

CONSENT FOR MEDICAL TREATMENT BY INDIVIDUALS WITH MENTAL RETARDATION

Individuals with mental retardation should be allowed to participate meaningfully in making decisions that affect their lives and to have their preferences respected to the greatest extent possible. Meaningful participation includes the right to give consent to medical treatment and the corollary right to refuse to consent to medical treatment. Consent must be voluntary (*i.e.*, not coerced) and expressed through any means appropriate to the individual (such as words, physical gestures, or demeanor).

Simple Consent -- Individuals with mental retardation need only give “simple” consent concerning routine supports that pose no risk of harm greater than that ordinarily encountered in daily living (such as dietary choices, participation in religious or recreational activities or work, and routine physical examinations, tests, and treatment).

Informed Consent -- More than simple consent is necessary for physical health care that poses a greater risk of harm than that encountered in daily life or during routine physical or psychological examinations and tests, such as surgery, invasive treatments, aversive treatments, and experimental treatments. Informed consent requires an explanation of the proposed action and its purpose; the possible adverse consequences and risks; the anticipated benefits; and alternatives.

Consent in Emergency Situations -- Consent will be implied in an emergency situation when (1) a person is unconscious or otherwise not capable of consent, and (2) and the failure to perform the procedure immediately could threaten the person's life or health unless it is known that the individual specifically refused the procedure when conscious and competent to make the decision. If there is enough time, however, the health care provider will seek a surrogate decision maker (either next-of-kin or appointment of an emergency guardian).

Competence to Give Informed Consent -- When informed consent is required, an individual's capacity or “competence” to consent must be determined. A person is competent to give or refuse consent if, when provided with appropriate medical information, communication supports and technical assistance, she can understand the potential material benefits, risks, and alternatives involved with the proposed health care decision, can make that health care decision on her own behalf, and can communicate that decision to the health care provider. An individual may have the capacity to understand and give informed consent to some, but not all, health care decisions. *A diagnosis of mental retardation does not automatically render a person incapable of giving informed consent.* Individuals with mental retardation should be afforded the opportunity to make their own health care decisions if they have the capacity to do so.

Persons with Mental Retardation and Advance Health Care Directives -- People with mental retardation who are able to do so should be encouraged to consider making advance health care directives. Advance health care directives can include either or both a durable health care power of attorney and a living will. In a durable health care power of attorney, the individual will appoint a “health care agent” to make medical decisions for him in the event he becomes incompetent to make any medical decisions. Durable health care powers of attorney are not limited to health care decisions when the individual has an end-stage medical condition or is permanently unconscious. Living wills, in contrast, afford

health care providers with direction on health care decisions only when the individual has an end-stage medical condition or is permanently unconscious. Family, friends, advocates, case managers and other involved persons may be able to assist individuals with mental retardation to create these health care documents. Providers and their employees, however, may not be named as a “health care agent” who will make decisions in the event the person becomes incompetent to make such decisions. 20 Pa. Cons. Stat. Ann. § 5455(b).

Surrogate Decision Makers for People Not Competent to Make Medical Decisions -- If an individual is not competent to make medical decisions and has not executed a valid advance health care directive, a substitute decision maker or surrogate must make medical decisions. Surrogate decision makers can include, but are not limited to, court-appointed guardians who have authority to make medical decisions. If there is no court-appointed guardian and a surrogate decision maker is needed, the question of who can serve as the surrogate will depend on whether the individual has an end-stage medical condition or is permanently unconscious or whether he does not have one of those conditions.

Surrogate Decision Making When A Person Has An End-Stage Medical Condition or Is Permanently Unconscious -- When a person has an end-stage medical condition or is permanently unconscious and is not competent to make medical decisions and has no guardian, Pennsylvania law allows for the selection of a “health care representative” to make necessary treatment and care decisions. 20 Pa. Cons. Stat. Ann. § 5461. The law identifies who can act as a health care representative in order of priority (with primacy given to a person identified by the infirm individual to her physician before she became incompetent, and then, in descending order, any spouse, adult child, parent, adult sibling, adult grandchild, or adult who has knowledge of the individual’s preferences and values to assess how she would make health care decisions). 20 Pa. Cons. Stat. Ann. § 5461(d). A health care provider and its employees *cannot* serve as the health care representative. 20 Pa. Cons. Stat. Ann. § 5461(f). Pennsylvania law outlines the types of information the health care representative must evaluate and the standards to be used in making decisions for the individual. 20 Pa. Cons. Stat. Ann. § 5461(c) (incorporating 20 Pa. Cons. Stat. Ann. § 5460(c)).

Surrogate Decision Making When A Person Does Not Have An End-Stage Medical Condition or Is Not Permanently Unconscious -- When an individual is not competent to make medical decisions, does not have a guardian, and does not have an end-stage medical condition or is not permanently unconscious, Pennsylvania law is less clear as to how to proceed. As a matter of custom, many health care providers will allow next-of-kin to make such decisions for the individual. In addition, the Mental Health and Mental Retardation Act of 1966 has been interpreted to allow a residential services provider to make medical decisions for individuals who are not competent and who do not have involved family members. 50 Pa. Cons. Stat. Ann. § 4417. In some instances, however, a health care provider might not be willing to accept an informal surrogate decision maker such as a family member or the residential services provider. In those circumstances, it may be necessary to seek an alternative health care provider who will except the surrogate decision maker’s consent. If it is not feasible to seek an alternative health care provider

willing to accept the surrogate's consent or such a search proves fruitless, it may be necessary to seek court-appointment of a limited guardian for the purpose of making the necessary medical decision.

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