A. Purpose
The purpose of this procedure is to ensure that individuals with intellectual disabilities are not discriminated against with regard to medical practice and that they receive medically-acceptable standards of care while honoring their right to accept or refuse medical treatment. The department expects the same quality of medical care for the individuals under its aegis as that provided to individuals without intellectual disabilities. Connecticut and federal law state that persons with intellectual disabilities must not be discriminated against with regard to medical practice.

B. Applicability
This procedure shall apply to all individuals who are placed and treated under the direction of the Commissioner of the Department of Developmental Services (DDS). This includes people living in residences operated, licensed, and/or funded by DDS including non-Connecticut residents living in such facilities. It also applies to people receiving individualized home supports through DDS, attending day programs or respite programs operated, funded, and/or licensed by DDS and people living in facilities licensed by the Department of Public Health if DDS was involved with the placement decision.

This procedure shall be implemented by staff employed by DDS and agencies licensed and/or funded by the department.

C. Definitions
Attending physician: A Connecticut-licensed doctor who is selected by, or assigned to, the individual and who has primary responsibility for the treatment and care of the individual. This physician may be the individual’s primary care physician or a senior hospital physician but may not be a house officer or resident.

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

Competent adult: An individual 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 the decision, and to reach and communicate an informed decision regarding treatment.

Department: The Department of Developmental Services.

Do Not Resuscitate Order or No Code (DNR): A medical order written by a physician to withhold CPR including breathing/ventilation by any assistive or mechanical means including but not
limited to: mouth-to-mouth, mouth-to-mask, bag-valve, mask, endotracheal tube, ventilator, chest compressions, and/or defibrillation.

**Final stage:** The end stage of a terminal illness or condition that is expected to result in death within days or weeks.

**Individual:** Those individuals who receive services defined in the *Applicability* section.

**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)).

**Long-Term-Care Facility (LTC):** Any nursing home licensed by the Connecticut Department of Public Health.

**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).

**Incompetent adult:** An individual who has been adjudicated incompetent and has a court-appointed guardian (plenary or medical) or conservator of person.

**Next-of-Kin:** Any member of the following classes of persons, in the order of priority listed per CGS 19a-570-8. The person’s:

1. Spouse
2. Adult son or daughter
3. Parent (either parent)
4. Adult brother or sister
5. Grandparent

**Permanently unconscious:** 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-580-4).

**Surrogate:** A legal guardian (plenary or medical) or health care agent or, in their absence, the next-of-kin or other close relative who is accepted by the physician according to standard medical practice (CGS 19a-579-8).

**Terminal disease or condition:** The final stage of an incurable medical condition, which, without the administration of a life support system, will result in death within a relatively short time, in the opinion of the attending physician (CGS 19a-570-3).
Terminally ill individual: One who is considered to be in a condition that will result in death.

D. Implementation

1. All contemplated or existing Do Not Resuscitate (DNR) orders shall be communicated to the appropriate DDS regional health service director or designee or training school medical director or designee as soon as such information is known or, after normal business hours, shall notify the regional on-call manager or training school on-call physician.

2. Any DDS employee or DDS licensed or funded provider who is aware that a DNR order is being considered either at the individual’s residence or upon admission to an acute or long-term care facility, shall ensure that the individual’s DDS case manager is notified within 24 hours or the next working day. If there is no case manager assigned or immediately available, the case management supervisor and/or health service director shall be notified.

3. Within 24 hours of an individual’s admission to an acute or long-term care facility, the case manager or case management supervisor shall ensure that:
   a. The medical record identifies the individual as a client of DDS.
   b. The medical record identifies the name, address and contact numbers of the individual’s case manager, case management supervisor, and DDS health service director, for during and after normal business hours.

4. A DNR order shall not be instituted prior to review by the department. Upon notice of a proposed or issued DNR order as quickly as possible, the regional health service director or designee or training school medical director or designee shall complete a review as follows:
   a. Obtain necessary information through direct personal contact with the individual, his or her family/guardian and the physician.
   b. Determine if the DNR order meets the following criteria:
      - The individual’s attending physician has diagnosed a terminal disease or condition based on appropriate test and studies.
      - The individual’s physician has indicated that death is imminent, or the person is in the final stages of a terminal disease or condition, or is permanently unconscious.
      - A second opinion from a physician in the specialty appropriate to the disease/condition confirms the diagnosis and stage of illness.
      - The physician has fully discussed the diagnosis and prognosis with the individual if he or she is a competent adult or with the individual’s surrogate if the individual is not competent or is incapacitated. If the individual is not legally competent, the physician and surrogate shall include the individual in the
discussion and decision to the fullest extent possible considering his or her ability to understand.

c. Complete the review and ensure completion of the DNR Documentation form (Attachment A) including all information obtained.

5. In sudden or unexpected situations, the regional health service director or designee, training school director or designee, or on-call manager shall immediately (informally) review a request for an urgent DNR order to determine if the criteria detailed in section 4 are met. The person conducting this immediate review shall document all discussions, complete the DDS DNR Documentation form and shall obtain written documentation as soon as possible following the informal review.

6. If the health service director or designee or training school director or designee has concerns about the DNR order, the following actions may include:

   a. Further discussions with the physician, individual/family/guardian including requesting and obtaining further information regarding the illness

   b. Consult with the DDS central office director of health and clinical services and/or director of legal and government affairs for further informal or formal actions as necessary.

7. If the DNR order meets criteria listed in section 4, the regional health service director or designee shall sign the DNR form and obtain the signature of the regional director or designee. The signed DNR Order Documentation Form (Attachment A) shall be maintained in the individual’s master file.

8. If the DNR order is medically appropriate but does not fully meet the criteria listed in section 4 (e.g., the physician cannot determine that death will occur within days or weeks or a second opinion has not been obtained), or if the individual is a CARC v.Thorne class member or training school resident, the regional health service director or designee or training school medical director or designee shall send the completed form with accompanying documentation to the central office director of health and clinical services for review.

9. If the DNR order appears to be a “medically acceptable decision” (CGS 17a-238 (g), the director of health and clinical services shall:

   a. Sign and date the form.

   b. Forward the documents to the commissioner or designee for final review and signature.

   c. Send the original form to the regional health service director for inclusion in the individual’s master file.
10. If the central office director of health and clinical services or the commissioner have concerns regarding the DNR order, the following actions may include but are not limited to the following:

a. Request additional information if necessary.

b. Discuss the circumstances directly with the individual, family and/or guardian and physician(s).

c. Consult the department’s director of legal and government affairs.

d. Initiate formal action such as referral to probate or superior court, or other legal actions

11. A DNR order may be rescinded at any time by the individual’s physician and shall be rescinded at the request of the individual or his or her surrogate.

12. The regional health service director or training school director shall ensure that all existing DNR orders are reviewed and documented quarterly for all individuals (Attachment B). The review shall be documented on the DNR Review Documentation Form (Attachment C).

13. For each individual who lives in a long-term care facility, the DDS case manager shall assure that a DDS DNR Status form (Attachment D) is placed in the individual’s medical chart. This form identifies whether the individual is placed or treated under the direction of the commissioner for purposes of adhering to the department’s DNR policy and procedures as follows:

a. The individual is placed or treated under the direction of the DDS commissioner and DNR orders, if instituted, shall be reviewed as detailed above.

b. The individual is NOT placed or treated under the direction of the DDS commissioner but is a DDS client who was placed in the facility according to the individual’s own choice or by his or her family/guardian. The DDS case manager shall advocate for adherence to the department’s DNR policy and procedure but shall not require adherence. No DNR review by DDS is required.

c. The individual is an OBRA registrant (has a related condition but does not have mental retardation) and does not fall under the jurisdiction of the department’s policies and procedures except for services required under the Federal OBRA legislations (Omnibus Reconciliation Act of 1987). No DDS review is required.

14. The regional health service director shall maintain a current list of individuals with DNR orders.
E. References

Federal Statutes
Federal Omnibus Reconciliation Act of 1987

Connecticut General Statutes
17a-238(g) Rights of Persons with Mental Retardation
19a-562 (5a) Durable Power of Attorney for Health Care Decisions
19a-570(1) Removal of Life Support
19a-570(3) Terminal Condition
19a-570(6) Incapacitated
19a-575 Living Wills
19a-576 Health Care Agent
19a-577 Health Care Agent Document
19a-573 Comfort Care and Pain Alleviation
45a-644 et. seq. Conservators
45a-668 et. seq. Guardianship
19a-580 (d) Recognition and Transfer of DNR Orders

Regulations of Connecticut State Agencies
19a-580 (d)-1 et. seq. Recognition and Transfer of DNR Orders

DDS Policies and Procedures
DDS Policy 1, Client Rights
DDS Case Management policies and procedures
DDS Policy I.E.PO.007, End-of-Life Decisions
DDS-Procedure, I.E.PR.007a, Advance Directives
DDS Procedure I.E.PR.007b, Withholding and/or Withdrawing Medical Treatment

F. Attachments
Attachment A: Documentation of Do Not Resuscitate (DNR) Order Form
Attachment B: Guidelines for Periodic Reviews of DNR Orders
Attachment C: DNR Renewal Form
Attachment D: DNR Advanced Directives Status Form