if they lose competency unless revoked in accordance with 20 Pa.C.S. Chapter 54.

(d) Advance health care directives should be reviewed and updated in writing periodically.

**§ 6000.1012. Individuals who are not competent and need emergency treatment.**

Consent is implied in law for emergencies and there is no need to seek a surrogate health care decision maker before providing emergency medical treatment. See the Medical Care Availability and Reduction of Error (MCARE) Act (40 P.S. §§ 1303.101 – 1303.1115; *In re Dorone*, 534 A.2d 452 (Pa. 1987)).

**§ 6000.1013. Individuals who are not competent and who do not have end-stage medical conditions or are not permanently unconscious.**

(a) If an individual is not competent to make a particular non-emergent health care decision, another person must make that decision on the individual's behalf.

(b) Under Act 169, where a guardian, health care agent, or health care representative will be making the decision, the attending physician determines whether an individual has an end stage medical condition or is permanently unconscious.

(c) When a surrogate health care decision maker is needed to make a non-emergent health care decision for an individual who neither has an end-stage medical condition nor is permanently unconscious, the health care decision maker should be chosen in the following order:

- (1) A health care agent. If the individual, while competent, has executed a valid advance health care directive that designates a health care agent and the health care agent is available and willing to make the decision, the health care agent should make the health care decision for the individual. See 20 Pa.C.S. Chapter 54, Subchapter C (relating to health care agents and representatives).
- (2) A guardian of the individual's person.
  - (i) If, under Pennsylvania's guardianship statute (20 Pa.C.S. Chapter 55 (relating to incapacitated persons)), a court has already appointed a guardian to make health care decisions on the individual's behalf, the guardian should make such decisions for the individual.
  - (ii) If a person who executed a valid health care power of attorney is later adjudicated an incapacitated person and a guardian of the person is appointed by the court to make health care decisions, the health care agent named in the health care power of attorney is accountable to both the guardian and the individual.
  - (iii) The guardian has the same power to revoke or amend the

appointment of a health care agent as the individual would have if he were not incapacitated, but may not revoke or amend the instructions in an advance health care directive absent judicial authorization. See 20 Pa.C.S. § 5460(a) (relating to relation of health care agent to court-appointed guardian and other agents).

- (3) A health care representative.
  - (i) In the absence of a health care agent designated under a valid advance health care directive or a court-appointed guardian of the person with authority to make health decisions, an available and willing health care representative should make the health care decision.
  - (ii) In descending order of priority, the following persons can act as health care representatives for individuals:
    - (A) A person chosen by the individual (in a signed writing or by informing the individual's attending physician) while the individual was of sound mind.
    - (B) The individual's spouse (unless a divorce action is pending).
    - (C) The individual's adult child.
    - (D) The individual's parent.
    - (E) The individual's adult brother or sister.
    - (F) The individual's adult grandchild.

- (G) An adult who has knowledge of the individual's preferences and values. See 20 Pa.C.S. Chapter 54, Subchapter C.
- (4) The facility director.
- (i) In the absence of any other appointed decision maker or willing next of kin, the facility director becomes the health care decision maker under the MH/MR Act.
  - (ii) Under the MH/MR Act, the director of a facility may, with the advice of two physicians not employed by the facility, determine when elective surgery should be performed upon any mentally disabled person admitted or committed to such facility when such person does not have a living parent, spouse, issue, next of kin or legal guardian as fully and to the same effect as if said director had been appointed guardian and had applied to and received the approval of an appropriate court therefor.
  - (iii) Section 417(c) of the MH/MR Act (50 P.S. § 4417(c)) specifies that the facility director may authorize elective surgery, but the Department has consistently interpreted that section to recognize that the facility director's authority also encompasses health care decisions generally.
  - (iv) The facility director may authorize elective surgery and other treatment only with the advice of two physicians not

employed by the facility.

- (v) Where the facility director becomes the surrogate health care decision maker for an individual who does not have an end-stage medical condition or is not permanently unconscious, the director should first review the individual's support plan and relevant medical history and records to help identify the individual's medical status historically and immediately prior to making a surrogate health care decision.
- (vi) The facility director should be informed of the decision to be made and gather information based on the direct knowledge of those familiar with the individual.
- (vii) In this manner, the facility director will have sufficient information to make the decision that the individual would make if able to do so.
- (viii) Even where another surrogate health care decision maker is identified, the facility director should continue to monitor the situation to ensure that decisions are made with the best interest of the individual as the paramount concern.
- (ix) In the event of a short-term absence of the facility director, the director may assign a designee to perform these functions.

- (x) The assigned designee may only be a person authorized to perform the facility director's functions in the director's absence.
- (xi) The facility director may not authorize a DNR Order for a person who is not competent and does not have an end stage medical condition.

**§ 6000.1014. Individuals who are not competent and who have either end-stage medical conditions or are permanently unconscious.**

- (a) Under Act 169, where a guardian, health care agent, or health care representative will be making the decision, the attending physician determines whether an individual has an end stage medical condition or is permanently unconscious.
- (b) In contrast, the MH/MR Act, which applies to health care decisions by facility directors, requires the advice of two physicians for recommended treatment of health care conditions, including end stage medical conditions.
- (c) When a surrogate health care decision maker is needed to make a non-emergent health care decision for an individual who has an end-stage medical condition or is permanently unconscious and who has not executed a valid living will that governs the decision, the surrogate health care decision maker should be chosen in the following order:

- (1) A health care agent. If the individual, while competent, has executed a valid advance health care directive that designates a health care agent and the health care agent is available and willing to make the decision, the health care agent should make health care decisions for the individual.
- (2) A guardian of the individual's person.
  - (i) If, under Pennsylvania's guardianship statute, a court has already appointed a guardian of the person to make health care decisions on the individual's behalf, the guardian should make the decisions for the individual.
  - (ii) If a person who executed a valid health care power of attorney is later adjudicated an incapacitated person and a guardian of the person is appointed by the court to make medical decisions, the health care agent named in the health care power of attorney is accountable to both the guardian and the individual.
  - (iii) The guardian has the same power to revoke or amend the appointment of a health care agent as the individual would have if he were not incapacitated, but may not revoke or amend the instructions in an advance health care directive absent judicial authorization.
- (3) A health care representative.

- (i) In the absence of a health care agent designated under a valid advance health care directive or a court-appointed guardian of the person with authority to make health care decisions, an available and willing health care representative should make the health care decision.
- (ii) In descending order of priority, the following individuals can act as health care representatives for individuals:
  - (A) A person chosen by the individual (in a signed writing or by informing the individual's attending physician) while the individual was of sound mind.
  - (B) The individual's spouse (unless a divorce action is pending).
  - (C) The individual's adult child.
  - (D) The individual's parent.
  - (E) The individual's adult brother or sister.
  - (F) The individual's adult grandchild.
  - (G) An adult who has knowledge of the individual's preferences and values.
- (4) The facility director.
  - (i) In the absence of any other appointed decision maker or willing next of kin, the facility director in his discretion becomes the surrogate health care decision maker under section 417(c) of the MH/MR Act.

- (ii) Section 417(c) of the MH/MR Act specifies that the facility director may authorize elective surgery, but the Department has consistently interpreted that section to recognize that the facility director's authority also encompasses health care decisions generally.
- (iii) The facility director may authorize elective surgery and other treatment only with the advice of two physicians not employed by the facility.
- (iv) When the facility director becomes the surrogate health care decision maker for an individual who has an end-stage medical condition or is permanently unconscious, the director shall first review the individual's support plan and relevant medical history and records to help identify the individual's medical status historically and immediately prior to making a surrogate health care decision.
- (v) The facility director must be informed of the decision to be made and gather information based on the direct knowledge of those familiar with the individual.
- (vi) In this manner, the facility director will have sufficient information to make the decision that the individual would make if able to do so.
- (vii) For a decision to withdraw treatment or life-sustaining care for a person who is not competent who has an end-stage

medical condition or is permanently unconscious, the Department recommends a facility director seek judicial authorization prior to the withdrawal of treatment or life-sustaining care due to a risk of conflict of interest claims.

- (viii) For a DNR Order for a person who is not competent who has an end-stage medical condition or is permanently unconscious, the Department recommends a facility director seek judicial authorization prior to requesting the issuance of a DNR Order due to a risk of conflict of interest claims.
- (ix) Pending the judicial authorization under subparagraphs (vii) and (viii), the Department recommends a facility director direct that treatment or life-sustaining care be continued for a person who is not competent who has an end-stage medical condition or is permanently unconscious.
- (x) Even when another surrogate health care decision maker is identified, the facility director should continue to monitor the situation to ensure that decisions are made with the best interest of the individual as the paramount concern.
- (xi) In the event of a short-term absence of the facility director, the director may assign a designee to perform these functions.

(xii) The assigned designee may only be a person authorized to perform the facility director's functions in the director's absence.

(d) In the rare circumstance that the individual with an end-stage medical condition or who is permanently unconscious does not have a living will, health care agent, court-appointed guardian, available and willing health care representative or facility director, then a court should appoint a guardian with authority to act. Appropriate medical care should be provided pending the appointment of a guardian.

(e) In reaching decisions about appropriate care, the following may be helpful:

- (1) Holding a team meeting including the health care provider, the family/health care representative, the mental retardation service provider and any other interested parties to clarify the issues and each party's understanding of the situation.
- (2) Involving the palliative care team, the patient advocate, or both at a hospital to act as an objective party and help communicate issues and assist each party in understanding the situation.
- (3) Using Hospital Ethics committees to review situations.
- (4) Having a second medical or surgical opinion, which can sometimes clarify the prognosis or possible treatments for a particular condition.
- (5) As a last resort, pursuing resolution through the courts.

**§ 6000.1015. Health care power of attorney.**

(a) Unless otherwise specified in the health care power of attorney, a health care power of attorney becomes operative when the following occurs:

- (1) A copy is provided to the attending physician.
- (2) The attending physician has determined that the principal is incompetent. See 20 Pa.C.S. §§ 5422 and 5454(a) (relating to definitions; and when health care power of attorney operative).

(b) Unless otherwise specified in the health care power of attorney, a health care power of attorney becomes inoperative when, in the determination of the attending physician, the principal is competent.

**§ 6000.1016. Limitations on authority of the surrogate health care decision maker.**

(a) A surrogate health care decision maker may not execute an advance health care directive or name a health care agent on behalf of an incompetent individual.

(b) Under 20 Pa.C.S. Chapter 54 (relating to health care) and applicable case law, (see *In re D.L.H.*, 2 A.2d. 505 (Pa. 2010)), neither a health care representative nor a guardian nor a facility director has authority to refuse life-preserving care for a person who has a life-threatening medical condition, but is neither in an end-stage medical condition nor permanently unconscious.

(c) Title 20 Pa.C.S. § 5462(c)(1) (relating to duties of attending physician and health care provider) provides:

“Health care necessary to preserve life shall be provided to an individual who has neither an end-stage medical condition nor is permanently unconscious, except if the individual is competent and objects to such care or a health care agent objects on behalf of the principal if authorized to do so by the health care power of attorney or living will.”

(d) A residential facility must provide necessary treatment, care, goods, or services to an individual except where otherwise permitted under 18 Pa.C.S. § 2713(e) (relating to neglect of care-dependent person) as follows:

- (1) The caretaker’s, individual’s, or facility’s lawful compliance with a care-dependent person’s living will as provided in 20 Pa.C.S. Chapter 54.
- (2) The caretaker’s, individual’s, or facility’s lawful compliance with a care-dependent person’s written, signed, and witnessed instructions, executed when the care-dependent person is competent as to the treatment he wishes to receive.
- (3) The caretaker’s, individual’s, or facility’s lawful compliance with the direction of one of the following:
  - (i) An agent acting under a lawful durable power of attorney under 20 Pa.C.S. Chapter 56 (relating to power of attorneys), within the scope of that power.

- (ii) A health care agent acting under a health care power of attorney under 20 Pa.C.S. Chapter 54, Subchapter C (relating to health care agents and representatives), within the scope of that power.
- (4) The caretaker's, individual's, or facility's lawful compliance with a DNR order written and signed by the care-dependent person's attending physician. Generally, a DNR order is appropriate in the presence of an end-stage medical condition.
- (5) The caretaker's, individual's, or facility's lawful compliance with the direction of a care-dependent person's health care representative under 20 Pa.C.S. § 5461 (relating to decisions by health care representative), provided the care dependent person has an end-stage medical condition or is permanently unconscious as these terms are defined in 20 Pa.C.S. § 5422 (relating to definitions) as determined and documented in the person's medical record by the person's attending physician.

**§ 6000.1017. Guidance for individuals without family or an advocate.**

- (a) For individuals that may not have living family members or anyone that is currently advocating for them, the County or Administrative Entity, supports

coordination organization, or the provider agency working with the individual should help the individual identify someone who knows the individual and would be willing to act as the individual's health care representative.

(b) The health care representative may be a friend, a family friend, someone in the individual's church or neighborhood, or someone that has worked with the individual in the past, but is no longer actively providing their services.

**§ 6000.1018. Intermediate Care Facility for the Mentally Retarded (ICF/MR) facility director as a guardian.**

The prohibition in 20 Pa. C.S. § 5461(f) (relating to decisions by health care representative) on a health care provider's being a health care representative is not applicable to a facility director under section 417(c) of the MH/MR Act (50 P.S. § 4417(c)), regarding powers and duties of directors, because a facility director is made a guardian under that section, not a health care representative.

## **RECORDS**

**§ 6000.1021. Access to records.**

Under the Health Insurance Portability and Accountability Act (HIPAA), guardians, agents or representatives as medical surrogates have the same

access to medical records that the principal does. See 45 CFR. 164.502 (g) and 164.510(b)(3) (relating to uses and disclosures of protected health information: general rules; and uses and disclosures requiring an opportunity for the individual to agree or to object).

## **STATUTES**

### **§ 6000.1031. Applicable statutes.**

Several other statutes also govern health care decision-making, and were not repealed by Act 169. Accordingly, they remain in effect. These statutes include the following:

- (1) Title 18 Pa. C.S. § 2713 (relating to neglect of care-dependent person).
- (2) Title 20 Pa. C.S. Chapter 55 (relating to incapacitated persons).
- (3) The Medical Care Availability and Reduction of Error (MCARE) Act (40 P.S. §§1303.101 – 1303.115).
- (4) Section 417(c) of the MH/MR Act (50 P.S. § 4417(c)), regarding powers and duties of directors.

**§ 6000.1032. Applicability of section 417(c) of the MH/MR Act to health-care decisions.**

(a) Notwithstanding that section 417(c) of the MH/MR Act (50 P.S. § 4417(c)), regarding powers and duties of directors, explicitly references only “elective surgery,” that section should be read as applicable to health care decisions generally.

(b) A facility director’s authority under section 417(c) of the MH/MR Act should be construed to include authority to make decisions regarding palliative care for persons in an end-stage (terminal) condition.

(c) For care provided in the MR facility itself, no surrogate consent is needed because 18 Pa. C.S. § 2713 (relating to neglect of care-dependent person) requires that necessary care and treatment be provided without it.

(d) For care outside the mental retardation facility, such as a doctor’s office or hospital, the primary care physician (PCP) and the specialist performing the procedure can serve as the two physicians (except in the rare circumstance where the PCP is a payroll employee of the MR facility) required under section 417(c) of the MH/MR Act.