Respect Life:

Human Experimentation and

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In the debate about medical experiments on human beings, 1984 was a landmark year.

- In England, a government commission concluded that experimentation should be allowed on newly-fertilized human embryos.
- A legislative debate gathered momentum in the United States over federal standards on fetal experimentation.
- In the celebrated cases of "Baby Fae," Barney Clark and William Schroeder, Americans contemplated the use of animal and mechanical organs in human beings and discussed the fine line between exotic treatment for an individual and medical research to benefit future generations.

These incidents involved different specialties within medicine and different classes of human subjects, but they all raised the same basic questions about the morality of human experimentation.

Those questions are perhaps best illustrated by a more detailed account of the controversy with the longest continuous history — the debate over federally funded research on the human fetus.

Congress first addressed this subject in 1974 when reports came to its attention of unethical experiments involving infants born *alive* during late-term abortions. The researchers claimed that since these children were dying from a procedure that was perfectly legal, and in any case could survive outside the womb for only a short time, they did not deserve full protection as human subjects. Congress disagreed and imposed a moratorium on all federal support for fetal experimentation. The moratorium was lifted only after a new National Commission for the Protection of Human Subjects drafted regulations to establish permanent federal safe guards for this area of research.

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But this interdisciplinary team of experts in law, medicine and ethics never reached a consensus on whether the unborn child deserves full protection as a fellow human being. Only one Commission member, legal scholar David Louisell, took a clear stand in defense of equal protection for all human subjects before and after birth.

On the key issues, Louisell's was the sole dissent from the compromise produced by the Commission. Its final proposal, promulgated as federal regulations in 1975 and still in force without substantial change, departed from what Louisell called "established human experimentation norms" on three points:

1. There was little disagreement that "therapeutic" research, designed primarily to meet the health needs of a particular child, was permissible. But a problem arose in the Commission's treatment of non-therapeutic research, designed not to benefit the research subject but to gain knowledge that may benefit others. Such experiments would be allowed, with the informed consent of the parents, if the experiments were of "minimal risk" — defined as the degree of risk the subject would experience in daily life or during routine physical or psychological examinations. These protections seemed meaningless when applied to the unborn child intended for abortion, since the parents have already committed themselves to destroying their child and the risks of "daily life" will soon include a violent death. The final regulations did not specifically address this ambiguity, but it was clear that many researchers saw the child-to-be-aborted as a prime subject for experiments that would be too dangerous for others.

2. A similar loophole involved regulations governing research on premature infants — a class of subjects which the regulations referred to as "fetuses ex utero." Again parental consent was required, and again seemed meaningless if the child struggling for survival had left the womb as the result of an abortion. Moreover, such infants were to be divided into three different categories. If viable (i.e., capable of sustained survival outside the womb), they would automatically fall under a separate set of fairly strict regulations governing experiments on children. If their viability was uncertain, they were not to be subjected to any interventions except those intended to bring them to viability. But if they fell under the category of "non-viable fetuses ex utero," they could be subjected to any form of non-therapeutic experimentation so long as nothing was done either to hasten death or to prolong the child's dying. Here there were no restrictions on the amount of injury or pain a researcher might inflict. Some Commissioners argued that a fetus probably could not feel pain before viability in any case — an opinion which now seems almost willfully ignorant.

3. Finally, the regulations contained a clause allowing the Secretary of Health, Education and Welfare to waive the "minimal risk" standard when an experiment was considered too important to leave undone. The only standard remaining in such a case was that "the risks to the fetus involved are . . . outweighed by the sum of the benefit to the fetus and the importance of the knowledge to be gained." In any such experiment, of course, the "benefit to the fetus" would be zero, because there would be no need for a waiver clause if the experiment was intended to benefit the subject. What this clause made possible was a straightforward utilitarian calculus in which the pain, injury or death of an unborn child or premature infant would be justified by projected benefits to socitey.

What led the Commission's majority to withdraw protection from intended abortion victims, even when they allowed such protection for other unborn children of the same stage of development? Some were certainly influenced by the Supreme Court's abortion decisions. In 1974 the Society for Developmental Biology unanimously resolved to support "the continued use of human tissues at all stages of development, embryonic and fetal, within the framework of the (abortion) ruling of the U.S. Supreme Court. But the assumption shared by those spokespersons — that the Court had authorized any and every form of damage to the unborn — proved invalid. Many states have enacted strong statutes against fetal experimentation since 1974. Some, like Massachusetts, have made it a felony to experiment on any unborn child intended for abortion. All these laws have been upheld in the federal courts, which have found protection of the unborn to be valid when it does not conflict with the constitutionally guarded interests of the mother.

Another argument, applied to both the intended victim of an abortion and the child born dying from an abortion, could be bluntly expressed as: "They are going to die anyway, so why not make use of them to advance medical progress?"

Louisell, in his 1975 dissent, gave this answer: "The argument that the fetus-to-be-aborted 'will die anyway' proves too much. All of us 'will die anyway.' A woman's decision to have an abortion, however protected ... does not change the nature or quality of fetal life. We do not subject the aged dying to unconsented experimentation, nor should we the youthful dying." In Louisell's view it was one thing to say one cannot legally prevent others from having abortions, and quite another to use this as a pretext for destructive actions *of one's own.*

One might add that the same issue was raised at the

Nuremberg trials concerning Nazi physicians ultimately convicted of crimes against humanity. According to Dr. Andrew Ivy, a medical consultant at the trials, these physicians said of their victims that "since they would die in the concentration camp one might as well obtain some good for humanity out of them."

Despite the absence of any cogent argument for their existence, these features of the 1975 regulations have survived into the present. In 1984, Congress approved new statutory standards that would repeal the "waiver clause" and specify that the child involved in abortion must not be subjected to an experiment that would not be carried out on children intended for live birth. But these standards were approved as amendments to a much larger bill authorizing several new programs at the National Institutes of Health, and the entire bill was vetoed by the President for fiscal reasons. Consideration of this bill has resumed in the present Congress.

Two key distinctions run through this debate on fetal research that can be applied to research at any stage of human life. These are the distinctions between "the-