PJR Subj.
6/3/83

MEMORANDUM

THE WHITE HOUSE

WASHINGTON

May 23, 1983

FOR: RICHARD A. HAUSER

FROM: PETER J. RUSTHOVEN

SUBJECT: Report of HHS Working Group on Proposed Infanticide Regulation

As we have discussed, attached for your review and signature on behalf of Mr. Fielding is a memorandum for Richard Darman, with copy to Messrs. Meese and Fuller, about the above-referenced report and accompanying "Notice of Proposed Rule Making," on which comments were requested by noon today.

The memorandum notes the points we discussed, namely the need for resolution of the question of what constitutes Federal financial assistance; the possibility of Justice Department assistance on "form pleadings" for "Baby Doe" cases; and the inadvisability of issuing a separate notice from the Attorney General to United States Attorneys on the possible applicability of 18 U.S.C. § 241, the criminal conspiracy statute for civil rights violations.

I have also added comments on a spelling error ("judgement" instead of "judgment") that occurs too frequently for yours truly to ignore it, and on a section of the "Comments solicited" portion of the NPRM asking whether hospital self-review boards might be required by Federal regulation and, if so, be an alternative to Federal enforcement under the proposed rule. Though there is no problem with soliciting comment on these points concerning self-review boards (which the medical profession evidently favors as the correct approach to this problem), I think we should point out the drawbacks to these ideas (which were discussed at working group meetings).

Attachment

Fred - This should bring you up to date on "Baby Doe." (RAH signed the attached memo). We can talk Monday a.m. if you wish — Thanks, Peter

- I need earlier memos
- status of Baylor case

K3
for Baby Doe meeting

THE WHITE HOUSE

WASHINGTON

May 23, 1983

MEMORANDUM FOR RICHARD G. DARMAN
ASSISTANT TO THE PRESIDENT AND
DEPUTY TO THE CHIEF OF STAFF

FROM: FRED F. FIELDING
COUNSEL TO THE PRESIDENT

SUBJECT: Report of HHS Working Group on
Proposed Infanticide Regulation

Our office has reviewed the above-referenced report and accompanying "Notice of Proposed Rule Making" ("NPRM"), and has the following comments:

We have no legal or other substantive objection to issuance of the NPRM, the preamble and appendix to which seem to do a good job of addressing the questions about the merits of Federal action under § 504 that were raised by Judge Gesell in dicta in his opinion invalidating the previous "interim final rule" on procedural grounds. Obviously, the question of what constitutes "Federal financial assistance" needs to be resolved, but this need not delay issuance of the NPRM. As a grammatical point, however, the word "judgment" is misspelled "judgement" throughout, a spelling abandoned on these shores since we were freed from the British yoke.

On a more substantive note, there is one issue in the "Comments solicited" portion of the NPRM that may merit some attention at this point. On page 23, the NPRM asks for comments on whether hospitals should be required to institute internal review boards and, if so, whether this should be "an alternative or an addition to the requirements of the proposed rule?" While there is no objection to soliciting comments in this area, there is serious question whether either part of this proposal should be adopted. On the first half, it is fine for hospitals to establish such boards on their own, but making it a "requirement" would give HHS the unwieldy tasks of establishing rules for what such boards must be like and then monitoring hospitals to insure compliance. On the second half, permitting such boards to be an "alternative" to the requirements of the proposed rule would be less than satisfactory, to say the least, to the groups most interested in preventing discrimination against handicapped newborns. Both of these points were raised at meetings of the working group.

There are two other points that, though they do not affect issuance of the NPRM, should be considered. First, it may be a good idea to have the Justice Department develop "form pleadings" for "Baby Doe" cases that could be distributed to United States Attorneys' offices. This may save considerable time (and potential legal problems) in cases of this sort, where time is always of the essence.

Second, we have very serious doubts about the wisdom of the Attorney General sending notices to U.S. Attorneys about the possibility of criminal prosecutions under 18 U.S.C. § 241, the criminal conspiracy statute for civil rights violations. This, too, was discussed at working group meetings, and if sending such notices is accurately described at all as a "recommendation" of the group, it is certainly not a unanimous one.

To be sure, it is possible that a particularly egregious case may justify prosecution under this statute, and there is nothing to prevent its use in such an instance. Realistically, however, the chances for obtaining a jury conviction of doctors or parents for "criminal conspiracy" would be exceedingly slight, an evaluation we believe the Justice Department shares. The additional deterrent effect of such a notice would likewise be slight or nonexistent. At the same time, sending such notices would almost certainly elicit an extremely strong and negative reaction from the medical community, hardening positions of opposition that other portions of the working group proposal seek to ameliorate.

Accordingly, we strongly recommend that this idea be discussed carefully with Justice and HHS and that, unless there are compelling reasons to proceed with it, notices of this sort not be sent to U.S. Attorneys. As noted, this will not prevent use of the statute in an appropriate case; it will, however, avoid raising, for little or no substantive gain, a new and potentially very divisive area of controversy about this matter.

cc: Edwin Meese III
Craig L. Fuller

ID # 073350 CU

WHITE HOUSE
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Subject: Report on Unfunded Regulation

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WHITE HOUSE STAFFING MEMORANDUM

DATE: May 20, 1983 ACTION/CONCURRENCE/COMMENT DUE BY: NOON MONDAY MAY 23, 1983

SUBJECT: Report on Infanticide Regulation

	ACTION	FYI		ACTION	FYI
VICE PRESIDENT	☐	☐	GERGEN	☑	☐
MEESE	☐	☑	HARPER	☑	☐
BAKER	☐	☑	JENKINS	☐	☐
DEAVER	☐	☑	MURPHY	☐	☐
STOCKMAN	☐	☐	ROLLINS	☑	☐
CLARK	☐	☐	WHITTLESEY	☑	☐
DARMAN	☐P	☑SS	WILLIAMSON	☑	☐
DUBERSTEIN	☑	☐	VON DAMM	☐	☐
FELDSTEIN	☐	☐	BRADY/SPEAKES	☐	☐
FIELDING	☑	☐	ROGERS	☐	☐
FULLER	☐	☐	_____	☐	☐

Remarks:

Please provide comments on the attached package and recommendation provided by the Infanticide Working Group concerning reissuance of the Infanticide Regulation to my office by Noon Monday, May 23.

Thank you.

Richard G. Darman
Assistant to the President
(x2702)

Response:

THE UNDER SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

May 18, 1983

MEMORANDUM FOR CRAIG FULLER

Pursuant to your instructions, attached is the report of the working group formed to review the HHS interim final rule published March 7, 1983.

We are recommending publishing a notice of proposed rulemaking which modifies the interim final regulation somewhat; including an extensive preamble discussing the issues raised by Judge Gesell; and concluding with an appendix to the regulation which provides examples of the type of case to which the regulation is directed.

As you can see in the report, the working group held several formal sessions and met with representatives of the physicians, hospitals, handicapped, and pro-life groups in an effort to assure that all concerns were recognized in our proposed action.

Much discussion surrounded the role of the state agencies in enforcement of Section 504. While recognizing that states should play a significant role, it was generally concluded that the ultimate responsibility for enforcement of civil rights legislation rests with the Federal Government. Nevertheless, we are recommending that a notice be sent to state agencies and that their role be clarified and enhanced.

Finally, the working group and more particularly, the group representing the handicapped and pro-life contingents felt that the Federal Government should utilize all available tools for enforcement, specifically criminal prosecution where warranted. Accordingly, we are recommending that a notice be sent to the United States Attorneys alerting them as to the applicability of Section 504 and the fact that a violation may be a violation of the criminal provisions of 18 USC 241.

I recommend that the attached notice of proposed rulemaking with preamble and appendix be published in the Federal Register.

John A. Svahn
Under Secretary

Attachments:
Tab A - Report of the work group
Tab B - Recommended notice of proposed rulemaking
Tab C - Working group members
Tab D - Attendees at meetings with non-governmental organizations

REPORT OF THE INFANTICIDE WORKING GROUP

Background

The working group created by memorandum from Craig Fuller to the Secretary of HHS met on two occasions (see Tab C for list of members). In addition, a sub-group of the working group led by the Chairman met with representatives of the health care industry and with groups representing pro-life positions and the handicapped (see Tab D for a list).

The results of those discussions and recommendations follow.

The President's April 30, 1982, memorandum instructed the Secretary of Health and Human Services to inform health care providers of the applicability of Section 504 to the care and treatment of handicapped infants. It indicated his decision that existing federal civil rights statutes afforded protection to handicapped infants and his determination that they will be "vigorously enforced".

On May 18, 1982, the Department of Health and Human Services notified approximately 6,800 hospitals which receive federal financial assistance that it is unlawful under Section 504 to withhold from handicapped infants nutritional sustenance or medical care required to correct a life threatening condition. (As the President stated in his March 8 Orlando address: "I have directed the Health and Human Services Department to make clear to every health care facility in the United States that the Rehabilitation Act of 1973 protects all handicapped persons against discrimination based on handicaps, including infants.")

The Department published on March 7, 1983, an interim final rule, which used Title VI of the Civil Rights Act procedures to make known to beneficiaries their right to federal protection against discrimination. In addition, it waived the ten day waiting period before referral to the Department of Justice for enforcement.

The March 7 rule provided a system for beneficiaries of federally assisted programs to be informed of their rights and in turn provided the beneficiaries and the public with a hotline informing the Department of suspected violations.

The interim rule required each hospital to post a notice in a "conspicuous place" in the delivery, maternity, and pediatric wards and in each nursery. The notice gave the hotline number and encouraged persons who had knowledge of an infant being discriminated against to call the hotline number.

This rule resulted, in part, from the understanding that vigorous enforcement of federal civil rights laws in situations such as that which led to the death of a handicapped child in Indiana could not be effected unless the Department provided an effective notice mechanism for beneficiaries and a timely reporting mechanism for enforcement agencies.

Supplementary information accompanying the interim final rule indicated that: "State agencies that receive federal financial assistance are under the same obligation as other recipients not to provide a qualified handicapped person with benefits or services that are less effective than those provided to others." The supplementary information stated also that: "The Secretary will make available to State agencies any information and assistance that is helpful and appropriate." It concluded that: "For those complaints that are expeditiously and effectively investigated and pursued by State agencies, the Secretary anticipates that additional federal efforts will often be unnecessary."

Judge Gesell invalidated the interim final rule on the narrow ground that it violated the requirements of the Administrative Procedure Act in failing to provide sufficient notice and opportunity for comment to those persons affected.

In addition, the Judge made considerable comment regarding broader issues of the regulations.

Discussion

During the past three weeks of meetings and research, it has become apparent that there are four major issues attendant to this regulation aside from the procedural aspects which caused Judge Gesell to invalidate the interim final regulation. The procedural defects can be cured by the notice and opportunity to comment provisions associated with the publishing of a notice of proposed rulemaking.

The other issues are discussed below.

What does HHS intend to prevent by publishing the regulation?

Much concern was expressed by industry groups in particular, but also within the working group, that the regulation was "vague" and unclear as to its intent. Questions were raised regarding the underlying principles of our regulation and the extent to which comments made by the President were to be used in interpreting the regulation.

The working group was firm in its assertion that our policy was to prevent discrimination against infants because they happen to have a handicap. The Administration is not advocating heroic or other extraordinary measures being taken to prolong a hopeless situation.

This position seemed to be accepted by all parties once understood. The industry groups were concerned that we were mandating expensive and useless procedures. Once explained, they concurred with our position. This position is spelled out in the recommended rule and appendix.

Who should be the Prime Enforcer of Section 504?

Much of the discussion surrounded the question of which entity should provide enforcement of the prohibition contained in Section 504.

Under the interim final rule and procedures adopted by HHS, HHS through its regional structure of the Office of Civil Rights was given responsibilities for initial investigation and enforcement. The states were also acknowledged to have a role in infant protection under the various child protection statutes.

The hospital groups would prefer enforcement and investigation to be done at the local level by a multi-disciplined board (including representation of handicapped groups) on a facility-by-facility or regional basis. They believe that individual cases are subject to considerable subjectivity and therefore require onsite analysis. The Federal role to them should be one of oversight, on a retroactive basis, rather than enforcement. Hospital spokesmen cited concern about federal employees tramping around in hospitals at all hours as a problem. The pro-life and handicapped groups and the working group feel that such a review board procedure would do little to prohibit past practices. Even attorneys for the handicapped felt that a properly constituted board would be a significant intrusion into hospital operations.

Several members of the working group and of the other groups felt the states should be the primary enforcers. DOJ put forth such a proposal and a similar proposal was made by attorneys for the handicapped. Valid questions do exist about this new role for the Federal Government, however it was the opinion of the group that on balance, the enforcement of civil rights statutes is a federal responsibility. States should be encouraged to exercise their authority, trained in the problem, and made aware of remedies available to them in order to more fully supplement the federal capability.

What system should be available to notify OCR of potential violations?

The interim final rule required the posting of the notice in "conspicuous" places in all the areas of a hospital frequented by infants. The notice contained the hotline number and urged people to call and report discrimination. Perhaps more than any other aspect of the regulatory scheme, this requirement infuriated the hospitals and particularly the physicians. Comments were made that it created "havoc" in the hospitals and "destroyed the trust" between the doctor and the patient's family.

Without acknowledging any merit in the providers claims, the handicapped groups recognized that the postings required under the interim final rule have had some unintended results. HHS too, reports that members of the public have misinterpreted the notices and called the hotline with irrelevant complaints.

All parties appear to recognize that legitimate complaints of the type of discrimination the notice is intended to prevent come from nurses working in the various wards.

It is probably advisable to modify the notice requirement and redirect it towards those most knowledgeable. Such a modification would not diminish the federal role or reduce protection of newborn infants.

What is the legal basis for HHS enforcement?

HHS has long maintained that payment of Medicare or Medicaid to a hospital constitutes federal financial assistance (FFA) to the facility and therefore the facility must meet such requirements as the department chooses to legally impose. Failure to do so would result in the loss of such federal financial assistance. The American Hospital Association maintains that the programs do not constitute FFA to the hospitals and therefore only hospitals which actually receive some type of grant (approximately 5% of the facilities) are covered under our March 7 rule. They further believe that the only penalty for failure to comply would be loss of the specific grant money.

The Department of Justice has not issued an opinion on this issue and there continues to be some disagreement within DOJ. The working group was promised a position from DOJ, but it was not forthcoming. Given the President's statements, both written and oral, the working group has concluded that the traditional HHS position is preferable.

Because of the potentially limited nature of a threat to withhold federal financial assistance to prevent or stop an ongoing, life threatening violation of Section 504, an effective response to life threatening discrimination against handicapped infants requires not only a cooperative effort between federal, state, and private agencies, but also the full utilization of federal civil rights protection. In the President's memorandum of April 30, 1982, he instructed that he be informed of the application of existing federal constitutional and statutory remedies, other than Section 504, to prevent the withholding of life-saving treatment to handicapped infants.

Several groups representing the handicapped and pro-life views made strong arguments for the Justice Department to vigorously enforce the criminal conspiracy provisions of the law.

Section 241, Title 18 of the United States Code provides that: "If two or more persons conspire to injure, oppress, threaten, or intimidate any citizen in the free exercise or enjoyment of any right or privilege secured to him by the Constitution or laws of the United States...They shall be fined not more than $10,000 or imprisoned not more than ten years, or both, and if death results, they shall be subject to imprisonment for any term of years or for life."

For example, agreement by parents and hospital personnel not to treat a congenital anomaly incompatible with life and amenable to surgical correction in a child with Downs syndrome may constitute conspiracy and therefore be a violation of Section 241.

Recommendations

A. It is recommended that the Department of Health and Human Services:

1. Issue a Notice of Proposed Rulemaking (see Tab B) which restates the March 7, 1983, interim final rule with the following modifications:

(a) the requirement that the notice be posted "in each delivery ward, each maternity ward, each pediatric ward, and each nursery, including each intensive care nursery" be changed to require that the notice be posted in the nurses' station having responsibility for such sections in the hospital;

(b) the notice to be posted be no smaller than 8½ by 11 inches (the notices distributed by the Department will in fact be 8½ by 11 inches);

(c) require hospital personnel to identify on the space provided on the notice the state child protection agency where child neglect or abuse violations can be reported, rather than simply providing this as an option;

(d) the proposed regulation be published with an appendix which further clarifies issues raised in discussions with outside groups and in Judge Gesell's opinion since such an appendix would provide more authoritative guidance and would be accorded greater weight by a reviewing court;

(e) that the preamble published with the proposed regulation further clarify issues raised in the litigation and specifically request comments on a number of questions raised by Judge Gesell and others.

2. In order to clarify the role of State child welfare agencies and to encourage their involvement in protecting the rights of handicapped infants:

   (a) send a notice, similar to the May 1982 Notice to Health Care Providers, to State child protection agencies to clarify their responsibilities as recipients of federal financial assistance under Section 504:

   (b) develop technical and other appropriate assistance to State and private child protection agencies consistent with their Section 504 responsibilities and communicate the assistance to those agencies.

B. It is recommended that the Department of Justice notify United States Attorneys that a life threatening violation of Section 504 may constitute a violation of federal criminal law prohibiting conspiracy against rights of citizens (18 U.S.C. 241) and that they be prepared to institute timely proceedings as necessary regarding an ongoing or past life threatening violation of Section 504.

Supplementary Information: The President's directive of April 30, 1982, and the HHS Office for Civil Rights "Notice to Health Care Providers" of May 18, 1982, reminded recipients of federal financial assistance of the applicability of Section 504 of the Rehabilitation Act of 1973. Section 504 provides: "No otherwise qualified handicapped individual.... shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance."

The Notice to Health Care Providers explained what is already clear from the language of Section 504 and the implementing regulations (45 CFR Part 84): The discriminatory failure of a federally assisted health care provider to feed a handicapped infant, or to provide medical treatment essential to correct a life-threatening condition, constitutes a violation of Section 504.

Section 504 requires that health services be provided to the handicapped "on a basis of equality with those not handicapped," Doe v. Colautti, 592 F. 2d 704, 709 (3d Cir. 1979), in order to assure "the evenhanded treatment of qualified handicapped persons." Southeastern Community College v. Davis, 442 U.S. 397, 410 (1979).

Section 504 is in essence an equal protection, non-discrimination standard. Congress expressly intended Section 504 to prohibit discrimination based on handicap in the same way that Title VI of the Civil Rights Act prohibits discrimination based on race. Programs or activities receiving federal financial assistance may not deny a benefit or service on grounds of a person's handicap, just as they may not deny a benefit or service on grounds of a person's race.

The Rehabilitation Act of 1973 defines a "handicapped individual" as "any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, ... or (iii) is regarded as having such an impairment." 29 U.S.C. 706(7)(B). Thus it is clear that a handicapped infant is an "individual" within the protection of the statute and is a "person" within the protection of the regulation. Nothing in the plain language of Section 504 or its legislative history provides a basis for excluding infants from the statutory coverage of "individuals". It is equally clear, however, that the great majority of seriously ill children who require acute medical attention are not included in the term handicapped persons as used in Section 504. For example, a premature or otherwise low birth weight infant would not on that basis alone be considered a handicapped person for purposes of Section 504 even though he may require acute medical care.

The definition of a qualified handicapped person was clarified by the Supreme Court in Southeastern Community College v. Davis, 442 U.S. 397 (1979). In that case the Court addressed the question of whether a nursing school was prohibited by Section 504 from imposing certain physical qualifications for admission to its clinical training program. Noting that Section 504 prohibits discrimination on the basis of handicap against otherwise qualified handicapped individuals, the Court focused on the question of whether the plaintiff was otherwise qualified. It concluded that she could benefit from the program without fundamental alteration of the program. Id. at 409-410. As applied in the context of health care to handicapped infants, Section 504 would hold that where an infant would not benefit medically from a particular treatment, the infant would not be "qualified" to receive the treatment; thus, its denial would not violate Section 504.

Section 504 does not compel medical personnel to attempt to perform impossible or futile acts or therapies. Thus, Section 504 does not require the imposition of futile therapies which merely temporarily prolong the process of dying of an infant born terminally ill, such as a child born with anencephaly or intra-cranial bleeding. Such medical decisions, by medical

personnel and parents, concerning whether to treat, and if so, what form the treatment should take, are outside the scope of Section 504. The Department recognizes that reasonable medical judgements can differ when evaluating these difficult, individual cases.

The Department's existing regulations prohibit a recipient in providing any aid, benefit, or service from denying a qualified handicapped person "the opportunity to participate in or benefit from the aid, benefit, or service." 45 C.F.R. 84.4(b)(1)(i). The regulations also prohibit a recipient from affording a qualified handicapped person "an opportunity to participate in or benefit from the aid, benefit, or service that is not equal to that afforded others." 45 C.F.R. 84.4(b)(1)(ii) (emphasis supplied).

Recognizing that Section 504 protects only those infants who are able to benefit from treatment, the Department's May 18, 1982 Notice to Health Care Providers explained that a violation of Section 504 occurs when the treatment is withheld because of the existence of a handicap and the handicap does not render the treatment medically contraindicated.

Thus, Section 504 simply preserves the decision-making process customarily undertaken by physicians in any treatment decision: will the treatment be medically beneficial to the patient and are those benefits outweighed by any medical risk associated with the treatment? It is only when non-medical considerations, such as subjective judgements that an unrelated handicap makes a person's life not worth living, are interjected in the decision-making process that the Section 504 concerns arise.

The judgement Section 504 requires of a physician is a medical judgement concerning what medical treatment shall be provided an individual. Not all judgements made by a health care provider, however, are medical judgements. For example, a judgement not to treat a black infant because of the infant's race is not a medical judgement. A judgement not to remove a stomach block or repair a heart of a Down's Syndrome infant because the infant suffers the handicap of Down's Syndrome is likewise not a medical judgement.

The decision to forego medical treatment of a correctable life-threatening defect because an infant also suffers from a permanent, irremediable handicap that is not life-threatening, such as mental retardation, is a violation of Section 504. In this context, Section 504 provides that usual and customary

medical care afforded to non-handicapped infants not be denied to handicapped infants when they would benefit from such treatment. Similarly, where a course of medical care is usual and customary to correct or ameliorate a life impairing condition among a particular class of patients, for example, such as infants suffering from meningomyelocele (spina bifida), such beneficial care may not be withheld from an individual infant because of a subjective judgement that such infants as a class possess an insufficient quality of life.

While these are often difficult decisions to make, as well as to review, the standard of customary medical care is not one unfamiliar in the medical community and the Department appreciates the standard set forth in the recent Report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, entitled, "Deciding to Forego Life-Sustaining Treatment."

The Commission concluded that "a very restrictive standard is appropriate" in decisions regarding the treatment of handicapped infants and the Department requests comments on the following statement of the Commission:

> Though inevitably somewhat subjective and imprecise in actual application, the concept of "benefit" excludes honoring idiosyncratic views that might be allowed if a person were deciding about his or her own treatment.... As in all surrogate decision-making, the surrogate is obligated to try to evaluate benefits and burdens from the infant's own perspective. The Commission believes that the handicaps of Down Syndrome, for example, are not in themselves of this magnitude and do not justify failing to provide medically proven treatment, such as surgical correction of a blocked intestinal tract.
>
> This is a very strict standard in that it excludes consideration of the negative effects of an impaired child's life on other persons, including parents, siblings, and society. Although abiding by this standard may be difficult in specific cases, it is all too easy to undervalue the lives of handicapped infants, the Commission finds it imperative to counteract this by treating them no less vigorously than their healthy peers or than older children with similar handicaps would be treated.

Events of the past several years suggest that handicapped infants have died from denial of food in federally assisted programs. The full extent of discriminatory and life-threatening practices toward handicapped infants is not yet known, but the Secretary believes that for even a single infant to die due to lack of an adequate notice and complaint procedure is unacceptable.

There is a great deal of evidence documenting that the "very strict standard" advocated by the President's Commission and the requirements of Section 504 are not being uniformly followed and that medically indicated treatment is sometimes

withheld from infants with congenital anomalies on the basis of their handicaps. For example, a 1973 article by Doctors Duff and Campbell of the Yale-New Haven Hospital documenting that of 299 consecutive deaths occurring in that special care nursery, 43 (14 percent) were related to withholding treatment. 289 N. Engl. J. Med. 890. The following was among the cases documented:

> An infant with Down's Syndrome and intestinal atresia, like the much publicized one at Johns Hopkins Hospital, was not treated because his parents thought the surgery was wrong for their baby and themselves. He died several days after birth. Id. at 891.

The Johns Hopkins case became the subject of a documentary produced by the Joseph P. Kennedy Foundation, excerpts from which were shown as part of the "Death in the Nursery" documentary series presented by a Boston television station in February 1983. The facts of this particular case cited by Duff and Campbell were also much like the 1982 Bloomington, Indiana case cited by President Reagan in his statement of April 30, 1982, in which an infant with Down's Syndrome and a correctible esophageal atresia was allowed to die.

Another specific case investigated by the HHS Office for Civil Rights similar to the Yale-New Haven, Johns Hopkins, and Bloomington cases related to a 1979 death of an infant with Down's Syndrome and an intestinal obstruction at the Kapiolani-Children's Medical Center in Honolulu, Hawaii. As a resolution to the complaint, HHS and the hospital, in May of 1980, agreed to an an amendment to the hospital's written consent procedures to assure that cases involving a lack of parental consent to medically indicated treatment for handicapped infants be reported to the State child protective services agency in the same manner as similar cases involving non-handicapped children.

In addition to the four documented cases, Yale-New Haven, Johns Hopkins, Kapiolani, and Bloomington, and the other cases cited by Duff and Campbell, there is persuasive evidence that cases involving discriminatory denial of care are not unique. A 1977 article, "Ethical Issues in Pediatric Surgery," 60 Pediatrics 588, reported the results of a survey of 400 members of the Surgical Section of the American Academy of Pediatrics and an additional 308 chairpersons of teaching departments of pediatrics and chiefs of divisions of neonatology and genetics in departments of pediatrics. Responses were received from 267

of the former group (66.8%) and 190 of the latter (61.7%). Id. at 588-9. Responses were anonymous. Among the results of the survey were:

-- 76.8% of the pediatric surgeons and 59.5% of the pediatricians said they would "acquiesce in parents' decision to refuse consent for surgery in a newborn with intestinal atresia if the infant also had Down's Synrome." Id. at 590.

-- 23.6% of pediatric surgeons and 13.2% of pediatricians would encourage parents to refuse consent for treatment of a newborn with intestinal atresia and Down's Syndrome. Only 3.4% of pediatric surgeons and 15.5% of pediatricians would get a court order directing surgery if the parents refused. Id. at 591-2.

-- 63.3% of the pediatric surgeons and 42.6% of the pediatricians said in cases of infants with duodenal atresia and Down's Syndrome, where they "accept parental withholding of lifesaving surgery," they would also "stop all supportive treatment including intravenous fluids and nasal gastric suction." Id. at 592-3.

-- 62% of all respondents who believe that children with Down's Syndrome "are capable of being useful and bringing love and happiness into the home" would nevertheless acquiesce in parents' decisions not to allow surgery for the atresia. Only 7% who so believe indicate that they would go to court to require surgery. Id. at 595.

These data strongly suggest that instances, such as occurred in Bloomington, Indiana in 1982, in which infants are denied life-sustaining, medically indicated treatment solely on the basis of their handicap cannot be dismissed as isolated events.

For purposes of applying Section 504, it is important to note that only 7.9% of Surgical Section members, and only 2.6% of other pediatricians, would acquiesce in parental refusal to treat intestinal atresia in an infant with no other anomaly. Their acquiescence in non-treatment of Down's children is apparently because of the handicap represented by Down's Syndrome. A significant number of Surgical Section members indicated that they would do considerably more than "acquiesce" i parental decisions not to treat: 23.6% said that, given parents who are indecisive about treatment of a Down's Syndrome infant with intestinal atresia, they would encourage the parents not to consent. Only 3.4% of Surgical Section members said they would get a court order if parents refused consent in such situations. Moreover, the underlying rationale of the surgeons' responses appears not to be so much a deference to parental judgement as a personal view that Down's Syndrome children are not worth having. A large majority (78.3% of surgeons, 88.4% of others) said they would get a court order directing surgery on a young child with a treatable malignant tumor whose parents refused consent out of belief in faith healing. But when asked, "If you were the parent of a newborn infant with Down's Syndrome and intestinal obstruction, would you consent to intestinal surgery?", only 27% of surgeons answered Yes. Other pediatricians responded 53.7% Yes.

In addition, other surveys produced similar results. For example, 61% of California pediatricians responding to a 1975 survey said they would not object to a parental decision not to correct a life-threatening intestinal obstruction of an infant with Down's Syndrome. Another study found that 51% of Massachusetts pediatricians responding to a survey would not recommend surgery for such infants. Only 18.5% of the total sample of pediatricians would get a court order to treat intestinal atresia in a Down's Syndrome infant whose parents refused consent. See, "Treating the Defective Newborn: A Survey of Pediatricians' Attitudes," 6 Hastings Ctr. Rep. 2 (April 1976) and Todres, et al., "Pediatricians Attitudes Affecting Decision-Making in Defective Newborns," 60 Pediatrics 197 (1977).

The Department recognizes that parents retain the fundamental right, coupled with the high duty, to nurture and direct the destiny of their children (Pierce v. Society of Sisters, 268 U. S. 510). Yet, parental rights over their children are not absolute (Prince v. Massachusetts, 321 U. S. 158). The Department has determined that under every state law, failure of parents to provide necessary, medically indicated care to a child is either explicitly cited as grounds for action by the state to compel treatment or is implicitly covered by the

state statute. These state statutes also provide for appropriate administrative and judicial enforcement authorities to prevent such instances of medical neglect, including requirements that medical personnel report suspected cases to the state child protective service agency, agency access to medical files, immediate investigations and authority to compel treatment.

For example, in Application of Cicero, 421 N.Y.S. 2d 965 (1970), the child was born with spina bifida. Without an operation, it was unlikely that the child would live to the age of six months. The parents elected not to have the surgery and the court reversed this decision stating:

> This is not a case where the court is asked to preserve an existence which cannot be a life. What is asked is that a child born with handicaps be given a reasonable opportunity to live, to grow, and hopefully to surmount those handicaps. Id. at 937.

The court further noted the argument that this would interfere with the parents' rights to control the upbringing of their child but found that such parental rights are not absolute "where, as here, a child has a reasonable chance to live a useful, fulfilled life." Id. at 968.

The requirement imposed by state law that health care providers report instances of improper denial of medical care is no less a part of their program than is the provision of care itself. Both arise from the recipient's program of administering to the medical interests of its patients. Section 504 prohibits discrimination on the basis of handicap in the operation of federally-assisted programs and activities. Thus, a recipient which as a matter of practice or law reports to state authorities the withholding of needed medical treatment from an infant may not deny the same service or benefit to a qualified handicapped infant because the infant is handicapped. 45 C.F.R. 84.4(b)(1), 84.52(a).

Accordingly, while recipients may be restricted in their provision of treatment by the lack of parental consent, it is no less their obligation to operate their program without discrimination. This includes the obligation to report to appropriate officials instances of parental refusal to consent to the provision of necessary medically indicated treatment and to cooperate with those officials while continuing to provide all care not disallowed by the parents.

For quick and effective response to complaints, the Secretary counts on not only the enforcement resources of the Federal Government, but also on the assistance of state child protective agencies, which can respond quickly and effectively to referrals from the Federal Government, and which are often closest to the scene for speedy investigation of life-threatening child abuse and neglect. The Secretary intends to contact state child protective agencies whenever a complaint is received that falls within the definition of child abuse or neglect, in order to give States an opportunity to make their own investigation and to take appropriate action.

The Secretary expects that States will follow all necessary procedures for investigating allegations of child abuse and neglect that involve an imminent danger to life. State child protective agencies that receive federal financial assistance are under the same obligation as other recipients not to provide a qualified handicapped person with benefits or services that are less effective than those provided to others.

For those complaints that are expeditiously and effectively investigated and pursued by State agencies, the Secretary anticipates that additional federal efforts will often be unnecessary. The Secretary will closely monitor all investigation and enforcement activity taken pursuant to complaints. The

Secretary will make available to State agencies any information and assistance that is helpful and appropriate. For those cases where direct federal action appears helpful, the Secretary will have at her disposal the usual means of federal civil rights enforcement.

In order to conduct immediate investigations and to make immediate referrals to the Department of Justice for such legal action as may be necessary to save the life of a handicapped child who is subjected to discrimination by a recipient, the Department proposes to amend 45 C.F.R. 80.8 as referenced by 45 C.F.R. 84.61 which sets forth procedures for the Secretary to effect compliance with Section 504, including referrals to the Department of Justice for the initiation of appropriate legal proceedings. The existing regulations require a 10-day waiting period from the time the Secretary notifies a recipient of its failure to comply to the time the Secretary makes a referral to the Department of Justice or takes other legal action to effect compliance. When a handicapped infant is being denied food or other necessary medical care, however, more expeditious action is required. The proposed regulation creates a narrow exception to the 10-day waiting period when in the judgement of the responsible Department

official, immediate remedial action is necessary to protect the life of a handicapped individual.

A recipient of federal financial assistance must not only comply with the requirements established by the federal statute, but must also provide access to information pertinent to ascertain compliance with Section 504.

45 C.F.R. 80.6(c) as incorporated by 45 C.F.R. 84.61, clearly states that, "asserted considerations of ... confidentiality may not operate to bar" the Department from seeking access to sources of information. Thus, a reading of the existing Section 504 regulations discloses a clear intent that records kept by recipients be subject to disclosure to ascertain compliance. The disclosure of records to ascertain compliance is one of the requirements a recipient must comply with to obtain and then continue to receive federal funding. 45 C.F.R. 80.8(a) as incorporated by 45 C.F.R. 84.61. The Supreme Court has observed:

> Disclosures of private medical information ... to public health agencies are often an essential part of modern medical practice ... Requiring such disclosures to representatives of the State having responsibility for the health of the community does not automatically amount to an impermissable invasion of privacy." (Whalen v. Roe 429 U.S. 589, 602.

The Department has for over a decade balanced its need to gain access to medical information under the various civil rights statutes it administers, including Section 504 with the need to perserve confidentiality and it continues to be sensitive to such concerns.

> Information of a confidential nature obtained in connection with compliance evaluation or enforcement shall not be disclosed except where necessary in formal enforcement proceedings or where otherwise required by law." (45 C.F.R. 80.6(c)).

In addition, the confidentiality of medical records obtained in the course of a Section 504 investigation will be protected through nondisclosure under the Freedom of Information Act; the deletion of patient's and parents' names and other identifying information to the extent such deletion does not impede the Department's ability to ascertain compliance; and a special and separate filing system maintained in locked files.

In regard to access to medical records, the Department proposes only a limited modification of its existing ability to gain access to such records to assure compliance with Section 504.

45 C.F.R. 80.6(c), as referenced by 45 C.F.R. 84.61 requires each recipient to permit access by Department officials to facilities and information pertinent to ascertaining compliance with Section 504, during normal business hours. Allegations of denial of food or other necessary medical care to handicapped infants may require an immediate effort to ascertain compliance. The Department's proposed change provides that access to records and facilities of recipients shall not be limited to normal business hours when, in the judgement of the responsible Department official, immediate access is necessary to protect the life or health of a handicapped individual.

The May 4, 1977, regulations of the Department regarding Section 504 incorporate by reference the procedural provisions applicable to Title VI of the Civil Rights Act of 1964. These procedures provide in part:

> "information to beneficiaries and participants. Each recipient shall make available to participants, beneficiaries, and other interested persons such information regarding the provisions of this regulation and its applicability to the program for which the recipient receives Federal financial assistance, and make such information available to them in such manner, as the responsible Department official finds necessary to apprise such persons of the protections against discrimination assured them by the Act and this regultation." (45 C.F.R. 80.6(d)).

45 C.F.R. 80.6(d), as referenced by 45 C.F.R. 84.61, which requires recipients to make available such information, in such a manner, as the Department finds necessary to apprise appropriate persons of the protections afforded under Section 504. The proposed regulation specifies the type of information and manner of posting that is necessary to bring the protections of Section 504 for handicapped infants to the attention of those persons within the recipient program or activity who are most likely to have knowledge of possible violations as they occur. The requirement with regard to the posting of notices is a time-honored and reasonable method for providing notice to concerned individuals with respect to civil rights protections now utilized under a variety of programs (Cf., the Contract Compliance Program administered by the Department of Labor pursuant to E.O. 11246; Title VII of the Civil Rights Act of 1967).

In addition, the purpose of the proposed posting requirement is to acquire timely information concerning violations of Section 504 that are directed against handicapped infants, and to save the life of the infant. The Secretary believes that those having knowledge of violations of Section 504 against handicapped infants do not now have adequate opportunity to give immediate notice to federal authorities. A telephone complaint procedure can provide information to federal authorities in time to save the life of a handicapped infant who is being discriminatorily denied nutrition in a federally assisted program or activity.

Federal enforcement action can also be taken against any recipient that intimidates or retaliates against any person who provides information concerning possible violations of Section 504 45 C.F.R. 80.7(e), as referenced by 45 C.F.R. 84.61, prohibits intimidatory or retaliatory acts by recipients against individuals who make complaints or assist in investigations concerning possible violations of Section 504. This provision fully protects individuals who make compliants or assist in investigations concerning possible withholding of food or other necessary medical care from handicapped infants.

This proposed regulation does not in any way change the substantive obligations of health care providers previously set forth in the statutory language of Section 504, in the implementing regulations, and in the Notice to Health Care Providers. The proposed regulation sets forth procedural specifications designed (1) to specify a notice and complaint procedure, within the context of the existing regulations, and (2) to modify existing regulations to recognize the exigent circumstances that may exist when a handicapped infant is denied food or other necessary medical care.

Comments solicited. The Secretary seeks public comment on all aspects of the proposed regulation and on the appendix to the proposed regulations, especially on those categories cited in the appendix as clear violations of Section 504 and on additional situations that may represent clear violations of Section 504. Comments will be considered and modifications made, as appropriate, following the comment period.

The Secretary also solicits comments on the following questions:

1. Should recipients providing health care services to infants be required to perform a self-evaluation, pursuant to 45 C.F.R. 84.6(c)(1), with respect to their policies and practices concerning health services to handicapped infants?

2. Should such recipients be required to identify for parents of handicapped children born in their facilities those public and private agencies in the geographical vicinity that provide services to handicapped infants?

3. Should recipients be required to institute internal review boards, such as were suggested by the report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, to review cases where the parents and/or physician have decided to withhold life-sustaining treatment? If so, should this be an alternative or an addition to the requirements of the proposed rule? If it is proposed to be an alternative, what procedures should the Department follow to meet its responsibilities under existing law and regulations to investigate complaints and effect compliance with Section 504?

4. Should existing procedures requiring prompt investigations of complaints of violations of Section 504 relating to health care for handicapped infants be revised? If so, how should these investigations be conducted so as to assure timely and effective investigations while minimizing any disruptive impact on the hospital?

5. As indicated above, Section 504 requires that medically beneficial treatment not be withheld on the basis of handicap. Are there further explanations which would assist health care providers and the public in understanding the requirements of Section 504 in connection with health care for handicapped infants?

6. Are there implications concerning cost and the allocation of medical resources in requiring that medically indicated treatment not be withheld from infants solely on the basis of handicap which are different from the implications inherent in all cases of determining the appropriate course of treatment for patients? If so, what are examples of cases where medically indicated treatment would, but for the legal requirements of Section 504, be withheld? In such cases, is cost or resource allocation the reason medically indicated treatment would be withheld?

7. In balancing the interests of parents in deciding matters relating to their children with the interests of the government in protecting the lives of all of its citizens, if the appropriate dividing line is not the deprivation of life-sustaining, medically indicated treatment, what should the dividing line be? Is there disagreement with the Department's position that the fact that a handicapped infant may

be unwanted by parents due to perceived economic, emotional and marital effects does not justify the deprivation of life-sustaining, medically indicated treatment?

8. In addition to the existing safeguards, explained above, regarding the confidentiality of information obtained by HHS in connection with civil rights investigations, are there other safeguards which should be implemented?

9. Are there other alternative means for the Department to meet its responsibilities to implement and enforce Section 504 in connection with health care for handicapped infants?

Part 84--(Amended)

45 C.F.R. 84.61 is proposed to be amended by designating the existing provision as paragraph (a) and by adding paragraphs (b), (c), and (d) to read as follows:

S. 84.61(Amended)

(b) Pursuant to 45 C.F.R. 80.6(d), each recipient that provides covered health care services to infants shall post and keep posted in a conspicuous place in each nurses' station with responsibility for each delivery ward, each maternity ward, each pediatric ward, and each nursery, including each intensive

care nursery, which shall be no smaller than 8-1/2 by 11 inches, the following notice:

DISCRIMINATORY FAILURE TO FEED AND CARE FOR HANDICAPPED INFANTS

IN THIS FACILITY IS PROHIBITED BY FEDERAL LAW

Section 504 of the Rehabilitation Act of 1973 states that no otherwise qualified handicapped individual shall, solely by reason of handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

Any person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should immediately contact:

Handicapped Infant Hotline
U. S. Department of Health and Human Services
Washington, D. C. 20201
Phone: 800---368-1019 (Available 24 hours a day)
or
Your State Child Protective Agency

Federal law prohibits retaliation or intimidation against any person who provides information about possible violations of the Rehabilitation Act of 1973.

Identity of callers will be held confidential.

Failure to feed and care for infants may also violate the criminal and civil laws of your State.

(1) Recipients shall add to the notice, in type face or handwriting, under the words "Your State Child Protective Agency," the identification of an appropriate State agency, with address and telephone number. No other alterations shall be made to such notice.

(2) Copies of such notice may be obtained on request from the Department of Health and Human Services.

(c) Notwithstanding the provisions of paragraph (a), the requirement of 45 C.F.R. 80.8(d)(3) shall not apply when, in the judgement of the responsible Department official, immediate remedial action is necessary to protect the life or health of a handicapped individual.

(d) Notwithstanding the provisions of paragraph (a), access to pertinent records and facilities of a recipient pursuant to 45 C.F.R. 80.6(c) shall not be limited to normal business hours when, in the judgement of the responsible Department official, immediate access is necessary to protect the life or health of a handicapped individual.

APPENDIX

Applicability of Section 504 to the Provision of Health Care to Handicapped Infants

By a notice to Health Care Providers dated May 18, 1982, the Department reminded hospitals that Section 504 of the Rehabilitation Act of 1973 (29 U.S.C. Section 794) applies to the provision of health care services to handicapped infants. Regulations in effect since 1977 have applied Section 504 to providers of health services. (45 C.F.R. Sections 84.51-52). The protections of Section 504 apply to all handicapped persons without regard to age.

The following comments are intended to explain the manner in which Section 504 applies to the provision of health care services to handicapped infants.

The Notice to Health Care Providers of May 18, 1982, explained that under Section 504 "it is unlawful for a recipient of federal financial assistance to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition, if:

(1) the withholding is based on the fact that the infant is handicapped; and

(2) the handicap does not render the treatment or nutritional sustenance medically contraindicated."

The Secretary's experience in enforcing this standard, along with comments received by the Department, suggest a need to clarify in what situations Section 504 does and does not apply.

Section 504 is in essence an equal protection, nondiscrimination standard. Congress expressly intended Section 504 to prohibit discrimination based on handicap in the same way that Title VI of the Civil Rights Act prohibits discrimination based on race. Programs or activities receiving federal financial assistance may not deny a benefit or service on grounds of a person's handicap, just as they may not deny a benefit or service on grounds of a person's race.

Regulations governing federally assisted health care providers implement the nondiscrimination approach of Section 504 by stating that "a recipient may not, on the basis of handicap ... (d)eny a qualified handicapped person these benefits or services ...." 45 C.F.R. Section 84.52(a).

Section 504 applies when (1) a handicapped person is qualified to receive benefits or services from a federally assisted program or activity and (2) these benefits or services are denied because of the person's handicap.

In the context of health care services provided to handicapped infants, a handicapped infant is qualified to receive those benefits and services that are (1) generally provided by the program or activity, and (2) are appropriate, in the exercise of reasonable medical judgement, to the circumstances of the particular handicapped infant.

Section 504 does not intrude upon legitimate medical judgement. A handicapped infant is not "qualified" to receive medical care or treatment that is contrary to reasonable medical judgement -- i.e., "medically contraindicated."

Not all judgements made by a health care provider, however, are medical judgements. For example, a judgement not to treat a black infant because of the infant's race is not a medical judgement. A judgement not to treat a physical complication in a Down's Syndrome infant because the infant suffers the handicap of Down's Syndrome is likewise not a medical judgement.

The Secretary does not interpret Section 504 to apply to any case in which care or treatment is withheld on the basis of legitimate medical judgement. If a particular form of treatment is of dubious medical benefit to the patient or if the patient could not long survive even with the treatment, reasonable medical judgement could withhold the treatment, and Section 504

does not require that the treatment be given. Section 504 does not compel medical personnel to attempt to perform impossible or futile acts or therapies. Thus, Section 504 does not require the imposition of futile therapies which merely temporarily prolong the process of dying of an infant born terminally ill.

For example, a child born with anencephaly will inevitably die within a short span of time; therefore, treatment to correct life-threatening complications may be withheld. Such withholding is on the basis of the legitimate medical judgement that the child would die imminently even with the treatment. The decision to withhold treatment is therefore not based on handicap, and is not prohibited by Section 504.

Also, a decision to withhold extraordinary care from an extremely low-birthweight infant does not implicate Section 504 if the decision is based on a reasonable medical judgement concerning improbability of success in a course of treatment, or risks and potential harm in the course of treatment.

At the same time, the basic provision of nourishment, fluids, and routine nursing care is a fundamental matter of human dignity, not an option for medical judgement. Even if a handicapped infant faces imminent and unavoidable death, no

health care provider should take upon itself to cause death by starvation or dehydration. Routine nursing care to provide comfort and cleanliness is required to respect the dignity of such an infant. To deny these forms of basic care to handicapped individuals would constitute discrimination contrary to Section 504.

For those handicapped infants, on the other hand, who could live if given treatment for a life-threatening congenital anomaly, any decision to withhold treatment which is based on the infant's handicap rather than on a medical judgement, constitutes discrimination contrary to Section 504. Sector 504 prohibits any denial of benefits or services because of a handicap such as mental retardation, blindness, paralysis, deafness, or lack of limbs. Any judgement that a person is not worthy of treatment due to such handicap is not, of course, a medical judgement, even if made by doctors within a medical facility.

A clear violation of Section 504 occurs if a federally assisted program or activity denies a benefit or service to a handicapped infant that would be provided but for the individual's handicap. The Secretary deems the following to be examples -- not a comprehensive list -- of denials of treatment that constitute a violation of Section 504:

1. Down's Syndrome with intestinal obstruction, denial of surgery to correct obstruction. Current medical practice in the United States is to correct intestinal atresia in infants with no other congenital anomaly. See 60 Pediatrics 588, 591 (1977). Any decision not to correct intestinal atresia in a Down's Syndrome child, unless an additional complication medically warrants such decision, must be deemed a denial of services based on the handicap of Down's Syndrome. The same reasoning applies to a case of Down's Syndrome with esophogeal atresia, denial of surgery to correct atresia. Any refusal to give treatment to a Down's Syndrome infant for other physical complications, such as operable heart defects, if such complications would be treated for children without Down's Syndrome, similarly constitutes a violation of Section 504.
2. Denial of care or treatment that would be given to a non-handicapped infant, on grounds that a particular infant is potentially mentally impaired, or blind, or deaf, or paralyzed, or lacking limbs, or impaired in any other major life activity.
3. Denial of treatment for medically correctable physical anomalies in children born with Spina Bifida, when such denial is based on anticipated mental impairment, paralysis,

or incontinence of such child, rather than on reasonable medical judgements that treatment would be futile or too unlikely of success given complications in the particular case.

4. Denial of food or fluids to any handicapped infant, except in cases where such care would be harmful to the infant.

TAB C

INFANTICIDE WORKING GROUP MEMBERS

DEPARTMENT OF HEALTH & HUMAN SERVICES

John A. Svahn
Carl Anderson
Juan del Real
John Casciotti
Betty Lou Dotson
George Siguler
C. Everett Koop

DEPARTMENT OF JUSTICE

Bradford Reynolds
Richard Willard
Neil Koslowe
Mark Disler

EXECUTIVE OFFICE OF THE PRESIDENT

Becky Norton Dunlop
Stephen Galebach
Peter Rusthoven
William Barr
John Cogan
Ken Clarkson

LIST OF ATTENDEES
FOR APRIL 29, 1983 MEETING

AMERICAN ACADEMY OF PEDIATRICS

James Strain, M.D. - President
George Little, M.D. - Chairman, Fetus & Newborn Committee

AMERICAN MEDICAL ASSOCIATION

Dorothy Moss - Assistant Director, Dept. of Federal Affairs
Randy Fenninger - Counsel

NATIONAL ASSOCIATION OF CHILDRENS HOSPITALS

Robert Sweeney - President
Robert Grett, M.D. - Past Chmn. & Chmn. of Task Force on Medical Ethics

AMERICAN HOSPITAL ASSOCIATION

Richard Epstein - Senior Vice President
James Marrinan - Director, Federal Agency Affairs

FEDERATION OF AMERICAN HOSPITALS

Mary Grealy - Legislative Counsel

CHILDREN'S HOSPITAL NATIONAL MEDICAL CENTER

Robert H. Parrott, M.D. - Director
Anne Fletcher - Director of the Nursery

NATIONAL PERINATAL ASSOCIATION

George K. Degnon - Executive Director

AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS

Ervin E. Nichols, M.D. - Director, Practice Activities

LIST OF ATTENDEES
FOR MAY 3, 1983 MEETING

ASSOCIATION FOR RETARDED CITIZENS

Paul Marchard - Director of Governmental Affairs Office
Martin Gerry

DISABILITY RIGHTS CENTER

Tom Neerney - Fellow at the Kennedy Foundation

DISABILITY RIGHTS EDUCATION AND DEFENSE FUND

Craig Coble - Research Consultant

AMERICANS UNITED FOR LIFE

Burke Balch

AMERICAN LIFE LOBBY

Gary Curran

CHRISTIAN ACTION COUNCIL

Doug Badger

NATIONAL RIGHT TO LIFE COMMITTEE

Janet Carroll - Associate Legislative Director
William Olson

SPINABIFIDA ASSOCIATION

Martin Holtz

DOWN SYNDROME CONGRESS

Greg Weigle - Board of Directors

AD HOC COMMITTEE IN DEFENSE OF LIFE

Robert Tobin