## STUDIES IN LAW AND MEDICINE

Prenatal Diagnosis and the Human Right to Life

by Leon R. Kass, M.D., Ph.D.

An Educational Publication of Americans United for Life, Inc.



**No.8** 

# Prenatal Diagnosis and the Human Right to Life

by Leon R. Kass, M.D., Ph.D.

An Educational Publication of Americans United for Life, Inc.



Law and Medicine Series

Americans United for Life, Inc.

230 N. Michigan Ave., Suite 915 Chicago, Illinois 60601 (312) 263 - 5029

## INTRODUCTION

That one should be allowed to abort defective offspring has been an argument of uncommon force employed in defense of abortion. It is not a recent one--the American Law Institute included a provision for aborting abnormal fetuses in its 1962 model abortion law, and the infamous Sherry Finkbine case in 1964 involved a woman wishing to abort a child possibly damaged by the tranquilizer thalidomide.

But neither has the "abort the defectives" approach lost any of its importance over the years. If anything, the development and availability of refined prenatal diagnostic procedures, including amniocentesis, fetoscopy and ultrasound, have made the question even more important by making possible eugenic abortion on a scale never before possible. Mass prenatal screening programs, designed to detect handicapped offspring and allow for their subsequent abortion, offer the promise of countless dollars saved, a fact far from lost on governmental and private health planners.

Lurking behind any comtemporary discussion of eugenic abortion must now be found Roe v. Wade and Doe v. Bolton. the 1973 United States Supreme Court decisions that made possible the termination of any fetal life, handicapped or not, at any time in pregnancy. These decisions changed the nature of the entire abortion debate, and to many commentators the wholesale destruction of "normal" fetuses to the order of more than one million per year has made the question of eugenic abortion seem pale in ethical significance.

Yet, the aborting of the handicapped remains significant precisely *because* their handicap is used to mitigate against their continued existence. What conditions we view as insuperable, how we treat the less privileged among us, and who should decide beyond what parameters a handicapped life holds no value, are questions demanding answers in their own right, and cannot be washed away in the post-*Roe* flood of unrestricted abortion.

Questions like these, raised most pointedly by the issue of eugenic abortion, gain in importance as their relevance to postnatal application via infanticide becomes apparent. As Dr. C. Everett Koop, the internationally known pediatric surgeon, and others have warned, the step from killing handicapped offspring before birth to their elimination after birth is a short one indeed, one taken with considerable ease in theory and soon after in practice.

Dr. Leon Kass, author of the essay that follows, is a biologist and philosopher who has spent much of his academic career wrestling with questions of life and death. His conclusions frequently vex more people than they please, but even his staunchest critics respect his sensitivity, his probing insight, and his intellectual honesty.

The essay reprinted here, presented at a top-level conference on human genetics in 1971, provoked a mild furor among conference participants who advocated unrestricted abortion of handicapped fetuses. One suspects that, to many in attendance, the most disquieting aspect of Dr. Kass' paper was not his conclusions, but rather his approach-he set out to find a socially and intellectually acceptable standard for justifying eugenic abortion, only to discover that he could find none.

We reprint Dr. Kass' paper here for several reasons-his analyses of various justifications for abortion stand as classics still unsurpassed, and his honest treatment of the ethical realities involved in eugenic abortion are still valuable to those who labor to affirm life's dignity in all its various circumstances and afflictions.

One may find Dr. Kass' essay an interesting historical signpost, a still-relevant discussion of still-relevant moral problems, or any combination thereof. Whatever one finds, we trust Dr. Kass' essay will be found of value.

# Prenatal Diagnosis and the Human Right to Life\*

by Leon R. Kass, M.D., Ph.D.\*\*

It is especially fitting on this occasion to begin by acknow-ledging how privileged I feel and how pleased I am to be a participant in this symposium. I suspect that I am not alone among the assembled in considering myself fortunate to be here. For I was conceived after antibiotics yet before amniocentesis, late enough to have benefited from medicine's ability to prevent and control viral infectious diseases, yet early enough to have escaped from medicine's ability to prevent me from living to suffer from my genetic diseases. To be sure, my genetic vices are, as far as I know them, rather modest, taken individually-myopia, asthma and other allergies, bilateral forefoot adduction, bowleggedness, loquaciousness, and pessimism, plus some four to eight as yet undiagnosed recessive lethal genes in the heterozygous condition—but, taken together, and if diagnosable prenatally, I might never have made it.

Just as I am happy to be here, so am I unhappy with what I shall have to say. Little did I realize when I first conceived the topic, "Implications of Prenatal Diagnosis for the Human Right to Life," what a painful and difficult labor it would lead to. More than once while this paper was gestating, I considered obtaining permission to abort it, on the grounds that, by prenatal diagnosis, I knew it to be defective. My lawyer told me that I was legally in the clear, but my conscience reminded me that I had made a commitment to deliver myself of this paper, flawed or not. Next time, I shall practice better contraception.

Any discussion of the ethical issues of genetic counseling and prenatal diagnosis is unavoidably haunted by a ghost called the morality of abortion. This ghost I shall not vex. More precisely, I shall not vex the reader by telling ghost stories. However, I would be neither surprised nor disappointed if my discussion of

<sup>\*</sup>Reprinted with permission from Ethical Issues in Human Genetics: Counseling and the Use of Genetic Knowledge, edited be Hilton Callahan, et. al., Plenum Press (1973). This article was originally titled "Implications of Prenatal Diagnosis for the Human Right to Life," and was presented as part of a conference on human genetics.

<sup>\*\*</sup> Henry R. Luce Professor of the Liberal Arts of Biology, University of Chicago.

an admittedly related matter, the ethics of aborting the genetically defective, summons that hovering spirit to the readers' mind. For the morality of abortion is a matter not easily laid to rest, recent efforts to do so notwithstanding. A vote by the legislature of the state of New York can indeed legitimatize the disposal of fetuses, but not of the moral questions. But though the questions remain, there is likely to be little new that can be said about them, and certainly not by me.

Yet before leaving the general question of abortion, let me pause to drop some anchors for the discussion that follows. Despite great differences of opinion both as to what to think and how to reason about abortion, nearly everyone agrees that abortion is a moral issue (1). What does this mean? Formally, it means that a woman seeking or refusing an abortion can expect to be asked to justify her action. And we can expect that she should be able to give reasons for her choice other than "I like it" or "I don't like it." Substantively, it means that, in the absence of good reasons for intervention, there is some presumption in favor of allowing the pregnancy to continue once it has begun. A common way of expressing this presumption is to say that "the fetus has a right to continued life" (2). In this context, disagreement concerning the moral permissibility of abortion concerns what rights (or interest or needs), and whose, override (take precedence over, or outweigh) this fetal "right." Even most of the "opponents" of abortion agree that the mother's right to live takes precedence, and that abortion to save her life is permissible, perhaps obligatory. Some believe that a woman's right to determine the number and spacing of her children takes precedence, while yet others argue that the need to curb population growth is, at least at this time, overriding.

Hopefully, this brief analysis of what it means to say that abortion is a moral issue is sufficient to establish two points. First, that the fetus is a living thing with some moral claim on us not to do it violence, and therefore, second, that justification must be given for destroying it.

Turning now from the general questions of the ethics of abortion, I wish to focus on the special ethical issue raised by the abortion of "defective" fetuses (so-called "abortion for fetal indications"). I shall consider only the cleanest cases, those cases where well-characterized genetic diseases are diagnosed with a high degree of certainty by means of amniocentesis, in order to sidestep the added moral dilemmas posed when the diagnosis is suspected or possible, but unconfirmed. However, many of the questions I shall discuss could also be raised about cases where genetic analysis gives only a statistical prediction about the genotype of the fetus, and also about cases where the

defect has an infectious or chemical rather than a genetic cause (e.g., rubella, thalidomide).

My first and possibly most difficult task is to show that there is anything left to discuss once we have agreed not to discuss the morality of abortion in general. There is a sense in which abortion for genetic defect is, after abortion to save the life of the mother, perhaps the most defensible kind of abortion. Certainly, it is a serious and not a frivolous reason for abortion defended by its proponents in sober and rational speech-unlike justification based upon the false notion that a fetus is a mere part of a woman's body, to be used and abused at her pleasure. Standing behind genetic abortion are serious and well-intentioned people, with reasonable ends in view; the prevention of genetic diseases, the elimination of suffering in families, the preservation of precious financial and medical resources, the protection of our genetic heritage. No profiteers, no sex-ploiters, no racists. No arguments about the connnection of abortion with promiscuity and licentiousness, no perjured testimony about the mental health of the mother, no arguments about the seriousness of the population problem. In short, clear objective data, a worthy cause, decent men and women. If abortion, what better reason for it?

Yet if genetic abortion is but a happily wagging tail on the dog of abortion, it is simultaneously the nose of a camel protruding under a rather different tent. Precisely because the quality of the fetus is central to the decision to abort, the practice of genetic abortion has implications which go beyond those raised by abortion in general. What may be at stake here is the belief in the radical moral equality of all human beings, the belief that all human beings possess equally and independent of merit certain fundamental rights, one among which is, of course, the right to life.

To be sure, the belief that fundamental human rights belong equally to all human beings has been but an ideal, never realized, often ignored, sometimes shamelessly. Yet it has been perhaps the most powerful moral idea at work in the world for at least two centuries. It is this idea and ideal that animates most of the current political and social criticism around the globe. It is ironic that we should acquire the power to detect and eliminate the genetically unequal at a time when we finally succeeded in removing much of the stigma and disgrace previously attached to victims of congenital illness, in providing them with improved care and support, and in preventing, by means of education, feelings of guilt on the part of their parents. One might even wonder whether the development of amniocentesis and prenatal diagnosis may represent a backlash against these same humanitarian and egalitarian tendencies in the practice of medi-

cine, which, by helping to sustain to the age of reproduction persons with genetic disease has itself contributed to the increasing incidence of genetic disease, and with it, to increased pressures for genetic screening, genetic counseling, and genetic abortion.

No doubt our humanitarian and egalitarian principles and practices have caused us some new difficulties, but if we mean to weaken or turn our backs on them, we should do so consciously and thoughtfully. If, as I believe, the idea and practice of genetic abortion points in that direction, we should make ourselves aware of it. And if, as I believe, the way in which genetic abortion is described, discussed, and justified is perhaps of even greater consequence than its practice for our notions of human rights and of their equal possession by all human beings, we should pay special attention to questions of language and in particular, to the question of justification. Before turning full attention to these matters, two points should be clarified.

First, my question "What decision, and why?" is to be distinguished from the question "Who decides, and why?" There is a tendency to blur this distinction and to discuss only the latter. and with it, the underlying question of private freedom versus public good. I will say nothing about this, since I am more interested in exploring what constitutes "good," both public and private. Accordingly, I would emphasize that the moral question--What decision and why?--does not disappear simply because the decision is left in the hands of each pregnant woman. It is the moral question she faces. I would add that the moral health of the community and of each of its members is as likely to be affected by the aggregate of purely private and voluntary decisions of genetic abortion as by a uniform policy imposed by statute. We physicians and scientists especially should refuse to finesse the moral question of genetic abortion and its implications and to take refuge behind the issue, "Who decides?" For it is we who are responsible for choosing to develop the technology of prenatal diagnosis, for informing and promoting this technology among the public, and for the actual counseling of patients.

Second, I wish to distinguish my discussion of what ought to be done from a descriptive account of what in fact is being done, and especially from a consideration of what I myself might do, faced with the difficult decision. I cannot know with certainty what I would think, feel, do, or want done, faced with the knowledge that my wife was carrying a child branded with Down's syndrome or Tay-Sachs disease. But an understanding of the issues is not advanced by personal anecdote or confession. We all know that what we and others actually do is often done out of weakness, rather than conviction. It is all-too-

human to make an exception in one's own case (consider, e.g., the extra car, the "extra" child, income tax, the draft, the flight from the cities). For what it is worth, I confess to feeling more than a little sympathy with parents who choose abortions for severe genetic defect. Nevertheless, as I shall indicate later, in seeking for reasons to justify this practice, I can find none that are in themselves fully satisfactory and none that do not simultaneously justify the killing of "defective" infants, children and adults. I am mindful that my arguments will fall far from the middle of the stream, yet I hope that the oarsmen of the flagship will pause and row more slowly, while we all consider whither we are going.

## GENETIC ABORTION AND THE LIVING DEFECTIVE

The practice of abortion of the genetically defective will no doubt affect our view of and our behavior toward those abnormals who escape the net of detection and abortion. A child with Down's syndrome or with hemophilia or with muscular dystrophy born at a time when most of his (potential) fellow sufferers were destroyed prenatally is liable to be looked upon by the community as one unfit to be alive, as a second class (or even lower) human type. He may be seen as a person who need not have been, and who would not have been, if only someone had gotten to him in time.

The parents of such children are also likely to treat them differently, especially if the mother would have wished but failed to get an amniocentesis because of ignorance, poverty, or distance from the testing station, or if the prenatal diagnosis was in error. In such cases, parents are especially likely to resent the child. They may be disinclined to give it the kind of care they might have before the advent of amniocentesis and genetic abortion, rationalizing that a second-class specimen is not entitled to first-class treatment. If pressed to do so, say by physicians, the parents might refuse, and the courts may become involved. This has already begun to happen.

In Maryland, parents of a child with Down's syndrome refused permission to have the child operated on for an intestinal obstruction present at birth. The physicians and the hospital sought an injunction to require the parents to allow surgery. The judge ruled in favor of the parents, despite what I understand to be the weight of precedent to the contrary, on the grounds that the child was Mongoloid, that is, had the child been "normal," the decision would have gone the other way. Although the decision was not appealed to and hence not affirmed by a higher court, we can see through the prism of this case the possibility that the new powers of human genetics will strip the blindfold from the lady of justice and will make

official the dangerous doctrine that some men are more equal than others.

The abnormal child may also feel resentful. A child with Down's syndrome or Tay-Sachs disease will probably never know or care, but what about a child with hemophilia or with Turner's syndrome? In the past decade, with medical knowledge and power over the prenatal child increasing and with parental authority over the postnatal child decreasing, we have seen the appearance of a new type of legal action, suits for wrongful life. Children have brought suit against their parents (and others) seeking to recover damages for physical and social handicaps inextricably tied to their birth (e.g., congenital deformities, congenital syphilis, illegitimacy). In some of the American cases, the courts have recognized the justice of the child's claim (that he was injured due to parental negligence), although they have so far refused to award damages, due to policy considerations. In other countries, e.g., in Germany, judgments with compensation have gone for the plaintiffs. With the spread of amniocentesis and genetic abortion, we can only expect such cases to increase. And here it will be the soft-hearted rather than the hard-hearted judges who will establish the doctrine of secondclass human beings, out of compassion for the mutants who escaped the traps set out for them.

It may be argued that I am dealing with a problem which, even if it is real, will affect very few people. It may be suggested that very few will escape the traps once we have set them properly and widely, once people are informed about amniocentesis, once the power to detect prenatally grows to its full capacity, and once the "superstitious" opposition to abortion dies out or is extirpated. But in order even to come close to this vision of success, amniocentesis will have to become part of every pregnancy-either by making it mandatory, like the test for syphilis, or by making it "routine medical practice," like the Pap smear. Leaving aside the other problems with universal amniocentesis, we could expect that the problem for the few who escape is likely to be even worse precisely because they will be few.

The point, however, should be generalized. How will we come to view and act toward the many "abnormals".that will remain among us-the retarded, the crippled, the senile, the deformed, and the true mutants--once we embark on a program to root out genetic abnormality? For it must be remembered that we shall always have abnormals--some who escape detection or whose diease is undetectable in utero, others as a result of new mutations, birth injuries, accidents, maltreatment, or disease-who will require our care and protection. The existence of "defectives" cannot be fully prevented, not even by totalitarian breeding and weeding programs. Is it not likely that our prin-

ciple with respect to these people will change from "We try harder" to "Why accept second best?" The idea of "the unwanted because abnormal child" may become a self-fulfilling prophecy, whose consequence may be worse than those of the abnormality itself.

## GENETICS AND OTHER DEFECTIVES

The mention of other abnormals points to a second danger of the practice of genetic abortion. Genetic abortion may come to be seen not so much as the prevention of genetic disease, but as the prevention of birth of defective or abnormal children-and, in a way, understandably so. For in the case of what other diseases does preventive medicine consist in the elimination of the patient-at-risk? Moreover, the very language used to discuss genetic disease leads us to the easy but wrong conclusion that the afflicted fetus or person is rather than has a disease. True, one is partly defined by his genotype, but only partly. A person is more than his disease. And yet we slide easily from the language of possession to the language of identity, from "He has hemophilia" to "He is a hemophiliac," from "She has diabetes" through "She is diabetic" from "The fetus has Down's syndrome" to "The fetus is a Down's." This way of speaking supports the belief that it is defective persons (or potential persons) that are being eliminated, rather than diseases.

If this is so, then it becomes simply accidental that the defect has a genetic cause. Surely, it is only because of the high regard for medicine and science, and for the accuracy of genetic diagnosis, that genotypic defectives are likely to be the first to go. But once the principle, "Defectives should not be born," is established, grounds other than cytological and biochemical may very well be sought. Even ignoring racialists and others equally misguided-of course, they cannot be ignored-we should know that there are social scientists, for example, who belive that one can predict with a high degree of accuracy how a child will turn out from a careful, systematic study of the socio economic and psycho-dynamic environment into which he is born and in which he grows up. They might press for the prevention of socio-psychological disease, even of "criminality," by means of prenatal environmental diagnosis and abortion. I have heard rumor that a crude, unscientific form of eliminating potential "phenotypic defectives" is already being practiced in some cities, in that submission to abortion is allegedly being made a condition for the receipt of welfare payments. "Defectives should not be born" is a principle without limits. We can ill-afford to have it established.

Up to this point, I have been discussing the possible implications of the practice of genetic abortion for our belief in and adherence to the idea that, at least in fundamental human matters such as life and liberty, all men are to be considered as equals, that for these matters we should ignore as irrelevant the real qualitative differences amongst men, however important these differences may be for other purposes. Those who are concerned about abortion fear that the permissible time of eliminating the unwanted will be moved forward along the time continuum, against newborns, infants and children. Similarly, I suggest that we should be concerned lest the attack on gross genetic inequality in fetuses be advanced along the continuum of quality and into the later stages of life.

I am not engaged in predicting the future; I am not saying that amniocentesis and genetic abortion will lead down the road to Nazi Germany. Rather, I am suggesting that the principles underlying genetic abortion simultaneously justify many further steps down that road. The point was very well made by Abraham Lincoln (1854):

"If A can prove, however conclusively, that he may of right, enslave B--Why may not B snatch the same argument and prove equally, that he may enslave A?

"You say A is white, and B is black. It is color, then; the lighter having the right to enslave the darker? Take care. By this rule, you are to be slave to the first man you meet with a fairer skin than your own.

"You do not mean color exactly? You mean the whites are intellectually the superiors of the blacks, and, therefore have the right to enslave them? Take care again. By this rule, you are to be slave to the first man you meet with an intellect superior to your own.

"But, say you, it is a question of interest; and, if you can make it your interest, you have the right to enslave another. Very well. And if he can make it his interest, he has the right to enslave you."

Perhaps I have exaggerated the dangers; perhaps we will not abandon our inexplicable preference for generous humanitarianism over consistency. But we should indeed be cautious and move slowly as we give serious consideration to the question "What price the perfect baby?" (3).

## STANDARDS FOR JUSTIFYING GENETIC ABORTION

The rest of this paper deals with the problem of justification. What would constitute an adequate justification of the decision

to abort a genetically defective fetus? Let me suggest the following formal characteristics, each of which still begs some questions. (1) The reasons given should be logically consistent. and should lead to relatively unambiguous guidelines--note that I do not say "rules"--for action in most cases. (2) The justification should make evident to a reasonable person that the interest or need or right being served by abortion is sufficient to override the otherwise presumptive claim on us to protect and preserve the life of the fetus. (3) Hopefully, the justification would be such as to help provide intellectual support for drawing distinctions between acceptable and unacceptable kinds of genetic abortion and between genetic abortion itself and the further practices we would all find abhorrent. (4) The justification ought to be capable of generalization to all persons in identical circumstances. (5) The justification should not lead to different actions from month to month or from year to year. (6) The justification should be grounded on standards that can, both in principle and in fact, sustain and support our actions in the case of genetic abortion and our notions of human rights in general.

Though I would ask the reader to consider all these criteria, I shall focus primarily on the last. According to what standards can and should we judge a fetus with genetic abnormalities unfit to live, i.e., abortable? It seems to me that there are at least three dominant standards to which we are likely to repair.

The first is societal good. The needs and interests of society are often invoked to justify the practices of prenatal diagnosis and abortion of the genetically abnormal. The argument, full blown, runs something like this. Society has an interest in the genetic fitness of its members. It is foolish for society to squander its precious resources ministering to and caring for the unfit, especially for those who will never become "productive," or who will never in any way "benefit" society. Therefore, the interests of society are best served by the elimination of the genetically defective prior to their birth.

The societal standard is all-too-often reduced to its lowest common denominator: money. Thus one physician, claiming that he has "made a cost-benefit analysis of Tay-Sachs disease," notes that the total cost of carrier detection, prenatal diagnosis and termination of at-risk pregnancies for all Jewish individuals in the United States under 30 who will marry is \$5,730,281. If the program is set up to screen only one married partner, the cost is \$3,122,695. The hospital costs for the 990 cases of Tay-Sachs disease these individuals would produce over a thirty-year period in the United States is \$34,650,000 (4). Another physician, apparently less interested or able to make such a precise

audit has written: "Cost-benefit analyses have been made for the total prospective detection and monitoring of Tay-Sachs disease, cystic fibrosis (when prenatal detection becomes available for cystic fibrosis) and other disorders, and in most cases, the expenditures for hospitalization and medical care far exceed the cost of prenatal detection in properly selected risk populations, followed by selective abortion." Yet a third physician has calculated that the costs to the state of caring for children with Downs syndrome is more than three times that of detecting and aborting them. (These authors all acknowledge the additional non-societal "costs" of personal suffering, but insofar as they consider society, the costs are purely economic.)

There are many questions that can be raised about this approach. First, there are questions about the accuracy of the calculations. Not all the costs have been reckoned. The aborted defective child will be "replaced" by a "normal" child. In keeping the ledger, the "costs" to society of his care and maintenance cannot be ignored-costs of educating him. or removing his wastes and pollutions, not to mention the "costs" in non-replaceable natural resources that he consumes. Who is the greater drain on society's precious resources, the average inmate of a home for the retarded or the average graduate of Harvard College? I am not sure we know or can even find out. Then there are the costs of training the physician, and genetic counselors, equpping their laboratories. supporting their research, and sending them and us to conferences to worry about what they are doing. An accurate economic analysis seems to me to be impossible, even in principle. And even if it were possible, one could fall back on the words of that ordinary language philosopher, Andy Capp, who, when his wife said that she was getting really worried about the cost of living, replied: "Sweet'eart, name me one person who wants t'stop livin' on account of the cost."

A second defect of the economic analysis is that there are matters of social importance that are not reducible to financial costs, and others that may not be quantifiable at all. How does one quantitate the costs of real and potential social conflict, either between children and parents, or between the community and the "deviants" who refuse amniocentesis and continue to bear abnormal children? Can one measure the effect on racial tensions of attempting to screen for and prevent the birth of children homozygous (or herterozygous) for sickle cell anemia? What number does one attach to any decreased willingness or ability to take care of the less fortunate, or to cope with difficult problems? And what about the "costs" of rising expectations? Will we become increasingly dissatisfied with anything short of the "optimum baby"? How does one quantify anxiety? humiliation? guilt? Finally, might not the medical profession

pay an unmeasurable price if genetic abortion and other revoluntionary activities bring about changes in medical ethics and medical practice that lead to the futher erosion of trust in the physician?

An appeal to social worthiness or usefulness is a less vulgar form of the standard of societal good. It is true that great social contributions are unlikely to be forthcoming from persons who suffer from most serious genetic diseases, especially since many of them die in childhood. Yet consider the following remarks of Pearl Buck (1968) on the subject of being a mother of a child retarded from phenylketonuria:

"My child's life has not been meaningless. She has indeed brought comfort and practical help to many people who are parents of retarded children or are themselves handicapped. True, she has done it through me, yet without her I would not have had the means of learning how to accept the inevitable sorrow, and how to make that acceptance useful to others. Would I be so heartless as to say that it has been worthwhile for my child to be born retarded? Certainly not, but I am saying that even though gravely retarded it has been worthwhile for her to have lived.

"It can be summed up, perhaps, by saying that in this world, where cruelty prevails in so many aspects of our life, I would not add the weight of choice to kill rather than to let live. A retarded child, a handicapped person, brings its own gift to life, even to the life of normal human beings. That gift is comprehended in the lessons of patience, understanding, and mercy, lessons which we all need to receive and to practice with one another, whatever we are."

The standard of potential social worthiness is little better in deciding about abortion in particular cases than is the standard of economic cost. To drive the point home, each of us might consider retrospectively whether he would have been willing to stand trial for his life while a fetus, pleading only his worth to society as he now can evaluate it. How many of us are not socially "defective" and with none of the excuses possible for a child with phenylketonuria? If there is to be human life at all, potential social worthiness cannot be its entitlement.

Finally, we should take care of the ambiguities in the very notion of societal good. Some use the term "society" to mean their own particular political community, others to mean the whole human race, and still others speak as if they mean both simultaneously, following that all-too-human belief that what is



good for me and mine is good for mankind. Who knows what is genetically best for mankind, even with respect to Down's syndrome? I would submit that the genetic heritage of the human species is largely in the care of persons who do not live along the amniocentesis frontier. If we in the industrialized West wish to be really serious about the genetic future of the species, we would concentrate our attack on mutagenesis, and especially on our large contribution to the pool of environmental mutagens.

But even the more narrow use of society is ambiguous. Do we mean our "society" as it is today? Or do we mean our "society" as it ought to be? If the former, our standards will be ephemeral, for ours is a faddish "society." (By far the most worrisome feature of the changing attitudes on abortion is the suddenness with which they changed.) Any such socially determined standards are likely to provide too precarious a foundation for decisions about genetic abortion, let alone for our notions of human rights. If we mean the latter, then we have transcended the societal standard, since the "good society" is not to be found in "society" itself, nor is it likely to be discovered by taking a vote. In sum, societal good as a standard for justifying genetic abortion seems to be unsatisfactory. It is hard to define in general, difficult to apply clearly to particular cases, susceptible to overreaching and abuse (hence, very dangerous). and not sufficient unto itself if considerations of the good community are held to be automatically implied.

A second major alternative is the standard of parental or familial good. Here the argument of justification might run as follows. Parents have a right to determine, according to their own wishes and based upon their own notions of what is good for them, the qualitative as well as the quantitative character of their families. If they believe that the birth of a seriously deformed child will be the cause of great sorrow and suffering to themselves and to their other children and a drain on their time and resources, then they may ethically decide to prevent the birth of such a child, even by abortion.

This argument I would expect to be more attractice to most people than the argument appealing to the good of society. For one thing, we are more likely to trust a person's conception of what is good for him than his notion of what is good for society. Also, the number of persons involved is small, making it seem less impossible to weigh all the relevant factors in determining the good of the family. Most powerfully, one can see and appreciate the possible harm done to healthy children if the parents are obliged to devote most of their energies to caring for the afflicted child.

Yet there are ambiguities and difficulties perhaps as great as

with the standard of societal good. In the first place, it is not entirely clear what would be good for the other children. In a strong family, the experience with a suffering and dying child might help the healthy siblings learn to face and cope with adversity. Some have even speculated that the lack of experience with death and serious illness in our affluent young people is an important element in their difficulty in trying to find a way of life and in responding patiently yet steadily to the serious problems of our society (Cassell, 1969). I suspect that one cannot generalize. In some children and in some families, experience with suffering may be strengthening, and in others, disabling. My point here is that the matter is uncertain, and that parents deciding on that basis are likely as not to be mistaken.

The family or parental standard, like the societal standard is unavoidably elastic because "suffering" does not come in discontinuous units, and because parental wishes and desires know no limits. Both are utterly subjective, relative, and notoriously subject to change. Some parents claim that they would not tolerate having to raise a child of the undesired sex; I know of one case where the woman in the delivery room, on being informed that her child was a son, told the physician that she did not even wish to see it and that he should get rid of it. We may judge her attitude to be pathological, but even pathological suffering is suffering. Would such suffering justify aborting her normal male fetus?

Or take the converse case of two parents, who for their own very peculiar reasons, wish to have an abnormal child, say a child who will suffer from the same disease as grandfather or a child whose arrested development would preclude the threat of adolescent rebellion and separation. Are these acceptable grounds for the abortion of "normals"?

Granted, such cases will be rare. But they serve to show the dangers inherent in talking about the parental right to determine, according to their wishes, the quality of their children. Indeed, the whole idea of parental rights with respect to children strikes me as problematic. It suggests that children are like property, that they exist for the parents. One need only look around to see some of the results of this notion of parenthood. The language of duties to children would be more in keeping with the heavy responsibility we bear in affirming the continuity of life with life and in trying to transmit what wisdom we have acquired to the next generation. Our children are not our children. Hopefully, reflection on these matters could lead to a greater appreciation of why it is people do and should have children. No better consequence can be hoped for from the advent of amniocentesis and other technologies for controlling human reproduction.

If one speaks of familial good in terms of parental duty, one could argue that parents have an obligation to do what they can to insure that their children are born healthy and sound. But this formulation transcends the limitation of parental wishes and desires. As in the case of the good society, the idea of "healthy and sound" requires an objective standard, a standard in reality. Hard as it may be to uncover it, this is what we are seeking. Nature as a standard is the third alternative.

The justification according to the natural standard might run like this. As a result of our knowledge of genetic diseases, we know that persons afflicted with certain diseases will never be capable of living the full life of a human being. Just as a nonecked giraffe could never live a giraffe's life, or a needle-less porcupine would not attain true "porcupine-hood," so a child or fetus with Tay-Sachs disease or Down's syndrome, for example, will never be truly human. They will never be able to care for themselves, nor have they even the potential for developing the distinctively human capacities for thought or self-consciousness. Nature herself has aborted many similar cases, and has provided for the early death of many who happen to get born. There is no reason to keep them alive; instead, we should prevent their birth by contraception or sterilization if possible, and abortion if necessary.

The advantages of this approach are clear. The standards are objective and in the fetus itself, thus avoiding the relativity and ambiguity in societal and parental good. The standard can be easily generalized to cover all such cases and will be resistant to the shifting sands of public opinion.

This standard, I would suggest, is the one which most physicians and genetic counselors appeal to in their heart of hearts, no matter what they say or do about letting the parents choose. Why else would they have developed genetic counseling and amniocentesis? Indeed, the notions of disease, of abnormal, of defective, make no sense at all in the absence of a natural norm of health. This norm is the foundation of the art of the physician and of the inquiry of the health scientist. Yet, as Motulsky and others in this volume have pointed out, the standard is elusive. Ironically, we are gaining increasing power to manipulate and control our own nature at a time in which we are increasingly confused about what is normal, healthy, and fit.

Although possibly acceptable in principle, the natural standard runs into problems in application when attempts are made to fix the boundary between potentially human and potentially not human. Professor Lejeune (1970) has clearly demonstrated the difficulty, if not the impossibility, of setting clear molecular, cytological, or developmental signposts for this boundary.

Attempts to induce signposts by considering the phenotypes of the worst cases is equally difficult. Which features would we take to be the most relevant in, say, Tay-Sachs disease, Lesch-Nyhan syndrome, Cri du chat, Down's syndrome? Certainly, severe mental retardation. But how "severe" is "severe"? As Abraham Lincoln and I argued earlier, mental retardation admits of degree. It too is relative. Moreover it is not clear that certain other defects and deformities might not equally foreclose the possibility of a truly or fully human life. What about blindness or deafness? Quadriplegia? Aphasia? Several of these in combination? Not only does each kind of defect admit of a continuous scale of severity, but it also merges with other defects on a continuous scale of defectiveness. Where on this scale is the line to be drawn: after mental retardation? blindness? muscular dystrophy? cystic fibrosis? hemophilia? diabetes? galactosemia? Turner's syndrome? XYY? club foot? Moreover, the identical two continuous scales-kind and severity -- are found also among the living. In fact, it is the natural standard which may be the most dangerous one in that it leads most directly to the idea that there are second-class human beings and sub-human human beings.

But the story is not complete. The very idea of nature is ambiguous. According to one view, the one I have been using, nature points to or implies a peak, a perfection. According to this view, human rights depend upon attaining the status of humanness. The fetus is only potential; it has no rights, according to this view. But all kinds of people fall short of the normal--children, idiots, some adults. This understanding of nature has been used to justify not only abortion and infanticide, but also slavery.

There is another notion of nature, less splendid, more human and, though less able to sustain a notion of health, more acceptable to the findings of modern science. Animal nature is characterized by impulses of self-preservation and by the capacity to feel pleasure and to suffer pain. Man and other animals are alike on this understanding of nature. And the right to life is ascribed to all such self-preserving and suffering creatures. Yet on this understanding of nature, the fetus--even a defective fetus--is not potential, but actual. The right to life belongs to him. But for this reason, this understanding of nature does not provide and may even deny what it is we are seeking, namely, a justification for genetic abortion, adequate unto itself, which does not simultaneously justify infanticide, homicide and enslavement of the genetically abnormal.

There is a third understanding of nature, akin to the second, nature as sacrosanct, nature as created by a Creator. Indeed, to speak about this reminds us that there is a fourth possible stan-

dard for judgments about genetic abortion: the religious standard. I shall leave the discussion of this standard to those who are able to speak of it in better faith.

Now that I am at the end, the reader can better share my sense of frustration. I have failed to provide myself with a satisfactory intellectual and moral justification for the practice of genetic abortion. Perhaps others more able than I can supply one. Perhaps the pragmatists can persuade me that we should abandon the search for principled justification, that if we just trust people's situational decisions or their gut reactions, everything will turn out fine. Maybe they are right. But we shoud not forget the sage observation of Bertrand Russell: "Pragmatism is like a warm bath that heats up so imperceptibly that you don't know when to scream." I would add that before we submerge ourselves irrevocably in amniotic fluid, we take note of the connection to our own baths, into which we have started the hot water running.

## NOTES AND REFERENCES

- 1. This strikes me as by far the most important inference to be drawn from the fact that men in different times and cultures have answered the abortion question differently. Seen in this light, the differing and changing answers themselves suggest that it is a question not easily put under, at least not for very long.
- 2. Other ways include: one should not do violence to living or growing things; life is sacred; respect nature; fetal life has value; refrain from taking innocent life; protect and preserve life. As some have pointed out, the terms chosen are of different weight, and would require reasons of different weight to tip the balance in favor of abortion. My choice of the "rights" terminology is not meant to beg the questions of whether such rights really exist, or of where they come from. However, the notion of a "fetal right to life" presents only a little more difficulty in this regard than does the notion of a "human right to life," since the former does not depend on a claim that the human fetus is already "human." In my sense of the terms "right" and "life," we might even say that a dog or a fetal dog has a "right to life," and that it would be cruel and immoral for a man to go around performing abortions even on dogs for no good reason.
- 3. For a discussion of the possible biological rather than moral price of attempts to prevent the birth of defective children see Neel (1970) and Motulsky, Fraser, and Felsenstein (1971).
- 4. I assume this calculation ignores the possibilities of inflation, devaluation, and revolution.
- Buck, P.S. (1968). Foreward to The Terrible Choice: The Abortion Dilemma, New York, Bantam Books, pp. ix-xi
- Cassell, E. (1969). Death and the Physician, Commentary, (June) pp. 73 79.
- Lejeune, J. (1970). American Journal of Human Genetics, 22, 121.
- Lincoln, A. (1954). In <u>The Collected Works of Abraham Lincoln</u>, R. P. Basler editor. New Brunswick, New Jersey, Rutgers University Press, Vol. II, p. 222.
- Motulsky, A. G., G. R. Fraser, and J. Felsenstein (1971). In Symposium on Intraauterine Diagnosis, D. Bergsma, editor, Birth Defects: Original Article Series, Vol. 7, No. 5.
- Neel, J. (1972). In <u>Early Diagnosis of Human Genetic Defects: Scientific and Ethical Considerations</u>, M. Harris, editor. Washington, D.C. U.S. Government Printing Office, pp. 366 380.