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Genetic Counseling

The avalanche of new genetic discoveries and revolutionary techniques (such as amniocentesis, fetoscopy, and fetal biopsy) has introduced into our social consciousness an awareness of moral, ethical, and philosophical concepts at the grass-roots level that were formerly left to the ivorytower scholars. Suddenly we are faced with choices previously left to fate: Should a genetically defective child be aborted? Should parents be allowed to select the sex of their offspring? Do parents have an inalienable right to knowingly produce defective children?

These and related questions are receiving increasing attention in professional journals and in articles for the layman. The bioethicists promulgate heated arguments, convincing me that there are no right or wrong answers to the questions posed. Most of the recent articles on genetic counseling have pointed out the complex issues involved, the difficulties in communication, and the ethical dilemmas posed. Many authors have taken a stand on the "best" way to counsel. Each reflects a different point of view.

My point of view is that we need to preserve these different points of view. As a geneticist, I cherish human variability. Our collective strength lies in our pluralistic attitudes. Freedom of speech preserves our right to shout our convictions and to try to persuade others. But the power to make rational decisions preserves our ability to resist coercion from others. There is no opportunity for rational choice, however, when a counselor does not disclose this variety of viewpoints which enables the counselee to arrive at an independent, autonomous decision.

I am not afraid that genetic screening will lead to genocide, nor that abortion will lead to infanticide, as many have warned. If we need checks on our behavior the law will provide them.

The relationship of the genetic counselor to the counselee is a very personal one. It involves a discussion of procreation decisions. Should the counselor describe only the genetic risks, inform the counselee of the range of decisions available, or advise the counselee on the action to be taken? Different counselors do different things. The counselor has freedom to persuade, according to his personal convictions, but he does not have freedom to coerce, based upon his inherent power in the counseling milieu. He must accept the counselee as the ultimate decision-maker. Different parents have a variety of motives for their ultimate decisions. Thus, the outcome of their deliberations will vary. And we will preserve our genetic heterogeneity!

Professionals in general, and physicians in particular, tend to adopt a paternalistic attitude in dealing with patients or experimental subjects or relatives. But only those who desire "parenting" will blindly follow another's advice. The rest will be influenced to a greater or lesser degree by the prescriptions of the counselor who is directive rather than permissive. Those who would argue that the counselee needs protection from directive counseling are themselves being paternalistic.

As our life-styles have become more individualized, so have our ethical codes. The Supreme Court has recognized this trend in the Roe ν . Wade decision on elective abortion. The proposed amendment to the Constitution to reverse this decision would narrow our options to make individual choices. I see no immediate need to arrive at a consensus or to make policy decisions. Let us keep our options open and preserve our diversity of opinion. By so doing, we preserve our diversity of people.

—MARGERY W. Shaw, Director, Medical Genetics Center, Health Sciences Center at Houston, University of Texas, Houston 77025