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**IDAPA 16
TITLE 06
CHAPTER 05**

16.06.05 - RULES GOVERNING ALLEGED MEDICAL NEGLECT OF HANDICAPPED INFANTS

000. LEGAL AUTHORITY.

The legal authority for promulgation of these rules is in accordance with the following provisions: (12-26-90)

01. Federal Authority. Federal authority for promulgation of rules governing activities involving alleged medical neglect of handicapped infants in health care settings is provided in 42 USC 5101 et seq., the federal “Child Abuse Prevention and Treatment Act”. (12-26-90)

02. State Authority. State authority is provided in: (12-26-90)

a. Section 56-202(b), Idaho Code, which requires the Director to promulgate, adopt and enforce such rules and regulations and methods of administration as may be necessary and proper to carry out the provisions of the Public Assistance Law, Section 56-201 et seq., Idaho Code, including services for children in accordance with Section 56-204A, Idaho Code, except where such authority is granted to the board; and (12-26-90)

b. Section 16-1623, Idaho Code, which empowers the Department to do all things reasonably necessary to carry out the purpose of the “Child Protective Act”. (12-26-90)

001. TITLE AND SCOPE.

01. Title. These rules are to be cited in full as Idaho Department of Health and Welfare Rules, IDAPA 16.06.05, “Rules Governing Alleged Medical Neglect of Handicapped Infants”. (12-26-90)

02. Scope. These rules are established to ensure protection of and attention to the needs of infants in health care facilities throughout the state, who have been continuously hospitalized since birth, who were born extremely prematurely, or who have a long-term disability. (12-26-90)

002. POLICY.

The Idaho Department of Health and Welfare shall coordinate with health care facilities in the implementation of these rules. (12-31-91)

003. PURPOSE.

The purpose of these rules is to ensure coordinated response to reports of alleged medical neglect of infants who are in health care facilities throughout the state and who have been continuously hospitalized since birth, who were born extremely prematurely, or who have a long-term disability. (12-26-90)

004. DEFINITIONS.

The following terms are used in this chapter as defined below: (12-26-90)

01. Central Office. The state-level administrative office of the Department of Health and Welfare located in Boise, Idaho. (12-26-90)

02. Department. The Idaho Department of Health and Welfare. (12-26-90)

03. Director. The Director of the Idaho Department of Health and Welfare or his designee. (12-31-91)

04. Family And Children’s Services (FACS). Those programs and services directed to families and children, administered by the Department of Health and Welfare. (12-31-91)

05. Field Office. A Department of Health and Welfare service delivery site. (12-26-90)

06. Infant. An infant less than one (1) year of age or older than one (1) year of age but less than two (2) years of age who has been continuously hospitalized since birth, who was born extremely prematurely, or who has a

long-term disability. (12-26-90)

07. Infant - Extremely Premature. An infant born before the twenty-seventh (27th) week or weighing less than one thousand (1,000) grams or having a crown-heel length that is less than forty-seven (47) centimeters or with occipito-frontal diameter less than eleven and one-half (11.5) centimeters. (12-31-91)

08. Reasonable Medical Judgment. A medical judgment that would be made by a reasonably prudent physician, knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved. Such a judgment may not take into account the future extent of the infant's disability or social or economic factors related to the infant or family. (12-26-90)

09. Regional Office. An Idaho Department of Health and Welfare office located in one (1) of seven (7) areas of the state which comprises a geographically defined service area for the administration and delivery of the Department's services. (12-26-90)

10. Withholding Of Medically Indicated Treatment. (12-26-90)

a. The failure to respond to the infant's life-threatening conditions by providing treatment, including appropriate nutrition, hydration and medication which, in the treating physician's reasonable medical judgment, will most likely be effective in ameliorating or correcting all such conditions. (12-26-90)

b. The term does not include the failure to provide treatment, other than appropriate nutrition, hydration, or medication, to an infant when, in the treating physician's reasonable medical judgment, any of the following circumstances apply: (12-26-90)

i. The infant is chronically and irreversibly comatose; or (12-26-90)

ii. The provision of such treatment would merely prolong dying, would not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or would otherwise be futile in terms of the survival of the infant; or (12-26-90)

iii. 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. (12-26-90)

005. -- 009. (RESERVED).

010. COMMUNICATION WITH HEALTH CARE FACILITIES.

01. Annual Check Of Health Care Facilities. Regional FACS managers or their designees shall make an annual check by October 1 of each year of health care facilities in their regions to obtain: (12-31-91)

a. The name, address and telephone number of the health care facility designated contact person; or (12-26-90)

b. If no individual is appointed the designated contact person, the name, address and telephone number of the health care facility or hospital administrator. (12-26-90)

02. List Of Contact Persons To Be Maintained. Regional FACS managers or their designees shall maintain a complete list of the health care facility contact persons or administrators for their regions. (12-31-91)

a. Copies of the list shall be distributed to all field offices within the regions within fourteen (14) working days of October 1 of each year. (12-26-90)

b. At the same time, copies shall be sent to the Department: (12-31-91)

i. Chief of the Bureau of Family Services; (12-31-91)

- ii. Chief of the Bureau of Maternal and Child Health; and (12-31-91)
- iii. Chief of the Bureau of Developmental Disabilities. (12-31-91)

03. Information To Be Provided To Facilities. Regional FACS managers or their designees shall provide each health care facility or hospital contact person or administrator in their regions, within fourteen (14) working days of October 1 of each year, a list including: (12-31-91)

- a. The names and telephone numbers of the regional director and the Regional FACS manager; (12-31-91)
- b. The addresses and telephone numbers of Department field offices in their regions; and (12-31-91)
- c. The twenty-four (24) hour child abuse and neglect reporting “hot-line” numbers. (12-26-90)

04. Notification Of Changes. (12-31-91)

a. The health care facility or hospital contact person or administrator shall notify the Regional FACS manager of any changes in the names and telephone numbers of the health care facility designated contact person or hospital administrator within five (5) working days of the change. (12-31-91)

b. The Regional FACS manager shall notify health care facility and hospital contact persons and administrators in the region of any changes in the Department personnel, addresses or telephone numbers identified above within five (5) working days of the change. (12-31-91)

011. -- 019. (RESERVED).

020. INVESTIGATIONS OF ALLEGED MEDICAL NEGLECT OR WITHHOLDING OF MEDICALLY INDICATED TREATMENT FROM DISABLED INFANTS WITH LIFE-THREATENING CONDITIONS.

01. Reports Of Suspected Medical Neglect. The Department shall receive notification from health care facility and hospital contact persons and administrators, and from any other individual reporting in accordance with provisions of the Child Protective Act, Section 16-1601 et seq., Idaho Code, of cases of suspected medical neglect, including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions. (12-26-90)

a. Reports of suspected medical neglect shall be received during regular office hours at any office of the Department. (12-26-90)

b. After regular business hours, weekends or holidays, reports shall be received through the twenty-four (24) hour child abuse and neglect reporting “hot-line” numbers in the local telephone directories. (12-26-90)

02. Investigation. (12-26-90)

a. The Department shall begin an investigation of a report of suspected withholding of medically indicated treatment in accordance with the provisions of the current FACS policy “Referral Response Priority Guide”. When appropriate, the investigation shall include an on-site investigation of such reports. (12-31-91)

b. The investigation shall be conducted pursuant to the authority granted under Sections 16-1619, 16-1623 and 16-1625, Idaho Code. (12-31-91)

c. The family services worker for the Department shall obtain: (12-26-90)

- i. The name and address of the health care facility or hospital; (12-26-90)
- ii. The administrator’s name and address; (12-26-90)

- iii. The infant's name and date of birth; (12-26-90)
- iv. The name, address and telephone number of the infant's parents; (12-26-90)
- v. The attending physician's name; (12-26-90)
- vi. The health care facility or hospital contact person's name if the report came from someone other than the health care facility or hospital; (12-26-90)
- vii. The infant's medical condition, prognosis and any indication that treatment, including nutrition, hydration or medication, is being withheld; (12-26-90)
- viii. The participation of any treatment review committee in the infant's case; and (12-26-90)
- ix. The extent of counseling provided to the parents. (12-26-90)

03. Unsubstantiated Reports. Should the report be unsubstantiated because the infant is not at the health care facility or hospital or because the pediatric consultant for the Department's Bureau of Maternal and Child Health or designee or the regional or central office committee deems the report to be unsubstantiated because there is no withholding of medically indicated treatment as defined in Subsection 004.10, written documentation shall be made of: (12-31-91)

- a. The investigative steps taken by the Department to determine the validity of the report; and (12-26-90)
- b. The Department's disposition of the report. (12-26-90)

04. Verification. If the medically handicapped infant is a patient at the health care facility or hospital: (12-26-90)

- a. The Department shall verify with the health care facility or hospital contact person or the hospital administrator, or the attending physician, or the infant's parents the information obtained through the investigation in accordance with Subsection 020.02.c. (12-31-91)
- b. The family services worker shall interview the infant's parents to assess their understanding of the infant's condition, treatment and prognosis with and without treatment. (12-26-90)
- c. The family services worker shall also interview the attending physician to obtain information about the infant's condition, treatment and prognosis with and without treatment. (12-26-90)
- d. The family services worker shall also obtain a copy of the infant's medical treatment record from the health care facility or hospital, as a function of the investigation process under Section 16-1625, Idaho Code. (12-26-90)

05. Findings. (12-31-91)

- a. Family services workers shall notify their immediate supervisor or the Regional FACS manager, within four (4) hours of receipt of a report, indicating if a handicapped infant does reside within a health care facility or hospital and the circumstances of the case. (12-31-91)
- b. The regional director, the Regional FACS manager, or the family services worker shall report all complaints and information gathered to the pediatric consultant, the Department's Bureau of Maternal and Child Health, or designee. (12-31-91)
- c. The initial determination that withholding of medically indicated treatment as defined in Subsection 004.10 is occurring or is being prescribed by the infant's physician will be made, with or without an

independent medical evaluation, by the pediatric consultant, the Department's Bureau of Maternal and Child Health, or designee. (12-31-91)

021. REVIEW OF ALLEGED MEDICAL NEGLECT OR WITHHOLDING OF MEDICALLY INDICATED TREATMENT FROM DISABLED INFANTS WITH LIFE-THREATENING CONDITIONS.

01. Regional Committee Review. There shall be a regional committee consisting of the Department's regional director, the Regional FACS manager or family services worker, and the pediatric consultant, the Department's Bureau of Maternal and Child Health, or designee. (12-31-91)

a. The pediatric consultant or designee shall immediately inform the regional committee of the determination made pursuant to Subsection 020.05.c. (12-31-91)

b. If the pediatric consultant or designee determined that indicated medical treatment is being withheld, the regional committee shall attempt to resolve the matter informally, if possible, in an expeditious manner. (12-26-90)

c. The regional committee shall ensure that the parents of the infant are fully informed of: (12-26-90)

i. The existence and function of any infant care review committee, chaplain services or other counseling services within the health care facility or hospital; and (12-26-90)

ii. The existence, function and opportunity to consult with parent support groups or other organizations that include parents of children with disabilities. (12-26-90)

d. If resolution is possible and the infant receives necessary treatment, the matter will not be referred for any further legal action. (12-26-90)

i. The Department's regional director shall verbally notify the administrator of the Division of FACS or the chief of the Bureau of Family Services, the health care facility or hospital contact person or administrator, the attending physician, the individual who reported the concern, and the parents of the infant that no legal action will be taken by the Department. (12-31-91)

ii. The Department's regional director shall provide written confirmation that no legal action will be taken by the Department within five (5) working days to the health care facility or hospital contact person or administrator. (12-31-91)

e. If informal resolution is not possible, the regional director shall notify the administrator of the Division of FACS or the chief of the Bureau of Family Services of the concern within four (4) hours of the receipt of the report. (12-31-91)

02. Central Office Committee Review. The administrator of the Division of FACS shall convene a central office committee within twenty-four (24) hours of the receipt of notice from the regional committee. (12-31-91)

a. The central office committee shall consist of the Department's chief of the Bureau of Family Services; the pediatric consultant to the Bureau of Maternal and Child Health; the chief of the Bureau of Developmental Disabilities; a deputy attorney general; or their designees; and other individuals deemed appropriate. (12-31-91)

i. The regional director, the Regional FACS manager and the family services worker shall be available, by telephone, to provide investigation information. (12-31-91)

ii. The county prosecuting attorney should be requested to participate, when appropriate. (12-26-90)

b. The committee shall make appropriate contacts, which may include the attending physician, the health care facility or hospital contact person or administrator, the parents of the infant, and other persons deemed

appropriate to gather information and work toward resolution of the matter. (12-26-90)

c. Efforts shall be made to resolve the matter on an informal basis. If informal resolution is not possible: (12-26-90)

i. The county prosecuting attorney and/or deputy attorney general will determine, within four (4) hours of the committee meeting, the need for legal intervention. Such intervention might include obtaining temporary legal custody of the infant until such time as the court can determine the appropriate disposition of the matter pursuant to Sections 16-1614 and 16-1616, Idaho Code. (12-26-90)

ii. Failure to provide treatment including appropriate nutrition, hydration or medication which is determined by the committee to be necessary to maintain the infant's life shall be considered grounds to initiate legal proceedings. (12-26-90)

022. CONTINUING CONSULTATION AND INVESTIGATION.

01. Further Consultation And Investigation. At any time during the decision-making or resolution process, as deemed appropriate and as time and agency resources permit, the pediatric consultant or designee, the regional committee or the central office committee may seek additional information or technical assistance from the physician, health care facility or hospital contact person or administrator, any treatment review committee, the parents of the infant, or other persons or agencies. (12-26-90)

a. If any independent medical examination is necessary, the family services worker shall seek voluntary compliance for such an examination. (12-26-90)

b. If consent to an independent medical examination is not expeditiously provided, the family services worker shall contact the county prosecuting attorney and/or a deputy attorney general to initiate legal proceedings to obtain an order pursuant to the "Child Protective Act" or other applicable law mandating such examination. (12-26-90)

02. Decision-Making Landmarks. At each stage of the decision-making and resolution process, the pediatric consultant or designee, the regional committee and the central office committee shall consider the following elements of the case: (12-26-90)

a. The extent of the counseling offered and received by the parents of the infant; (12-26-90)

b. The knowledge and experience of the attending physician in the diagnosis and treatment of the infant's life-threatening conditions; (12-26-90)

c. The existence within the health care facility or hospital of an infant care review committee or like agent and its participation in the infant's case; (12-26-90)

d. Any independent medical consultation or examination; (12-26-90)

e. Conformity with current Department of Health and Human Services guidelines regarding "Services and Treatment for Disabled Infants"; and (12-31-91)

f. The consistency of the medical treatment provided with the information available through the computer based neonatal information clearing house maintained by the Department of Health and Human Services. (12-26-90)

023. RESPONSIBILITIES OF THE DEPARTMENT RELEVANT TO INFANTS WITH LIFE-THREATENING CONDITIONS.

01. Report To The Court. The family services worker shall prepare and submit a written report of investigation which may be ordered by the court on the matter pursuant to Section 16-1609, Idaho Code. The report shall include copies of the medical information obtained regarding the matter. (12-26-90)

02. Case Staffing. If legal custody of the infant is granted to the Department, the family services worker, the Regional FACS manager, the regional director, the pediatric consultant for the Bureau of Maternal and Child Health, the chief of the Bureau of Family Services, the chief of the Bureau of Developmental Disabilities, the administrator of the Division of FACS, a deputy attorney general, the parents of the infant, and other individuals deemed appropriate shall: (12-31-91)

- a.** Staff the case in person or through telephone conference call; and (12-26-90)
- b.** Develop a service plan within ten (10) days of adjudication. The staffing may be conducted by telephone. (12-26-90)

024. -- 995. (RESERVED).

996. ADMINISTRATIVE PROVISIONS.

Contested case appeals shall be governed by Idaho Department of Health and Welfare Rules, IDAPA 16.05.03, Sections 000, et seq., "Rules Governing Contested Case Proceedings and Declaratory Rulings". (12-31-91)

997. CONFIDENTIALITY.

Before any information about a patient, client, registrant, applicant, or recipient contained in departmental records may be released to the person who is the subject of the record, to another departmental unit, to another governmental agency, or to a private individual or organization, the unit of the Department with custody of the record must comply with Idaho Department of Health and Welfare Rules, IDAPA 16.05.01, "Use and Disclosure of Department Records". (12-31-91)

998. INCLUSIVE GENDER AND NUMBER.

For the purposes of Idaho Department of Health and Welfare Rules, IDAPA 16.06.05, words used in the masculine gender include the feminine, and words used in the singular include the plural, and vice versa where appropriate. (12-26-90)

999. SEVERABILITY.

Idaho Department of Health and Welfare Rules, IDAPA 16.06.05, are severable. If any rule or part thereof or the application of such rule to any person or circumstance is declared invalid, that invalidity does not affect the validity of any remaining portion of this chapter. (12-26-90)

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