

# **DEVELOPMENTAL PROGRAMS BULLETIN**

## COMMONWEALTH OF PENNSYLVANIA DEPARTMENT OF PUBLIC WELFARE

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SUBJECT:

**Procedures for Surrogate Health Care Decision Making** 

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#### SCOPE:

Administrative Entity Administrators or Directors
County Mental Health and Mental Retardation Administrators
Supports Coordination Organization Directors
Providers of Community Mental Retardation Residential Services
State Center Directors
NonState ICF/MR Directors

## **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 the Act of November 29, 2006 (P.L. 1484, No. 169) (Act 169) which added 20 Pa.C.S. Chapter 54 (relating to advance directive health care) and other applicable laws. The Department of Public Welfare (Department) recognizes that it does not have statutory authority to interpret Act 169 and the Department does not assume any liability that may arise from the application of these guidelines with respect to private providers. This statement of policy, therefore, is not binding on these entities and does not offer protection against claims that may arise with respect to those entities.

Agencies are encouraged to consult their own legal counsel for advice on the implementation of the statutes discussed in this statement of policy.

### **BACKGROUND:**

When situations arise where a health care decision is necessary and an adult individual is not able to make that decision, then a decision shall be made on that individual's behalf. Bulletin 00-98-08, "Procedures for Substitute Health Care Decision Making", issued on November 30, 1998, detailed the applicable standards for surrogate decision-making for individuals with mental retardation over 18 years of age. Act 169 amended Pennsylvania's law concerning advance health care directives and authorized a "health care representative" (HCR) to make health care decisions for individuals who

COMMENTS AND QUESTIONS REGARDING THIS BULLETIN SHOULD BE DIRECTED TO:

The Appropriate Developmental Programs Regional Office

are not competent and do not have valid and applicable advance health care directives or court-appointed guardians of the person.

This statement of policy updates the Department's interpretation of the laws and procedures for surrogate health care decision-making for individuals receiving mental retardation services through the Department under Act 169 and other applicable law.

#### **DISCUSSION:**

#### **Act 169**

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

Generally, health care can be provided only with the consent of the patient. There are, however, exceptions in emergencies or if the patient is incompetent to make health care decisions. If a patient is incompetent, a surrogate health care decision maker is authorized by Pennsylvania law to make health care decisions on behalf of the patient. Historically, there has been some uncertainty about who can serve as a surrogate health care decision maker, and the extent of the surrogate health care decision maker's authority, particularly in doctors' offices, clinics, and hospitals.

The autonomy of persons who have the capacity to make particular health care decisions as they arise should be respected. In the event that a health care decision becomes necessary, a reasonable effort should be made to explain the proposed course of action, any alternate options, and the risks and benefits for each to the individual prior to instituting a course of action. However, situations may arise where a health care decision is necessary and the individual, whether incompetent as defined by Act 169 or adjudicated incapacitated, does not have the capacity to make that decision. In such cases, a decision shall then be made on that individual's behalf by a surrogate health care decision maker, as identified in several state statutes.

Though Act 169 covers many aspects of health care, 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:

- 18 Pa.C.S. § 2713 (relating to neglect of care-dependent person).
- 20 Pa.C.S. Chapter 55 (relating to incapacitated persons).
- The Medical Care Availability and Reduction of Error (MCARE) Act (MCARE Act) (40 P.S. §§1303.101–1303.910).
- Section 417(c) of the Mental Health and Mental Retardation (MH/MR) Act of 1966 (50 P.S. § 4417(c) (relating to powers and duties of directors)).

## Mental Health and Mental Retardation (MH/MR) Act of 1966

For multiple reasons, § 417(c) of the MH/MR Act of 1966 (50 P.S. § 4417(c) (relating to powers and duties of directors)), survives Act 169:

- 1. Section 5421(b) of 20 Pa.C.S. (relating to applicability) declares that "this chapter shall not impair or supersede any existing...responsibilities not addressed in this chapter." In addition, Act 169 does not address the situation that § 417(c) of the MH/MR Act does-- the identification of a surrogate health care decision maker for a resident of an MH/MR facility who has no other surrogate health care decision maker, not even a HCR.
- 2. The prohibition in 20 Pa. C.S. § 5461(f) (relating to decisions by health care representative) on a health care provider's being a HCR, is not applicable to the facility director under § 417(c) of the MH/MR Act because the facility director is made a guardian under § 417(c) of the MH/MR Act, not a HCR. While both guardians and HCRs are surrogate health care decision makers, the constraints specifically applicable to HCRs are applicable to them only. Act 169 does not affect the rules for the identification of guardians. There are policy justifications for the distinction. In ordinary nursing homes, the need for a facility director as an HCR is less because there will usually be others available, and the facility may have had only days or weeks of contact with the patient; therefore, a facility director would not likely be a good HCR. In contrast, at an Intermediate Care Facility for the Mentally Retarded (ICF/MR) or group home, some residents lack any involved family, thereby triggering the need for default surrogate health care decision makers. Facility staff in ICF/MRs and group homes have often known the residents for years or even decades, thereby becoming aware of the residents' preferences, unlike the circumstance in the ordinary nursing home.
- 3. Section 417(c) of the MH/MR Act and Act 169 need to be read in *pari materia*. The plain purpose of both statutory provisions is to permit surrogate health care decision-making for incompetent individuals without the need to obtain a court order. If Act 169 were construed to repeal § 417(c) of the MH/MR Act, court orders would be required where there was not an HCR, thereby defeating a principal purpose of Act 169 itself.

In addition, although § 417(c) of the MH/MR Act explicitly references only "elective surgery," this section should be read as applicable to health-care decisions generally. There are several reasons for this:

1. Section 417(c) of the MH/MR Act was enacted at the dawn of the doctrine of informed consent, when only elective surgery was thought to require explicit informed consent. Consent to emergency surgery was (and still is) implied in law, and consent to routine medical procedures such as immunizations and x-rays was thought to be implied by the mere fact of the patient's cooperation. See Fay Rozovsky, Consent to Treatment §1.10.1 (3d ed. 2000). See also Paul Appelbaum, et al, Informed Consent (1987). Even today in Pennsylvania, only a limited number of procedures require "informed consent," see section 504 of the MCARE Act (40 P.S. §1303.504) regarding informed consent. Competent patients, or in the case of incompetent patients, their surrogate health care decision makers, are often expected in practice to "sign for" a wide range of procedures, whether informed consent is

required by law or not. Because statutes are to be construed liberally to effectuate their purposes (with certain exceptions not applicable here), <u>see</u> 1 Pa. C.S. §1928(c) (relating to rule of strict and liberal construction), and because the obvious purpose of § 417(c) of the MH/MR Act is to provide for a surrogate decision maker for medical decisions when decision makers are needed, and to do so without petitioning a court, its scope must be read in light of its purpose.

- 2. Under the legal doctrine that "the greater power includes the lesser," see, for example, Griffin v. SEPTA, 757 A.2d 448 (Pa. Commw. 2000), the power to consent to "elective surgery," for example, amputation of a leg with a malignant tumor, necessarily includes the power to consent to diagnostic procedures to determine the appropriateness of any such amputation. Similarly, the facility director's authority under § 417(c) of the MH/MR Act should be construed to include authority to make decisions regarding palliative and life-sustaining care for persons in an end-stage (terminal) condition.
- 3. Section 417(c) of the MH/MR Act explicitly limits the facility director's authority to decision-making after receiving "the advice of two physicians not employed by the facility". This requirement, however, will rarely create a practical problem. For necessary care and treatment provided in the mental retardation facility itself, consent from a surrogate is not needed because 18 Pa.C.S. § 2713 (relating to neglect of care-dependent person) requires that necessary care and treatment be provided without such consent. For care outside the mental retardation facility, such as in a doctor's office or hospital, the primary care physician and the specialist performing the procedure can serve as the two physicians (except in the rare circumstance where a primary care physician is a payroll employee of the mental retardation facility) as required under § 417(c) of the MH/MR Act.

## **GUIDELINE:**

The guideline is contained in Annex A to this Bulletin.

#### **EFFECTIVE DATE:**

This statement of policy is effective immediately upon publication in the *Pennsylvania Bulletin*.

#### **OBSOLETE BULLETIN:**

This bulletin replaces and supersedes Bulletin 00-98-08, "Procedures for Substitute Health Care Decision Making".

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