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| Chapter: | Intake and Assessment | Page 1 of 3 |
| Subject: | Investigating Reports of Inadequate Health Care of Infants with Disabilities | Replaces: Policy 53, dated 1/8/99 |
| Approved | Cynthia K. Walcott, Deputy Commissioner | Effective: 12/1/06 |

Purpose

Reports alleging inadequate health care of infants with disabilities are accepted as mandated under 33 VSA, Chapter 49 and by federal statute. This policy establishes special procedures to respond to these reports, including reports of withholding of medically-indicated treatment for infants with life-threatening conditions.

Policy

Definition of Inadequate Health Care

Inadequate health care of infants with disabilities includes failure to respond to an infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication), which in the treating physician's reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions. Exceptions to the requirement to provide treatment (but not the requirement to provide appropriate nutrition, hydration, or medication) may be made only in cases in which:

- the infant is chronically and irreversibly comatose;
- the provision of such treatment would merely prolong dying or not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or
- the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

Commencing an Investigation

Investigations of reports of inadequate health care of an infant with disabilities will commence immediately by contacting the child protection director or child safety assessment manager and the designated contact person at the hospital at which the infant is being treated.

Pediatric Consultant

The division contracts with a pediatric consultant to assist in the assessment of the situation. The role of the pediatric consultant is to:

- determine whether or not the attending physician or parents have been offered and/or

| | | |
|----------|--|-----------------------------------|
| Chapter: | Intake and Assessment | Page 2 of 3 |
| Subject: | Investigating Reports of Inadequate Health Care of Infants with Disabilities | Replaces: Policy 53, dated 1/8/99 |
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voluntarily consulted with the hospital's ethics committee if such a committee exists, or with the pediatric consultant;

- if that consultation has occurred, determine whether or not the infant is receiving the prescribed treatment and nourishment; and,
- participate in staffings necessary to determine an appropriate course of action, including the necessity for filing a petition under Chapter 55.

Professional Staffing

If the infant's parents refuse to consult with or follow recommendations of the pediatric consultant, the following persons (at a minimum) will staff the situation (by telephone, if necessary):

- district director and other appropriate district staff, as determined by the director;
- child protection director or child safety assessment manager;
- assistant attorney general for Family Services; and,
- pediatric consultant.

The staffing will result in a recommendation to the deputy commissioner, who will decide the final course of action.

Substantiating Neglect

Neglect of an infant with disabilities will be substantiated if:

- recommendations of the hospital ethics committee, approved by the pediatric consultant, are not being followed; or,
- recommendations of the pediatric consultant are not being followed.

If the pediatric consultant and the ethics committee disagree, the division will follow the recommendations of the pediatric consultant.

Religious Exemption

Neglect will not be substantiated if the parents refuse to follow the recommendation due to the legitimate practice of their religious beliefs. Under those circumstances, court action may be initiated under Chapter 55, if necessary to assure the child's well-being.

| | | |
|----------|--|-----------------------------------|
| Chapter: | Intake and Assessment | Page 3 of 3 |
| Subject: | Investigating Reports of Inadequate Health Care of Infants with Disabilities | Replaces: Policy 53, dated 1/8/99 |
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District Director (or designee) Tasks:

- Immediately informs Child Protection Director or Safety Assessment Manager of any complaint of inadequate health care of an infant with disabilities, requesting **one of these people** contact the pediatric consultant.
- Contacts designated hospital contact for inadequate health care to ascertain:
 - whether the infant is a patient there and if so, the name of the parents, name, date of birth, and sex of the infant; and the name of the attending physician; and,
 - the medical condition and treatment of the infant and whether the child's condition and treatment fall under the stated definition.
- Coordinates investigation with pediatric consultant and child protection director or safety assessment manager.
- Participates in any staffing necessitated, and carries out the decisions made.

Pediatric Consultant: Joseph F. Hagan, M.D.
Telephone: 658-4387 (home)
860-1928 (work and after hours emergencies)