

DRAFT

GUIDELINES APPLICABLE TO HEALTH CARE AND CHILD PROTECTIVE SERVICES FOR INFANTS WITH LIFE THREATENING CONGENITAL IMPAIRMENTS PURSUANT TO SECTION 504 OF THE REHABILITATION ACT OF 1973 AND THE CHILD ABUSE PREVENTION AND TREATMENT ACT

I. Summary

These guidelines reaffirm responsibilities of recipients of Federal financial assistance to prevent the unjustified deprivation of life-sustaining medical treatment to infants with congenital impairments. The primary thrust of these guidelines is to insure that health care providers and State child protective agencies take appropriate action to insure that available medical treatment is not unjustifiably withheld.

For health care providers, these responsibilities include a duty, already required in every State, to report suspected cases of medical neglect of children by parents or guardians to the State child protective agency. For State child protective agencies, these responsibilities include a duty to take effective action to prevent the unjustified withholding of life-sustaining medical treatment.

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These guidelines recognize that not every withholding of medical treatment is unjustified. For example, in cases where imminent death is virtually certain regardless of the treatment, or a possible treatment is medically contraindicated, the withholding of that treatment does not constitute unlawful discrimination against the handicapped or medical neglect of a

a child. These guidelines do not interfere with reasonable medical judgment or proper parental discretion in considering alternative courses of treatment.

These guidelines also recognize, within the framework of the Federal prohibition against discrimination on the basis of handicap, the primary authority and responsibility of States in matters affecting the health and welfare of children.

II. Purpose and Applicability of Guidelines

A. The purpose of these guidelines is to reaffirm existing responsibilities of recipients of Federal financial assistance to insure that infants with life-threatening congenital impairments are not deprived of available life sustaining medical treatment due to discrimination by health care providers on the basis of handicap or due to parental neglect. Although these guidelines do not have independent force and effect of law, they do represent the Department's interpretations of existing responsibilities of recipients of Federal financial assistance under applicable statutes and regulations. Nothing in these guidelines should be construed as limiting the responsibilities of recipients or authorities of the Department under applicable laws and regulations.

B. These guidelines apply to:

1. Responsibilities of recipient health care providers under Section 504 of the Rehabilitation Act of 1973, 29 USC §794, and 45 CFR Part 84 (Nondiscrimination on the Basis of Handicap in Programs and Activities Receiving or Benefiting from Federal Financial Assistance); and

2. Responsibilities of child protective agencies under Section 504 of the Rehabilitation Act of 1973, the Child Abuse Prevention and Treatment Act, 42 U.S.C. §5101 et seq., 45 CFR Part 84, 45 CFR Part 1340 (Child Abuse and Neglect Prevention and Treatment) and rules applicable to child abuse and neglect programs funded under Titles IV-A and IV-B of the Social Security Act (presently at 45 CFR Part 1392, Subpart E; proposed to be in a new Part 1357, 47 F.R. 30932 et seq.).

III. Definitions of Terms Used in These Guidelines.

A.1. "Qualified handicapped infant" means a handicapped infant with a life threatening congenital impairment for which life sustaining medical treatment is available which will benefit the infant.

2. "Failure to provide adequate medical care" means the withholding by a person responsible for the infant's health or welfare of authorization for life sustaining medical treatment of such infant with a life threatening congenital impairment when such treatment is available which will benefit the infant.

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3. Medical treatment will not be judged to benefit the infant under the definitions of "qualified handicapped infant" and "failure to provide adequate medical care" only if a conclusion, based on reasonable medical judgment, has been made that:

- a. imminent death of the infant is virtually certain regardless of the treatment;

- b. the possible treatment involves an undue risk of death or worsening the overall condition of the infant;
- c. even after the treatment, the best reasonable prognosis is for a life of noncognitive existence; or
- d. even after the treatment, the best reasonable prognosis is that the infant will not survive very early childhood and will, during that period, experience extreme pain and suffering.

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B. "Medical treatment" includes the plural of that term and includes all medical or surgical treatment and the providing of nutritional ^{*and fluid*} sustenance and other support services by a health care provider.

C. "Life sustaining medical treatment" means medical treatment to correct or ameliorate a condition which is generally life threatening.

D. "Impairment" includes the plural of that term.

E. "Responsible State agency" means the State agency responsible under State law for activities relating to the prevention and treatment of child abuse and neglect.

F. "Federal financial assistance" means its definition under 45 CFR Section 84.3(h). Health care providers which participate in the Medicare or Medicaid programs are recipients of Federal financial assistance.

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- b. the possible treatment involves an undue risk of death or worsening the overall condition of the infant;
 - c. even after the treatment, the best reasonable prognosis is for a life of noncognitive existence; or
 - d. even after the treatment, the best reasonable prognosis is that the infant will not survive very early childhood and will, during that period, experience extreme pain and suffering.
- B. "Medical treatment" includes the plural of that term and includes all medical or surgical treatment and the providing of nutritional sustenance and other support services by a health care provider.
- C. "Life sustaining medical treatment" means medical treatment to correct or ameliorate a condition which is generally life threatening.
- D. "Impairment" includes the plural of that term.
- E. "Responsible State agency" means the State agency responsible under State law for activities relating to the prevention and treatment of child abuse and neglect.
- F. "Federal financial assistance" means its definition under 45 CFR Section 84.3(h). Health care providers which participate in the Medicare or Medicaid programs are recipients of Federal financial assistance.

IV. Responsibilities of Recipient Health Care Providers.

A. In general. Under 45 CFR Sections 84.4 and 84.52, a recipient health care provider may not, on the basis of handicap, deny the benefits of life sustaining medical treatment to a qualified handicapped infant. Nor may a recipient health care provider aid or perpetuate the withholding, on the basis of handicap, of life sustaining medical treatment to a qualified handicapped infant.

B. Specific applications.

1. A recipient health care provider may not, in contravention of the wishes of the parents or guardian, withhold, on the basis of handicap, life sustaining medical treatment of a qualified handicapped infant.
2. A recipient health care provider may not encourage parents or guardians to make decisions which, if made by a recipient health care provider, would be a violation of 45 CFR Sections 84.4 and 84.52.
3. A recipient health care provider may not acquiesce in a decision by the parents or guardian of a qualified handicapped infant to withhold, on the basis of handicap, life sustaining medical treatment.
 - a. Where State law provides that medical treatment for a child may not be provided without the consent of the parents or guardian, but where circumstances indicate there are reasonable grounds to suspect that the withholding of such consent represents a

failure to provide adequate medical care, the recipient health care provider must make an immediate and complete report of those circumstances to the responsible State agency.

- b. A recipient health care provider must fully comply with all lawful requests of the responsible State agency for all information and documentation necessary to determine what actions, if any, the agency will undertake, and to carry out those actions.
 - c. A recipient health care provider's responsibilities to report suspected cases of failure to provide adequate medical care are not relieved by the discharge or transfer of the infant from the provider's facility.
 - d. A recipient health care provider must, to the extent possible and permitted by law, seek to prevent worsening of the infant's condition during the pendency of any action taken by the responsible State agency.
4. A recipient health care provider may not permit, by the granting of privileges or otherwise, physicians practicing in their facilities to engage in conduct which, if engaged in by a recipient health care provider, would be a violation of 45 CFR Sections 84.4 and 84.52.

V. Responsibilities of Responsible State Agencies Which are Recipients of Federal Financial Assistance.

A. Responsibilities in general pursuant to Section 504 of the Rehabilitation Act. Under 45 CFR Sections 84.4 and 84.52, the responsible State agency may not, on the basis of handicap, deny

the benefits of its authority under State law to take action to prevent instances of child abuse and neglect to, or otherwise discriminate against, a qualified handicapped infant who is otherwise qualified to receive such benefits. Nor may such an agency, on the basis of handicap, fail to take action in behalf of such an infant that is as effective as that provided for non-handicapped children.

B. Specific applications pursuant to Section 504 of the Rehabilitation Act. Unless the recipient responsible State agency clearly has no authority under State law to take action, the agency may not, on the basis of handicap, with respect to a qualified handicapped infant:

1. fail to take action to investigate any report of a suspected failure to provide adequate medical care that is as effective as action provided for non-handicapped children in imminently life threatening situations;
2. if the circumstances indicate there is a failure to provide adequate medical care, fail to seek a remedy that is as effective as that which would be sought in behalf of nonhandicapped children in imminently life threatening situations, including, if necessary and authorized by state law, obtaining an appropriate court order to provide for the necessary medical treatment; and
3. fail to take any other action as effective as that which would be taken with respect to nonhandicapped children in imminently life-threatening situations.

C. Responsibilities in general pursuant to the Child Abuse Prevention and Treatment Act. Under section 4(b)(2) of the Child Abuse Prevention and Treatment Act and 45 CFR Section 1340.14, to qualify for state grants, the State must demonstrate that it has in effect procedures and services to deal effectively with child abuse and neglect cases. Under Section 3 of the Act, child abuse and neglect includes negligent treatment, and under 45 CFR Section 1340.2, negligent treatment includes the failure to provide adequate food, clothing, shelter, and medical care. Under Section 4(b)(3) of the Act, these same provisions are applicable to child abuse and neglect programs assisted under Parts A or B of Title IV of the Social Security Act.

D. Specific applications pursuant to the Child Abuse Prevention and Treatment Act. A responsible State agency which is assisted by funds under these laws, must, in the administration of its program, unless clearly not authorized by State law, consider "failure to provide adequate medical care" to include the circumstances described in the definition of that term contained in these guidelines.

VI. Responsibilities of State Medicaid Agencies

A. In general. Under 45 CFR Section 84.5(b)(1)(v), a recipient may not aid or perpetuate discrimination against a qualified handicapped person by providing significant assistance to an agency, organization or person that discriminates on the basis of handicap in providing any service to beneficiaries of the recipient's program.

B. Specific application. The State agency responsible for the administration of the State's Medicaid program which receives Federal financial assistance, may not permit health care providers which do not comply with the regulations cited in part IV of these guidelines to participate in the State's Medicaid program.

VII. Methods of Administration Access to Information and Procedures.

A. Under 45 CFR Section 84.4, recipients may not utilize methods of administration that have the effect of substantially impairing the provision of services and benefits to handicapped persons. The procedures and methods of administration of recipient health care providers and recipient responsible State agencies must be consistent with these guidelines.

B. Under 45 CFR Sections 84.61 and 80.6(c), recipients must permit access by the Department to records, sources of information and facilities as may be pertinent to ascertain compliance. Section 80.6(c) further provides that asserted considerations of privacy or confidentiality may not operate to bar the Department from evaluating or seeking to enforce compliance. The evidentiary rule of doctor-patient confidentiality is not recognized in federal courts, and State statutory provisions may not, under the Supremacy Clause of the U.S. Constitution, operate to defeat to objectives of federal statutes. In addition, Section 80.6(c) provides that information of a confidential nature obtained in connection with compliance evaluation or enforcement shall not be disclosed by the Department except where necessary in formal enforcement proceedings or where otherwise required by

law. Recipient health care providers and recipient State agencies must comply with these requirements. The Department may, to the extent it will not impede the Department's responsibilities to evaluate and enforce compliance, permit recipients to not disclose names and other related identifying information associated with records asserted to be of a private or confidential nature. The access provided to the Department to review relevant records must be under terms reasonable to permit the Department to accurately determine the circumstances of the case. This may require allowing the Department to obtain possession of copies of records so they may be examined by appropriate medical specialists.

C. The provisions of 45 CFR Section 80.8(d) concerning providing recipients 10 days notice before the Department initiates certain remedies authorized by law, such as a recommendation to the Department of Justice that appropriate legal proceedings be brought, do not apply in a case where HHS and the Department of Justice seek emergency injunctive relief to preserve the life of a handicapped infant pending a formal administrative determination of compliance or noncompliance with Section 504 by a recipient health care provider or responsible State agency. Such emergency relief is not "action to effect compliance" within the meaning of Section 80.8(d), and the general rule of providing for a 10-day period for seeking voluntary compliance is inappropriate where

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irreparable harm is likely to result from any delay in providing medical care. The authority of the Department to initiate action to obtain emergency relief is in addition to the authority contained in 45 CFR Section 80.8 to suspend or terminate Federal financial assistance or pursue other remedies authorized by law.