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The Case of Baby Andrew

Peter Singer

Helga Kuhse

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Who says that the most important and perplexing human dilemmas do not arise in the context of administrative law? Consider

The Case of Baby Andrew*

One month after the premature birth of her son Andrew, Peggy Stinson wrote in her journal:

What threatened to be a simple, private sorrow has changed unexpectedly into something so altogether different, so altogether complicated that thoughts and feelings tangle hopelessly and give no guidance.

Andrew is not our baby anymore — he's been taken over by a medical bureaucracy. The bureaucracy controls Andrew — access to Andrew, information about Andrew, decisions about what will happen to Andrew. It rolls inexorably onward, oblivious to our attempts to communicate, participate; oblivious equally to angry reaction and attempts to reconcile.

If this sounds bad, it's not half so bad as it will be if President Reagan gets his way. The Stinsons' problem was that they had doctors who followed a rigid ethic of preserving life at virtually any cost, and they could not get their son out of the hands of their doctors. Now, however, the president who promised to cut back on the intrusion of big government into the private lives of American citizens is taking steps to ensure that even when parents, doctors, and a hospital "Infant Care Review Committee" agree on the best course of action for an infant born severely


An exchange of letters analyzing the review may be found in the June 14, 1984 issue of the New York Review of Books, at page 48.
handicapped, there will be another layer of bureaucracy — the federal government — to step in and see that the baby is treated, regardless of what the parents and their doctors think.

The Long Dying of Baby Andrew consists of the daily journals in which Peggy and Robert Stinson recorded their private thoughts between December 1976 and June 1977. At the beginning of that period, Mrs. Stinson was twenty-four weeks pregnant and the pregnancy was going seriously wrong. The Stinsons contemplated an abortion to avoid the risk of a life-threatening hemorrhage, but decided against it. A few days later the pregnancy began to miscarry. Mrs. Stinson was rushed to the hospital (in a town she does not identify) where, to everyone's surprise, a baby was born alive, weighing one pound twelve ounces. The doctors expected the baby to die, but Andrew struggled on.

Against the Stinsons' better judgment, they were persuaded to allow him to be taken from the local community hospital to a downtown specialist pediatric hospital with a neonatal intensive care unit. There, despite a host of problems including periodic fits, infections, and a very uncertain prognosis for mental development, Andrew was put on a respirator and all the resources of modern medical technology were used to keep him alive. The Stinsons repeatedly made it plain that they did not want these heroic measures to be taken. Their wishes were ignored. Not until June 14 did Andrew die. Mrs. Stinson wrote in her journal, "Modern medicine makes possible a sad new epitaph: He died too late for grief." The hospital sent the Stinsons a statement listing charges of $104,403.20. The doctor in charge told them: "We were all lucky to get out of this as easily as we did."

The most unusual thing about Andrew Stinson's case is that he had educated, articulate parents who were angry at what had happened and chose to write about it. More often, parents either do not fully understand what is happening to their baby, or they feel so powerless that they do not even protest. For instance, in doing research on this issue, we received a letter from a distinguished British pediatrician describing a visit to an American university hospital. During a ward round in the neonatal intensive care unit, an eighteen-month-old infant suffered a cardiac arrest and was resuscitated. The pediatrician was told that the infant had no forebrain, which means it had no potential for intelligent life. Moreover this cardiac arrest was the infant's twentieth — it had been resuscitated each time. When the British pediatrician expressed his amazement at such a practice, his American colleague privately agreed that it was both pointless and very expensive, but said that the pressure from "pro-life" groups and the law was so great that he felt he must persist in attempting to preserve life.

The Stinsons' book is timely, for it presents the parents' point of view at a time when the Reagan administration is trying to impose its conservative and religiously motivated moral attitudes on the rest of the community. Apparently unable to do anything to stop women from making their own decisions about terminating pregnancy (unless the women happen to be poor), Reagan has shown his support for the pro-life groups by interfering with family decisions in that most tragic, personal, and delicate of situations, the birth of a severely handicapped infant.
Reagan's actions stem from the now-famous "Baby Doe" case (not to be confused with the more recent case of Baby Jane Doe in New York). The original Baby Doe was born on April 9, 1982, in Bloomington, Indiana, with Down's syndrome (also known as mongolism) and a blockage in the digestive system. Without surgery to remove the blockage, such a baby will die. The prospects for successful surgery were fair, but even if surgery were successful, of course, the underlying mental retardation would be unaffected. For this reason the parents refused to consent to surgery. Both the county court and the Indiana Supreme Court upheld the parents' right to make this decision. Before an appeal to the United States Supreme Court could be mounted, Baby Doe died.

Public reaction to this case began with outraged protests from the "right-to-life" movement, but soon spread beyond these circles, with The Washington Post and The New York Times both editorially deploring the decision. Letters of protest began to flow into Congress and the White House. The White House responded with unusual speed. In a memorandum dated April 30, 1982, President Reagan ordered Richard Schweiker, Secretary of Health and Human Services, to ensure that federal laws protecting the rights of handicapped citizens were being adequately enforced. In particular, the president instructed Secretary Schweiker to notify all who provide health care that section 504 of the Rehabilitation Act of 1973 forbids medical institutions receiving federal funds to withhold from handicapped citizens, simply because they are handicapped, any benefit or service that would ordinarily be provided to people without handicaps. Regulations under this law, the president continued, prohibit hospitals receiving federal assistance from discriminating against the handicapped. President Reagan then instructed the attorney general to report on constitutional and legal means of preventing the withholding from the handicapped of potentially life-saving treatment. His memorandum concluded with the following words:

Our Nation's commitment to equal protection of the law will have little meaning if we deny such protection to those who have not been blessed with the same physical or mental gifts we too often take for granted. I support Federal laws prohibiting discrimination against the handicapped, and remain determined that such laws will be vigorously enforced.

In accordance with the president's instructions, the Secretary of Health Services sent 6,800 hospitals a "Notice to Health Care Providers." The notice told hospital administrators that it was 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
the withholding is based on the fact that the infant is handicapped; and

(2) the handicap does not render treatment or nutritional sustenance contra-indicated.

Hospital administrators were told that they would have federal government funds cut off if they allowed handicapped infants to die when nonhandicapped infants in similar circumstances would be saved. The "Notice" was saying, in effect, that no matter how severe an infant's handicap might be, the efforts made to preserve its life must be no less than the efforts that would be made to preserve the life of a nonhandicapped infant in an otherwise similar condition.

When confronted with complex ethical questions, one is tempted to look for a simple answer. The Reagan administration has found its simple answer in the idea that all human life is of equal worth. That is the answer that lies behind the "Notice," and its appeal to a principle of "nondiscrimination" against infants born with severe handicaps.

This simple line about the equal worth of all human lives is the basis of Reagan's own excursion into moral philosophy, his article "Abortion and the Conscience of the Nation," in the spring 1983 issue of The Human Life Review. After writing proudly of his action in applying civil rights regulations to "protect" handicapped newborns, he quotes both the Declaration of Independence and Abraham Lincoln to make the point that we must regard all lives as being of equal value.

We shall soon see that this position cannot be taken seriously. No one, not even Reagan's own surgeon general, Dr. C. Everett Koop, a man much admired by right-to-life groups and praised by Reagan himself in the article just mentioned, can carry it out in practice. But to appreciate this, we must first return to the story of the administration's response to the Baby Doe case.

Strong as its language was, the "Notice" was not sufficient for the White House. In March 1983 the Department of Health and Human Services therefore issued a more forceful follow-up regulation. Officially, the new regulation had the contradictory title "Interim Final Rule," but it has become known as the "Baby Doe guidelines." These guidelines specified that a poster was to be conspicuously displayed in each delivery ward, maternity ward, pediatric ward, and intensive care nursery. The department sent out large, seventeen-by-fourteen-inch posters with heavy black lettering which read as follows:

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

(2) the handicap does not render treatment or nutritional sustenance contra-indicated.
NOTICE
Department of Health and Human Services
Office for Civil Rights
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
US Department of Health and Human Services
Washington, D.C. 20201
Phone 800-368-1019
(Available 24 hours a day)
TTY Capability
In Washington, D.C., call 863-0100
OR
Your State Child Protective Agency.
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.
Later in the year, the administration worked out the finer details of how to enforce the notice. It was decided to set up a special "Baby Doe Squad." According to a March 4, 1983 memo from the deputy director of program operations to Betty Lou Dotson, director of the Office of Civil Rights within Health and Human Services, the Baby Doe Squad was to consist of "Cadres especially selected and trained" who would be provided with individually numbered copies of "Baby Doe complaint" investigation procedures, which were not to be duplicated or released outside the Office for Civil Rights. Depending on the nature of the complaint, one, two, or three squad members would be immediately dispatched to the hospital site, where they would have power to demand hospital records and to interview all relevant personnel. These "special squad assignments" were to "take precedence over any and all assignments."

The Baby Doe guidelines incensed many of the nation's most senior pediatricians — not surprisingly, since they invited all and sundry to make confidential complaints about the way doctors treated their patients. As a result the American Academy of Pediatrics, an association of twenty-four thousand pediatricians, joined with the National Association of Children's Hospitals and the Children's Hospital National Medical Center, in Washington, D.C. to contest the regulations in the courts.

Among the grounds for opposition to the guidelines was the question of their scope. The American Academy of Pediatrics submitted affidavits describing medical conditions which are, it said, "simply not treatable"; should we still try to prolong the lives of these infants, as we would, of course, if the infants did not have the conditions in question? In other words, the academy was asking, are doctors now supposed to do everything in their power to prolong all infant lives, no matter what the prospects?

The affidavits referred to three conditions. The first is anencephaly. This means "no brain" and refers to a condition that occurs approximately once in every two thousand births. The infant is born with most or all of its brain missing. Many of these babies die at birth or very soon after, but some have lived for a week or two, and it would be possible, with modern artificial support systems, to keep them alive even longer. The absence, or virtual absence, of a brain means that even if such infants could be kept alive indefinitely, they would never become conscious or respond in any way to other human beings.

The second condition is an intracranial hemorrhage — less technically, a bleeding in the head. Dr. Robert Parrott, director of the Children's Hospital National Medical Center, described some cases as "infants who have such severe bleeding in their heads that they will never breathe without mechanical respiratory assistance yet /sic/ never will have the capacity for cognitive behavior." (Andrew Stinson appeared to have an intracranial hemorrhage in the first month of his life, although his parents were given conflicting information about the severity of the hemorrhage and its likely consequences.)
The third condition is one in which the infant lacks a substantial part of its digestive tract, for instance its intestine and bowels. The infant cannot be fed by mouth, for it will not obtain anything of nutritional value. It is not possible to correct the condition by surgery. Feeding such infants by means of a drip directly into the bloodstream will keep them alive, but nutritional deficiencies are likely and the long-term prospects are poor.

In mentioning these three conditions, the academy was suggesting that the guidelines were, at best, unclear on whether in these cases infants might be allowed to die without receiving life-sustaining treatment; or at worst, the guidelines would direct that such life-sustaining treatment be given, despite the apparent futility of such treatment.

The hearing took place before Judge Gerhard Gesell. It is worth examining the transcript in some detail, because it reveals the thinking of those within the administration who were responsible for the Baby Doe guidelines.

At the hearing the Department of Health and Human Services denied that the Interim Final Rule would compel doctors to provide life-sustaining treatment in extreme cases. The chief spokesman for the department's position was Dr. C. Everett Koop, the surgeon general, an experienced pediatric surgeon and a strong advocate of the right-to-life viewpoint. Dr. Koop told the court that he had been involved in the decision to Issue the "Notice to Health Care Providers," and the subsequent formulation of the Interim Final Rule. Referring to the case of a child having "essentially no intestine," Dr. Koop said:

...the regulations never intended that such a child should be put on hyperalimentation /i.e., artificially nourished/ and carried for a year and a half. Incidentally, I was the first physician that ever did that, so I know whereof I speak. And we would consider customary care in that child the provision of a bed, of food by mouth, knowing that it was not going to be nutritious, but not just shutting off the care of that child...nor do we intend to say that this child should be carried on intravenous fluids for the rest of its life.

Dr. Koop made a similar remark about one of the other cases mentioned by the academy:

When you talk about a baby born without a brain, I suspect you meant an anencaphalic child and we would not attempt to interfere with anyone dealing with that child. We
think it should be given loving
attention and would expect it to
expire in a short time.

To Dr. Koop, it was apparently plain common sense that one did not attempt
to prolong the lives of infants born with such hopeless conditions. We
agree. But is not this "plain common sense" at odds with the view that all
human lives are of equal worth?

Since it clearly is possible, by means of artificial feeding and
respiration, to prolong the lives of anencephalic infants by several days,
perhaps even weeks or months, anyone who believes that the life of an
anencephalic infant is of the same value as the life of a normal human
being should consider it wrong to decide not to take any steps to prolong
life in these cases. Similarly, those who hold this view would also seem
to be committed to advocating life-sustaining measures for infants born
without intestines. For example, in the passage quoted above, Dr. Koop
referred to the possibility of "carrying" an infant without an intestine
for "a year and a half"; yet Dr. Koop did not advocate that infants born
without an intestine should be kept alive for as long as possible. (In
fact it is possible for children being artificially fed to survive consider-
ably longer than this, but the precise period is not relevant here.) Why
does Dr. Koop not think such infants should be kept alive as long as
possible? Would he not think an eighteen-month extension of life worth-
while for a normal child? Would he not think it worthwhile for a normal
adult? If he would, the obvious explanation for his different view in the
first case is that he does not regard the life of an artificially nourished
infant as being of the same worth as that of a normal infant or a normal
adult.

Is there any other possible explanation for the views expressed
by Dr. Koop? The way in which the Department of Health and Human Services
formulated its Interim Final Rule suggested that the department was
appealing to a standard of "customary medical care." This standard was
explicit in the reference, in the notice to be posted in the hospitals, to
"infants discriminatorily denied food or customary medical care." It may be
that the department was seeking to deflect criticism by claiming that it was
not asking for heroic measures or extraordinary means, but merely the usual
form of medical care. If the department thought that in this way it could
avoid the ambiguities and difficulties of that distinction, however, it soon
received a rude awakening. For the Department of Health and Human Services
the appeal to "customary medical care" posed a special problem which it
really ought to have foreseen. The problem was that the department, in docu-
menting the need for new guidelines on the treatment of handicapped infants,
had clearly established that the treatments it was attempting to mandate were
not customary.

The difficulty the department was in emerged very clearly at the
hearing before Judge Gerhard Gesell. As we have seen, the chief witness
for the department at that hearing was Dr. C. Everett Koop, surgeon general
of the United States, and a key person in the drawing up of the Interim Final
Rule. Judge Gesell asked Dr. Koop whether there was documentation of the problems they were discussing. Dr. Koop gave a lengthy reply which included the following passages:

There was a very telling survey done by the surgical section of the Academy of Pediatrics....At the time of the survey there were approximately six hundred members of that surgical section. I cannot remember how many were questioned there, but it was over half and that was reported in a journal called Pediatrics in the year 1977 and there it was very clear that a very large proportion of pediatric surgeons in this country, and there was also a little section about pediatricians, were perfectly willing to acquiesce to the request of a family not to treat a child if they didn't want that child, and many of the circumstances that were mentioned in that survey were very simple procedures such as simple intestinal obstruction, not associated with any other anomaly, and as I recall, fourteen percent of the surgeons questioned said if indeed the parents said they didn't want the child operated upon even though they knew it would be certain death, and it was a simple, easy thing and a normal child would be the result of the procedure, they said they would acquiesce to the family's concern.

And in the President's Advisory Commission on Biomedical Ethics...there are two other surveys mentioned...which I think are also very telling. One was a survey of pediatricians in the West who said that the majority of them would acquiesce to the parents' request not to operate upon the child if they didn't want that child, and in a Massachusetts survey of pediatricians a majority of those who answered the survey said that they would not even suggest an operation in a child who had Down's syndrome, so I think it is widespread.

Our reason for quoting Koop's testimony at this length is that it served as a preliminary to the following series of devastating questions from Judge Gesell:
Judge Gesell: So what is it that you consider customary medical care? I mean how would you as a practicing physician, how would you understand that?

Dr. Koop: It would have to be — the reasons that those regulations don't go into chapter and verse for everything that occurs in a child is because that would result in a textbook.

Judge Gesell: They don't go into anything? 

Dr. Koop: They don't go into anything.

Judge Gesell: So what does the regulation mean when it says "customary medical care"?

Dr. Koop: Well, I think that every physician knows what is essentially customary.

Judge Gesell: Would you mind telling me?

Dr. Koop: Yes. It differs for every case but let's take the ones that you mentioned a moment ago when you talked about a child who is born without an intestine.... We would consider customary care in that child the provision of a bed, of food by mouth, knowing that it was not going to be nutritious, but not just shutting off the care of that child...nor do we intend to say that this child should be carried on intravenous fluids for the rest of its life.

Judge Gesell: How are the number [sic: read "members"] of your organizations, the pediatric associations to find out what you think is right?

Dr. Koop: I think we all essentially agree, sir.

Judge Gesell: Is it written down anywhere?

Dr. Koop: No, but again it's customary.

Judge Gesell: The affidavits seem to indicate that there's some disagreement between physicians as to what is customary care....

Poor Dr. Koop. Having argued that the regulations were needed because a very large proportion of pediatricians were ready to go along with the wishes of parents and not operate on a Down's syndrome infant — precisely the result the regulation had been devised to prevent — he was in an impossible situation in trying to maintain that all the regulation demanded was "customary medical care."
The Department of Health and Human Services soon had a second chance to explain its stance on the type of case we have been considering. Judge Gerhard Gesell found in favor of the Academy of Pediatrics and its co-plaintiffs on the grounds that the department had, by issuing the regulation without allowing a period for public comment, failed to comply with the requirements of the Administrative Procedure Act, an act designed to curb bureaucratic actions taken without consultation and notice to those affected. The department therefore issued, on July 5, 1983, a new "Proposed Rule." The new rule was essentially similar to the ill-fated Interim Final Rule, but it was issued with considerably more information on the circumstances in which it was to apply. In particular, it was stated that:

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 will_[sic]_, such as a child born with anencephaly or intracranial 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 judgments can differ when evaluating these difficult, individual cases.

Here the department takes the common-sense view that it is not obligatory to keep alive infants with anencephaly or intracranial bleeding. It is interesting to see how the department tries to take this view without basing it on the fact that infants with these conditions have no prospect of a reasonable quality of life. What the department suggests is that in these cases treatment is "futile" and will "merely temporarily prolong the process of dying" of an infant born terminally ill. Whether a treatment is futile in this way is, the department states, a "medical decision" and "reasonable medical judgments can differ" in these cases. The department seems to be saying that it does not wish to interfere in these "medical decisions." Since this remains the position of the department in the final version of its rule, published on January 9, 1984, its approach requires close scrutiny.

The department's position cannot be maintained. As we have seen, sophisticated modern medical techniques could indefinitely prolong the lives of children with anencephaly or intracranial bleeding. The judgment that someone whose life could be indefinitely prolonged by available medical means is "terminally ill" and therefore should not have his or her life prolonged is not a medical judgment; it is an ethical judgment about the desirability of prolonging that particular life.
Could the department defend its view by saying that whether a patient is dying is a medical judgment, based on the fact that the patient can survive only with the help of medical treatment? Such a test would be far too broad. By this standard, a patient suffering from diabetes would be "terminally ill" and it would not be required to provide "futile" insulin therapy. The fact that no one in his or her right mind would regard insulin therapy for a diabetic as "futile" should make us realize that judgments about the futility of treatment are not purely medical judgments based on the prospect of the underlying condition being cured. At present we cannot cure diabetes, any more than we can cure anencephaly, or intracranial bleeding, or the absence of an intestine. In all these conditions, the patient will remain, for his or her entire life, dependent for survival on continuing medical treatment. The difference between diabetes and the other three conditions is, of course, that the diabetic will be able to enjoy a near-normal life, while no matter how much we prolong the life of the infant with severe intracranial bleeding, for instance, the infant's life will always remain devoid of everything that we regard as making life worthwhile.

As we read on through the "supplementary information" issued by the Department of Health and Human Services it becomes still more clear that, despite protestations to the contrary, the department's position is based on thinly veiled judgments that some lives are not worth living. The department's statement continues:

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 out-weighed by any medical risk associated with the treatment? It is only when non-medical considerations, such as subjective judgments 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.

In issuing the January 9 "Final Rule," the department indicated that so far as the provision of all "medically beneficial treatment" is concerned, "the Department's position remains unchanged." The problem with this unchanged position is that we need to decide what treatments are "medically beneficial to the patient." The simple answer, and the only answer that is consistent with the idea that all human life is of equal worth, is that all treatments which prolong life are beneficial. Yet this is clearly not the answer the department would give: it does not regard it as beneficial to prolong the lives of infants born with virtually no brain, or who have suffered severe intracranial bleeding. Why is this not "medically beneficial to the patient" in the same way that giving insulin is medically beneficial to the diabetic?

Once again, the answer must be that it is not medically beneficial to prolong the lives of infants who will never experience anything, and will
remain alive but in a state without feelings or awareness, unable to enjoy their lives in any way. Plainly, the prolongation of such a life is not "medically beneficial" because it is not beneficial in any sense. Karen Ann Quinlan, the New Jersey woman who has been in an irreversible coma since 1975, has not benefited from the fact that her life has been prolonged for many years. She has not been aware of the extra years of life she has had, and thus has had no benefit from them.

Similarly, prolonging the life of an infant without a brain does the infant no good because it is not possible for the infant to benefit from the additional period of life. This is not, however, a medical judgment. It is, quite obviously, a "non-medical consideration" based on the judgment that the handicap — in this case, the virtual absence of a brain — "makes a person's life not worth living." The department seems to think that such judgments are "subjective" and must not be "interjected in the decision-making process"; yet its own position is based on just this type of judgment.

Admittedly, the department does refer to judgments about "an unrelated handicap," and in criticizing its position we have not taken account of the stipulation that the judgment be about a handicap that is "unrelated." But it is difficult to see exactly what this means or how it can make a difference. Presumably it is supposed to be wrong to take account of a handicap unrelated to the treatment needed to keep the infant alive; but how do we define what the handicap is? This may seem clear enough in a case like that of Baby Doe, where Down's syndrome is the reason for not operating on the blockage in the digestive system. But what about the case of, say, an intracranial bleeding? The treatment needed to keep the infant alive might be artificial respiration. A baby who was having breathing problems, but was otherwise normal, would certainly be put on a respirator; the baby who, as Dr. Parrott put it, "never will have the capacity for cognitive behavior" would not be put on a respirator.

But if the lack of any "capacity for cognitive behavior" is a factor in the decision to put the baby on the respirator, this would have to be a "subjective judgment that an unrelated handicap makes a person's life not worth living." As such, it should give rise to what the department calls "Section 504 concerns." Yet apparently the department does not think it does. On the other hand, the department presumably would think that "Section 504 concerns" arise even in some cases where the decision not to sustain life is made because of a handicap that is directly related to the form of treatment — for instance, if a doctor did not give insulin to a diabetic patient because in the doctor's judgment diabetes is a handicap that makes life not worth living. Thus, whether the life-sustaining treatment is or is not related to the patient's handicap cannot be, even in the department's view, a crucial factor in whether a decision not to prolong life is a case of discriminating against the handicap.

The Department of Health and Human Services received 16,739 comments on the proposed rule it issued on July 5, 1983. Ninety-seven percent were in
support of the rule, many written in virtually identical terms as a response to appeals by groups like the "Christian Action Council." One hundred and forty-one pediatricians or newborn care specialists sent in comments: of these, 72 percent opposed the rule. The American Academy of Pediatrics has also made a lengthy submission, which includes documentation of the harm done to hospitals trying to cope with medical and human crises by sudden descents of the "Baby Doe Squad." For instance, at Vanderbilt University Hospital, a "hotline" call led to three investigators and a neonatologist examining, after midnight, each infant in the facility, and diverting the hard-pressed hospital staff from patient care for a total of fifty-four staff-hours. The neonatologist described the hospital's care as "exemplary." More dramatic still is a comment quoted from a New Mexico pediatrician:

Because of the fear I had in being "reported,"
I recently spent one agonizing hour trying
to resuscitate a newborn who had no larynx,
and many other congenital anomalies. The
sad part was that both the parents in the
delivery room watched this most difficult
ordeal. It was obvious to me that this was
no way a viable child but I felt compelled
to carry on this way out of fear someone in
the hospital would "turn me in." I am sure
that you who sit in Washington are not faced
with such difficult decisions at two o'clock
AM.

This comment becomes especially ominous in the light of the Stinsons' experience. Not for one hour but for nearly six months they had to stand by while doctors kept their tiny, suffering infant alive. (At one point a doctor told them that Andrew must "hurt like hell" every time he breathed.)

Comments like this appear to have had some effect on the wording of the Final Rule issued on January 9. Chastened by the hostile reaction to its earlier attempts, the department retreated from the heavy-handed intimidation that had characterized previous versions of the rule. This gradual retreat is reflected in the size and positioning of the notice to be posted in hospitals: the notice sent out with the March 1983 Interim Rule measured seventeen inches by fourteen; the July Proposed Rule required the notice to be no smaller than eleven by eight and a half inches; now the notice can be as small as seven by five inches. Moreover the notice does not have to be posted where parents and visitors can see it, but only at nurses' stations where it can be seen by health care professionals. The wording of the notice has been toned down: for instance, the reference to violations of state criminal and civil laws has been deleted on the grounds that the statement is "unnecessary" and "potentially inflammatory."

The most significant innovation in the new rule of January 9 is the suggestion that hospitals may wish to set up "Infant Care Review Committees" which would discuss problem cases, and with which the department would consult,
in the first instance, if any alleged violations were reported to it. This suggestion picks up a recommendation of the American Academy of Pediatrics, and is clearly another attempt to conciliate.

That the department should seek the views of those on the spot before rushing to its own decision is, of course, desirable; but the department makes it clear, beneath its conciliatory language, that it is still the boss. As Dr. Koop said at the press conference at which the Final Rule was announced: "The rules do no more than continue to provide an effective method of enforcing Section 504 in connection with the health care of handicapped infants."

The new rule itself says "the Department does not seek to take over medical-decision-making regarding health care for handicapped infants" but then adds that the parents and physicians must act within the framework set by law, including the Section 504 prohibition of discrimination. The department specifically rejects the suggestion that with the review boards in place, the government could refrain from playing a role in enforcing this statute with regard to handicapped infants.

So far as the interpretation of Section 504 is concerned, the new rule contains only minor changes. Not surprisingly, references to "customary medical care" have been dropped. The criterion of "medically beneficial treatment" must now bear all the weight of distinguishing cases like anencephaly (which the department still says need not be treated) from cases of Down's syndrome with an intestinal blockage (which the department says should be treated). We have seen that this distinction cannot really be a medical judgment, yet the new rule continues to insist that "present or anticipated physical or mental impairments of an infant" are not a permissible basis for withholding treatment.

The department no longer discusses intracranial bleeding as a case in which treatment is not "medically beneficial" because the severity of such bleeding varies greatly. Instead the department discusses spina bifida, a condition in which the infant is born with an open wound on its back exposing the spinal cord. Depending on the size and location of the wound, the child may be paralyzed from the waist down, lack bowel and bladder control, and be mentally retarded.

The recent and much publicized case of Baby Jane Doe is about an infant with this condition, although Jane Doe also has microcephaly, an abnormally small head, which in itself is a sign of severe mental retardation. With so poor a prognosis for a minimally satisfactory quality of life, Jane Doe's parents decided not to do everything possible to increase her prospects for survival. In this decision they were supported by Jane Doe's physicians and neurosurgeons, as well as by social workers and clergymen. Yet an unknown caller alerted a right-to-life lawyer who managed to drag the baby's parents through all three levels of the New York State court system before the suit was thrown out by the New York Court of Appeals. Even then, Dr. Koop and his 'Baby Doe Squad' threatened to cut off federal funds from Stony Brook Hospital if it were found to have "discriminated" against Jane Doe on grounds of her multiple handicaps. According to a report in the London Sunday Times, Dr. Koop has said that he
is not so much interested in Baby Jane Doe as in "the idea of her" as a way of "fighting for the principle of this country that every life is individually and uniquely sacred."

Spina bifida is one of the most common birth defects. It is controversial because in many countries, including Britain and Australia, it is standard practice to allow the more severely afflicted babies to die. Less severe cases are operated on and given every available assistance, often with the result that the children go on to lead fulfilling lives; the remainder, if the parents agree, are not operated upon, and if infections appear or pneumonia develops, these children are not given antibiotics.

There is no hypocrisy or pretense about this practice of selection, which has been accepted by the British Department of Health and Social Service. The practice derives largely from the work of Dr. John Lorber of Sheffield. For several years Lorber and his colleagues in Sheffield treated every case of spina bifida as vigorously as possible. Then, looking back on the results of more than a thousand cases, Lorber decided that this was a mistake; in many cases, the lives he had saved were not worth living and the burden on families was sometimes barely tolerable. Lorber switched to treating about 25 percent of the cases brought before him, obtaining the parents' consent for whatever course he followed: in advocating this policy in medical journals he has stated candidly that he does not operate on the more severely affected infants because he thinks it better that they do not survive beyond infancy.

The Reagan administration is now insisting that treatment for spina bifida infants may be withheld only if there is a medical judgment that it is "futile" and "not of medical benefit to the infant." If this were taken seriously in Great Britain, thousands of infants who would be allowed to die there would survive, often against the wishes of the parents. Apparently the Reagan administration believes that infants must be treated even if in the opinion of the parents, the doctors, and the hospital Infant Care Review Committee the life thus "saved" will be so miserable that the infant would be better off dead. "Medical benefit," remember, is not supposed to involve considerations of the quality of life.

In practice it is very likely that the new rule will simply widen the already considerable gap between appearance and reality in American medicine. American doctors will start to disguise their inevitable judgments about quality of life under the cloak of "medical judgments" about the "futility" of treatment. A cynic might see the new rule as an open invitation to doctors to do just this, thus defusing the politically damaging war of words between pediatricians and pro-life forces.

Those who reject judgments about quality of life should not forget that pregnant women who run an abnormal risk of carrying a defective child are standardly advised to have a prenatal test with a view to abortion if the test does reveal that the infant will be handicapped. These women are obviously making quality-of-life judgments, and presumably will continue to be allowed to do so.
The Stinsons nicely bring out the moral absurdity of the present legal situation and the ethical attitudes that support it. Before Andrew was born, they could have legally had an abortion and planned another pregnancy. Had Andrew not been born at twenty-four weeks a legal abortion would still have been possible for another two weeks. Yet once Andrew emerged from the womb, the Stinsons lost control of the situation. Why? The pro-life groups are right about one thing: the location of the baby inside or outside the womb cannot make such a crucial moral difference. We cannot coherently hold that it is all right to kill a fetus a week before birth, but as soon as the baby is born everything must be done to keep it alive. The solution, however, is not to accept the pro-life view that the fetus is a human being with the same moral status as yours or mine. The solution is the very opposite: to abandon the idea that all human life is of equal worth.

The statement will assuredly bring letters saying that once we abandon our belief in the equal worth of all human life we are well on the way to Nazism and to ridding the world of all social undesirables, political undesirables, and racial undesirables. The Nazi parallel is an old bogey which has no historical basis.* But history apart, the unequal worth of human life is really so obvious that we have only to cast off our religious or ideological blinkers to see it as plain as day. If the life of a human being is more valuable than the life of, say, a cabbage, this must be because the human being has qualities like consciousness, rationality, autonomy, and self-awareness which distinguish human beings from cabbages. How, then, can we pretend that the life of a human being with all these distinctive qualities is of no greater value than the life of a human being who, tragically, has never had and never will have these qualities? As we said earlier: in practice, not even Dr. C. Everett Koop treats the life of a baby without a brain as if it were of the same value as the life of a normal child.

This insight is not a solution to all the ethical problems raised by the treatment of severely handicapped newborns. Just what the solution might be is not within the scope of this article. At a minimum, though, any fair and honest solution must recognize that those who will care for the child throughout its life — if it survives — should have the largest say in what steps are taken to keep it alive. Midway through Andrew Stinson's life, at a time when it looked as if he might survive but be severely handicapped, Peggy Stinson wrote bitterly in her journal:

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* See the comments criticizing such comparisons by Lucy Dawidowicz in "Bio-medical Ethics and the Shadow of Nazism," Hastings Center Report, vol. 6, no. 4 (August 1976), Special supplement, pp. 2-4, 9-10.
One thing is clear enough — Bob will keep on writing, Bob will keep on teaching his classes, sitting in his office, talking to his students, correcting his exams — his life will go on much the same no matter what happens to Andrew. That's because he's not the one who will take care of Andrew.

Neither will any of those doctors.

As Mrs. Stinson later realized, this wasn't entirely fair to her husband; as so often happens in these situations, the Stinsons' marriage was coming apart under the strain. Still, the essential point stands: no one has the right to impose on anyone else the lifetime burden of caring for a severely handicapped child who has no reasonable prospect of a satisfying life. This point applies with special force to the Reagan administration, which has been cutting back on facilities for state care for the handicapped at the very time when it is taking steps to overrule decisions by the parents — even joint decisions by parents and doctors who, unlike the Stinsons and their doctors, are in agreement about the best course to take in the individual circumstances they are facing. The administration's new rule means that not even the support of the hospital's Infant Care Review Committee will be sufficient to exclude the possibility of interference by outsiders motivated by their own special brand of ideological or religious zeal.

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On July 4, 1984, the New York Times announced (p. 1, col. 1) that liberal and conservative Senators, hospital officials, civil rights advocates and anti-abortion groups had reached tentative agreement on a proposal to amend the Child Abuse Prevention and Treatment Act of 1974 by incorporating a new standard for treating severely handicapped infants. In a copyrighted article under the byline of Robert Pear, the Times reported that the proposal, with which the Surgeon General concurred, would, if enacted:

'redefine child neglect and abuse to include the 'withholding of medically indicated treatment from disabled infants with life-threatening conditions.' The 'medically indicated treatment' includes those steps that, in the judgment of treating physicians, are 'most likely to be effective in ameliorating or correcting all of a handicapped infant's life-threatening conditions.'
'But doctors and hospitals would not have to make heroic efforts to save a baby's life in any of these situations, as set forth in the proposed Senate amendment:

'The infant is chronically and irreversibly comatose.'

'The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions or otherwise be futile in terms of the survival of the infant.'

'The provision of such treatment would be virtually futile in terms of the survival of the infant, and the treatment itself under such circumstances would be inhumane.'

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