A. Purpose
The purpose of this procedure is to provide guidelines for individuals, families, staff, and administrators regarding individuals’ rights under Connecticut law to accept or refuse medical treatment and to formulate advance directives.

B. Applicability
This procedure shall apply to all individuals for whom the department bears direct or oversight responsibility for medical care. This includes people living in programs operated, licensed, and/or funded by the department, including non-Connecticut residents living in such facilities. It also applies to individuals receiving supported living services, respite services in DMR-operated or -funded facilities, and individuals living in facilities licensed by the Department of Public Health if the department was involved with the placement decision.

C. Definitions
Advance directive: A legal document prepared before any condition occurs which prevents the individual’s participation in decision making that states whether the person wishes to have life-sustaining procedures or treatment administered.

Department: The Department of Mental Retardation.

Individual: For this procedure, individual means a person receiving services described in the Applicability section.

Cardiopulmonary Resuscitation (CPR): An emergency procedure consisting of artificial and manual chest compressions performed in an attempt to revive a person who has gone into cardiac arrest (heart stops beating) and/or respiratory arrest (stops breathing).

Competent Adult: A person who has not been adjudicated incompetent and who, by interdisciplinary team consensus, is clearly capable of understanding the nature and consequences of health care decisions, including the benefits and disadvantages of such treatment, and to reach and communicate an informed decision regarding treatment.

Do Not Resuscitate (DNR): A medical order written by a physician to withhold CPR including breathing/ventilation by an assistive or mechanical means including but not limited to, mouth-to-mouth, mouth-to-mask, bag-valve mask, endotracheal tube, ventilator, and/or chest compressions, and/or defibrillation.

Durable Power of Attorney: An adult person named in a legal document to make medical decisions other than withdrawal of life support systems. (CGS 19a-562 (-5a))

Health Care Agent: An adult person to whom authority to convey health care decisions involving withholding and/or withdrawing life support systems is delegated in a written document by another adult person, known as the principal (CGS 19a-570(5)).
Incapacitated: A previously competent adult who is presently unable to understand and appreciate the nature and consequences of health care decisions, including the benefits and disadvantages of such treatment, and to reach and communicate an informed decision regarding the treatment (CGS 19a-570(6)).

Life Support System: Any medical procedure or intervention which, when applied to an individual, would serve only to postpone the moment of death or maintain the individual in a state of permanent unconsciousness. In these circumstances, such procedures shall include, but are not limited to, mechanical or electronic devices including artificial means of providing nutrition or hydration (CGS 19a-570(1)).

Living Will: A written statement in compliance with CGS 19a-575 containing a declarant’s wishes concerning any aspect of his health care, including the withholding or withdrawal of life support systems (CGS 19a-570(7)).

Permanently Unconscious: Includes permanent coma and persistent vegetative state and means an irreversible condition in which the individual is at no time aware of himself or the environment and shows no behavioral response to the environment. (CGS 19a-570(7)).

Terminal Condition: The final stage of an incurable or irreversible medical condition which, without the administration of a life support system, will result in death in a relatively short time, in the opinion of the attending physician. (CGS 19a-570(3)).

D. Implementation
1. Discussion
   a. Advanced directives recognized in Connecticut are Living Wills, Health Care Agent, and Durable Power of Attorney for Health Care Decisions.
   b. A living will, executed by an individual at a time when the individual was competent to do so, provides direction for physicians regarding the individual’s wishes concerning the use of life support systems. Life support systems may include the use of respirators and dialysis, cardiopulmonary resuscitation, food and fluids supplied by artificial means, medications such as antibiotics, and whether or not the individual wishes to be transported to an acute care facility (from home or a long-term care facility).
   c. A living will goes into effect only when the person:
      i) Is unable to make or communicate his or her decision regarding medical care AND
      ii) Is in a terminal condition and/or is permanently unconscious.
   d. There are no special provisions regarding the execution of a living will in Connecticut law relating to individuals with mental retardation. An individual with mental retardation is not excluded from executing a living will. However, the living will is not valid if it is clear that the individual does not or did not have the capacity at the time of execution (i.e. was either under a guardianship for medical decisions OR there is other evidence of such incapacity).
   e. A guardian of an individual with mental retardation does not have the authority to execute a valid living will on behalf of an incompetent ward. A plenary guardian and a limited medical guardian whose powers and duties include medical decision-making, do have the authority to make medical decisions concerning end-of-life treatment at the time the issue arises (e.g. consent for DNR orders, and/or withholding or withdrawing life support) (CGS 45a-677).
   f. A parent of a minor child (under age 18) does not have the authority to execute a living will for his or her child in that Connecticut law refers to the execution of a living will and/or health care agent by a person eighteen years or older (CGS 19a-575, 19a-576, 19a-577).
g. An individual with mental retardation who is competent, may appoint a health care agent with the following provisions:
   i) At least one witness (of two required) shall be an individual who is not affiliated with the facility **AND**
   ii) At least one witness shall be a physician or clinical psychologist with specialized training in developmental disabilities (CGS 19a-576).

2. In the event that an individual with mental retardation expresses the desire to execute a living will or appoint a health care agent, the interdisciplinary team shall take the following actions:
   a. Discuss and document team efforts to ensure that the individual has the capacity to fully understand the decision;
   b. Document any evaluations conducted to assess the individual’s capacity or competency;
   c. Adhere to Connecticut law regarding witness requirements for the appointment of a health care agent; and
   d. Notify the individual’s DMR case manager and the DMR regional health service director when such decisions are contemplated.

3. The DMR health services directors and training school medical director shall:
   a. Provide assistance with issues regarding living will and health care agent issues
   b. Notify the DMR regional or training school director as appropriate
   c. Notify the central office director of health and clinical services as appropriate.

4. The director of health and clinical services shall:
   a. Review the appropriate documentation
   b. Discuss concerns with the DMR director of legal and government affairs, the commissioner, and
   c. Make recommendations as appropriate.

E. References

**Statutes**
CGS 17a-238 Rights of Persons with Mental Retardation
CGS 19a-562 (-5a), Durable Power of Attorney for Health Care Decisions
CGS 19a-570(1), Removal of Life Support
CGS 19a-570(3), Terminal Condition
CGS 19a-570(6), Incapacitated
CGS 19a-575, Living Wills
CGS 19a-576, Health Care Agent
CGS 19a-577, Health Care Agent Document
CGS 19a-573, Comfort Care and Pain Alleviation
CGS 45a-644 et. seq., Conservators
CGS 45a-668 et. seq., Guardianship

**Rules, regulations (Internal)**
DMR Policy I.E.PO.007, End-of-Life Decisions
DMR Procedure I.E.PR.007b, Withholding and/or Withdrawing Medical Treatment
DMR Procedure I.E.PR.007c, Withholding Cardiopulmonary Resuscitation