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FREE CONTRIBUTIONS

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THE ETHICS OF GENETIC COUNSELING

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Amniocentesis was developed as a therapeutically-oriented procedure, and still is when performed in the third trimester of pregnancy. But mid-trimester amniocentesis (14th to 18th week) is at present applied only for eugenic reasons: (1) to determine the sex of the baby, (2) to diagnose the presence and nature of a chromosomal disorder, (3) to diagnose an inborn error of metabolism by an appropriate enzyme assay on cells cultured from amniocentesis-obtained fluid.
Since most of the diseases that can be diagnosed in this way are not treatable as yet, antenatal diagnosis is used only to inform the parents and/or facilitate selective abortion of defective babies or carriers. It is obvious that ethical principles must be applied to human acts such as these. These principles applied depend on the philosophical and religious views one brings to bear on such problems.
It is suggested that standards derived from a secular humanist philosophy, such as the 'good' of society, familial or parental 'good', a 'natural' standard such as 'quality of life', are all inadequate and indeed dangerous.
The argument is presented that these grave issues can safely be resolved only in an ethical system that is based on optimal value judgements; they will be optimal if they are informed by a sound metaphysics of being, and suffused by the light of a vision of man derived from Divinely-revealed truth as transmitted chiefly by the teaching authority of the Church founded by God.

Genetic counseling is a term applied to a service provided to people by a wide variety of professionals. It is, strictly speaking, applied genetics or clinical genetics. The science of genetics itself is of much broader scope, necessarily, since it is concerned with the inheritance of discernible traits, both normal and abnormal, and the action of genes in the environment.

Human genetics comprises, not only clinical or applied genetics, but also population genetics, cytogenetics, biochemical genetics, immunogenetics, and somatic-cell genetics.

For many years genetic counselors could only inform an individual or a family of the statistical risk of having an abnormal child, and even today, despite the great increase in knowledge of the genetic code and the parallel advances in cytogenetics and biochemical genetics, much of genetic counseling is still concerned with such statistical risk estimates.

But a new and powerful tool has been developed in recent years which enables the genetic counselor to give a family exact information as to the status of their unborn child in regard to an increasing number of genetically-determined disorders. This tool is antenatal diagnosis by means of amniocentesis, a technique of sampling the amniotic fluid through a transabdominal needle. It was introduced originally as a means of applying the new science of immunogenetics to the problem of blood-group incompatibility, usually of the Rh factors, between mother and baby, which resulted in a serious, frequently fatal diseases of the newborn, Erythroblastosis Fetalis. It was a therapeutically oriented procedure, and still is, though less and less indicated

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for Rh sensitisation, since the product called Rho-Gam was developed. Its value, for instance, in the diagnosis of pulmonary maturation problems in the baby, so that the mother can be prophylactically treated with steroids which get to the baby through the placenta, is well-established. Therapeutically-oriented amniocentesis is performed in the third trimester of pregnancy.

But amniocentesis in *mid-trimester*, i.e., between the 14th and 18th weeks, is a different matter. Its purpose is (1) to determine the sex of the baby; (2) to diagnose the presence of a chromosomal disorder in the baby by tissue-culture of the cells in the fluid (which are derived from the baby), and examination of the chromosomal pattern of those cells, and (3) to diagnose the presence of a genetically-determined deficiency by assaying a variety of enzymes in homogenates of those cells.

All the chromosomal abnormalities, such as Down's syndrome (mongolism), Turner's syndrome, Klinefelter's syndrome, etc., and about 20 different inborn errors of metabolism, can be diagnosed in this way, a rapidly expanding list to be sure (Hirschorn 1973).

But while diagnostic capabilities are growing rapidly, no corresponding advance has occurred in therapeutic approaches to these disorders. Accordingly, the only purposes that can be served by providing antenatal diagnosis by amniocentesis in mid-trimester at this stage of medical genetics are:

1. To inform the parents of the genetic status of the child so that they may be prepared for the birth of an abnormal son or daughter, and/or
2. To facilitate the selective abortion of defective babies. It is not surprising, therefore, to read that one of the prerequisites for undertaking the antenatal diagnosis of congenital disorders by amniocentesis is that pregnancy termination, i.e., abortion, be an acceptable option. (American College of Obstetricians and Gynecologists 1972). In many centers, in the U.S. at least, this policy of restricted amniocentesis is followed.

It is evident from the foregoing that a variety of moral and ethical problems arise in the practice of clinical genetics and genetic counseling. I do not propose to discuss each in detail. Rather, I wish to present some reflections on the development of the ethical principles that apply and must be applied to this growing field of scientific medical practice.

Let us begin by saying that any rational discussion of ethics presupposes acceptance of a number of 'Givens' in moral philosophy, for example:

1. Morality is attributable only to human acts: we do not judge the actions of nonhuman species as moral or immoral.
2. Only *free* human acts can be judged moral or immoral from the subjective point of view; ethics presupposes free will — if man is not free, ethics is a sterile exercise.
3. Ethical principles are normative of human actions in their moral aspect.
4. Ethics does not exist in a vacuum: it derives from our concepts of the human condition.

Dr. John Fletcher of Interfaith Metropolitan Theological Education, Inc., of Washington, D.C., put it very well when he wrote (1973): "Underlying every inquiry in ethics is a vision of the meaning of life and a set of claims and obligations proceeding forth from that vision. In our time many visions of life prevail." Let us grasp the nettle straightaway by saying that the vision of life and of man prevailing among many contemporary scientists is such as to cause grave disquiet.

At the very first session of the meeting at which Dr. Fletcher presented his paper, one such scientist raised the banner of atheism and scientific humanism when he said:

> Some of us, though profoundly awed by the universal as we apprehend it, do not believe in a supernatural God and we reject divine authority for an ethical code. Nor can we accept the idea of an eternal, universal, absolute ethics imprinted in the conscience of man...
>
> It seems to me, therefore, that the authority for ethical decisions, for decisions as to what is right and good, come from man himself, from his own choices, individually and in groups... the touchstone of man's choices, of his ethical choices, is simply his judgment of whether it is right and good for man. Man is the measure of all things. (Sonneborn 1973).

In a paper presented later on during that same conference, Dr. Leon Kass of the Committee on the Life Sciences and Social Policy of the National Academy of Sciences, Washington, D.C., rejected implicitly the standards suggested as justifying the abandonment of "the belief in the radical moral equality of all human beings, the belief that all human beings possess, *equally and independently of merit*, certain fundamental rights, one among which, is of course, the right to life."

His criticisms of such standards, standards derived from the secular humanist vision, are very compelling. He rejects the societal standard, the good of society, because there is nothing in the history of man to suggest that secular standards have ever been or will ever be anything but a precarious foundation for moral behavior. The standard of parental or familial good is unavoidably elastic because "suffering" and "good" do not come in discrete measurable units, and because parental wishes and desires know no bounds.

The natural standard is rejected as being perhaps the most dangerous of all for it leads directly to the idea that there are second-class human beings and sub-human beings. This idea of course has been used to justify, not only abortion and infanticide, but slavery as well. 'Nature' in the context of this standard implies and points to a peak, a perfection. It ignores another notion of nature, the notion of animal nature, characterised by impulses of self-preservation and by the capacity to feel pleasure and suffer pain. The right to life is ascribed to all such self-preserving and suffering creatures, with especial vehemence by those secular humanitarians who deny any such right to human infants in utero. Dr. Kass goes on to say, "There is a third understanding of nature, akin to the second, nature as sacrosanct, nature as created by a creator." (Kass 1973).

And so there *is* a standard, the only sane standard by which the morality of human actions can be judged — the religious standard. And so we come to contemplate the only complete and integral vision of man, the only vision by which he may safely be guided, the vision by which he is truly free and fully human. Ethics, as Dietrich von Hildebrand (1973) has argued so lucidly and cogently, is concerned with categories of importance, with values. He distinguishes two different kinds of 'good' — that which has objective value, and the subjectively satisfying, a difference that is reflected in our language: we speak of things that are "agreeable" or "pleasant" *to* us or *for* us, whereas value predicates, such as "sublime" or "holy", are used without such prepositions, or reference to anyone's satisfaction.

Value, however, is not only a category of importance — it is what objectively enriches the universe, it is that which not only *is* but *ought* to be. Value is therefore also that to which an appropriate response is *due*. It is metaphysically rooted in the concept of 'being'. Value response is the act by which man conforms to value by giving an appropriate response to it.

Applying the concept of value response to ethics we see that value response is the soul of

the morally good act. It is possible to show that peaks in what we call civilisation coincided with periods in the history of mankind when value responses, within the limits of available acquired or intuitive knowledge of the nature of things, were optimal on the part of a significant number of the members of a society, be it tribe, city, or state.

These value responses were optimal when value was not restricted to the horizontal dimension, but rather when men recognised a hierarchy of 'being', and value as well as value-response were vertically as well as horizontally-oriented.

In a word, ethics can be optimal and complete only when value is attributed to the things of God as well as the things of man.

It was not possible to remain content with a 'natural' ethics, no matter how well-argued and well-ordered, once the Second Divine Person of the Blessed Trinity became man, and completed in time the revelation of God to man.

It was not possible when the civilisation of pagan Rome was proven to be founded on quicksand; it is not possible now.

The vision of man derived from Divinely-revealed truth must prevail. We are certain it will prevail in the end; for that we have God's promise.

It must prevail now! In the light of that vision, and only in its light as transmitted and refracted by the prism of the authentic magisterium of the Church founded by God, to which He committed that vision, ethical principles can be derived whereby the major ethical issues in genetics and genetic counseling must be resolved. We must make our own the words of the Psalmist:

> The Lord is the keeper of little ones...
> I will walk in the presence of the Lord in the land
> of the living. [Ps. 114 (115) W. 6 and 9]

If we do not, we must know that the wages of our sin will indeed be death.

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