

**MEDICAL NEGLECT
OF DISABLED
CHILDREN**

The Child Abuse Amendments of 1984, PL 98-457, including section 4 (b) (2) (K) of the federal Child Abuse Prevention and Treatment Act, 42 USC 5101 et. seq. and USC 5116 et. seq., and subsequent federal regulations implementing the act, establish the role and responsibility of the state's CPS system in responding to complaints of medical neglect of children, including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions.

The federal regulations implementing the act emphasize the role and functions of the CPS system, its focus on the family, and the locus of decision-making in relation to the medical neglect of disabled children. The decision to provide or withhold medically indicated treatment is, except in highly unusual circumstances, made by the parents or legal guardian.

Parents are the decision-makers concerning treatment for their disabled children, based on the advice and reasonable medical judgment of their physicians. The counsel of an Infant Care Review Committee (ICRC) or other hospital review committee might be sought, if available. Therefore, if a complaint is made to CPS regarding the withholding of medically indicated treatment from disabled infants with life-threatening conditions, the focus of CPS's work will be, as it is in responding to other complaints of child abuse or neglect, to protect the child and to assist the family.

The federal regulations further emphasize that it is not the CPS program, the ICRC or similar committee that makes the decision regarding the care of and treatment for the child. This is the parents' right and responsibility. Nor is the aim of the statute, regulation, and the child abuse program to regulate health care.

The parents' role as decision-maker must be respected and supported unless they choose a course of action inconsistent with applicable standards established by law. Where hospitals have an ICRC or similar committee and the review and counsel of the ICRC is sought, it is the role of the ICRC to review the case, provide additional information as needed to ensure fully informed decision-making, and recommend that the hospital seek CPS involvement when necessary to ensure protection for the infant and compliance with applicable legal standards.

The federal regulations highlight several key points:

- Current procedures and mechanisms already in place for CPS for responding to complaints of suspected child abuse and neglect should be used for responding to complaints of the withholding of medically indicated treatment from disabled infants with life-threatening conditions.
- CPS must coordinate and consult with individuals designated by and within the hospital in order to avoid unnecessary disruption of hospital activities.
- The legislation is not intended to require CPS workers to practice medicine or second guess reasonable medical judgments. Rather CPS must respond to complaints under procedures designed to ascertain whether any decision to withhold treatment was based on reasonable medical judgment consistent with the definition of “withholding of medically indicated treatment.”
- If CPS determines on the basis of medical documentation there is withholding by the parent/guardian of medically indicated treatment from a disabled infant with life-threatening conditions, CPS must pursue the appropriate legal remedies to prevent the withholding.

Definitions

Medical Neglect

The failure to provide adequate medical care in the context of the definitions of “child abuse and neglect”. The term “medical neglect” includes, but is not limited to, the withholding of medically indicated treatment from a disabled child with a life-threatening condition.

Withholding of Medically Indicated Treatment

The failure to respond to the disabled child’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, except that 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:

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

Infant

A child less than one year of age. The reference to less than one year of age must not be construed to imply that treatment should be changed or discontinued when an infant reaches one year of age, or to effect or limit any existing protections available under state laws regarding medical neglect of children over one year of age.

Children

In addition to infants less than one year of age, the standards set forth in the above definition of "withholding of medically indicated treatment" should be considered thoroughly in the evaluation of any issues of medical neglect involving a child older than one year of age who has been continuously hospitalized since birth, who was born extremely prematurely, or who has a long-term disability. This includes children who may be seen as medically fragile, or those who may be seen at an increased level of vulnerability based on their medical needs; see PSM 713-04.

Reasonable Medical Judgment

A medical judgment made by a reasonably prudent physician, knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved.

Infant Care Review Committee (ICRC)

A voluntarily established, generally hospital based multidisciplinary group which may be composed of, but is not limited to, such members as a practicing physician (e.g., a pediatrician, a neonatologist, or pediatric surgeon), a practicing nurse, a hospital administrator, a social worker, a representative of a disability group, a lay community member, and a member of the facility's organized medical staff, whose purpose and functions are:

- To educate hospital personnel and families of disabled infants with life-threatening conditions.
- To recommend institutional policies and guidelines concerning the withholding of medically indicated treatment from disabled infants with life-threatening conditions.
- To offer counsel and review in cases involving disabled infants with life-threatening conditions.

Report and Investigation

To clarify when CPS is the appropriate department for responding to the alleged medical neglect of a disabled child, the chart below indicates the appropriate system or process available for responding based on the party alleged to be neglecting the child and the reporting person.

CPS RESPONSE TO COMPLAINTS OF MEDICAL NEGLECT OF DISABLED CHILDREN		
	NEGLECTING PARTY	
Reporting Person	Parents	Hospital Staff
Hospital Staff	CPS investigates	Not applicable
Parents	Not applicable	Existing hospital review process
Other/Anonymous	CPS investigates	Existing hospital review process

CPS is responsible for responding to complaints that parents are neglecting their child's health and welfare by withholding medically indicated treatment, as noted in Column A. Complaints from parents or others that the hospital or health care provider is neglecting (Column B) to provide proper or suitable care for the infant is outside the scope and responsibility of CPS and are not appropriate for CPS investigation. Existing procedures, including medical review committees within the health care facility, should be used for addressing such concerns.

Complaint of Parental Neglect from Health Care Provider or Hospital

Most complaints of medical neglect involving the withholding of medically indicated treatment from disabled children with life-threatening conditions by parents are reported by a health care provider or hospital staff. This reporting person is logically in the best position, with their medical expertise, to know what is medically indicated and necessary treatment. The complaint must be accepted for investigation with appropriate steps taken to ensure that necessary care and treatment are provided.

Required steps include:

1. Contact the designated hospital liaison person regarding the condition of the child and treatment needed and confirm or determine:
 - a. Does the child have a life-threatening condition which falls outside the three conditions specified in the federal regulation in which treatment is not considered medically indicated? Examples are:
 - (1) The child involved is chronically and irreversibly comatose.
 - (2) Treatment would merely prolong dying, not be effective in ameliorating or correcting all of the life-threatening conditions, or otherwise be futile in terms of the survival of the child.
 - (3) Treatment would be virtually futile in terms of the survival of the child and the treatment itself under such circumstances would be inhumane.
 - b. What is the diagnosis and condition of the child?
 - c. What treatment has been provided and what treatment is still needed?
 - d. Consequences if treatment is not provided?
 - e. Has the treating physician recommended that treatment be provided?
 - f. Have parents refused to consent to treatment? If so, on what basis?

the parents. Services may include information about parental support groups composed of parents with children having similar disabilities as well as community services and resources to assist families in the care of children. At an appropriate time and when parents can better evaluate their options and decisions, they may also be advised of voluntary release services if they are unable to provide the continuing care necessary for the child.

b. Yes.

There remains some doubt or uncertainty regarding the hospital's recommendations, the parents refuse to authorize medically indicated treatment, or there is a need for additional documentation to arrive at a conclusion, there must be further consultation with the ICRC, other review committee or medical consultant, if available.

If further consultation with the ICRC or other medical staff does not yield sufficient information to assist in determining whether there is medical neglect involving withholding of medically indicated treatment from a disabled child with a life-threatening condition and the parents are not cooperative in authorizing medical treatment, a petition must be filed with the Family Division of Circuit Court requesting that the court make an appropriate decision regarding the provision of care for the child.

If the court orders an independent medical evaluation, it should empower the court appointed medical consultant to make whatever inquiries and investigations he/she considers appropriate including access to hospital personnel and to pertinent hospital records.

The medical consultant should determine whether a child is at risk due to the withholding of medically indicated treatment, and may include:

- (1) Notifying the designated hospital liaison person that a judicial order has been obtained to conduct an independent investigation and to gain access to the hospital and its pertinent records.

- (2) Interviewing the treating physician and others involved in treatment.
- (3) Reviewing medical records.
- (4) Interviewing parents to determine the basis for their decisions.
- (5) Arranging, if necessary, a meeting with the ICRC, its designees, or other hospital review mechanism to determine the following: Did the ICRC or other hospital review committee verify the diagnosis? Were all the facts explained to the parents? Did the parents have time to think about their decision? Did the parents appear at the meeting and articulate their objections to treatment before the committee? Were all the facts before the committee? Did all physicians, nurses and others involved in treatment have an opportunity to present information to the committee? Did the committee recommend treatment or make any other recommendation? Was there significant dissent among committee members and/or medical staff? Was the committee recommendation consistent with the terms of “withholding medically indicated treatment.”

The medical consultant is to notify the court of the findings and recommendations and submit a report in writing to the court and the department.

4. If requested or ordered by the court, the department is to provide follow-up services which may include:
 - Monitoring the case through regular contact with the health care facility designee to assure that appropriate nutrition, hydration, medication and medically indicated treatment is provided. The court is to be notified whenever there is failure to authorize or provide necessary care or treatment for the child.
 - Assisting the parents by initiating referrals to appropriate agencies that provide supportive services for disabled children and their families.

Complaint of Parental Neglect From Other Than a Health Care Provider or Hospital

If a complaint is received from someone other than a health care provider or hospital alleging medical neglect involving the withholding of medically indicated treatment from a disabled child with a life-threatening condition, the following steps must be taken:

1. Obtain the following information from the reporting person:
 - a. Name, address, and telephone number of the health care provider.
 - b. Names, addresses and telephone numbers of the child and parents.
 - c. Name of the reporting person, source of their information (first hand or otherwise), position to have reliable information (such as a nurse on the ward, a friend or other), affiliation, address, and telephone number.
 - d. Specific information as to the nature and extent of the child's condition and the reason and basis for suspecting that medically indicated treatment or appropriate nutrition, hydration or medication is being or will be withheld.
 - e. Whether the child may die or suffer harm within the immediate future if medical treatment or appropriate nutrition, hydration or medication is withheld.
 - f. Names, addresses and telephone numbers of others who might be able to provide further information about the situation.
2. Decide whether the information provided is sufficient to warrant an investigation based on the following criteria:
 - a. The circumstances reported, if true, would constitute "child medical neglect" as defined by state law, e.g., "harm or threatened harm to a child's health or welfare by a parent or legal guardian which occurs through negligent treatment, including the failure to provide adequate...medical care".
 - b. There is **reasonable cause to believe** that circumstances indicate the withholding of medically indicated treatment. Reasonable cause to believe is defined as: what

reasonable people, in similar circumstances, would conclude from such things as the nature of the condition of the child, health care professional statements, and information that the parents have refused to consent to recommended treatment.

The intake worker and supervisor, in consultation with a medical consultant if necessary, must decide whether these elements are present and an investigation is warranted. (Payment for medical consultation may be made using procedures described in PSM 713-04-Medical Examination and Assessment.) If an investigation is not warranted, the reporting person must be informed that the criteria for initiating an investigation are not present and an investigation will not be conducted. If an investigation is warranted, proceed under the steps indicated above for responding to a complaint received from a health care provider or hospital.

MEDICAL NEGLECT BASED ON RELIGIOUS BELIEFS

It is a parent's right and responsibility to consider recommendations from medical practitioner(s) and make an informed decision for treatment that they believe is in their child's best interest. These decisions may involve the need to weigh several competing opinions and recommended courses of treatment. Decisions are often made in the context of the family's religious or spiritual beliefs. A determination of medical neglect must include sufficient evidence that the parent had the opportunity, but failed to provide medical care for the child's health or welfare.

Under the Child Protection Law (MCL 722.634), when a particular type of intervention or a specific recommended medical treatment for a child is not provided based on a parent or guardian practicing his/her religious beliefs, the parent or guardian must **NOT** be considered negligent for that reason alone. To be clear, a finding of medical neglect may still be confirmed in such cases if sufficient evidence of neglect exists, but if so, the parent or guardian cannot be considered a perpetrator. The perpetrator must be indicated as "unknown." See below for guidance.

No Perpetrator

If medical neglect is confirmed as the result of a CPS investigation based **only** on the parent or guardian not providing the recommended medical treatment due to his/her religious beliefs, the parent's or guardian's name(s) must not be listed on the central registry as a perpetrator of child abuse or neglect. When completing the disposition in MiSACWIS, select the victim(s) of medical neglect and an unknown perpetrator. The disposition must provide a narrative documenting why an unknown perpetrator is being identified.