

**DIVISION OF DEVELOPMENTAL SERVICES
POLICY NUMBER THREE (1996)
CRITICAL HEALTH CARE DECISIONS**

1. Introduction

The role of the Division of Developmental Services (DDS) is to protect and promote the health of all people we serve. Staff and programs funded through DDS are expected to provide and seek treatment which will best promote the individual's overall well-being and functioning.

The role of Developmental Services staff is to seek health care and make treatment decision which will:

- A. Preserve life and maintain function.
- B. Consider the desires of the individual, his/her family, and his/her significant others.
- C. Be respectful of the dignity and integrity of the individual.
- D. Promote the individual's comfort and peace of mind.

The balance among these goals becomes a major concern in critical health care decisions.

II. Definitions

- A. "Critical health care decision" means a decision to authorize or withhold medical treatment which raises significant ethical considerations.
- B. "Persistent terminal condition" means an incurable condition which, regardless of the application of life-saving procedures will, within reasonable medical judgement, produce death, and where application of life sustaining procedures would only postpone the moment of death.
- C. "Irreversible condition" means a condition which is incurable, and in which the burden of treatment would outweigh the benefits to the person.

III. Role of the Guardian

All individuals who are unable to give consent to medical treatment should have a responsible person who is available to authorize medical treatment. For people with developmental disabilities, this may be a family member who is actively involved with the individual, a private guardian (appointed by probate court), or Guardianship Services Specialist (appointed by family

court). A guardian bears primary responsibility for decisions regarding initiation, continuation, or abatement of life-sustaining treatment.

A private guardian who has been appointed by a Vermont Probate Court must clear any major decision regarding treatment with the Probate Court.

Court approval is not required for medical treatment decisions by State Guardianship Services Specialists; however, any decision to withhold or abate medical treatment must be reviewed by the Ethics Committee, as provided in Section IV.

IV. **Making Critical Health Care Decisions**

In making critical care decisions for a patient with a persistent terminal condition or an irreversible condition, a guardian, together with the team which is supporting the individual, shall follow these steps:

- A. Before accepting a medical opinion that a patient's condition is terminal or irreversible, obtain a least one independent second medical opinion that supports the conclusion regarding the patient's condition. (There may be an exception in extraordinary situations where the diagnosis, prognosis, and treatment options are unquestionable, and further evaluation would be intrusive to the patient.)

If the second physician is of the opinion that the individual may recover with treatment, the guardian shall proceed on the basis of the opinion unless the guardians does not feel the second opinion is reliable, in which case yet another opinion should be sought.

- B. Discuss the options with the individual, his or her family, his or her religious representative, and friends and staff who know the individual well. The primary focus of these discussions is to assist the guardian to determine what the preferences of the individual would be if he or she were in a position to decide.
- C. Prioritize the goals of health care for this individual at this time. In those situations where the patient's condition is terminal or irreversible, the primary goal of care may be to promote the comfort, dignity, and peace of mind of the individual.

V. **The Ethics Committee**

A. Composition

The Ethics Committee is a diverse group of people appointed by the Director of the Division of Developmental Services who have a personal or professional interest in the well being of people with developmental disabilities. The Chair of the Committee is the Department of Developmental and Mental Health Services' Medical Director. The other members are not employees of DD/MHS.

B. Role of the Ethics Committee

The function of the Ethics Committee is to review and give advice regarding critical health care decisions for people with developmental disabilities.

1. The Committee is available to assist any interested person who is concerned with the ethical aspects of a critical care decision for a person who receives developmental services. An “interested person” must know the individual personally.
2. Any decisions by a Guardianship Services Specialist to withhold or abate life-sustaining treatment for a client **must** be reviewed by the Ethics Committee. Where prior review is not possible, review should be sought at the next meeting to the Ethics Committee. The director of the Guardianship Services Program is responsible for deciding whether to request an emergency meeting of the Ethics Committee.
3. Any interested person who is dissatisfied with a critical care decision made for a non-consenting individual who receives services through the Division of Developmental Services (DDS) may request a review of the decision by the Ethics Committee.
4. The Ethics Committee may advise the Division of Developmental Services in the development of policy concerning health care decisions about people with developmental disabilities.

C. Frequency of meetings

The Ethics Committee meets bimonthly, and is available to convene on an emergency basis if necessary.

D. Confidentiality

Proceedings of the Ethics Committee are confidential. Any participants in the Ethics Committee process shall maintain the confidentiality of information specifically pertaining to an individual.

E. Advisory role

The role of the Ethics Committee is advisory. Final responsibility for any critical health care decision lies with the guardian or the individual.

If the Ethics Committee disagrees with a decision by a Guardianship Services Specialist, the committee shall notify the Director of Developmental Services and the Commissioner of the disagreement.