STATEMENT
of
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on behalf of the
COMMITTEE FOR PRO-LIFE ACTIVITIES
of the
NATIONAL CONFERENCE OF CATHOLIC BISHOPS

before the
SUBCOMMITTEE ON SELECT EDUCATION
of the
COMMITTEE ON EDUCATION AND LABOR
U.S. HOUSE OF REPRESENTATIVES

Oversight Hearings Regarding
the Treatment of Infants Born
with Handicapping Conditions

October 1982
On behalf of the Committee for Pro-Life Activities of the National Conference of Catholic Bishops, I thank the Subcommittee for allowing us to submit this written statement on H. R. 6492, the Handicapped Infants Protection Act. In the event that further hearings are held on this legislation in the 98th Congress, I respectfully request that a representative of the bishops' conference be allowed to present additional testimony at that time.

As moral and religious leaders, the Catholic bishops of the United States have much to say about the values which H. R. 6492 attempts to express. Our interest in this legislation is all the stronger because of the special circumstances in which it has arisen. In testifying before Congress on three separate occasions on behalf of a Human Life Amendment, we have warned that the moral and legal reasoning of the U. S. Supreme Court's abortion rulings was eroding our society's respect for the lives of the handicapped and the elderly. Now, only a few months after our most recent testimony on this matter -- in which we warned that the fatal neglect of handicapped newborns was becoming more prominent and even routine in some intensive-care nurseries -- we find ourselves testifying on legislation addressing just this kind of gross neglect. We support this legislation and commend those who have introduced it, yet we regret that this destructive national trend has continued until a particularly obvious case of judicially sanctioned infanticide brought the matter to national attention. The tragic death in Bloomington, Indiana, of the handicapped child known as "Infant Doe" is doubly tragic if it serves as a barometer for our true national attitude toward handicapped children. Some good may still come of that death.
if we take its warning to heart and re-direct our nation toward respect for all defenseless human life.

Federal legislation dealing with children in general, and with handicapped children in particular, already contains many provisions worthy of praise. The Child Abuse Prevention and Treatment Act of 1978 recognized that child abuse and neglect are national problems warranting standardized prevention and treatment provisions. The Rehabilitation Act of 1973, and other legislation insuring services for handicapped Americans, indicates that we feel a public responsibility to give to every child, whatever his or her disability, the necessary means for survival and self-advancement.

We support the goals of such legislation. Indeed, we feel that further efforts are needed toward these goals, so that every child in the United States may be able to make the best use of his or her talents regardless of disability or family background. Yet such efforts are ultimately doomed to failure if they do not rest on an unconditional respect for the very lives of these children.

The principle behind all child abuse legislation -- that the State must protect defenseless children even when threatened by their own parents -- becomes empty if it does not extend to handicapped children, who are even more defenseless than their more fortunate brothers and sisters. Laudable attempts to provide education, employment, and other opportunities to the handicapped are without foundation, if we are unwilling to defend the handicapped infant's right to survive long enough to make use of such resources. The right to life, aptly described by some jurists as "the right to have rights," must be the firm basis for all other rights and opportunities.
The Catholic Church has witnessed to its convictions on this point in a number of statements on the rights of handicapped people. The American Bishops' Pastoral Statement on Handicapped People of 1978\(^2\) observed that the first and most fundamental of human rights is the right to life, and that the defense of the right to life of handicapped persons is "a matter of particular urgency," because handicapping conditions are increasingly seen as a justification both for abortion and for the denial of "ordinary and usual medical procedures" after birth:

All too often, abortion and postnatal neglect are promoted by arguing that the handicapped infant will survive only to suffer a life of pain and deprivation. We find this reasoning appalling. Society's frequent indifference to the plight of handicapped citizens is a problem that cries aloud for solutions based on justice and conscience, not violence. All people have a clear duty to do what lies in their power to improve living conditions for handicapped people, rather than ignoring them or attempting to eliminate them as a burden not worth dealing with.

This statement was echoed on March 12, 1981, when the Vatican published its Statement on the International Year of Disabled Persons.\(^3\) The Holy See observed that "since the person suffering from handicaps is a subject with full rights, he or she must be helped to take his or her place in society in all aspects and at all levels as far as is compatible with his or her capabilities." This statement quoted secular documents to indicate the continuity between Church teaching and a common human commitment to the rights of human beings. For example, the United Nations' Declaration of the Rights of the Disabled states in section 3:

Disabled persons have the right to respect for their human dignity. Disabled persons, whatever the origin, nature and seriousness of their handicaps and disabilities,
have the same fundamental rights as their fellow citizens of the same age, which implies first and foremost the right to enjoy a decent life as normal and full as possible.

The Holy See's document went on to comment:

One cannot but hope that such statements as those of the declaration cited will be given full recognition in the international and national communities, avoiding limiting interpretation and arbitrary exceptions and perhaps even unethical applications which end by emptying the statements of meaning and import.

One way in which such lofty declarations could indeed be emptied of meaning is by tolerating abortion for the handicapped child before birth and deliberate neglect after birth. Besides condemning the practice of eugenic abortion as an attack upon human dignity, the Holy See stated:

The deliberate failure to provide assistance or any act which leads to the suppression of the newborn disabled person represents a breach not only of medical ethics but also of the fundamental and inalienable right to life.

The transcendent importance of defending this right with regard to severely handicapped persons was also highlighted:

One cannot at whim dispose of human life by claiming an arbitrary power over it. Medicine loses the title of nobility when instead of attacking disease, it attacks life; in fact prevention should be against the illness, not against life. One can never claim that one wishes to bring comfort to a family by suppressing one of its members. The respect, the dedication, the time and means required for the care of handicapped persons, even those whose mental faculties are gravely affected, is the price that a society should generously pay in order to remain truly human.

Thus the Church does not see this as a debate over whether handicapped newborns are "fully human" or whether they have a sufficient "quality of life" to be accorded human rights and reasonable medical care. This is not a debatable matter. The
denial of rights to these newborns in accordance with a false "quality of life" ethic is incompatible not only with Judeo-Christian ethical principles but also with national and international declarations on human rights. The true question under debate is whether American society is sufficiently "human" to live up to its responsibilities in this area, which include protection of the right to life in the face of threatened medical neglect -- although our responsibilities do not cease with that protection but continue throughout the life of every handicapped person.

A genuine defense of the rights of handicapped persons, then, begins with their right not to be discriminated against with regard to nutrition and basic medical care. This principle, grounded in the conviction that all human beings have innate dignity, is entirely consistent with Catholic ethical teaching on euthanasia and the withdrawal of medical treatment. But since some have imagined that Catholic morality could justify the withdrawal of treatment and nutrition from handicapped newborns, it is appropriate to re-state briefly what the Catholic Church teaches with regard to life-prolonging treatment. The basic principles involved are as follows:

(1) Euthanasia is a violation of the fundamental right to life, and is absolutely forbidden. By "euthanasia" is meant an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated.4

(2) A patient is morally obliged to seek "ordinary" treatment -- i.e., treatment which can be of real benefit and which is not
excessively burdensome. One is not morally obliged, but is certainly permitted, to accept treatment which is complex, burdensome, and of uncertain benefit. Physicians generally have an obligation to supply the treatment that a patient reasonably requests.

(3) In the case of a child or mentally incompetent patient who cannot choose for himself, those who make the decision should endeavor to choose as the patient himself would if he were able to do so. As a general rule one should look to the decisions made by others who are in similar situations, and assume that the patient would make decisions in his own best interests. In this regard, the Church has never accepted the claim that handicapped people would refuse treatment ordinarily chosen by others, or more generally that they have any less will to live. All the evidence, in fact, points to the opposite conclusion.5

The application of these principles to cases such as "Infant Doe" is fairly straightforward. If public accounts of the Indiana case are accurate, this was a clear case of both invidious discrimination and involuntary euthanasia, and fine distinctions concerning the use of "ordinary" and "extraordinary" means are not even appropriate.6 Parents and physicians were faced with two clear courses of action. Expert medical testimony indicated that Infant Doe required a simple surgical procedure in order to take nourishment orally. The countervailing testimony -- to which the courts deferred -- argued not that the treatment was unusually dangerous or burdensome, but that the life which would almost surely be saved by treatment did not have the "minimal quality of life" that would make it worth living. In accordance with this second approach, the child was
deprived not only of surgery, but even of the intravenous feedings which would have kept him alive until surgery could be ordered.

Both sides in this court dispute, then, agreed that this was a clear choice between life and death for the child; the side that prevailed, however, considered insuring the child's death as one "medical option" among others, and therefore as a choice best left to the parents. Infant Doe's handicap was not itself life-endangering, and played no role in the infant's death except insofar as it decreased the willingness of parents and courts to care for him. The "treatment" of complete neglect did, in fact, have its clearly intended effect of causing the child's death by starvation. Although achieved by omission of the necessary means for survival, rather than by invasive action, this particular case seems best referred to simply as infanticide or as involuntary euthanasia.

Even if one were to present such cases in terms of "ordinary" and "extraordinary" treatment, the result in the Infant Doe case would be equally unacceptable. The treatment in question would obviously have been considered "usual and ordinary" for a child not affected by Down's Syndrome, and the existence of this disability did not make the treatment more difficult or less effective. It is thus precisely the sort of unjustified and invidious discrimination against the handicapped child that we rejected in our Pastoral Statement on Handicapped People of 1978.

Some forms of medical neglect addressed by H. R. 6492 might not clearly fall under the category of involuntary euthanasia, but would still constitute this kind of unwarranted discrimination against the handicapped in cases where treatment would have been ordered for other children in similar situations. This legislation
seems consistent with Catholic teaching in this area, as it seems to forbid only those forms of neglect which the Church rejects as fundamentally unjust.

A brief glance at American law on medical treatment for children and other dependent individuals reveals that the moral principles stated above are well represented in our country's legal traditions. The case could hardly be otherwise, since moral principles such as those stated above have guided Western jurisprudence for hundreds of years. So clear and strong is the tradition on these matters that congressional failure to clarify federal law along the lines now under consideration could only be interpreted as a step backward in our nation's defense of the helpless.

Parents' responsibility for the care and support of their children -- including all reasonable medical treatment -- has long been recognized in common law. As the 18th century jurist Blackstone remarked,

The duty of parents to provide for the maintenance of their children, is a principle of natural law; an obligation...laid on them not only by nature herself, but by their own proper act, in bringing them into the world: for they would be in the highest manner injurious to their issue, if they only gave their children life that they might afterwards see them perish. By begetting them, therefore, they have entered into a voluntary obligation to endeavor, as far as in them lies, that the life which they have bestowed shall be supported and preserved. And thus the children will have the perfect right of receiving maintenance from their parents....The municipal laws of all well-regulated states have taken care to enforce this duty: though Providence has done it more effectively than any laws, by implanting in the breast of every parent...that insuperable degree of affection, which not even the deformity of person or mind, not even the wickedness, ingratitude, and rebelling of children, can totally suppress or extinguish.
Statutory provisions assuring such treatment to children date from at least the nineteenth century in both Britain and the United States. Since that time, state and federal courts in the U. S. have consistently reaffirmed that the State has power to order life-saving medical treatment for children whose parents are unwilling or unable to provide it. The guiding attitude was aptly expressed by the New York Court of Appeals in 1903:

Children, when born into the world are utterly helpless, having neither the power to care for, protect or maintain themselves. They are exposed to all the ills to which flesh is heir, and require careful nursing, and at times when danger is present, the help of an experienced physician. But the law of nature, as well as the common law, devolves upon the parents the duty of caring for their young in sickness and in health, and of doing whatever may be necessary for their care, maintenance, and preservation, including medical attendance, if necessary; and an omission to do this is a public wrong, which the state, under its police powers, may prevent.

The chief principles laid down by our legal system in this area may be summarized as follows:

(1) The "parens patriae" power of the state extends without question to cases in which parents have failed to give proper medical care to their children. Even where parents may not be criminally liable, because of sincere good intentions or other reasons, this does not mean that the State is helpless to protect the children involved. Conversely, the fact that the State sees a need to take temporary custody of a child and provide certain care does not necessarily imply that parents are generally unfit or neglectful or that they must permanently lose custody of the child. This aspect of the issue at hand should receive particular emphasis. The intent of most legislation in this area, certainly including
H. R. 6492, is not to be punitive against parents but to help children when necessary.  

(2) The State's responsibility to provide proper care for children is universally recognized to extend to emergency medical treatment required to save a child's life, regardless of parents' opposition to such treatment. There is somewhat less unanimity on the ordering of treatment where neglect would constitute a threat to general well-being but not to the child's life; but even here, parents' refusal of treatment has often been overruled by courts for the sake of the child's best interests. Medical testimony has been relevant to such cases as a means for determining whether the condition is indeed a serious danger to life or health, and whether the proposed treatment does indeed have a good possibility of curing the condition or reasonably prolonging life. There is no support in American legal history for allowing physicians in such cases to determine that certain lives are or are not "worth living."

(3) Public responsibility for protecting children from gross neglect overrides even our constitutional protections for the parents' freedom of conscience or religion. This question has most often been raised with regard to blood transfusions ordered for the children of Jehovah's Witnesses. The basic rule applicable here is that while freedom of belief or conscience is absolute, freedom of action based on belief is not, particularly where such action would result in death or serious injury to others. The U. S. Supreme Court's ruling in Prince v. Massachusetts has been quoted in dozens of rulings on medical treatment for children:
The right to practice religion freely does not include liberty to expose the community or child to communicable disease or the latter to ill health or death...Parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves.12

This principle was held in Prince to apply even where children might be exposed to ill health by participation in their parents' religious pamphleteering on public streets. Lower courts have rightly remarked that an a fortiori argument exists for the State's power to order life-prolonging treatment for children, even against their parents' sincere religious objections.

Since the Catholic Church has a strong interest in the defense of religious freedom, this aspect of the legal issue deserves a few additional observations to prevent misinterpretation:

(a) Although the principle of State interference with matters of religious worship is certainly open to abuse, its application in this case does not conflict with Catholic teaching on religious freedom. As stated in the Second Vatican Council's Declaration on Religious Liberty, the Church recognizes that religion is exercised in human society and therefore is subject to certain "regulatory norms" protecting the common good:

In availing of any freedom men must respect the moral principle of personal and social responsibility: in exercising their rights individual men and groups are bound by the moral law to have regard for the rights of others, their own duties to others, and the common good of all. All men must be treated with justice and humanity.13

The situations contemplated by the legislation now under consideration clearly fall under the category of legitimate government interest in protecting the rights of the defenseless.
(b) It should also be emphasized that the courts which developed this line of argument had no intention of expressing a disrespect for or indifference toward religious values. On the contrary, they saw their responsibility to protect children from parents' neglect as being intensified by their recognition that these children's rights were God-given and hence inviolable. This was succinctly expressed in 1952 by the Kansas City Court of Appeals:

Every human being is endowed by God with the inalienable right to live. The fact that the subject is the infant child of a parent who, arbitrarily, puts his own theological belief higher than his duty to preserve the life of the child cannot prevail...\textsuperscript{14}

This viewpoint is not anti-religious, but is a defense of our common rights and responsibilities under God against abuses of religious freedom.

(c) We believe that these "religious freedom" cases are applicable to the tragic case of Infant Doe, although the connection might not be immediately apparent to some. The testimony to which the Indiana courts deferred, and which was used to justify the medical neglect of this child, was not "medical testimony" in any real sense. Rather, it was ideological testimony, given by a physician whose area of specialty was not even relevant to the determination of the infant's medical needs. The ideology in question urged approval of a "quality of life" ethic, in which a human being's possession of full human rights is made to depend on certain mental and physical perfections.\textsuperscript{15} Such a viewpoint is no more "scientific", no less based on belief or value judgment, than any other religious or ethical conviction, and therefore should have no rights that are not given to other judgments of conscience.
Further, such a viewpoint is much more directly inimical to our nation's stated commitment to human rights than any religion involved in the medical treatment cases under discussion. At the very least, therefore, an American court should have rejected this ideology as having no effect on the helpless child's need for medical attention or on the State's responsibility to order that treatment.

This brings us to the final aspect of American legal traditions on this issue.

(4) The State's responsibility to provide proper care and medical treatment for neglected children is valid for children of every age and condition, including the handicapped. This principle should be self-evident, for the drawing of an exception here in order to exclude handicapped children from the law's protection would be grossly unjust. Courts have recognized this and ordered treatment even in cases where legitimate medical disagreement existed over the benefits and burdens of treatment. In the famous Phillip Becker case, custody of a 14-year old boy with Down's Syndrome was given to a sympathetic couple referred to in the ruling as his "psychological parents," so that they could order difficult heart surgery which had been refused by the boy's biological parents; the latter had expressed unwillingness to order treatment which would insure the boy's survival after their own deaths, in part because of their concern over the "quality of life" he might expect in an institution. The New York Appeals Court has ordered blood transfusions for a mentally retarded adult whom it considered as a mental child, overruling the objections of the man's mother and guardian despite claims that the treatment was somewhat burden-
some and of uncertain benefit. Judges have even ordered medical treatment for unborn children over their parents' objections, and this trend has continued despite the virtually absolute legalization of abortion by the U. S. Supreme Court. The straightforward situation addressed by H. R. 6492 -- that of life-saving treatment which is part of usual and ordinary medical practice -- is clearly not problematic in our legal system.

Court rulings which have allowed withdrawal of treatment from mentally incompetent patients do not, in our view, present any conflict with the legal trend we have discussed. Such rulings have generally been very narrowly drawn, dealing primarily with situations in which patients who are already terminally ill are confronted with treatment which is particularly burdensome or which holds doubtful chances of recovery or of a reasonable prolongation of life. These difficult or marginal cases are not directly addressed by H. R. 6492.

In short, Congress has strong precedent in prior court rulings for deciding that equitable medical treatment for handicapped infants is an important and legitimate concern of our public policy. Although state legislation already exists which touches on the issue of child abuse and neglect, the Indiana Supreme Court's actions -- as well as the less visible but very real practice of infanticide in intensive-care nurseries in other states -- indicate that the law requires clarification. And since this is a matter touching upon the fundamental rights of the handicapped person, it requires federal involvement in order that certain basic principles of justice and uniformity be maintained. The existence of federal
legislation on the civil rights of the handicapped and on child abuse and neglect indicates that enactment of H. R. 6492 would be a helpful clarification of the existing legislative framework rather than a radical departure.

In conclusion, we suggest a three-pronged response by Congress to the plight of handicapped newborns whose lives are threatened by medical neglect.

First, we urge enactment of H.R. 6492 or comparable legislation as soon as possible. The final weeks of the 97th Congress offer an excellent opportunity for discussions as to technical improvements, so that this bill can be re-introduced and enacted during the 98th Congress in the best possible form.

Second, this defense of the lives of handicapped children should be backed up by continuing and increased concern for programs to help their parents assume the special burdens and responsibilities of caring for them. Federal policies should not only help each child to survive, but also assist in developing all his or her abilities to their full potential.

Third, we are convinced that the dignity and rights of handicapped people will not be secure in our society until the Supreme Court's abortion decisions of 1973 are overturned. Those decisions have woven into our judicial fabric phrases such as "meaningful life" and "not a person in the whole sense" which, used at first with regard to unborn children, have been extended by other courts to handicapped and terminally ill individuals. The Supreme Court's legalization of abortion for virtually any reason throughout the term of pregnancy, and its invalidation of laws assuring life-saving treatment to children born alive during late-term abortions, have
had a devastating effect on parents' and physicians' attitudes toward children in general and handicapped children in particular.\textsuperscript{22} Some state and federal courts, by accepting the concept of "wrongful life" and "wrongful birth," have already suggested that a handicapped child's very existence is a "wrong" for which monetary damages can be assessed; and these rulings have drawn much of their rationale from the Supreme Court's legitimation of the "right" of abortion.\textsuperscript{23} Humane public policy with respect to handicapped children will not be complete until these grotesque decisions are extirpated, and our legal system can once again be directed toward the defense of all helpless human life, whatever its age or condition.

Thank you for your consideration.
NOTES


5 On the application of the Church's moral tradition to such situations, see: John R. Connery, S.J., "Prolonging Life: The Duty and its Limits", Catholic Mind, October 1980, pp. 42-57; idem, "An Analysis of the HHS Notice on Treating the Handicapped", Hospital Progress, July 1982, pp. 18-20; "The Woe of Infant Doe", Ethics and Medics (Publication of the Pope John XXIII Medical-Moral Research and Education Center, St. Louis, Missouri), June 1982. On the attitudes of handicapped people toward the quality of their own lives, see, for example, David Milne, "Urges MDs to Get Birth Defects Patients' Own Story", Medical Tribune, December 12, 1979, p. 6.


NOTES (continued)

9. People v. Pierson, 68 NE 243 at 246-7 (1903); cited in Owens v. State, 116 P. 345 at 346-7 (1911).


15. See the sources cited in note 6.


NOTES (continued)


22 For the radical nature of the Supreme Court's decisions, see the U. S. Senate Judiciary Committee's legislative report on S. J. Res. 110, the Human Life Federalism Amendment (Report No. 97-465), pp. 7-20. For the effect of these decisions on physicians' attitudes toward defenseless life in general, see ibid., p. 46.

23 For example: Curlender v. Bio-Science Laboratories, 106 Cal. App. 3d 811, 165 Cal. Rptr. 477 (1980) (Child with Tay-Sachs disease should be able to sue her own parents for not having aborted her); Robak v. USA, 658 F. 2d 471 (1981) (Failure to provide information facilitating the decision to abort a handicapped child is malpractice and physician can be required to pay the lifetime costs of raising the child).