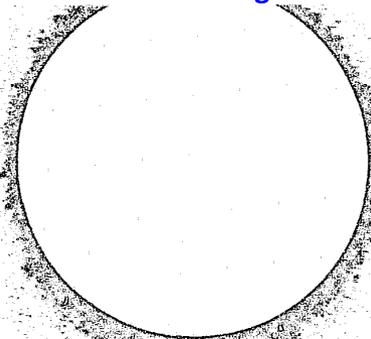
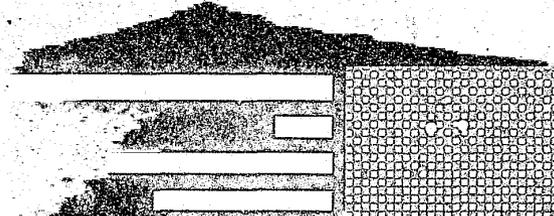


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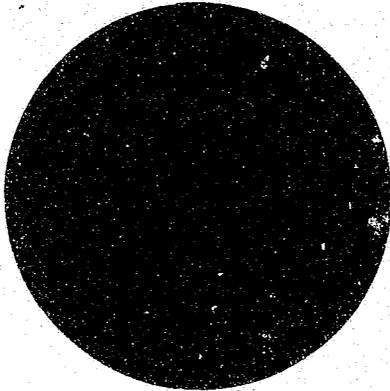
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MODEL PROCEDURES

FOR CHILD PROTECTIVE SERVICE AGENCIES
RESPONDING TO REPORTS OF
WITHHOLDING MEDICALLY INDICATED TREATMENT
FROM DISABLED INFANTS
WITH LIFE-THREATENING CONDITIONS



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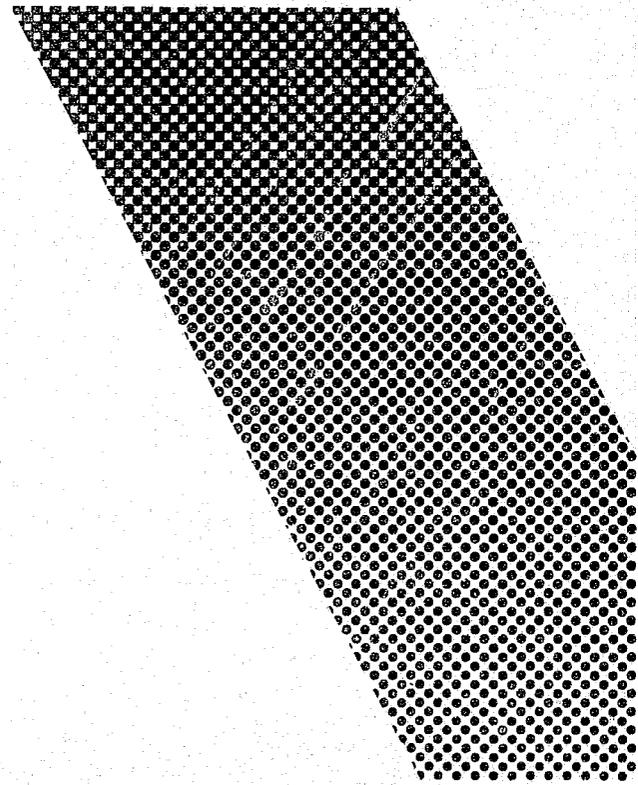
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COMMISSION ON
THE MENTALLY
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PREFACE AND ACKNOWLEDGMENTS

The Child Abuse Amendments of 1984 require states receiving funds under the federal Child Abuse Prevention and Treatment Act to develop written policies to respond to reports of withholding medically indicated treatment from disabled infants with life-threatening conditions. In October, 1984, the American Bar Association's National Legal Resource Center for Child Advocacy and Protection and Commission on the Mentally Disabled were awarded a grant by the United State Department of Health and Human Services, Office of Human Development Services to develop model procedures to assist states to meet this mandate.

The model procedures were developed by the American Bar Association staff over a fifteen month period. They underwent a lengthy review process to secure the best and widest input from distinguished experts across the country. Foremost among them were the members of our advisory board who extensively reviewed two drafts of model procedures. They are: Mary Layne Ahern, Health Affairs Legal Counsel, American Hospital Association, Chicago, IL; Paul S. Appelbaum, M.D., Professor of Psychiatry, University of Massachusetts, Worcester, MA; James Bopp, Jr., Brames, Bopp, Haynes & Abel, Terre Haute, IN; Robert Burt, Professor of Law, Yale University, School of Law, New Haven, CT; Diane DePanfilis, MSW, ACPS, Director, Washington Office, Action for Child Protection, Washington, D.C.; Martin H. Gerry, Pickard and Gerry, Washington, D.C.; Richard D. Krugman, M.D., Director, C. Henry Kempe National Center, Denver, CO; John W. Reynolds, M.D., Professor, Department of Pediatrics, Director, Neonatal Intensive Care Center and Intermediate Care Nursery, Oregon Health Sciences University, School of Medicine, Portland, OR; Francine J. Vecchiolla, ACSW, Assistant Director, Dept. of Children and Protective Services, Hartford, CT; William B. Weil, Jr., M.D., Professor of Pediatrics, Dept. of Pediatrics & Human Development, Michigan State University, East Lansing, MI.

We wish to express thanks to our project officer, Jay D. Olson, of the National Center on Child Abuse and Neglect for his indispensable involvement and guidance throughout the project. We thank Howard Davidson, Director of the National Legal Resource Center for Child Advocacy and Protection, for his ideas and direction throughout the project.

Many others also contributed to the ideas, content, and format of the procedures. We also want to thank the following individuals for their review and commentary: George Annas, J.D., M.P.H.; Harriet Bakalar, A.C.S.W.; William Bartholome, M.D.; Watson Bowes, Jr., M.D.; Donald Bross, J.D., Ph.D.; Kathy Bryant, J.D.; Allen Buchanan, Ph.D.; Alexandra Calcagno; Ronald Cranford, M.D.; Alan Fleischman, M.D.; Ann Fletcher, M.D.; Ray E. Helfer, M.D.; Sandra Hodge, M.S.W.; Albert Jonsen, Ph.D.; Darlene Kamine, J.D.; Arthur Kohrman, M.D.; Steven E. Lawton, J.D.; Nancy Lee Jones, J.D.; Faye Lindemann-Tayler, M.S.W.; Sally Mack, LICSW; Jeffrey Pomerantz, M.D.; Evelyn Van Allen, M.P.H.; Thomas Villiger, M.S.W.; Ellen Weiss, J.D.

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The model procedures are the final product of this project. They do not represent the views, in whole or in part, of the advisory board members or any of the individual reviewers listed above. Neither does the content of the model procedures necessarily represent the policy of the sponsoring organizations.

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INTRODUCTION

The federal Child Abuse Amendments of 1984 (Amendment)¹ and implementing regulations (Final Rule)² established a significant responsibility for child protective service agencies: the protection of disabled infants from discriminatory denial of medical treatment. The Amendment requires states that receive federal funds for their child abuse and neglect agencies to define withholding of medically indicated treatment from disabled infants with life-threatening conditions as a form of child neglect.

The Final Rule states that "to qualify for [a federal] grant, a State must have programs, procedures, or both, in place within the State's child protective service system for the purpose of responding to the reporting of medical neglect, including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions."³ These Model Procedures are intended to help state child protective service agencies meet this mandate. They were developed by the Legal Procedures for Handicapped Infant Care Project, a joint effort of the American Bar Association's Commission on the Mentally Disabled and the National Legal Resource Center for Child Advocacy and Protection. Funding was provided by the U.S. Department of Health and Human Services, National Center on Child Abuse and Neglect.

The Project used a three part process to develop these procedures: (1) research and analysis of existing and proposed state law and child protective service agencies' policies and procedures affecting disabled infants; (2) interviews with professionals experienced with treatment and decision-making regarding treatment of disabled infants; and (3) input of the project's advisory board and other expert reviewers.

The model procedures are divided into seven parts: I - Definitions; II - Planning; III - Intake; IV - Preliminary Investigation; V - On-Site Investigation; VI - Decision-Making and VII - Follow-Up. They are accompanied by three appendices: Appendix A — Information Needed for CPS Assessment of Child's Status; Appendix B — Information Needed to Assess Parental Decision-Making, and Appendix C — Information Needed to Assess Hospital Review Committee Actions.

The procedures address: qualifications of CPS personnel, use of medical consultation, coordination with hospital personnel, and conduct of investigations. Special attention is given to CPS investigative issues involving parents and hospital review committees.

The procedures are intended to assist child protective service agency administrators in adopting procedures to respond to reports involving disabled infants. The bracketed language in certain sections attempts to take account of certain state-by-state variations, such as administrative, economic or geographic idiosyncracies. In addition, it is hoped that state protective service agencies will adapt the model to their own needs, but remain consistent with the purposes of the model.

The issue of withholding life-sustaining treatment for disabled newborns was first debated in professional journals in the early 1970's.⁴ This debate arose largely from advances in neonatal care during the previous two decades. Medical developments made it possible to forestall death in seriously ill newborns, thereby increasing the already difficult task of assessing and deciding which infants will benefit from vigorous medical treatment. In the early 1980's, two nationally publicized court cases and the federal government's troubled attempt to provide legal protection to handicapped infants under section 504 of the Rehabilitation Act of 1973 brought this issue into the public's eye.

In the first court case, an infant called "Baby Doe" was born with Down's Syndrome and a surgically correctable blockage of the esophagus. He died after his parents and doctor elected not to perform surgery and to withhold food from him. *In re Infant Doe*, No. GU8204-004A (Cir. Ct. Monroe County, Ind. Apr. 12, 1982), *cert. denied*, *Doe v. Bloomington Hospital*, 104 S.Ct. 394 (1983). As a direct result of this case, the U. S. Department of Health and Human Services (Department) issued a notice on May 18, 1982, 47 Fed. Reg. 26,027, stating that section 504 of the Rehabilitation Act of 1973 applied to handicapped infants. The Department subsequently issued an interim rule that established a hotline for reports of failure to feed and care for handicapped infants. This interim rule was struck down by a federal court on procedural grounds. *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983).

The second case involved a Long Island, N.Y. infant known as "Baby Jane Doe," who was born with multiple neural tube defects, including spina bifida (an open lesion on the spine), microcephaly (an abnormally small head), and hydrocephaly (an accumulation of fluid on the brain). After consulting with many parties, including their priest, the parents approved medical treatment to decrease the chance of infection, but refused surgery to correct the baby's defects. The parents' decision was upheld by the New York courts. *Weber v. Stony Brook Hospital*, 95 A.D.2d 587, 467 N.Y.S.2d 685, *cert. denied*, 104 S.Ct. 560 (1983).

When the Department petitioned a federal court for access to the medical records of Baby Jane Doe one year later, the U.S. Court of Appeals for the Second Circuit determined that section 504 did not permit the federal government to investigate the treatment of a disabled infant because, in its opinion, the legislation did not "apply to treatment decisions concerning defective newborn infants." *United States v. University Hospital*, 729 F.2d 144 (1984).

On January 12, 1984, the Department's final regulations under section 504, 49 Fed. Reg. 1622, were struck down. *American Hospital Association v. Heckler*, 585 F. Supp. 541 (S.D.N.Y. 1984). This ruling was subsequently affirmed by the Second Circuit Court of Appeals. *American Hospital Association v. Heckler*, No. 84-6211 (2d Cir. Dec. 27, 1984). The United States Supreme Court granted certiorari to review this decision, and oral arguments were made January 15, 1986. *Bowen v. American Hospital Association*, No. 84-1529. As of the date of this publication the Court has not issued its opinion.

A consensus regarding treatment/nontreatment decisions affecting disabled newborns began to emerge from this decade of uncertainty. A report from the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Foregoing Life-Sustaining Treatment* (1983), concluded that decision-making would be improved if three treatment situations were identified: "(1) a treatment is available that would clearly benefit the infant, (2) all treatment is

expected to be futile, or (3) the probable benefits to an infant from different choices are quite uncertain. . . .”⁵ The President’s Commission also recommended that palliative care should always be provided. Even “infants whose lives are destined to be brief are owed whatever relief from suffering and enhancement of life can be provided, including feeding, medication for pain, and sedation, as appropriate.”⁶

The President’s Commission made recommendations that presage the Child Abuse Amendments of 1984. It recommended that hospitals have explicit policies regarding decision-making procedures involving life-sustaining treatment for these infants (including “ethics” committees), and that to the extent possible, an infant’s life should be sustained long enough to gather the best information and to permit expeditious review.⁷

The varied and oftentimes competing concerns of medical, professional, pro-life and disabilities groups required that the 1984 Child Abuse Amendments be developed through a consensus process. This consensus was an outgrowth of prior efforts to articulate fair and reasonable guidelines to deal with this complex issue. This includes the influential “Principles of Treatment of Disabled Infants,” issued in 1983 by a broad coalition of leading medical associations and advocacy organizations for the disabled. (*Pediatrics*, Vol. 73, No. 4, April 1984, p. 559.) This document stated:

When medical care is clearly beneficial, it should always be provided. When appropriate medical care is not available, arrangements should be made to transfer the infant to an appropriate medical facility. Considerations such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care. The individual’s medical condition should be the sole focus of the decision. These are very strict standards.

It is ethically and legally justified to withhold medical or surgical procedures which are clearly futile and will only prolong the act of dying. However, supportive care should be provided, including sustenance as medically indicated and relief of pain and suffering. The needs of the dying person should be respected. The family also should be supported in its grieving.

In cases where it is uncertain whether medical treatment will be beneficial, a person’s disability must not be the basis for a decision to withhold treatment. At all times during the process when decisions are being made about the benefit or futility of medical treatment, the person should be cared for in the medically most appropriate ways. When doubt exists at any time about whether to treat, a presumption always should be in favor of treatment.

CHILD ABUSE AMENDMENTS OF 1984

Within the existing legal framework of the federal Child Abuse Prevention and Treatment Act and state child abuse and neglect laws, the 1984 Amendment requires state child protective service (CPS) agencies to protect disabled infants from medical neglect.

All states have child abuse and neglect laws that protect children who do not receive needed medical care. States require physicians and other professionals to report suspected child abuse or neglect to the CPS agency, while also providing immunity from civil or criminal liability for anyone making such reports in good faith. Reports are taken twenty-four hours a day, either through a toll free state-wide or local telephone numbers. Interdisciplinary teams with expertise in social work, medicine and law are theoretically available to investigate such reports on a twenty-four basis.⁸

The Final Rule adds certain duties for state CPS agencies. Agencies are required to ascertain at least annually the names, titles, and telephone numbers of the individuals designated by each health care facility for the purpose of reporting suspected or known instances of medical neglect,⁹ and to coordinate and consult with the designated liaison in contacts with the facility. Agencies must also provide for obtaining access to medical records and for obtaining a court ordered independent medical evaluation of the infant, where necessary.¹⁰

The Final Rule specifies that these procedural elements be part of formal child protective services policy under which CPS agencies respond to reports of suspected medical neglect including the withholding of medically indicated treatment from disabled infants.¹¹ As long as the basic requirements are met, each CPS agency may work out its own internal investigative procedures and develop mechanisms to coordinate and consult with local health care facilities and other organizations.

The Amendment and Final Rule carefully balance the right of disabled infants to receive appropriate medical care with the need to avoid unreasonable governmental intervention into the practice of medicine or parental decision-making. Certain key principles should be kept in mind in adopting appropriate investigative procedures:

- a. Unless there is judicial intervention, parents are the legal decision-makers regarding their child’s medical care.
- b. The existence and operation of a designated hospital liaison and/or hospital review committee does *not* affect the legal duty of medical personnel to report instances of suspected medical neglect to the child protective service agency.
- c. Congress intended that the CPS agency respond to reports of suspected medical neglect under procedures designed to ascertain whether any decision to withhold treatment was based on reasonable medical judgment consistent with the definition of “withholding medically indicated treatment.”
- d. Child protective service investigative procedures should require coordination and consultation between the CPS agency and hospital, to assure that reports of medical neglect are made at optimum speed, and that CPS investigations proceed with a minimum of disruption to hospital activities.
- e. “This communications system should operate whether the reports are made by the designated individual(s) or by any other person, and whether they are reports requesting CPS agency intervention and legal protection of an infant or reports requesting an initial CPS agency investigation. Under all these circumstances, rapid communication is of the utmost importance.”¹²

**MODEL PROCEDURES
FOR CHILD PROTECTIVE SERVICE AGENCIES
RESPONDING TO REPORTS OF
WITHHOLDING MEDICALLY INDICATED TREATMENT
FROM DISABLED INFANTS WITH LIFE-THREATENING CONDITIONS**

PART I: DEFINITIONS

1.1 Withholding of medically indicated treatment.

“Withholding of medically indicated treatment” means the failure to respond to the infant’s life-threatening conditions by providing treatment which, in the treating physician’s reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions. The term does not include, however, the failure to provide treatment to an infant when, in the treating physician’s (or physicians’) reasonable medical judgment any of the following circumstances apply:

- (A) The infant is chronically and irreversibly comatose;
- (B) The provision of such treatment would merely prolong dying, 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
- (C) 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.

Appropriate nutrition, hydration and medication (palliative care) should be provided in all cases.

The term “reasonable medical judgment” means 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.

COMMENTARY

“Withholding of medically indicated treatment”¹³ was the lynchpin of the “compromise amendment” that resulted from a consensus process among medical, disability, right to life and professional groups.¹⁴ The definition used in these procedures is identical to that in the Amendment and Final Rule¹⁵ with one exception. The two phrases “including appropriate nutrition, hydration, and medication” and “other than appropriate nutrition, hydration, or medication” have been omitted and a separate statement, that “Appropriate nutrition, hydration, and medication (palliative care) should be provided in all cases,” has been substituted for the purpose of clarity. In all cases, the question whether appropriate nutrition and hydration has been provided is a separate determination. The term “palliative care” and “care” is used to denote appropriate nutrition, hydration, and medication.

The definition of “reasonable medical judgment” is identical to the definition used in both the House Conference Report and the Final Rule.¹⁶

The definition of “withholding of medically indicated

treatment” is explained in the “Supplementary Information” and “Interpretative Guidelines” accompanying the Final Rule.¹⁷ The interpretative guidelines explain the following terms: “life-threatening condition,”¹⁸ “treatment,”¹⁹ “merely prolong dying,”²⁰ “not be effective in ameliorating or correcting all of the infant’s life-threatening conditions,”²¹ “virtually futile,”²² and “the treatment itself under such circumstances would be inhumane.”²³ These explanations are not “binding rules of law.”²⁴

Several basic interpretive guidelines regarding the statutory definition “withholding of medically indicated treatment” are emphasized in the supplementary information accompanying the Final Rule. These are as follows:

- 1) All disabled infants with life-threatening conditions must be given medically indicated treatment.²⁵
- 2) The statutory definition carefully spells out three circumstances under which treatment is not considered “medically indicated.”²⁶
- 3) Decisions based on subjective opinions about the future “quality of life” of a retarded or disabled person are not sanctioned.²⁷

4) The statutory definition relies on the “reasonable medical judgment” of the treating physician or physicians based on what a reasonably prudent physician should know about the case and treatment alternatives. This standard of care is used widely in other treatment contexts, and only its application to the issue of withholding of medically indicated treatment from disabled infants with life-threatening conditions is new.²⁸

The “quality of life” issue is controversial. The American Academy of Pediatrics has argued that “nowhere in the legislative history or in the extensive deliberations leading up to the enactment of [the Amendment] is there any indication that Congress clearly intended to exclude consideration of the infant’s quality of life.”²⁹

Nonetheless, the Principles of Treatment, coauthored by the Academy, specify that “considerations such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decision concerning medical care. The individual’s medical condition should be the sole focus of the decision. These are very strict standards.”³⁰ Whether or not Congress addressed the “quality of life” issue, the decision to withhold medical treatment or care from a disabled infant with life-threatening conditions is to be made only in terms of the statutory definition. This definition does not include non-medical factors in the “reasonable medical judgment” used to determine “withholding of medically indicated treatment.”

1.2 Disabled infant.

The term “infant” means a child less than one year of

age. This definition does not imply that treatment should be changed or discontinued when an infant reaches one year of age. Nor does it affect or limit existing protections under state laws regarding medical neglect of children over one year of age.

"Disabled infant" means an infant with a physical or mental impairment which substantially limits or holds the reasonable prospect of in the future substantially limiting one or more major life activities. "Major life activities" include functions such as, but not limited to, breathing, seeing, hearing, walking, caring for one's self, performing manual tasks, learning and working.

COMMENTARY

The definition of "infant" corresponds with the definition in the House Conference Committee Report³¹ and in the Final Rule.³² The Conference Committee Report states that the protection provided to disabled infants should not end arbitrarily at age one nor limit any existing legal protection for children older than one year. Before the 1984 Amendment, issues of medical treatment for infants over one year of age normally were to be considered under the less precisely defined, applicable standards of "medical neglect" provided by existing state law. However, the more precisely defined standards of "withholding medically indicated treatment," which applies to issues of medical treatment for disabled infants with life threatening conditions under one year of age, "may" be applied to certain children older than one year who share important characteristics with those infants under one year of age. The Conference Committee Report definition includes children "who have been continuously hospitalized since birth, who were born extremely prematurely or who have long-term disabilities."³³

The second paragraph in this subsection defines what is meant by infants with disabilities (or "disabled infants"). It is drawn from the federal definitions of "Handicapped person," "Physical or mental impairment" and "Major life activities" in 45 C.F.R. §84.3(j)(1984). The only substantive difference is that the phrase "or holds the reasonable prospect of in the future substantially limiting [a major life activity]" is added. This reflects the fact that infants and young children, in the normal course of development, do not yet possess the capability of performing many of the enumerated "major life activities."

As long as basic federal requirements are met, state definitions of "disabled" and "disability" may be substituted for this paragraph. Definitions which may fall short of the federal requirements should be reviewed carefully.³⁴

1.3 Child protection service (CPS) specialist.

The "child protection service specialist" is a regular employee of the [state] [child protective service agency] who has specialized training in and is responsible for investigating reports of suspected withholding of medically indicated treatment from disabled infants. The CPS specialist will have either a M.S.W. degree and training in investigation of neglect of disabled infants cases, or other appropriate specialized training (such as that of a regis-

tered nurse with experience working in a neonatal intensive care unit).

COMMENTARY

The qualifications of the child protective service (CPS) personnel primarily responsible for conducting investigations of reports of "withholding medically indicated treatment" are set forth in this subsection. These cases require special qualifications because they often involve complex medical information. To ascertain whether any decision to withhold treatment was based on reasonable medical judgment consistent with the definition of "withholding medically indicated treatment" will require extensive consultation with physicians and a basic understanding of medical issues that often arise in these cases.

The CPS specialist will also assess and carry out the social work functions in these cases. Assessments include an evaluation of psycho-social support available to parents, which in turn requires access to information regarding community and state resources for the disabled and their families. Also the CPS specialist will facilitate coordination between parents and hospital based, community, state and national resources.

The CPS specialist should be a medical social worker, or perinatal social worker, with a Masters in Social Work, or some other professional with experience working in a hospital setting and with specialized training regarding medical treatment decision-making for disabled infants with life-threatening conditions. Training CPS staff with a B.A. in Social Work and no medical background is not practical. The complexity of the CPS role in assessing whether reasonable medical judgment was used in regard to withholding medical treatment or care from a disabled infant with life-threatening conditions should not be underestimated.

The definition in this section provides that the CPS specialist may be a "regular employee." Each state will determine how best to allocate its funds.

The bracketed terms "[state]" and "[child protective service agency]" reflect the fact that states adopting the language of this section are likely to substitute specific terms. States in which the CPS agency is supervised and run at a county level may want to substitute the term county for state. Where it is not feasible to train investigators for each county in the state, a statewide responsibility would be indicated. The bracketed term [child protective service agency] reflects that states have flexibility under the Final Rule to designate a specific agency or agencies within their child protective service system to assume responsibility. The term "child protective service (CPS) agency" is used throughout these procedures to indicate the designated agency within the state child protection system.

1.4 Child protection service (CPS) medical consultant.

The "child protection service medical consultant" is a physician with a board certified specialty in pediatrics or neonatology. The medical consultant, either as an employee of [CPS] or on a contract basis, is responsible for reviewing medical information and consulting with the CPS specialist (and other experts as deemed necessary in

view of the facts of individual cases) in cases of reported suspected withholding of medically indicated treatment from disabled infants with life-threatening conditions.

COMMENTARY

The judgment of physician(s) who specialize in the medical problems and disabling conditions of newborn infants is necessary to assess whether reasonable medical judgment was employed in a decision to withhold medical treatment or care from a disabled infant. Additional specialists should be consulted as-needed, such as experts in neurology, cardiology, hematology, oncology, nephrology, and pulmonary diseases.

The medical consultant may be a full-time employee or on contract to the agency. Pediatricians who already consult with the CPS agency on multidisciplinary review boards may or may not meet the level of expertise needed to review these cases.

Recruiting appropriate specialists should take place as soon as possible. State chapters of the American Academy of Pediatrics and other medical organizations, working with the state CPS agency, have compiled lists of volunteer medical consultants in several states. In Oregon, for example, existing consultation arrangements with hospitals with neonatal intensive care units is used when a report involving suspected withholding of medically indicated treatment or care requires the involvement of a CPS medical consultant.

The medical consultant's primary role in the investigation is to assist the CPS specialist to determine the medical facts of the reported case. The consultant will be available during a preliminary investigation and review medical records and interview health care providers during an on-site investigation. Consultation regarding decision-making will be available at any stage. The CPS specialist, however, is responsible for the ultimate decision as to whether the report is indicated or not indicated based upon the CPS medical consultant's conclusions and other facts determined in the investigation.

1.5 Child protection service (CPS) supervisor.

The "child protection service supervisor" is an administrative officer of the [state] child protection service agency who is responsible for the supervision of CPS activities in responding to reports of suspected withholding of medically indicated treatment from disabled infants with life-threatening conditions. The CPS supervisor will have specialized training in this area and be involved in all CPS case related decision-making.

COMMENTARY

The "child protection service supervisor" should meet existing CPS agency standards for supervisory personnel and have additional training appropriate for cases of suspected withholding of medically indicated treatment. The CPS supervisor's responsibilities include overseeing the activities of the CPS specialist in responding to reports of suspected withholding of medically indicated treatment from disabled infants with life-threatening conditions, and participation in all CPS case related decision-making.

1.6 Designated hospital liaison.

The "designated hospital liaison" is the person named by the hospital or health care facility to act as the contact with [CPS] in cases of suspected withholding of medically indicated treatment from disabled infants with life-threatening conditions.

COMMENTARY

The term "designated hospital liaison" is used throughout these procedures to denote the person named by each hospital or health care facility to serve as a contact for CPS agency personnel regarding the investigation of reports of withholding of medically indicated treatment or care from disabled infants with life-threatening conditions.

Pursuant to the Final Rule, the designated hospital liaison is to be: identified at least annually by name, title and telephone number;³⁵ responsible for providing prompt notification to CPS of cases of suspected withholding of medically indicated treatment from disabled infants with life threatening conditions;³⁶ and responsible for "coordination and consultation" with CPS agency personnel in their investigatory activities within the hospital and with its staff.³⁷ These model procedures require that such "coordination and consultation" will be used in the preliminary investigation, on-site investigation, and other CPS activities where consultation will minimize disruption of normal hospital activities and contribute to rapid resolution of reports.

Using physicians as designated hospital liaisons has clear advantages over designees who are non-health professionals. Physicians would be particularly helpful during a preliminary investigation, as set out in Part IV, where rapid communication of medical information is needed. Also, communication will be facilitated when a CPS medical consultant is involved. Some states provide that the hospital liaison will be a physician. One example is Florida, which uses a pre-existing hospital-CPS liaison system that requires a physician at each hospital to be designated for this role.³⁸ In Kansas, by agreement between the hospitals and the Kansas State Department of Social and Rehabilitation Services, neonatologists at each of the hospitals in the state with specialized neonatal care units will serve as the designated hospital liaison. The Final Rule discussed the possibility of naming, if there is such a person, the chairperson of the hospital review committee to serve as this liaison, but does not require it. If the physician named as the designated liaison works in the neonatal unit of the hospital, this has the further advantage of simplifying communication, which may often include complex medical information. The decision as to who is the designated liaison rests with the hospitals. The designated hospital liaison will be named by and within each hospital and health care facility.

The terms "hospital and health care facility" or "hospital," for purposes of these procedures, means those hospitals and facilities providing neonatal care.

1.7 Hospital Review Committee.

A "hospital review committee" (HRC) is an entity es-

established to deal with medical and ethical dilemmas arising in the care of patients within a hospital or health care facility. Where they exist, HRCs may take many organizational forms, such as an "infant care review committee" or an "institutional bioethics committee." The functions for an HRC may differ from institution to institution, including the authorization to review and recommend treatment in specific cases.

COMMENTARY

The term "hospital review committee" for the purposes of these procedures means any hospital based, interdisciplinary group that may be available to consult, to review diagnosis and prognosis, or to recommend treatment options in cases involving withholding treatment or care from disabled infants with life-threatening conditions. This definition includes such entities as hospital ethics committees, infant bioethics committees, and infant care review committees. The term also includes any hospital review process which may review care given to infants including prognosis committees, specialized team consultants and individual consultants who have a formal review role. The word "committee" may be misleading since such groups, as currently operating and proposed, do not usually have the regulatory or decision-making roles typical of other hospital committees.

Federal law does not require that such committees exist or take any particular form or function. Only one state currently requires that hospitals or health care facilities form such committees,³⁹ and none require that committees which do exist take any particular form as to membership, development of policies, or involvement in review of cases. The Department of Health and Human Services *Model Guidelines for Health Care Providers to Establish Infant Care Review Committees*,⁴⁰ issued with the Final Rule, and previous federal regulations,⁴¹ however, strongly encourage hospitals that treat infants to develop "Infant Care Review Committees." The U.S. Department of Health and Human Services, agreeing with the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research,⁴² observed that because review committees are largely untried, they are not so demonstrably effective as to justify making them mandatory for nearly 7,000 hospitals nationwide.⁴³

Both federal policy and the recommendations of the President's Commission and medical organizations, including the American Academy of Pediatrics⁴⁴ and American Medical Association,⁴⁵ have stimulated the formation of hospital review committees.⁴⁶ It is quite possible that many health care facilities, especially hospitals with neonatal intensive care units, will establish review committees which might include as part of their mandates the review of treatment of infants with disabilities. A survey completed in 1984 of 710 hospitals identified as having special care pediatric units found that 56.6 percent of the 426 hospitals responding have an infant care review or a bioethics committee.⁴⁷

The growing availability of such committees was spurred by the President's Commission Report on *Deciding to Foregoing Life-Sustaining Treatment*, which examined decision-making problems in withholding medical treatment and care from disabled infants. The President's Commission found the

following shortcomings in the existing doctor-parent decision-making system: (1) appropriate information may not be communicated to all those involved in the decision; (2) professionals as well as parents do not at times understand the bases of a decision to treat or not treat (see Section 4.6); and (3) actions can be taken without the informed approval of parents.⁴⁸

The Commission concluded that "hospitals that care for seriously ill newborns should have explicit policies on decision-making procedures in cases involving life-sustaining treatment for these infants These policies should provide for internal review whenever parents and the attending physician decide that life sustaining therapy should be withheld. The policy should . . . be flexible enough to deal appropriately with the range of cases that could arise."⁴⁹ However, the President's Commission gives little guidance as to specific procedures of a committee. The Commission noted that review committees remained largely "untried," and suggested that their development required continuing evaluation and refining of their functions.

Both the Department of Health and Human Services and the American Academy of Pediatrics issued guidelines that organize the major activities of hospital review committees largely in terms of the following functions:

1. *Educating hospital personnel and families of disabled infants with life-threatening conditions:*

The American Academy of Pediatrics (AAP) has recommended in its *Guidelines for Infant Bioethics Committees* that committees act as a resource to hospital staff, to families of infants, and to the community. The AAP also recommends that hospitals publicize the existence and functions of infant bioethics committees, including its policies, procedures and method of contacting the committee.⁵⁰

The U.S. Department of Health and Human Services Model Guidelines also recommend that the hospital review committee act as a resource to hospital personnel and families of disabled infants with life-threatening conditions "concerning medical treatment procedures and resources in the hospital" and community services which may be needed for the "provision of services and treatment."⁵¹ This would include information on: (1) national and regional information resources and clearinghouses; (2) facilities and agencies in the community that provide treatment and services; and (3) community public and private programs, including counseling and support, and adoptive placement counseling and services.

2. *Recommending institutional policies and guidelines:*

Both the U.S. Department of Health and Human Services and American Academy of Pediatrics recommend that committees develop, and hospitals adopt, policies on foregoing life-sustaining treatment for infants with life-threatening conditions and guidelines for decision-making where specific types of cases such as Down's syndrome or myelomeningocele are involved.

3. *Offering counsel and review in cases involving disabled infants with life-threatening conditions:*

The AAP Guidelines provide for mandatory review of all cases in which the attending physician and parents propose to forego life-sustaining treatment for an infant, except when the infant is in imminent danger of dying.⁵² Certain diagno-

ses, such as Down's syndrome or myelomeningocele, should receive mandatory review if decisions are made to forego treatment. Discretionary review is recommended at the request of hospital staff, family members, and wherever there is serious disagreement among the staff responsible for the care of an infant or between the attending physician and the parents. In doubtful cases, the presumption should favor review. The attending physician should notify the committee of any case requiring mandatory review.

The U.S. Department of Health and Human Services Guidelines generally agree with the AAP but specify that emergency hospital review committee meetings should take place within 24 hours or less, provide for telephone and other forms of review when necessary, and direct that in all cases "the hospital should, to the extent possible, require in each case that life-sustaining treatment be continued, until the HRC can review the case and provide advice."⁵³

Committees may also have a retrospective role. The American Academy of Pediatrics Guidelines call for reviews "to determine whether cases that should come before the committee are being missed," and to assist in compiling data on the treatment of all critically ill infants in the hospital.⁵⁴ The U.S. Department of Health and Human Services Model Guidelines similarly recommend review of all records involving withholding of treatment from infants unless the case was previously before the HRC for emergency review.⁵⁵

Both AAP and HHS recommend that the status quo be maintained while a case is under review and, if necessary steps should be taken to prevent worsening of the infant's condition until "such time as a course of action has been ordered by a person acting under the authority of the court."⁵⁶

PART II: PLANNING BY [CPS AGENCY]

2.1 Planning with hospitals and medical organizations.

Advance planning is essential to implement successfully procedures to respond to reports of suspected withholding of medically indicated treatment. The [child protective service agency] shall work with medical organizations, hospitals and health care facilities in order to implement procedures which assure a timely response and resolution of reports while minimizing intrusion upon normal hospital activities. To that end, the [child protective service agency] shall:

- A. Contact each hospital at least yearly and identify the name, title, and telephone number of its liaison.**
- B. Coordinate with the hospital liaison plans for regular training between child protective service agency personnel and hospital personnel potentially involved in cases of suspected withholding of medically indicated treatment from disabled infants with life-threatening conditions. Subjects to be addressed include, but are not limited to:**
 - 1. The respective roles of the hospital personnel (liaison, treating medical personnel, any hospital review personnel) and child protective services per-**

sonnel (specialist, supervisor and medical consultant).

- 2. Written hospital review procedures and child protective service agency policies.**
 - 3. Coordination among hospital and child protective service agency personnel during an investigation, particularly how CPS will interview parent(s) and medical professionals, review medical records and obtain an independent medical evaluation.**
- C. Review state law and policy governing the reporting of suspected instances of child abuse and neglect with the hospital liaison and other affected hospital personnel. This includes:**
- 1. Mandatory reporting duties of persons—physicians, health care personnel, and others—who have reason to believe or suspect that medically indicated treatment is being withheld from a disabled infant with life-threatening conditions. (Neither the designation of the hospital liaison nor the existence or operation of the hospital review committee amends, enlarges or contracts the responsibilities under state law of medical professionals and the hospital to report to the child protective services agency suspected instances of withholding of medically indicated treatment, or other instances of child abuse and neglect.)**
 - 2. Reporter immunity from civil and criminal liability for good faith participation in the making of a report.**
 - 3. Protection for the reporter against employer reprisal.**
 - 4. Waiver of the physician-patient and other applicable privileges as to duty to report to the child protective service agency and admissibility of evidence in any civil or criminal litigation relating to the alleged neglect or abuse of the child.**
 - 5. Confidentiality of reports and child protective service agency investigations and records.**

COMMENTARY

Part II recommends activities CPS agencies should take to improve their implementation of the Amendment and Final Rule. Unlike the remaining parts, this part does not deal with individual cases. This part calls for close working relationships and planning and mutual education programs among CPS agencies, hospitals, agencies providing resources and services to disabled infants and their families, and attorneys providing legal representation to the agency.

Planning is important for two reasons. First, an immediate, emergency-type response must be planned because these cases by definition involve "life-threatening" conditions. Second is the complexity of the task. The CPS agency may need to contact hospital personnel, interview parent(s), and decide whether to seek protective action, including the filing of emergency court petitions based on highly complex medical information. An established cooperative relationship with the key entities involved will enhance the CPS agency's ability to respond effectively.

These plans, in accordance with the Amendment and Final Rule, do not confer authority to regulate internal hospital

activities of hospital personnel⁵⁷ beyond preexisting duties under state child abuse and neglect law. The Amendment specifies only that CPS is to look to the designated hospital liaison to provide prompt notification⁵⁸ of suspected instances of withholding medically indicated treatment and with whom CPS is directed to "coordinate and consult."⁵⁹

The Final Rule notes that many letters from health care facilities indicated plans for the hospital liaison to assist the CPS agency staff and/or agency medical consultant to investigate reports and facilitate other protective actions as needed.⁶⁰ These procedures anticipate cooperative roles for hospital liaisons with CPS personnel both in regard to planning and investigative activities.

Section 2.1 anticipates a case role for the hospital liaison and the development of a rapidly operating line of communications between CPS and the hospital. This section identifies information that the CPS agency should share with the hospital liaison and other hospital personnel.

Section 2.1(A) restates the Final Rule's requirement that CPS identify and annually verify a designated individual at each hospital.⁶¹ Sections 2.1(B) and (C) expand upon the Act's direction that CPS "coordinate and consult" with hospital liaisons. These sections require CPS personnel to conduct educational exchanges with appropriate hospital personnel.

Section 2.1 (B) recommends training activities regarding the investigative role of CPS. Where the hospital liaison and relevant hospital personnel generally know what interviews and information will be sought by CPS, individual case investigations will take place in a more timely and less disruptive manner. Plans should anticipate that information about the infant, his or her condition, treatment alternatives, attending and consulting physician recommendation(s), parental-physician communication, medical records and availability and involvement of hospital review processes will be sought by CPS to evaluate a report. This information is set forth in question form in Appendices A, B and C.

The CPS agency should exchange any written policy it has developed regarding CPS investigative duties with hospitals (and state medical organizations). The CPS agency should also be informed regarding hospital policies for review of cases involving withholding medical treatment or care from disabled infants. Hopefully, this will lead to increased mutual understanding of respective responsibilities and a narrowing of possible areas of conflict. For example, the Illinois Department of Children and Family Services and state medical organizations agreed that "recommendations" of hospital review committees should be reviewed but not the full "records."⁶² See Section 5.4.

Section 2.1(C) recommends that relevant aspects of state child abuse and neglect reporting laws be included in training or written materials developed for dissemination to hospital personnel, including the basic scheme of the child protective system under state law. "[T]hese laws typically include: a purpose clause, definitions of abuse and neglect, classes of person covered, mandated reporting requirements, protective or emergency custody authority and criteria, responsibilities of child protection agencies, creation of multidisciplinary teams, establishment of central child abuse registries and confidentiality of their records, provision of guardians

ad litem or counsel for the child and counsel for the parents, authorization to take photographs and X-rays of injured children, and abrogation of certain privileged communications."⁶³

The Final Rule explicitly stated that the basic child protective service structure is not changed by the Amendment.⁶⁴ The existence and operation of a designated hospital liaison or a hospital review mechanism does not "enlarge, contract, or amend the applicable legal standards for reporting to child protective services agencies."⁶⁵ In other words, the responsibility under state law of medical professionals, or other persons, to report to the CPS agency is not changed by these hospital mechanisms.

Several reporting duties under state law should be carefully reviewed. First and most important for planning purposes is that the definition of "withholding medically indicated treatment" sets a standard for reporting suspected instances of neglect under the state child abuse and reporting law. See commentary to Section 1.1. Secondly, certain professionals, including physicians and other health professionals, are mandated reporters in every state. If they suspect or have reason to believe that an infant is being neglected, they have a legal duty to report it to the applicable CPS or law enforcement agency. A professional who fails to make a report may be subject to criminal penalties or monetary damages.

Although the majority of states have statutorily created a physician-patient privilege which would ordinarily render communications between doctor and patient privileged from communication to third parties,⁶⁶ most have legislatively abrogated such privileges in child abuse and neglect proceedings.⁶⁷ At least two states enacted legislation in 1985 which makes medical records available to CPS agencies in their investigation following a report of child abuse or neglect.⁶⁸ See Section 5.3 for discussion of medical records and Section 5.2 for discussion of confidentiality.

Third, mandated reporters in all states who report in good faith are immune from any civil or criminal liability which might otherwise be incurred, such as suits for libel, slander, invasion of privacy, or breach of confidentiality. In the large majority⁶⁹ of states, immunity extends to participation in judicial proceedings arising from the reports. Finally, it should be stressed that reports and the records of CPS agencies are confidential under state law.⁷⁰

2.2 Planning with other agencies.

The [CPS agency] shall meet with [the designated state agency] to plan for the provision of case managers for families of infants with disabling conditions and to coordinate available resources. Regional clearinghouses, expected to be established with the most current and complete information regarding medical treatment procedures and community resources for the provision of services and treatment for disabled infants with life-threatening conditions, shall be contacted regularly.

COMMENTARY

Section 4(c)(2)(A)(ii) of the Amendment requires the U.S.

Department of Health and Human Services to create national and regional information and resource clearinghouses. These clearinghouses will provide the most current and complete information regarding medical treatment procedures and service resources for disabled infants with life-threatening conditions.

The Department indicated in the Final Rule that it was then "in the process of determining how best to implement these clearinghouse requirements,"⁷¹ and that once in operation it would inform the health care community, the state CPS agencies, and various consumer groups of procedures for getting access to the information.

The decision by the CPS agency whether to consult with the clearinghouse should be based on the circumstances of each individual case. However, Section 2.2 recommends that the CPS agency identify community and state agencies that provide resources and services to disabled infants and their families in addition to the above mentioned national and regional clearinghouses. Although the CPS agency will not be legally responsible for informing hospitals or parents of these resources, it should be prepared to do so in individual cases as a matter of sound practice.

The CPS specialist involved in any given case should make contact with applicable state agencies (e.g., state department of mental health, state department of developmental disabilities) so that the department providing case management services will itself be in coordination and consultation with CPS in appropriate cases. See Section 7.2.

2.3 Planning with agency attorneys.

The [CPS agency] shall meet with the [District Attorney] to prepare procedures for expedited court filings to obtain: (1) access to medical records, (2) a court ordered independent medical evaluation, (3) an emergency injunction against withholding medically indicated treatment, and (4) a medical treatment order.

COMMENTARY

The bracketed term "District Attorney" reflects state-by-state variations in the office providing legal representation to the CPS agency. Depending on the state, this representation may be provided by in-house child protective service agency counsel or representation through a local, county or state corporation counsel or prosecutor's office.

Because of the possible need to have courts order access to medical records, an independent medical evaluation, or treatment, the attorney representing the agency should be prepared to file appropriate pleadings on short notice.

The CPS agency should contact attorneys providing representation for the agency and plan for emergency action. Written agency policies and procedures should be reviewed.

PART III: INTAKE

3.1 Refer report immediately.

All reports of suspected withholding of medically indi-

cated treatment from disabled infants with life-threatening conditions shall be referred immediately to the CPS specialist.

COMMENTARY

The purpose of intake is to: (1) identify reports of suspected withholding of medically indicated treatment from disabled infants with life-threatening conditions; (2) obtain sufficient information to initiate follow-up investigation; and (3) refer the report immediately to the CPS specialist for follow-up investigation.

These procedures do not require the intake worker to evaluate the sufficiency of the report or reach a decision whether to "accept" the report for investigation. This decision-making is reserved for the CPS specialist.

When a child's life is suspected or believed to be in immediate danger, every state defines the report as an "emergency" and assigns it the highest priority for investigation. These "life-threatening" cases should be referred immediately from intake to experts for evaluation.

Intake workers must be able to identify potential cases covered by the procedures based upon the definitions of "withholding medically indicated treatment" and "disabled infant." See Sections 1.1 and 1.2. Any report which seems to involve a disabled infant, an infant at a neonatal intensive care unit, or parents not consenting to provision of medical treatment or palliative care for an infant, should be referred to the CPS specialist. These decisions to refer a report to the CPS specialist should err on the side of overinclusiveness since the CPS specialist and CPS medical consultant(s) are best able to evaluate such reports. The CPS specialist can transfer the case to other CPS investigators if it is not a case involving the withholding of medically indicated treatment to disabled infants.

3.2 Obtain basic information from reporter.

When a report is made by someone other than the hospital liaison, the intake worker shall first obtain the following basic information from the reporter before referring the call to the CPS specialist, to the extent that this information is known to the reporter:

- A. The name and address of the infant and parents.
- B. The name and address of the hospital where the infant is being treated.
- C. The condition of the infant and in particular information regarding whether the infant may die or suffer harm within the immediate future if medical treatment or appropriate nutrition, hydration or medication is withheld.
- D. The basis of the reporter's suspicion or belief that medically indicated treatment or appropriate nutrition, hydration or medication is being or will be withheld.
- E. The name and the address of the person making the report, the source of their information (first hand or otherwise) and his or her position to have reliable information (nurse on the ward, friend, other affiliation).

F. The names, addresses, and telephone numbers of others who might be able to provide further information about the situation.

COMMENTARY

In order to allow follow-up investigation by the CPS specialist, the intake worker must learn the identity of the infant and the hospital or health care facility.⁷² In addition to this basic information, Section 3.2 requires different types of information gathering based upon the reporter's identity. Reports by the designated hospital liaison should simply be referred to the CPS specialist (see Section 3.1) and no other information is needed. Under this or similar models, designated hospital liaisons may bypass the general CPS intake procedure entirely and report directly to the pre-identified CPS specialist.

Since the laws of many states allow reporters to remain anonymous, the intake worker may not be able to elicit information regarding the reporter's identity or affiliation. Therefore, it is recommended that information in Section 3.2 be obtained in all cases where the reporter is not the designated liaison. In addition, since the reporter may be the only person with first-hand knowledge of the incident, the caller should be told that his or her willingness to be identified and interviewed by the CPS specialist is important. Also the reporter should be asked whether his or her information is based on first-hand observations or has been related to the reporter by others. Even where the report is not anonymous, the reporter may be unavailable to the CPS specialist at preliminary investigation.

PART IV: PRELIMINARY INVESTIGATION

COMMENTARY

This Part, together with Parts V (On-Site Investigation) and VI (Decision-Making), comprises the CPS agency investigation.

The protection of disabled infants with life-threatening conditions from denial of medically indicated treatment or care is the primary goal of the CPS investigation. The investigation is a fact finding process to determine the validity of reported allegations, and to mobilize remedial programs and services for disabled infants.

These procedures permit a considerable degree of flexibility. The preliminary investigation, conducted by the CPS specialist, is the first, and sometimes final, stage of the investigation. This particular investigatory role is not within the usual competence of child protective workers. While investigations of abuse and neglect of children generally require an unusual degree of tact and complex and demanding decision-making, little in that work prepares child protective personnel to grapple with the specialized medical knowledge and distinct social work factors that are the basis of decision-making in these cases. A high degree of training and expertise is required. See discussion at Section 4.6. Due to the relatively small number of reports so far,⁷³ states may choose not to train CPS workers on the local level to handle these

cases. Unless the volume increases, state or regional offices will be able to handle the cases more effectively.

A CPS specialist trained either as a medical social worker or neonatal or pediatric nurse (see Section 1.4), and supported by appropriate consultation with the CPS medical consultant(s) will be able to conduct the assessment involved in the preliminary investigation. Virtually every state surveyed by this project has reported that it will use a medical consultant to help evaluate these reports. Some states also have adopted procedures to refer reports at intake to medical consultants who make the initial assessments.⁷⁴ The knowledge and professional standing of such experts may be a decided advantage in assessing the medical situation and interviewing other physicians.

One disadvantage of using a medical consultant in this capacity is the potential cost of having them respond to reports which may prove to be groundless, particularly where a screening procedure would have revealed that there was either no such infant or no genuine issue of withholding treatment. The incidence of reports ultimately deemed "not indicated" in other categories of reported cases of child abuse and neglect⁷⁵ suggests that a substantial percentage of these cases may also not require protective action. In order to minimize the unnecessary use of the medical consultant(s), the procedures recommend that the CPS specialist conduct the preliminary investigation before the medical consultant is asked to review medical records or conduct interviews.

4.1 Presume emergency time frame.

Normally, the CPS specialist shall conduct a preliminary investigation immediately, and complete it within 24 hours after receipt. However, if after contacts with the hospital liaison, responsible physician, or others as individual cases require, it is clear that the infant's life or health is not in immediate danger, the preliminary investigation may extend to 72 hours.

COMMENTARY

Until reliable information demonstrates that the infant is not in immediate danger, the CPS specialist must presume that the report involves a potentially life-threatening situation to the infant. Therefore, in all cases, the CPS specialist will make immediate contact with the designated hospital liaison (see Section 4.2) and such other contacts as necessary to assess the medical status of the infant (see Section 4.3) within 24 hours. The CPS specialist must respond on a 24-hour, emergency basis because the failure to provide medical treatment or care may result in the death or irreparable harm to the infant within a short period of time. The preliminary investigation may be conducted entirely by telephone.

The first CPS response is to determine the risk of withholding medical treatment or care from the infant, and the consequent time frame necessary for CPS protective action. If it is determined from initial contacts that the infant's life or health is not in immediate danger, then the time frame for the preliminary investigation may be relaxed.

In all instances, the basic steps of the preliminary investigation should be completed within 72 hours. The CPS spe-

cialist should make contacts and obtain information sufficient to assess the infant's status and indications for treatment, determine what parental decisions regarding withholding medical treatment or care have been made and the basis of those decisions, and determine the availability and/or involvement of a hospital review committee.

As noted in Section 6.6(B), a decision may be made to await further developments when the infant's diagnosis is unclear. For example, if a report were received by CPS shortly after the birth of a disabled infant with complex medical problems, then the CPS specialist should request and arrange consultation with the designated hospital liaison or responsible physician when any change in the infant's condition(s) occurs. See Section 6.6(B).

The term "responsible physician" is used in this section and elsewhere in these procedures to identify the physician charged intrastitutionally and legally with medical care responsibility for the infant patient. This term is used to minimize any confusion associated with the terms "treating physician" or "attending physician," which may refer to more than one doctor in a given case. There is only one responsible physician.

4.2 Contact hospital liaison.

The CPS specialist shall telephone the designated hospital liaison immediately to coordinate the preliminary investigation. If the designated hospital liaison is not available, the specialist shall call the office of the chief administrator of the hospital to coordinate the investigation.

COMMENTARY

The first contact should be with the designated hospital liaison. Section 2.1(A). Since the liaison will coordinate the interviews he or she should be available on a 24 hour a day basis. If the designated liaison is not available, the office of the chief administrator of the hospital should be prepared to direct the CPS specialist to the person providing coverage for this function.

This section, along with Section 5.2, requires "coordination and consultation" with the designated hospital liaison to minimize disruption of hospital activities and time and effort expended when a CPS investigation is initiated. The designated liaison should be well-acquainted with the role of the CPS specialist and medical consultant(s) and aware of the informational needs, and applicable state legal standards, of the CPS agency in making determination whether "withholding medically indicated treatment or care" is indicated or not. See Part II.

4.3 Determine status of infant.

If the information is available, the child's status (see Appendix A) shall be determined through the hospital liaison. Otherwise, telephone (or when feasible in-person) interviews with the responsible physician and others involved in treatment shall be arranged as quickly as possi-

ble. In order to make a determination whether medically indicated treatment or appropriate nutrition, hydration and medication is being withheld, all of the questions in Appendix A should be considered fully.

COMMENTARY

Appendix A sets out the information necessary to reach a determination whether the case meets the criteria for "withholding medically indicated treatment or care." It is not meant to function as a checklist, but as a set of standardized open-ended questions that must be considered (among others) to develop this information. Further, to the extent that such basic informational needs can be identified in some standardized form, this format may be useful, as suggested in Part II, in planning and education, and serve to narrow misunderstanding and conflict between the CPS agency and hospital or health care facility.

Appendix A contains the following elements in assessing the infant's condition in terms of "withholding medically indicated treatment or care": (1) the nature of the child's medical condition(s); (2) the proposed treatment; (3) how the infant's course of treatment was selected; (4) whether alternative treatment options were considered; (5) whether physicians other than the primary physician participated in the formulation of the treatment and/or second opinions from other specialists were obtained; (6) whether there was consensus among the treatment providers (e.g., nurses, physicians) with regard to the appropriateness of the treatment; (7) whether parents have refused to consent to any recommended treatment or care; and (8) whether the treatment decisions were reviewed by a hospital review committee or comparable review body.

At the preliminary investigation stage, the designated hospital liaison may be especially useful. For example, reports may be closed as unsubstantiated if the designated hospital liaison reports to the CPS specialist that the infant either named or described in the report is not at that hospital or is not otherwise identifiable. It also should be possible to close an investigation where the hospital liaison supplies information indicating that treatment is being rendered. If the CPS specialist doubts the completeness or accuracy of the hospital liaison's information he or she should, of course, investigate further. However, where there is no doubt that treatment is being provided or is not medically indicated, closing the investigation protects the privacy of the family and spares them unnecessary distress. Assistance with referrals should be offered even in these cases, and whenever it would be helpful. See Part VII.

If the designated hospital liaison informs the CPS agency that the parents have refused to consent to treatment which is immediately needed, then a decision to go to court for a medical treatment order would be indicated. The role of the hospital liaison presumably would be to coordinate and consult with the CPS specialist regarding the possible court appearance of the responsible physician or others involved in treatment.

Once the designated hospital liaison confirms that there is an infant meeting the description in the report at the hospital, then the role of the liaison is to assist the CPS specialist to arrange interviews (as set out in this Part).

Several questions in Appendix A require medical judgment. Seriously ill newborns frequently pose complex medical problems to physicians. There may be a legitimate difference in qualified medical opinion as to what the prognosis is with or without the proposed treatment, if treatment is medically indicated, and how complex, risky, or novel the proposed treatment is. The CPS specialist should always obtain qualified and appropriate medical consultation in dealing with this information.

Once it is determined that to assess the infant's condition interviews must be conducted with the responsible physician, hospital review committee chair or others, the parents should be notified of the agency's duty to conduct an investigation. The CPS specialist and hospital representative should determine if it is more appropriate for the hospital liaison to discuss this with them. At this point the parents' signed consent to allow hospital personnel to discuss the child's medical status and release the infant's medical records is desirable. See Section 5.3 for discussion of confidentiality.

If the CPS specialist meets with difficulties in obtaining access to information at this stage, a court order should be sought immediately to permit the agency to conduct its investigation. See Section 5.4.

4.4 Interview HRC chairperson or designee.

The CPS specialist shall find out whether a hospital review committee exists and whether a HRC meeting has taken place or is planned to review the infant's treatment. As applicable, the CPS specialist shall arrange the earliest possible telephone (or if feasible in-person) interview with the HRC chairperson or designee(s). All questions found in Appendix C should be considered fully.

COMMENTARY

In making the initial contact with the designated hospital liaison, the CPS specialist should ask whether a hospital review committee is available to review treatment in the reported case, whether it has met, and if so, its findings.

Many hospitals will not have a hospital review committee, particularly small or rural hospitals. Normally, infants born with life-threatening conditions or with complex medical problems are transferred to hospitals with special care nurseries. When a child born at such hospitals has not been transferred, the inquiry required in Section 4.3 would apply and the central concern of the CPS specialist should be (1) whether appropriate consultation consistent with "reasonable medical judgment" has been or is being sought (see Section 1.1), and (2) whether immediate action is needed to transfer the infant to an appropriate facility. See Section 4.7.

Specialized treatment centers are more likely to have a formalized review process and available consultation with specialists.⁷⁶ Neonatal intensive care units (NICUs) typically use a team approach. The involvement of several professionals in the care and treatment of a life-threatened infant will increase the likelihood that "reasonable medical judgment" based on appropriate knowledge of the conditions involved will result.

If a hospital review committee exists, the chairperson or

designee should be interviewed. If the HRC exists, but has not met, the CPS specialist should determine whether the infant will be given treatment and care while the review takes place. If the hospital will maintain the status quo, the CPS specialist should confer with the CPS medical consultant and supervisor to decide whether to postpone the CPS investigation until the HRC review occurs. See Section 6.2.

Several factors go into this decision. The most critical is whether the hospital review committee can meet on short notice. An expedited review may be necessary to assure the protection for the infant. In some cases a review may not even occur. For example, in hospitals with a voluntary review system, parental consent or the responsible physician's request may be prerequisites. Other hospitals may have mandatory review of all cases in which withholding life-sustaining treatment is under consideration.⁷⁷

Where appropriate, CPS policy should strongly favor allowing this internal review process to precede court action. Normally, consultations with a hospital review committee will reduce the chance for misperceptions about diagnosis, prognosis and treatment outcomes and can increase the likelihood that decisions to withhold medical treatment or care are informed, reasonable and legal. A review committee meeting may be the parents' best opportunity to hear options, obtain the thoughts of several knowledgeable medical providers and ethicists, and, perhaps, consult with other parents. Also, a hospital committee review may identify non-medical factors, such as concerns about finances and the impact of a disabled infant on siblings, which should be distinct from the medical treatment decision.

The CPS specialist must determine what bearing the HRC meeting has on the resolution of the report. The CPS specialist should always keep in mind that committee composition and functions may vary by hospital. Although recommendations by a hospital review committee, for or against treatment, may be a good indication of what is medically indicated, the CPS specialist cannot assume what a given hospital committee is or what its review entails. The CPS specialist must know what information was provided to the HRC (other than the patient's medical record) and the process followed by the committee. Using the questions in Appendix C, the CPS specialist should interview the chairperson or designee of the hospital review committee and decide (1) whether the review provided an opportunity for consultation consistent with the terms of "reasonable medical judgment," and (2) whether the review provided a means for the parents to give informed consent to the treatment decision.

Depending on the committee model used and the case under consideration, the HRC review could result in a specific recommendation, a report delineating a range of choices and the committee's thinking, or a discussion of the issues in a case. Each consultation may result in a single recommendation, or as the case evolves, a series of interactions between the committee and the physicians and parents. Moreover, if the HRC's recommendation is merely a one-line notation in the patient's medical records, the CPS agency can give little weight to that recommendation as it assesses (1) reasonable medical judgment, and (2) parental understanding and the "informed" nature of their refusal to consent to treatment or care. In contrast, when the CPS agency can see

that the HRC employed good decision-making practices, it is more likely to endorse the recommendation of that committee. Ultimately, the CPS agency is charged with responsibility for reaching its own determination.

The composition and function of the committee will have important implications for the CPS preliminary investigation. Some committee reviews may be formal and involve the full committee; others may be informal and involve only one or two members. Therefore, "committee review" in a given case may only involve a single person, who is not even a physician.

In some hospitals, parents may be excluded from a committee meeting. For example, a prognostic committee may consist of doctors and have a narrowly defined role of assisting medical personnel in performing their jobs. It may not be intended to help the principal decision-makers, the parents. Other committees may permit parents to participate. As a result, parents will be better able to give informed consent to any given treatment decision, and the CPS specialist may focus upon other issues.

The standards adopted by hospitals for review committees are likely to vary. Although the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, U.S. Department of Health and Human Services, and American Academy of Pediatrics all call explicitly for the development of written institutional guidelines regarding withholding (or withdrawing, as applicable) of life-sustaining treatment from disabled infants,⁷⁸ there is no law or regulation that mandates such guidelines or standards for individual hospitals. Few hospitals have policy even on such crucial matters as "do not resuscitate" orders.⁷⁹ Thus, there is no assurance of relatively uniform results among thousands of hospitals or that recommendations will be consistent with the standards enunciated in the definition of "withholding medically indicated treatment."⁸⁰

4.5 Interview reporter.

The CPS specialist shall interview the person, if this person is known and available, who made the initial report to the child protective service agency intake unit. In addition to the information obtained at intake, the CPS specialist shall inquire about other relevant information consistent with Appendices A, B, and C.

COMMENTARY

After initial contacts have been made by the CPS specialist with the designated hospital liaison, responsible physician and others as indicated, the person who made the initial report shall be interviewed. This will be possible only when the reporter did not exercise the right to remain anonymous.

Once initial contacts have been made the preliminary investigation should reconcile contradictory information. If the reporter has first hand knowledge of treatment decisions, especially when the reporter is a medically trained person such as a nurse, normally it will be beneficial to arrange for an interview with the CPS medical consultant. Also, reports in which an infant subject cannot be identified should be discussed with the reporter. It is good policy to inform the

reporter of the findings of the investigation in cases in which the report is plainly "not indicated."⁸¹ This is to relieve the concern of the reporter for the safety of the infant, and also demonstrate the concern and responsiveness of the agency to the report. State law may control whether such feedback is permitted.

4.6 Interview parent(s).

The CPS specialist shall obtain information regarding the parent(s)' treatment decisions. The information sought in Appendix B should be considered fully. The CPS specialist shall determine whether and at what time to interview the parent(s) after consulting with the hospital social worker or other person with counseling responsibility. Telephone (or if feasible in-person) interviews with the parent(s) shall be conducted where indicated.

COMMENTARY

The intervention by the child protective service system into an emotionally charged situation, in which the parents may already be dealing with a medical specialist(s), medical nursing staff, social work(ers) and clergy, is a delicate process. In its role as protector of the infant's best interest, the CPS agency should be committed to "do no harm" to the significant relationships involved: the parent-child, the doctor-patient, doctor-family and hospital-family.

This section seeks to balance the legal duty of the CPS agency to protect disabled infants against inappropriate medical decisions and the right of the family to be free of unnecessary or harmful governmental intrusions. No single statement or procedure can provide for all possible situations. An absolute rule that parents should be interviewed immediately is inadvisable, since in some cases initial contacts with others will reveal that the report is unfounded, or is not indicated. Therefore, parents should not be interviewed as part of every preliminary investigation. See Sections 4.3 & 4.7. Reports should first be screened by the CPS specialist to determine whether there is any purpose in an interview. Then, the hospital social worker or other person(s) responsible for counseling parents of newborn disabled infants should be consulted before arranging the interview.

Timing of the interview should be decided in consultation with social work or other counseling support for the parents. For example, when an infant is not in any immediate danger, and a hospital review committee is about to meet, the CPS interview might await this process. See Section 6.2. Or, if it has been determined that an on-site investigation should be initiated immediately, then the CPS specialist with the CPS medical consultant should consider interviewing parent(s) later.

Appendix B sets out a series of open-ended questions. These may be used to help to gather information necessary to assess whether the parent(s)' refusal to consent to treatment is an informed decision. It cannot be assumed that parents have been provided with accurate information regarding the current medical condition of the infant, the infant's developmental potential and capabilities and concrete actions that can be taken to assist the infant's growth and development. Nor

should it be assumed that a parent will be able to make informed decisions without appropriate support and guidance. The questions in Appendix B explore both the parental/doctor communication and the quality of the parent(s)' informed refusal to consent to treatment. Specifically, the questions look at: 1) whether parent(s) fully understand the medical condition of their child; 2) what treatment options have been presented to them; 3) whether a second opinion (including appropriate expert consultation) was sought and obtained; 4) what opportunity parent(s) have had to participate in a hospital review process (if available); and 5) what psycho-social counseling and support has been made or is available to them. Parental decision-making should be discussed first-hand, during an appropriately timed interview with the parents.

The CPS examination should scrutinize closely parental decisions to withhold medically indicated treatment made too quickly and without the necessary "reasonable medical judgment." Parental decisions to withhold medical treatment or care made in the first few days after birth raise special concern that the decision was made too quickly or without adequate review, especially where the infant involved is not in a hospital with a neonatal intensive care unit.⁸²

Parents are particularly vulnerable in the period following the birth of a disabled infant. It is at this time, when parents are in a state of psychological and emotional crisis, that they often are asked to assimilate extremely complex medical information and confronted with a life or death decision of whether to withhold treatment or care from their newborn disabled infant.⁸³ "[T]here is almost always an initial phase of severe shock lasting days to months."⁸⁴ During this period the mother is recuperating from childbirth and often receiving medication or other medical treatment.

Physicians disagree whether parents can make an informed decision regarding life or death within hours or days after the birth of a disabled infant. Many physicians believe parents, if properly informed, are able to understand and make reasonable decisions.⁸⁵ Other physicians believe that parents are often too upset to understand the nature of the options presented to them.⁸⁶ As a result of psychological and emotional trauma that generally surrounds the birth of a handicapped infant, they are unable to assimilate properly the information which is provided about the infant's condition or to exercise rational judgment concerning a decision to withhold treatment presented by a physician.⁸⁷

Parental support is addressed in the provisions of Section 7.2, *Coordination with Resource Clearinghouses*. In cooperation with the State's designated Protection and Advocacy Agency and other appropriate public or private groups, the CPS specialist should encourage the parents of the infant to consult with parent support groups or other organizations that include parents of children with disabilities, and should provide parents with information and referral concerning financial, counseling, medical, educational, adoption and other resources.

The CPS specialist also should make appropriate consultation with the agency medical consultant(s). The CPS medical consultant(s) should be made available to consult with the parent(s), responsible physician and/or hospital review committee, should they desire. Such a meeting may provide the

clearest assurance of parental understanding of the infant's condition(s) and treatment options.

4.7 Decide upon CPS action.

The CPS specialist should be prepared to decide upon necessary CPS action (see Part VI) at any time during the preliminary investigation, using appropriate consultation with the CPS medical consultant and supervisor.

COMMENTARY

As the language in this section indicates, decision-making during the preliminary investigation should be a fluid process. At all times the condition of the infant is the paramount concern in CPS agency decision-making and to a large extent will dictate the timing and flexibility of CPS action. The preliminary investigation is a fact gathering process. It should lead to one of several decisions in a very rapid manner: (1) identifying cases which require immediate protective action by CPS, such as seeking court action to obtain access to records or for a medical treatment order; (2) closing investigations which, based on an initial inquiry, are clearly not indicated; or (3) taking action to gain additional information, such as initiating an on-site investigation involving the CPS medical consultant(s), seeking an independent medical evaluation, or monitoring developments in the infant's conditions.

PART V: ON-SITE INVESTIGATION

5.1 Complete on-site investigation within 48 hours.

After a decision has been reached to initiate an on-site investigation (see Section 6.6), it shall be undertaken and completed in the shortest possible time appropriate and in any event all steps in Sections 5.2 - 5.5 (as applicable in a given case) should be completed within 48 hours.

COMMENTARY

The on-site investigation begins by coordinating and consulting with the designated hospital liaison and hospital social worker (Section 5.2), scheduling interviews with the medical professionals involved in treatment of the infant (Section 5.3), and interviewing the parent(s) (Section 5.5).

After a determination to conduct an on-site investigation has been made pursuant to Section 6.6, medical information and records will be reviewed by the independent medical consultant(s) working with the CPS agency. See Section 1.5.

Financial resources, the availability of qualified specialists locally or regionally to serve as consultants, and the cooperation of the medical community will bear on achieving an effective on-site investigation within this short time frame.

In some cases it may be necessary for the CPS medical consultant to conduct interviews with the responsible physician, and others, by telephone. In appropriate cases, arrangements may be made to deliver the pertinent records by mail or by hand when an on-site investigation is infeasible.

5.2 Coordinate investigation.

The CPS specialist and medical consultant shall contact the designated hospital liaison prior to initiating an on-site investigation. The CPS specialist shall consult with [hospital social service personnel] before interviewing the parent(s). The CPS specialist should attempt to obtain releases from the parent(s) to allow voluntary release of information to CPS personnel. At this time, the CPS medical consultant shall schedule interviews with medical personnel and HRC members, and schedule a review of the medical records.

COMMENTARY

The role of the designated hospital liaison in coordinating and consulting with the CPS specialist is discussed in full at Section 4.2 and in Part II: Planning. The CPS specialist should attempt to contact the designated hospital liaison to coordinate, to the extent possible, the necessary interviews and review of records before initiating the on-site investigation.

The CPS specialist should also use the hospital liaison to coordinate with the hospital social service unit, counseling department or whomever may be providing counseling services to the parents. See Section 4.6. The on site investigation requires interviews of medical personnel and a review of medical records. Some of this may involve information protected by state confidentiality laws. Parent(s) should be asked for consent to conduct these interviews and review medical records. Depending on the circumstances, it may be preferable for the hospital social worker or the designated hospital liaison to ask parents to authorize release of information. Some states may not require this consent in a child neglect investigation.⁸⁸ See Section 5.3.

If parental consent is not obtained and the individual from whom information is sought did not report under the state abuse and neglect statute, then he or she may violate the confidentiality of the patient by sharing information. In such instances the CPS specialist may still seek court orders to obtain this information. See Section 5.4.

5.3 Interview medical personnel and review medical records.

The medical consultant shall verify, or when necessary obtain for the first time, the information set forth in the procedure on preliminary investigations (Appendices A and C). As is necessary, the medical consultant shall:

- A. Interview the responsible physician and any other persons involved in treatment.
- B. Interview the hospital review committee (HRC) chairperson or designee(s).
- C. Interview any medical consultant who has been involved.
- D. Review medical records [including HRC records as available under state law].

COMMENTARY

The CPS medical consultant's role in conducting the on-

site investigation is to review the medical information, and make an independent evaluation whether the case involves withholding of medically indicated treatment or care. In performing this role, the CPS medical consultant will interview the medical professionals involved in the treatment of the infant including consultants, and the HRC chairperson or designee. The CPS medical consultant will review the medical records of the infant, and provide consultation with the CPS specialist and supervisor in making decisions regarding CPS action. All the matters raised in the questions in Appendices A and C should be adequately answered in the investigation. Consultation with appropriate specialists should be made as the case indicates. See Section 1.6 for discussion.

Medical records will be reviewed by the CPS medical consultant whenever the preliminary investigation has determined that more information is needed to reach a final CPS disposition. See Section 6.6. While the Final Rule requires states to have procedures to provide access to medical records, it does not require a review of records in every investigation. Such review should occur when it "is necessary to assure an appropriate investigation of a report of medical neglect."⁸⁹ Nonetheless, several states have provided for review of medical records as part of every investigation.⁹⁰

Records, if properly maintained, are the most objective data available. Interviews by themselves may be misleading, if persons alter, omit, or embellish facts. Also, records may reveal contrary views expressed by nurses, doctors and others. The medical records should provide documentary evidence of the course of the patient's medical evaluation, treatment, and change in condition, and of communication between the responsible physician and any other health professional contributing to the patient's care.⁹¹ The infant's medical record should specifically contain: (1) identification information; (2) evidence of appropriate informed consent or indication of why it is absent and what is being done to obtain the necessary consent; (3) patient's medical history; (4) report of patient's physical examination; (5) diagnostic and therapeutic orders; (6) observations of patient condition, including progress notes and nursing notes; (7) report of all procedures, tests, and their results; and (8) conclusions, including the provisional diagnosis, associated diagnoses, clinical resume, and necropsy reports.⁹²

An infant's medical records may include findings of the Hospital Review Committee. A separate record of such review proceedings may also exist. Where a record is kept it may be in the form of tape recordings, transcripts, minutes, summaries, or notes in the medical record and kept in accordance with institutional policies on confidentiality of medical information.

Since these committees are a relatively new phenomenon, there is little statutory or case law to indicate whether these records are privileged. If the committee process involves primarily a patient/physician relationship, then statutes which waive the physician-patient privilege inuring to the infant's parents in child neglect matters would apply to hospital review committee records.

If the committee functions as an administrative committee, however, its records could be considered confidential. A determination whether such statutory provisions are broad

enough to cover the activities of a hospital review committee charged with reviewing decisions to forego life-sustaining treatment for disabled infants may depend on state legislation and court decisions.

Little guidance is available on the confidentiality issue. A *Model Bill to Establish Hospital Ethics Committees* in the President's Commission Report⁹³ provides that the committee's minutes and recommendations should be discoverable and otherwise made available to the courts. The committee must submit its "case record," which includes "the patient's medical record, a summary of the opinions of consulting physicians, the hospital ethics committee meeting minutes, and the hospital ethics committee's written recommendation."

By statute, Arizona limits court discovery to the "recommendations" of the committee.⁹⁴ Illinois has, as a matter of policy, limited discovery to the recommendations of the committee and not the hospital review committee records or testimony.⁹⁵ The U.S. Department of Health and Human Services Model Guidelines recommend that hospital review committee records be kept in accordance with institutional policies on confidentiality and be made available to "appropriate government agencies, or upon court order, or as otherwise required by law."⁹⁶

5.4 Seek court action to obtain access to information.

If the CPS specialist or medical consultant encounters difficulties gaining access to the hospital or its pertinent records, the CPS specialist shall immediately seek the assistance of the [District Attorney] to obtain a court order directing such access.

COMMENTARY

The Final Rule requires that procedures provide, consistent with state law, "access to medical records and/or other pertinent information when such access is necessary to assure an appropriate investigation of a report of medical neglect."⁹⁷

Voluntary cooperation of the parent(s) and hospital personnel should always be sought. The CPS specialist should request that parents sign a release for relevant medical records. If the parents refuse to sign the release, the matter should be immediately referred for legal action under this section. Issues regarding confidentiality⁹⁸ and release of medical information and records should be familiar to hospital liaisons and others so that unnecessary conflict, litigation⁹⁹ and delay is avoided. See Section 2.2.

In most instances going to court under an expedited procedure will produce the quickest response where records or information is withheld. While a few states permit child protective service agencies to review medical records without a court order,¹⁰⁰ in most, access will be gained incident to the filing of a petition in court. A medical neglect petition may be required to provide the court with underlying jurisdiction before it can issue orders for and receive records.¹⁰¹

The decision to file such a petition to obtain a court order should be made jointly by the CPS supervisor and agency attorney. See Section 2.3.

5.5 Interview parent(s).

If they have not previously been interviewed, the CPS specialist shall interview the parent(s), and fully explore and discuss the questions found in Appendix B.

COMMENTARY

Unlike a preliminary investigation, the on-site investigation will always call for an interview with the parent(s). At this point a preliminary assessment has already revealed that there is a factual basis for seeking further information regarding parental non-consent to medically indicated treatment or care. The CPS specialist should discuss with the parent(s) the CPS report and the nature of the investigation, and determine their views and the answers to the questions found in Appendix B. See Section 4.6 for discussion.

PART VI: DECISION-MAKING

6.1 Make decision based on consultation.

A decision to seek informal resolution, court ordered treatment or additional information, refer a case involving an infant death, or to close a case which is not indicated (Sections 6.2 - 6.5), shall be made by the CPS specialist in consultation with the CPS medical consultant(s) and CPS supervisor.

It may be necessary to reach one of these decisions prior to the conclusion of a preliminary or an on-site investigation.

COMMENTARY

The CPS specialist should consult with the CPS supervisor before reaching any of the decisions set out in this Part. In addition, consultation with the CPS medical consultant should be sought whenever the medical assessment of the infant's condition is at issue during the preliminary investigation. With a medical social work or neonatal nursing (see Section 1.4) background, the CPS specialist has the training and experience to determine when consultation with the CPS medical consultant is indicated.

The CPS medical consultant(s) can advise the CPS specialist and supervisor when "withholding of medically indicated treatment or care" is involved in the reported case. Medical experts should be consulted as-needed.

However, it is the CPS specialist who is responsible for making the recommendation of "indicated" or "not indicated," based upon the CPS medical consultant's judgment and other facts of the report. The functions of the medical consultant(s) will be advisory. The medical consultant(s) who are not agency employees will not have authority to make the final decision about the care of infants, the activities of the CPS agency, or any interpretation of the law.

6.2 Pursue informal resolution.

When it has been determined that medically indicated

treatment or palliative care is being or will be withheld, the CPS specialist shall decide whether to seek informal resolution of the matter. The primary factor in such a decision is whether the infant is being sustained while efforts to obtain parental consent are being pursued. Other factors to be considered are: (1) the availability of a hospital review process that has not yet taken place, and (2) parental opportunities for appropriate medical consultation, counseling and/or education which have not been explored and offer some likelihood of leading to parental consent to medically indicated treatment.

Whenever possible, the specialist shall arrange a meeting with the parent(s) and responsible physician to explain why CPS arrived at its decision, share relevant information and ask the parent(s) to reevaluate the situation. If the parents consider themselves unable to raise the infant, the CPS specialist shall provide information regarding the availability of adoptive placements and referral to appropriate agencies.

COMMENTARY

This section and Section 6.3 describe the appropriate CPS actions once the report is indicated (or "substantiated"). The condition of the infant is the primary basis of the CPS response. When it is determined that a report involves a violation of the standard of "withholding medically indicated treatment," then the first concern in deciding the appropriate agency response, including immediate court action if necessary, is the immediacy of risk to the infant.

This section provides that informal (non-judicial) resolution should be pursued whenever the CPS specialist is assured that the infant's life or health is not in immediate danger. This assurance must include a commitment by the parent(s) and responsible physician and hospital that the infant will be sustained and any actions necessary to prevent the worsening of the infant's condition will be taken while efforts to obtain parental consent are pursued. A policy for providing this kind of protection to the infant has been recommended by the President's Commission,¹⁰² the HHS Model Guidelines,¹⁰³ and the American Academy of Pediatrics' Guidelines.¹⁰⁴

Where the infant's condition permits, informal resolution is preferred over court action. In any case where reconsideration by the parents would appear to be helpful it should be pursued.

As discussed at Section 4.6, where parent(s) have reached a nontreatment decision the CPS specialist should determine whether the parents received all relevant information, understand the medical options for their child, and have had appropriate counseling support. In making a decision to pursue informal resolution a critical consideration is the nature of the parent(s) "informed consent" in reaching a nontreatment decision.

In order to make a proper decision, parents may need psycho-social counseling, education, an opportunity to talk with other parents of disabled children, consultation with medical specialists, and feedback from the hospital review committee. The CPS specialist should consult with the parents' hospital counselor, who is often a social worker, to

assess the parent(s)' need for such information and services.¹⁰⁵

An available hospital review committee offers one safeguard against decisions made hastily and without full consideration. It often offers most of the above resources in their "model" forms, and may offer the most comprehensive form of additional information and consultation to the parents. (Possible functions of Hospital Review Committees are discussed more fully at Section 4.4.) When the CPS specialist is informed that parents may participate in a future committee meeting, court actions where feasible should be deferred to await that process.

6.3 Seek court action.

If it is determined that medically indicated treatment or palliative care is being or will be withheld, and (1) the child's condition requires an urgent response, or (2) efforts by CPS or hospital personnel to obtain parental consent to treatment would be futile or already have failed, then the matter shall be brought to court under a [medical treatment] petition. In all cases, the CPS specialist shall notify parent(s) and the responsible physician of the decision on court action. The CPS specialist shall immediately contact the [District Attorney] after such a decision is reached.

COMMENTARY

Court action should be sought whenever necessary to protect the health or life of the infant, including the situation under Section 6.2 where informal resolution has failed. It is recommended elsewhere (see Section 2.3) that based on existing state law, the CPS agency develop expedited procedures to seek court ordered treatment. In some states, an action for custody must be filed to establish court jurisdiction to provide such an order for medical treatment or care.

The CPS specialist should notify the parents and responsible physician as soon as possible after a determination to seek a court order for treatment has been reached. Such notification may lead to a decision at the hospital for interim treatment of the infant. The hospital may have policy to maintain the status quo and to take any possible action to prevent the worsening of the infant's condition while legal proceedings are in progress.

6.4 Refer reports of infant death.

In cases in which the infant has died before the investigation is completed, and the CPS specialist has reason to suspect that medically indicated treatment or palliative care was withheld, the matter shall be referred to the [special investigative unit dealing with child deaths].

COMMENTARY

Existing state laws require that specified persons or officials who have reasonable cause to suspect that a child died as a result of child abuse report that fact to the coroner or

medical examiner.¹⁰⁶ Consistent with existing state laws, this Section provides that such referrals be made to the “[special investigative unit dealing with child deaths].”

Although states vary as to their reporting requirements of infant deaths, the CPS specialist and/or other CPS personnel should forward the investigative findings with the report.

6.5 Close cases where report not indicated.

If it is determined that treatment is not medically indicated, or that medically indicated treatment has not been and will not be withheld, then the report shall be deemed [not indicated] and the case closed.

COMMENTARY

At any point during a preliminary or on-site investigation the CPS specialist, with appropriate consultation, may close a case that does not involve the “withholding of medically indicated treatment or care” from a disabled infant. Such reports may be deemed “unfounded,” “not indicated” or “unsubstantiated,” depending on state terminology.

Cases should be closed whenever it is determined that the infant in question is not seriously ill, the appropriate treatment is being rendered, or, as defined by the definitional standard, treatment is not medically indicated. Cases in which parent(s) initially refuse to consent to medically indicated treatment or care, but then provide consent to treatment, should be deemed “not indicated” when treatment is provided.

In all cases, even minimal CPS involvement must be considered to have potential negative impact on the family. Whenever the investigation results in a determination that agency action is “not indicated,” the parents and responsible physician should be immediately notified of that decision.

Depending on the circumstances, such notice may be provided through the designated hospital liaison. If this decision is reached while the CPS specialist is still on-site at the hospital, the CPS specialist should personally provide this notification. Otherwise, this notice should be given through an immediate phone call and follow-up letter.

6.6 Seek additional information where needed.

Where it is determined that there is not sufficient information to reach one of the above conclusions (Sections 6.2, 6.3, 6.4 or 6.5), then the CPS specialist may:

- A. Initiate an on-site investigation with the medical consultant.**
- B. Monitor developments in the infant’s condition until a conclusion is reached in cases where a decision will have to await further developments in the infant’s condition.**
- C. Seek an independent medical evaluation with appropriate experts. The CPS specialist shall recommend to the parent(s) that an independent medical evaluation be performed if it is necessary to resolve the matter. If the parent(s) do not consent, the specialist will seek a**

court order to obtain an independent medical evaluation.

- D. Take other action deemed appropriate.**

COMMENTARY

Subsection 6.6A provides that an on-site investigation will be initiated by the CPS specialist whenever it is necessary to gain additional information. This decision may be made at the outset of the preliminary investigation, but usually will be made after its completion. The decision to seek an on-site investigation is also discussed in Sections 4.1 and 4.7.

When a report has been received but it is too early to reach a diagnosis of the infant’s condition(s), Subsection 6.6B requires the CPS specialist, in consultation with CPS medical consultant(s) and the CPS supervisor, to await further developments in the infant’s condition(s). The CPS specialist should also request and arrange consultation with the designated hospital liaison or responsible physician when any change in the infant’s condition(s) occurs.

The Final Rule mandates that, consistent with state law, a court order should be obtained for an independent medical examination of the infant when necessary to assure an appropriate resolution of the report.¹⁰⁷ The Final Rule explains that, “although these actions will not be needed in every investigation of reported medical neglect, the specific identification of these procedures for use by agency staff increases the protections for disabled infants.”¹⁰⁸

The need for an independent medical examination should be determined on a case-by-case basis. It is more likely that an independent medical exam will be warranted in a case that arises in a hospital without a neonatal intensive care unit for infants, particularly in small or rural hospitals that have less experience with severely impaired newborns. In cases arising in hospitals with neonatal intensive care units, there usually would be available several consultants to confirm a diagnosis and advise on treatment, and it is more likely that the case will present a medical treatment and ethics dilemma rather than a need for further medical evaluation.

If an independent medical examination is warranted, every effort should be made to obtain it voluntarily. The CPS specialist (and/or medical consultant) should consult with the responsible physician regarding the CPS decision to seek an independent evaluation. The CPS specialist, in consultation with the hospital social worker (see Sections 4.6 and 5.5), shall recommend to the parent(s) that an independent medical evaluation be performed if it is necessary to resolve the matter. If the parent(s) do not consent, the specialist will seek a court order to obtain an independent medical evaluation, pursuant to Section 5.4. Depending on the circumstances, the CPS medical consultant may conduct the independent exam.

PART VII: FOLLOW-UP

7.1 Monitor court ordered treatment.

Where either the court has ordered or the parent(s) have agreed upon a course of treatment, the CPS agency shall assure that the case is monitored. Where there is a

failure to provide treatment, the CPS specialist or other CPS personnel shall notify the court and immediately petition the court to take appropriate action.

COMMENTARY

This section directs the CPS agency to monitor the provision of treatment. When it has been agreed to by the parents, the CPS agency may monitor the situation through telephone contacts with the designated hospital liaison, responsible physician and/or parent(s). If the parents do not follow-through with the agreed treatment or care, then the matter would be brought to court under Section 6.4.

When treatment is to be provided pursuant to a court order, the monitoring role of the CPS agency is likely to be determined by the court, and may be narrowly defined. Court decisions in medical neglect cases generally require the minimum amount of interference with the parent-child relationship needed to assure that the child receives necessary treatment.¹⁰⁹ Courts rarely will take physical custody or even full legal custody away from parents. In cases involving parental refusal to consent to treatment, the court is likely to issue an order under its authority or appoint a special guardian for the sole purpose of consenting to medical treatment.¹¹⁰

Courts generally will monitor these cases by requiring periodic reports, normally from the CPS agency. This section provides for immediate notice to the court when there is a failure of compliance for any reason.

Compliance problems may be anticipated and resolved without returning to court. For example, certain physicians or hospital staff may refuse to comply with a court order for treatment because the order is inconsistent with or contradicts their view of medical ethics or accepted standards of medical practice. This situation may be foreseeable through court testimony or interviews performed in the CPS investigation. It would be preferable, prior to entering the court order, for the CPS specialist or other personnel to explore with the parent(s) the transfer of the patient to another physician or facility so that court-ordered treatment will occur without further delays or court action. If this situation occurs after entry of an order, transfer options still should be reviewed. In that way, the focus would remain on meeting the infant's needs, rather than upon a conflict with a hospital or its staff.

The CPS agency should monitor the situation when the treatment agreed to or ordered involves multiple medical treatments and/or surgical procedures over a period of time that are designed to ameliorate or correct a life-threatening condition. When a course of treatment has been agreed to, the agency should monitor the situation until it is no longer concerned with compliance. The court also may determine the role of the agency when an order for more than one medical treatment or procedure is involved.

The CPS specialist or other CPS personnel may monitor these cases. The CPS specialist and medical consultant should be consulted when changes in the infant's condition require reevaluation of treatment options. When these developments occur, the conclusions of the report and CPS agency's involvement in the case may change correspondingly.

7.2 Coordinate with resource clearinghouses.

The CPS specialist or other appropriate CPS personnel shall contact agencies (referred to in Section 2.2) that provide services to children with special needs.

The CPS specialist shall consult with the [state agency providing case management services to families with children with special needs] to assist the parent(s) with referrals to appropriate agencies which provide services for infants with similar disabilities and for their families, and to agencies with financial resources for costs of medical and rehabilitative services. Information shall be provided regarding parental support groups and community educational resources. This information shall be made available, as is deemed appropriate under the circumstances, whether the CPS agency has taken legal action or not.

COMMENTARY

The CPS agency should help coordinate state agencies that provide case management services and organizations that provide resources for the parents. Although the CPS agency is not legally required to perform this role, and it may be one of several organizations capable of doing so, the CPS agency should make certain that this important linkage is made.

Coordination may already be assured at this point. In planning activities, the CPS agency will have identified the state agency that provides case management services. See Section 2.2. During the investigative interview, the CPS specialist usually will coordinate with the hospital social service or counseling department and ask parent(s) about their awareness of these services.

In cooperation with the state agency and the hospital social worker or counselor, the CPS agency should encourage the parent(s) to consult with a parent support group or other organization that includes parents of children with disabilities. It should also provide parents with information concerning financial, counseling, medical, and educational services and other resources for people with disabilities and their families. This information shall be made available, as is deemed appropriate under the circumstances, whether the CPS agency has taken legal action or not. The CPS agency need not perform this function if another agency, or the hospital, is already assisting the parents.

The hospital review committee may be another source of information. The HHS Model Guidelines recommend that the hospital review committee act as a resource to hospital personnel and families of disabled infants with life-threatening conditions "to provide current and complete information concerning medical treatment procedures and resources in the hospital"¹¹¹ and referral hospitals. The Model Guidelines also provide that the hospital review committee should act as a resource concerning community services which may be needed for the "provision of services and treatment" for disabled infants, including the following: (1) available national and regional information and resource clearinghouses; (2) facilities and agencies in the community that provide treatment and services, such as rehabilitative services and ongoing services; and (3) community public and private programs that provide counseling, support, and adoptive placement counseling and services.

The Final Rule called attention to national clearinghouses, specifically, the computer network being developed by the John F. Kennedy Institute in Baltimore. This nationwide network for the developmentally disabled may make it possible "for the physician, parents, or care-givers of a developmentally disabled individual to query a single source for information about that disability and pinpoint the best or most appropriate places to get help anywhere in the country for that individual." Another more consumer-oriented example is a statewide system operating in South Carolina. The system carries information on access to care and community support services within the state through a toll-free "800" number. Plans are underway to expand the system to seven other states in the region, and hopefully to extend the system nationally.

7.3 Terminate CPS involvement.

If CPS action in response to the report is deemed not

indicated (Section 6.5), or if treatment has voluntarily been provided or is provided pursuant to a court order, CPS shall terminate its case involvement.

Where long term follow-up treatment is indicated, CPS shall terminate its case involvement when it is satisfied that medically indicated treatment will be provided.

COMMENTARY

If agency action is deemed not indicated (See Section 6.5 for discussion), or where medically indicated treatment has been provided and the steps set-out in Sections 7.1 and 7.2 have been completed, CPS agency involvement should end. See also Section 4.7.

Where the infant will require long-term treatment and the agency believes the parents will comply with the accepted treatment plan, the agency should conclude its involvement. A case may be re-opened later if warranted by other or unexpected developments.

APPENDIX A

INFORMATION NEEDED FOR CPS ASSESSMENT OF CHILD'S STATUS

- Is the child at the hospital?
- What is the child's age?
- What are the child's diagnoses?
- Is the child's life endangered?
- What is the life or health-threatening problem requiring treatment?
- Are immediate actions necessary to keep the child alive?
- Has withholding of life-sustaining treatment been recommended?
- Has withholding of life-sustaining treatment been implemented?
- Have the parents refused consent to life-sustaining treatment?
- Will the hospital choose to sustain life-supporting care for the immediate future (24 to 72) hours while the CPS investigation is underway?
- Is sustenance (food or water, whether given orally or through an intravenous or nasogastric tube) or medication being denied?
- If so, on what basis?
- What, precisely, is the treatment (necessary for the child's life or health) that is being denied?
- What treatment or sustenance, if any, is being provided the child?
- How certain are the medical diagnoses among the treatment team?
- Is there unanimity among treating physicians and consultants about treatment and diagnosis?
- Have there been any other opinions, and what are they?
- Who has been consulted and what are their qualifications?
- What are the conclusions of the consultants?
- If there has been consultation, did it include an examination of the child?
- Who has discussed the case with the parents?
- What are the proposed treatments?
- Who has proposed them?
- What is the prognosis without the proposed treatments?
- What is the prognosis with the proposed treatments?
- What is the complexity, risk and novelty of the proposed treatments?
- What is the clarity of professional opinion as to what is standard and accepted practice?
- Has a hospital review process taken place?
- What was the review process?
- What were its recommendations?
- Is treatment medically indicated?
- Who, if anyone, has concluded that:
 - the child is irreversibly and chronically comatose?
 - the provision of such treatment would merely prolong dying, 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?

APPENDIX B

INFORMATION NEEDED TO ASSESS PARENTAL DECISION-MAKING

- Is there one or two parents of record?
- If two, do they agree on the course of action to be followed?
- Has the responsible physician recommended treatment for which the parent(s) have refused consent?
- Were the parent(s) presented with all treatment options?
- Was information about treatment options and the prognosis of the child withheld from the parent(s) or presented to them in an incomplete form or in a misleadingly pessimistic light?
- Did the parent(s) understand the information?
- What was the nature and degree of parental involvement in the decision to deny treatment or sustenance?
- What is the parent(s)' view of the child's problems?
- What are the parent(s)' major concerns for their child?
- Do the parent(s) feel that they are being asked to consent to treatment which is inhumane?
- What is the basis of the parent(s)' refusal to consent to treatment?
- Have appropriate counseling services been made available to them?
- Were the parent(s) provided information to facilitate access to services furnished by parent support groups, and public and private agencies concerned with resources for disabled persons and their families?
- Were the parent(s) provided an opportunity to speak with other parents of children with similar conditions?
- Did the parent(s) participate in or have access to the results of the hospital review process?
- Would the parent(s) agree to consultation with the hospital review committee?
- If they will not agree to treatment, are the parents likely to relinquish custody of the child?

APPENDIX C

INFORMATION NEEDED TO ASSESS HOSPITAL REVIEW COMMITTEE ACTIONS

- Is there a hospital review committee?
- Did the HRC verify the diagnosis?
- Were all the facts explained to the parent(s)?
- Were alternatives explored with the parent(s)?
- Did the parent(s) appear at the meeting and have the opportunity to articulate their objections about treatment before the committee?
- Were all the relevant 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 any significant disagreement among committee members (and/or medical staff)? What was this disagreement?
- Was the committee recommendation consistent with the terms of "withholding of medically indicated treatment"?

FOOTNOTES:

1. Child Abuse Amendments of 1984, Pub. L. No. 98-457, tit. 1, secs. 121-28, 98 Stat. 1749, 1752-55 (codified at 42 U.S.C.A. §§5101-5103 (Supp. 1985)) (hereinafter cited as *Amendment*).
2. U.S. Dept. of Health and Human Services, Off. of Human Dev. Services, *Child Abuse and Neglect Prevention and Treatment Program*, 50 Fed. Reg. 14,878 (April 15, 1985) codified at 45 C.F.R. §1340.5 (c)(1) (hereinafter cited as *Final Rule*).
3. *Id.* at 14,888.
4. Shaw, "Dilemmas of 'Informed Consent' in Children," 289 *New Eng. J. Med.* 885, 886 (1973); Robertson, "Involuntary euthanasia of defective newborns: Legal considerations," 27 *Stanford Law Rev.* 213 (1975); Fost, "Ethical Problems in Pediatrics," 6 *Curr. Prob. Ped.* 1 (1976).
5. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment*, Government Printing Office, 1983, p. 217 (hereinafter cited as *President's Commission Report*).
6. *Id.* at 220.
7. *Id.* at 226.
8. U.S. Dept. of Health and Human Services, Off. of Human Development Services, *Child Abuse and Neglect Prevention and Treatment Program; Proposed Rule*, 49 Fed. Reg. 48,160 (December 10, 1984).
9. The *Final Rule*, noting at 14,881 that the term "medical neglect" was not defined in the statute or preexisting regulation, adds a definition at 14,887 (codified at 45 C.F.R. §1340.15(b)) as follows: "The term 'medical neglect' means the failure to provide adequate medical care in the context of the definitions of 'child abuse and neglect' in section 3 of the Act and 1340.2(d) of this part. The term 'medical neglect' includes, but is not limited to, the withholding of medically indicated treatment from a disabled infant with a life-threatening condition."
10. *Final Rule* at 14,888 (codified at 45 C.F.R. §§1340.15(c)(4)(i) & 1340.15(c)(3)).
11. Although the *Final Rule* at 14,883 states that the Amendment does not require states to amend child abuse and neglect reporting statutes to include the definition of "withholding of medically indicated treatment," because they currently can receive reports and provide protection to disabled infants with life-threatening conditions under current statutes and definitions, nevertheless, several states enacted legislation to add the definition of "withholding of medically indicated treatment" to state statutes. See e.g., Minn. Stat. Ann. §260.015(10)(e) (1985); Montana Rev. Code Ann §41-3-102-5 (1985).
12. *Final Rule* at 14,883.
13. See 130 Cong. Rec. S8951-8956 (daily ed. June 29, 1984).
14. These groups include: American Academy of Pediatrics, American Association of Mental Deficiency, American Coalition of Citizens with Disabilities, American College of Obstetricians and Gynecologists, American College of Physicians, American Hospital Association, American Life Lobby, American Nurses Association, Association for Persons with Severe Handicaps, Association for Retarded Citizens, California Association of Children's Hospitals, Catholic Health Association, Christian Action Council, Disability Rights Center, Down's Syndrome Congress, National Association of Children's Hospitals and Related Institutions, National Child Abuse Coalition, National Right to Life Committee, Nurses Association of the American College of Obstetricians and Gynecologists, Operation Real Rights, People First of Nebraska, and Spina Bifida Association of America.
15. *Amendment*, *supra* note 1, §121(3); *Final Rule*, *supra* note 2, at 14,888 (codified at 45 C.F.R. §1340.15(b)(2)).
16. The term "reasonable medical judgment" is defined in §1340.15(b)(3)(ii) of the *Final Rule*, at 14,889. And see H. Conf. Rep. No. 1038, 98th Cong., 2d Sess. 40 (1984); 130 Cong. Rec., S09312 (daily ed. July 26, 1984).
17. *Final Rule*, *supra* note 2, *Appendix to Part 1340—Interpretative Guidelines Regarding 45 CFR 1340.15—Services and Treatment for Disabled Infants*, 50 Fed. Reg. 14,889 (April 15, 1985).
18. *Id.* at 14,889.
19. *Id.* at 14,890.
20. *Id.* at 14,890.
21. *Id.* at 14,891.
22. *Id.* at 14,891.
23. *Id.* at 14,892.
24. *Id.* at 14,889.
25. This fundamental assertion of the right of disabled infants to treatment, noted in the *Appendix to Part 1340*, at 14,889, 50 Fed. Reg. 14,889 (April 15, 1985), is similar to that found in "Joint Policy Statement: Principles of Treatment of Disabled Infants," 73 *Pediatrics* 554 (1984) at 559 (hereinafter cited as *Principles of Treatment*) and in the *President's Commission Report*, *supra* note 5, at 217.
26. *Amendment*, *supra* note 1, §§121(3)(A)-121(3)(C) (codified at 42 U.S.C.A. §§5101-5103 (Supp. 1985)); *Final Rule*, *supra* note 2, at 14,888 (codified at 45 C.F.R. §1340.15(b)(2)).
27. *Final Rule*, *supra* note 17 at 14,889.
28. See W. Prosser, *Handbook of the Law of Torts*, §32, at 161 (1982) (Prosser states that physicians who undertake work requiring special skill are required to possess a minimum standard of special knowledge and ability).
29. Comment of the American Academy of Pediatrics on Proposed Rules Regarding Child Abuse and Neglect Prevention and Treatment Program, February 8, 1985, at 30.
30. *Principles of Treatment*, *supra* note 25, at 559.
31. See H. Conf. Rep. No. 1038, 98th Cong., 2d Sess. 41 (1984).
32. *Final Rule* at 14,888 (codified at 45 C.F.R. §1340.15(b)(3)(i)).
33. *Supra* note 31.
34. Determination of suitable language may be affected by the U.S. Supreme Court decision in *Bowen v. American Hospital Association*, No. 84-6211 (2nd Cir. Dec. 27, 1984), *cert. granted*, 53 U.S.L.W. 3881 (No. 84-1529), argued before the Court on January 15, 1986 and under consideration at the time of this printing.
35. *Final Rule* at 14,888 (codified at 45 C.F.R. §1340.15(c)(3)).
36. *Id.*, (codified at 45 C.F.R. §1340.15(c)(2)(ii)).
37. *Id.*, (codified at 45 C.F.R. §1340.15(c)(2)(i)).
38. Fla. Stat. Ann. §395.005 (1984).
39. Ariz. Rev. Stat. §36-2284(B) (Supp. 1984).

40. U.S. Dept. of Health and Human Services, Off. of Human Development Services, *Services and Treatment for Disabled Infants; Model Guidelines for Health Care Providers to Establish Infant Care Review Committees*, 50 Fed. Reg. 14,893 (April 15, 1985) (hereinafter cited as *HHS Model Guidelines*).
41. Dept. of Health and Human Services, Off. of the Sec'y, *Nondiscrimination on the basis of handicap: Procedure and guidelines relating to health care for handicapped infants*, 49 Fed. Reg. 1622 (1984). The validity of these regulations is to be determined in the case before the U.S. Supreme Court, *Bowen v. American Hospital Association*, No. 84-1529, argued before the Court on January 15, 1986.
42. President's Commission Report, *supra* note 5 at 228.
43. *Supra* note 41 at p. 1624.
44. "Committee on Bioethics, American Academy of Pediatrics: Treatment of Critically Ill Newborns." 72 *Pediatrics* 565 (1983).
45. "Council Report: Guidelines for Ethics Committees in Health Care Institutions," 253 *J.A.M.A.* 2698 (1985); Bioethics committees in hospitals, substitute resolution 70. Adopted by the American Medical Association House of Delegates, Annual Meeting, Chicago, June 17-21, 1984.
46. A 1982 survey of 602 hospitals revealed only 3% with committees that had the potential to become involved in decision making in specific cases. Reported in Youngner, Jackson, Coulton, et al., *A National Survey of Hospital Ethics Committees*, in President's Commission Report, *supra* note 5, appendix F, pp. 443-449.
47. *Supra* note 29, Appendix II, *Summary, American Academy of Pediatrics Survey on Infant Care Review Committees*, Presented at Bioethics Committee Workshop on Infant Care Review Committees at the AAP Annual Meeting, Chicago, Illinois, September 18, 1984.
48. President's Commission Report, *supra* note 5 at pp. 160-170 and 224-228.
49. *Id.* at 227.
50. "American Academy of Pediatrics Task Force on Infant Bioethics Committees: Guidelines for Infant Bioethics Committees," 74 *Pediatrics* 306 (1984) (hereinafter cited as *AAP Guidelines*).
51. *HHS Model Guidelines*, *supra* note 40, Section IV(B), at 14,894.
52. *AAP Guidelines*, *supra* note 50, at 309.
53. *HHS Model Guidelines*, *supra* note 40, Sections VI(A)(1)-VI(A)(3), at 14,896.
54. *AAP Guidelines*, *supra* note 50, at 310.
55. *HHS Model Guidelines*, *supra* note 40, Section VI(B), at 14,896.
56. *AAP Guidelines*, *supra* note 50, at 310; *HHS Model Guidelines*, *supra* note 38, Section VI(A)(6), at 14,896.
57. *Final Rule*, *supra* note 2, at 14,883.
58. *Amendment*, *supra* note 1, §4(b)(2)(K)(i).
59. *Id.*, §4(b)(2)(K)(ii).
60. *Final Rule*, *supra* note 2, at 14,883.
61. *Supra* note 35.
62. Reported in presentation "State Responses to New and Complex Issues," Seventh National Conference on Child Abuse and Neglect, November 11, 1985 by Glenanne Farrington, Division of Policy and Plans, Illinois Department of Children and Family Services.
63. R. Horowitz, & H. Davidson, *Legal Rights of Children*, §7.11 (Shepards/McGraw Hill 1984).
64. *Final Rule*, *supra* note 2, at 14,878.
65. *HHS Model Guidelines*, *supra* note 40, at 14,901 discuss the relationship between the agency and the hospital infant care review committee in terms of reporting duties. The existence of an HRC does not affect the reporting duties of medical personnel in hospitals. HHS rejected several suggestions which would have resulted in: (1) a permissible delay in reporting where an HRC exists, (2) a requirement that all cases reviewed by an HRC which involve withholding of life-sustaining treatment be reported regardless of whether the HRC believes "medically indicated treatment" was being withheld, so that there might be an independent review by the agency, (3) allowing a simultaneous CPS review so that there would be a report to the CPS agency as soon as the HRC learns of a case.
66. *E.g.*, Cal. Evid. Code §§990-1007 (West 1966 & Supp. 1982); Minn. Stat. Ann. §595.02(4) (West Supp. 1984); Tex. Rev. Civ. Stat. Ann. art. 4495b, §508 (Vernon Supp. 1982).
67. *See, e.g.*, Ariz. Rev. Stat. §8-546.04(B), (C) (Supp. 1983); Ariz. Rev. Stat. §13-3620(D), (E) (Supp. 1983); Ky. Rev. Stat. §199.335(7) (Repl. Vol. 1980); Wis. Stat. Ann. §905.04(4)(e) (Supp. 1982).
68. Hawaii Rev. Stat. §350.1 (1985); Minn. Stat. Ann. §260.015(10) (Supp. 1985) and Minn. Stat. Ann. §626.556(2)(10) (Supp. 1985).
69. *See e.g.*, Alaska Stat. §47.17.050 (1984); Cal. Penal Code §11171(a),(b),(c) (West Supp. 1985); Iowa Code Ann. §232.73 (West Supp. 1983); Or. Rev. Stat. §418.762 (1983).
70. All fifty states provide by statute for confidentiality of CPS records. *See, e.g.* Colo. Rev. Stat. §19-10-115(1), (2) (1978 & Supp. 1983 & 1984 Colo. Sess. Laws ch. 145); Md. Ann. Code art. 88A, §6(b), (d) (Supp. 1984); Va. Code §16.1-305 (Supp. 1984).
71. *Final Rule*, *supra* note 2, at 14,884.
72. In many, if not most situations, information may be incomplete. For example, some reporters to the hotline system under previous HHS regulations could not identify a child, but only gave a vague description of the alleged discrimination. Upon investigation it was determined that no such child existed, or that the situation was described inaccurately. (*See*, 49 Fed. Reg. 1622, 1646, January 12, 1984).
73. The fact that few cases have been reported to child protective service agencies does not provide a reliable estimate of the number of possible reportable cases of withholding medical treatment. CPS involvement is new. There is no reliable national incidence data about the number of infant deaths due to withholding treatment. Several studies have analyzed very small samples. *See* Duff & Campbell, "Moral and Ethical Dilemmas in the Special-Care Nursery," 289 *New Eng. J. Med.* 890 (1973); Wolraich, "Medical, Ethical, and Legal Issues in Selective Use of Rehabilitative Care in the Management of Children with Spina Bifida," 2 *Spina Bifida Therapy* 213 (1980); Gross, Cox, Tatyrek, Pollay & Barnes, "Early Management and Decision-Making for the Treatment of Myelomeningocele," 72 *Pediatrics* 450 (1983); Ragatz & Ellison, "Decisions to Withdraw Life Support in the Neonatal Intensive Care Unit," 22 *Clin. Pediatrics* 729 (1983).
74. Ky. Cabinet for Human Resources, Interim Policy and Procedure 85-10, July 31, 1985; Md. Department of Human

- Resources, Circular Letter §SSA 86-3, Sept. 23, 1985; Or. Children's Services Division, Rule 412-61-000, Jan. 13, 1985.
75. See *Study Findings, National Study of the Incidence of and Severity of Child Abuse and Neglect*, U.S. Department of Health and Human Services, (DHHS Pub. No. (OHDS) 81-30325) at 5-11 (1981).
 76. *Supra*, note 47.
 77. *Id.*
 78. President's Commission Report, *supra* note 5, at 227; HHS Guidelines, *supra* note 40, at 14,894; AAP Guidelines, *supra* note 50, at 308.
 79. *Supra* note 47.
 80. See 130 Cong. Rec. H376-401 (daily ed. Feb. 2, 1984) (Congress rejected the Chandler Amendment and other proposals to rely exclusively on hospital review mechanisms instead of CPS agencies). In the debate in the House of Representatives on the parents' role in the decision-making process, it was argued that the CPS role defined in the Amendment would be too intrusive into a decision better left to the family. It was proposed that the final decision be made by the parents after an informed consultation with the treating physician and a hospital review committee. However, a majority of the House felt that this was inadequate assurance that the interest of the infant would be properly protected and adopted the version calling for a CPS determination whether "reasonable medical judgment" was used in reaching a decision regarding "withholding medically indicated treatment."
 81. The national rate of "substantiated" reports was estimated at 42.7 percent in *Study Findings, supra* note 75 at 12; 41 percent of all reports were found to be "substantiated or at risk" in *Highlights of Official Child Neglect and Abuse Reporting 1982*, American Humane Association (1984), p. 22.
 82. The President's Commission Report, *supra* note 5, at pp. 207-214, concluded that parents could usually be counted on to make decisions in the best interests of their child, given an appropriately supportive environment, and accurate and complete information. The Commission, however, noting tragic exceptions, cautioned against haste in decision-making and observed that the longer babies survive, the more reliable the prognosis for the infant becomes and the clearer parents and professionals can be on whether further treatment is warranted or futile. To prevent abuses, the Commission recommended that (1) decisions be made in infant's best interests, and, (2) all cases involving a parental decision to withhold life-sustaining treatment be reviewed by hospital ethics committee.
 83. See Strong, "The Neonatologist's Duty to Patient and Parents," 14 *Hastings Center Rep.* 10, 11 (August 1984); Charney, Weeler & Sutton, "Management of the Newborn with Myelomeningocele: Time for a Decision-making Process," 75 *Pediatrics* 58 (1985); McDonald, Carson, Palmer & Slay, "Physicians Diagnostic Information to Parents of Handicapped Neonates," 20 *Mental Retardation* 12, 13 (1982).
 84. Fost, "Counseling Families Who Have a Child With a Severe Congenital Anomaly," 67 *Pediatrics* 321 (1981).
 85. See Duff & Campbell, "Moral and Ethical Dilemmas in the Special Care Nursery," 289 *New Eng. J. Med.* 890 (1973); Shaw, "Dilemmas of 'Informed Consent' in Children," 289 *New Eng. J. Med.* 885, 886 (1973).
 86. *Supra* note 84.
 87. See generally Cohen, "The Impact of the Handicapped Child on the Family," 43 *Social Casework* 137 (1962); Fletcher, "Attitudes Toward Defective Newborns," 2 *Hastings Center Rep.* 21 (1974).
 88. See e.g., Ky. Rev. Stat. §199.335(3) (Supp. 1984); Hawaii Rev. Stat. §350-1.3 (1985); Mo. Rev. Stat. §210.140 (Supp. 1984).
 89. *Final Rule, supra* note 2, at 14,888 (codified at 45 C.F.R. §1340.15(c)(4)(i)).
 90. See Minn. Stat. Ann. §§260.015(10)(c) & (10)(f); Hawaii Rev. Stat. §350-1.1 (1985).
 91. *Joint Commission on Accreditation of Hospitals*, Accreditation Manual for Hospitals, 1981 Ed. (Chicago: 1980) at p. 83.
 92. *Id.* at 84-88.
 93. President's Commission Report, *supra* note 5, at 429 (App. F. §3(A)).
 94. Az. Rev. Stat. §36-2284 (Supp. 1984).
 95. *Supra* note 62.
 96. HHS Model Guidelines, *supra* note 40, at §III(B)(4), at 14,894.
 97. *Supra* note 89.
 98. *Supra* note 63, at §7.12.
 99. It will not be necessary to litigate the availability of records in most instances because this issue has been addressed by state statutes in proceedings involving child abuse and neglect matters. See *supra* note 67.
 100. *Supra* note 88. Also see, e.g., Ill. Ann. Stat. ch. 38, §302(17)(g)* providing that, "if a mandated reporter who is believed to have information about the subject of a report is not allowed or refuses to speak with or provide documents to a child protective service worker about the reported child or family, an administrative subpoena may be issued to obtain the necessary information." See Ind. Code Ann. §12-1-10-1 (Supp. 1982) (Burns) which provides for 10 days notice, however, for delivery of records pursuant to an administrative subpoena.
 101. *Supra* note 63 at §7.08.
 102. The President's Commission Report, *supra* note 5, at 228 states "Insofar as possible, infant's lives should be sustained long enough to gather the best information and to permit expeditious review."
 103. HHS Model Guidelines, *supra* note 40, §VI(A)(6), at 14,896 provides that "every effort should be made to continue treatment, preserve the status quo, and prevent worsening of the infant's condition until such time as the court or agency renders a decision or takes other appropriate action."
 104. The AAP Guidelines, *supra* note 50, at 310, provide that, "[W]hile legal proceedings are being instituted, it is expected that every effort should be made to continue treatment, preserve the status quo, and prevent worsening of the infant's condition, until such time as a course of action has been ordered by a person acting under the authority of the court."
 105. Several commenters stressed the value of taking this particular step to coordinate between the CPS agency and whoever at the hospital is serving as counselor to the parent(s).
 106. See e.g., S. C. Code Ann. ch. 7, §20-7-520 (Supp. 1982).
 107. *Final Rule, supra* note 2, at 14,888 (codified at 45 C.F.R. §1340.15(c)(4)(ii)).
 108. *Id.* at 14,883.

109. *Supra* note 63, at §7.08.

110. *Id.*

111. One state currently mandates by statute that parents receive information regarding support services available for handicapped persons pursuant to CPS involvement. Ariz. Rev. Stat. Ann. §36-2283 (West Supp. 1983).

**NATIONAL LEGAL RESOURCE CENTER
FOR CHILD ADVOCACY AND PROTECTION
A Project of the ABA Young Lawyers Division**

The ABA's National Legal Resource Center for Child Advocacy and Protection, sponsored by the Young Lawyers Division, began in 1978 with two attorneys and has grown to over 15 attorneys, professionals and staff working on issues such as:

- missing and exploited children,
- adoption,
- learning disabilities,
- child support,
- foster care and permanency planning,
- interstate child custody disputes, and
- child abuse and neglect.

The mission of the Center is to improve lawyer competency and judicial and public agency handling of cases involving children. For example, the Center is currently engaged in the promotion of an Interstate Adoption Compact. And a special program of the Center, the National Legal Resource Center for Child Advocacy Programs, provides training and technical assistance directly to the child welfare and protection community. A prospectus explaining the services is available from the Resource Center.

Another important activity of the Center is the publication of a new monthly law reporter for attorneys, judges, prosecutors and others toiling in the child welfare/juvenile justice arena. The *ABA Juvenile and Child Welfare Law Reporter* is the most comprehensive digest of new cases, laws, journal articles and publications in the juvenile justice and child welfare field.

The Resource Center has also published over 30 books, monographs and manuals. A complete listing is available from the Center. Many of these works cover voids in legal literature and served as an impetus for change. In the early 1980s, the Center published a series of books on child sexual abuse which included recommendations covering such issues as videotaping children's statements for court room use, using court-appointed child-victim advocates, and eliminating special competency requirements for child witnesses. At the time these ideas were considered innovative; today the recommendations are the subject of dozens of state laws.

**AMERICAN BAR ASSOCIATION
COMMISSION ON THE MENTALLY DISABLED**

The American Bar Association's Commission on the Mentally Disabled is a multidisciplinary entity with fifteen members that was established in 1973 to address legal matters of concern to mentally disabled persons. The Commission supports increased cooperation between legal and other professionals in the mental disability field and encourages the development of multidisciplinary approaches to enhance the delivery of legal services to this client group.

Its major project is the *Mental and Physical Disability Law Reporter* which has been the journal of record in the disability law field since 1976. Intended for use of lawyers, professionals and knowledgeable consumers, the *Reporter* serves as a comprehensive legal reporting service and journal summarizing and analyzing case law, legislation and regulations that affect mentally and physically disabled persons and the professionals who provide services to them. An adjunct to the *Reporter* is a resource center which provides texts of cases and other legal information to subscribers, and the public.

The Commission also has sponsored model advocacy projects in cooperation with local and state bar associations, developed model state developmental disability legislation with detailed commentaries, introduced a wide range of policy resolutions subsequently adopted by the ABA, testified at congressional hearings, and submitted amicus briefs in key Supreme Court cases.

One current project is preparing legal and financial materials for elderly and developmentally disabled persons to provide individualized life service plans that will help them live successfully in the community. These planning materials will be used in a local demonstration project in Northern Virginia, evaluated and then described in a handbook so the project may be replicated in other areas of the country.