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BIOMEDICINE AND ETHICS

WHAT ROLE FOR GENETIC ENGINEERING?

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Amitai Etzioni

If a raving maniac struck your child on the head with an iron bar, causing mental retardation, reduction of life expectancy to seven years, and institutionalization, the act would be considered a horrendous crime. The perpetrator would be instantly incarcerated.

When a physician refrains from telling a woman that her next child may be a mongoloid and that the tragic birth can be avoided, and then she bears a retarded child who dies young, nobody makes a fuss. As a matter of fact, many hundreds of thousands of women are not told. Three out of every hundred children born has a genetic defect; two more have a hidden genetic malformation that will affect them later in life (causing such illnesses as spinal cerebellar degeneration, which is a hereditary disorder of the central nervous system, appearing in the mid-20s, or Huntington's chorea, which causes a deterioration of the brain, usually between ages 30 and 60). However, a rapidly increasing number of these illnesses can now be avoided.

Until the early '60s, each child conceived represented a gamble. Researchers and doctors could tell pregnant women that the older they were, the likelier they were to have children afflicted by any one of a large set of crippling or even fatal, genetically caused diseases. Doctors could even give prospective parents fairly precise probability estimates. Yet, every woman who wanted a child had to take her chances, because statistical projections, of course, tell you nothing about the outcome of individual events. Thus, if you are told there is a 25 percent probability that your next child will be a mongoloid, you still don't know what your next child would be. Nor do you know whether out of three or five children all or none would be mongoloids, or whether your present pregnancy is any different from what future ones will be. Such a formulation provides a rather poor guide to action: it leaves parents only two drastic choices: the gamble that the next child will be all right, or the decision to have none.

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While many prospective mothers are still left with only these two choices, the situation need no longer be so drastic. A relatively simple test called amniocentesis can tell, with a very high degree of accuracy, whether or not the *specific* fetus a woman is carrying is deformed. Now even a woman with a high predisposition to mongolism can have healthy children.

The test is done by inserting a hollow needle into the sac in which the fetus floats. The doctor withdraws some of the fluid and sends it to a laboratory. Here, fetal cells found in the fluid are grown in a culture and subsequently studied to determine whether they carry any one of 40 or more (the number is rapidly rising) genetic abnormalities. If the test is negative, the parents can be quite sure the child to be born will not suffer from these diseases. If it is positive, prospective parents usually choose abortion, soon to be followed, in most cases, by another pregnancy. Other, later embryos can also be tested. In this way, a couple can be, in effect, secure of a child free from mongolism and other diseases like Turner's syndrome (which entails severe sexual abnormalities), Tay-Sachs disease, or galactosemia. Tay-Sachs occurs almost exclusively in Jewish families of Eastern European descent; infants become blind, deaf and mentally retarded, with death usually following in the second or third year. Galactosemia, a metabolic disorder, can mean cataracts, cirrhosis of the liver, or mental retardation.

**How doctors view
amniocentesis**

Many doctors I have interviewed are not familiar with amniocentesis; many more reply that they would *not* inform a pregnant woman about the availability of amniocentesis, or would do so only if the woman was over 40 years old, an age at which the risk of having a genetically deformed child sharply rises. (The risk of mongolism is one in 3,000 for women under 30; one in 600 for those aged 30 to 34; one in 280 for those 35 to 39; one in 80 for ages 40 to 44; and one in 40 for ages 44 and up, according to Virginia Apgar, clinical professor of Pediatrics at Cornell University Medical College.) Doctors who withhold the possibility of amniocentesis from their patients are motivated neither by greed nor malice but, as I shall try to show in some detail, by misguided notions about their role. The way amniocentesis is now managed deserves careful attention, not only because of the value of the technique itself, but also because it tells us, as we gain additional new genetic tools, what to watch for and what is to be done.

Unlike new drugs, new medical procedures are not reviewed by any public authority or agency to determine their safety. Hence, each doctor must personally decide about amniocentesis, and there is strong disagreement about how dangerous it is. One doctor flatly stated: "It [amniocentesis] is safe"; he uses it freely. Another said it should be *required* of all pregnant women. But most doctors oppose the test because they think it entails risks that are "too high." What are those risks? How high is high? And, how does one determine which risks are "too high"?

**The risks from
amniocentesis**

We are accustomed to expect risks to be expressed in neat figures, to be told, say, that the chances are one out of 1,000 or one out of 200 that medical intervention will kill you rather than give the desired therapy. No such figures are available on amniocentesis. The main research project aimed at getting a good fix on these figures is under way but will not be completed until mid-1974. Existing data have been pieced together from various smaller studies that differ in methods and measurements. In addition, the test presents a variety of risks, which differ in severity and frequency and are harder to total up than, say, the risk of being mugged or being involved in a traffic accident.

The list of risks runs as follows:

Between one and two percent of the women tested will have a spontaneous *abortion* after the test is made. (Some of these abortions might have occurred anyway, since most tests have been done for older women who have a higher rate of spontaneous abortion.)

Three percent of the women tested suffer an infection as the result of the procedure, but most infections respond to antibiotics.

In eight to 10 percent of the women, the test will cause some bleeding because the needle has punctured the placenta; in some cases there will be a puncture of the bladder; in some, of the intestines. All but the last, which seems very rare, usually have no serious consequences. Also, in those few cases, where both the mother's blood vessels and those of the fetus are punctured, and the mother is Rh negative, and the fetus Rh positive a reaction will tend to result that may adversely affect future pregnancies.

There is no record of fatality of an expectant mother as far as we know.

In very rare cases—there are only two or so on record—the needle punctures the fetus and harms it; in one case, an eye was lost.

Some doctors fear that the very "traumatization" of the fetus by jarring its environment with a needle, or by removing some of the amniotic fluid, may affect the child's IQ or its health; there is extremely little evidence to support or to refute this notion.

This list roughly covers the arena of risk in which the decision to test or not to test must be made. (Had we studied amniocentesis instead of, say, defoliants for the war in Vietnam, we would know much more about the exact degree of risk; after all, the procedure has been used to collect genetic information for over 10 years.)

However, the matter is not only one of getting a better fix on the magnitude of the risk. It will take years of follow-up studies to discover the effects of the procedure on the psychological and physiological developments of tested children, and we must

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**Giving patients
a choice**

judge the acceptability of these risks now, and decide whose values will be used in such judgments.

It requires no degree in probability theory to figure out that a risk, or more accurately, a package of different risks, that seems quite high to one person will not seem high at all to another. Not only do we all have different tolerances for risk, but our views of the consequences are affected by our personalities, social statuses, needs and values.

For example, a one-percent to two-percent danger that the fetus will be lost because of a test aimed at securing a normal child will seem, and in this sense will be, extremely high to a 40-year old woman who is desperate to have a child and who is quite willing to accept a deformed one rather than risk not being able to conceive again. A young woman, mother of three, who is desperately afraid of any deformities and rather ambivalent about having another child, might rate the same risk much lower. Moreover, no one can predict, by looking at a person's IBM card or medical record, if, faced with a choice between the risks amniocentesis entails and those it allows one to avoid, what a person or couple will decide. *Why try? Ask them!*

I cannot see what moral or other basis doctors use to disallow the prospective parents to render their own judgment. I do not quarrel with those doctors who feel that the risk is too "high," whatever this means, or with those who urge all women, or all but those above certain age, to avoid the risk. I quarrel only with those who do not give their patients the information that they do have a choice, and, if a woman wants the test, provide the necessary referrals if they themselves cannot or will not administer the procedure. If a child of mine were born deformed and I had not been told beforehand that I had a choice in the matter, I would sue the doctor and the public health department for not informing me of my choice. And I would have a hard time limiting the expression of my anger to such a civilized outlet.

Several of the doctors interviewed, and several who have written about the test, state that if a woman came to them to ask about amniocentesis, or was seriously worried about the abnormality of her fetus, perhaps because of a family history of genetic illness, then, oh yes, they would tell. But they would not suggest to a woman who did not fear genetic malformation the possibility that her child might be severely deformed. "Not on your life," my own doctor told me. They say, this would cause her anxiety, even if the test was negative. And her anxiety would continue for all the months until the child was born and likely even after that, until its normal development was obvious. This anxiety, they say, would harm both the woman and her fetus.

John Fletcher, director of Interfaith Metropolitan Theological Education, Inc., in Washington, D.C., points out that amniocentesis might be followed by "considerable anxiety," exacerbation of already existing marital and family problems, and, following positive diagnosis of a defective fetus, guilt in regard

to being a carrier of genetic disease. Princeton sociologist James Sorenson worries about the psychological consequences for the mother who may first identify with the developing fetus, and, in later months, with herself as mother-to-be, and then destroy these identifications with abortion.

Note, first of all, that most of the problems referred to concern abortion, not amniocentesis. Of course, the test is worse than useless if it cannot be followed up by an abortion, but the country has already allowed abortion for other purposes, despite the possibility of these psychological problems; it can hardly reject it for this purpose. Second, where is any evidence that the burden of information and decision and anticipation will damage mother and child? "Well," the doctors mumble, "there are indications that high stress is harmful." One doctor told me about a patient who, after being advised to take a genetic test when her twin sister was hit by a hereditary illness, committed suicide.

"How many days later?" I asked.

"Three weeks," was the answer.

"Any evidence that the fear of the test was the cause?"

"Well, it's rather obvious."

"Well, is it?"

Are there any data showing that the fear of the test causes a level of anxiety which can be called harmful? Not really. Could a few therapeutic discussions or group sessions for women who face the same problem reduce the anxiety to quite tolerable levels? "That is not our business," a conservative doctor exclaimed. *We* had better make it ours.

Will the race
be weakened?

Some of the many doctors opposed to the test echoed an objection that several distinguished scientists have stated: What about the welfare of the race? They fear that new medical developments, interfering with natural-selection processes, will lead to an ever weaker, less fit, race. Sir Julian Huxley, renowned author and biologist, calls for a drive to improve the race:

"... it is clear that the general quality of the world's population is not very high, is beginning to deteriorate, and should and could be improved. It is deteriorating, thanks to genetic defectives who would otherwise have died being kept alive, and thanks to the crop of new mutations due to fallout. In modern man the direction of genetic evolution has started to change its sign, from positive to negative, from advance to retreat: we must manage to put it back on its age-old course of positive improvement."

On the same issue biologist Bentley Glass has written: "... by surrounding ourselves with an ever more artificial environment, we unwittingly modify the rigor of natural selection in many ways. The price we must pay, in the end, for the mercies of medical care and surgical aid is a dysgenic increase in the frequencies of certain detrimental genes the effects of which we have learned to ameliorate. . . . No one, I think, would have it otherwise. Yet to contemplate the man of tomorrow who must begin

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his day by adjusting his spectacles and his hearing aid, inserting his false teeth, taking an allergy injection in one arm and an insulin injection in the other, and topping off his preparations for life by taking a tranquilizing pill, is none too pleasant. To say the least, medical science steadily increases the load it must carry."

On the face of it, these arguments would lead one to favor massive use of amniocentesis to try to correct for all of these faults by "weeding out" weak genes. However, other scientists have pointed out that biological traits that are highly undesirable in the present condition might be essential for survival if our environment were to change. Thus, sickle cell anemia, a terrible illness which plagues many black Americans, might be eliminated one day, only for us to find out that it is a useful combatant to malaria. It would serve us all well following a breakdown in civilization, say after a nuclear war, or—if we are sent to serve in Vietnam. Similarly, diabetes has been characterized as a "thrifty" genotype, useful when food supplies are very limited and "deleterious only in the context of the grossly excessive and unbalanced diets which characterize our civilization."

Will
amniocentesis
backfire?

Also, it has been forcefully argued that amniocentesis will backfire, causing more, rather than less defects. The argument is far from self-evident and runs as follows: if amniocentesis is not used, most afflicted children born will not reach reproductive age; hence the illnesses they carry will die with them, not be passed on to future generations. When amniocentesis is used, and afflicted fetuses are aborted, many parents go ahead and have another child. In many cases, the defect will be carried by the child in a latent manner, thus multiplying the sick genes of future generations.

However, meticulous calculations by Arthur G. Steinberg, professor of biology and human genetics at Case Western Reserve University, Cleveland, Ohio, indicate that even under the most unfavorable conditions, assuming a high rate of frequency of the defective gene (.1, which would make the rate of affected individuals, not just carriers, .01) and a high birth rate (of five offspring per average family), it would take 13 generations, or 390 years, to double the incidence of heterozygotes with the defective gene (that is, carriers). Under most assumptions, the time span would be much longer. By that time we might very well be able to correct such mishaps through genetic surgery—perhaps by sending corrective messages to the genes via a virus or replacing a damaged gene with a healthy one. And—meanwhile—all that the slow rise in defects entails is a slow rise in the number of amniocenteses to be administered and abortions to be carried out. The rise would not be trivial, but it would remain far from an unacceptable societal cost. Excessive use of X-ray machines seems to cause more genetic damage and has no positive payoff. And while our civilization may well break down one day and we

shall again live in malaria-infested slums, on starvation diets, no one should dare imply we must now live with sickle cell anemia or diabetes or hosts of other illnesses, so "the race" will do better when our world ends.

I am not saying one must never curb the rights of individuals to a particular procedure or test in the name of a societal need. But one of the greatest values of the Western tradition is that we only impose such curbs reluctantly, and justify them only when the societal damage to be caused is considerable. This is not the case here. Hence, if you tell a woman not to use amniocentesis because the race might suffer, you are either grossly misjudging the scope of the damage or implying a superiority of the society's needs over those of individuals.

How far should
we go?

"One thing leads to another; you're better off not touching the stuff, because while some of it may seem quite OK, soon you slip into even further out and more dangerous usages," some doctors say. The argument is familiar: it has been advanced to tell marijuana smokers they will end up shooting heroin, to tell girls that premarital sex will lead to promiscuity, and, now, to tell prospective parents that while amniocentesis might be quite fine for detection of mongolism, it opens a whole Pandora's box of genetic tricks.

Indeed, the answer is far from obvious. Mongolism is usually such a severe affliction that the decision of what to do about it is relatively straightforward. But the rapidly rising number of other genetic abnormalities, which can be detected by amniocentesis and by other means, offers no such clear indications.

Thus some genetic abnormalities generate only relatively mild disorders such as PKU and diabetes, which can be treated by strict diets or drugs. If the fetus is diagnosed as having these disorders, should the couple abort it, betting on a normal fetus next time, or should they allow it to be born and lead a less than normal life? And, once parents start to abort fetuses that are genetically different, would they not also eliminate children who might develop great intellectual and artistic talent to compensate for their abnormalities? Would the parents of future Dostoevskys, whose epilepsy may have been genetically caused, of future clubfooted Lord Byrons, and of Woody Guthries, who had Huntington's Chorea, abort them in the quest for a normal infant?

Who should
decide?

Moreover, amniocentesis can be used to discover not only disorders but also to discover undesirable biological attributes, for example, so called "criminal genes." There is accumulating evidence that people born with XYY genes, one out of every 1,000 male births, may have a predisposition toward criminal insanity. Many social scientists do not believe that genes could affect behavior in that way ("aggression can find many outlets;" "the kid could become a butcher, or a cop. . ."), but this is beside the point. As long as some scientists hold that genes have a predisposing effect, i.e., that one child is somewhat more likely to

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be criminally insane than others, and have some data to support their position, should the parents be spared the information? And *who* shall decide whether they should be spared or not? Does each doctor decide? The *state* health authorities? An AMA—or APA—Committee?

CHOOSING A CHILD'S SEX

A similar problem in "sliding the slope" appears with sex choice. The test also reveals quite easily whether the fetus is male or female. Most doctors, including those who are quite willing to recommend amniocentesis for health reasons, adamantly oppose people taking the risk for such a "whimsical, arbitrary" reason as learning the sex of their child. "If they are that desperate to have a boy (or a girl), let them adopt one!" exclaimed one doctor. But a survey commissioned by WNBC-TV in May 1972, revealed that 63 percent of the respondents said that they would consider adopting a child, 11 percent said that maybe they would adopt a child, and 24 percent said that they would not adopt a child. That is, one out of four Americans seems to feel rather strongly that they would rather have a child of his "own."

Also, we allow people to take health risks in other areas—to drink, overeat, smoke or drive. Clearly some people do feel rather strongly that they want to have a child "of their flesh and blood" and many have strong feelings about the desired sex of their child. Can we tell them: "No, you're not allowed"? Is it OK for medical societies, in effect, to pressure their members to refuse intervention for these nontherapeutic, eugenic purposes, by defining such utilization as "*unsound practice*"? (Unfortunately for doctors who will perform the test, such a definition may leave them out on a limb if a malpractice suit is brought.) And, if use of the procedure for this purpose is prohibited, will other interventions, to get a taller child (relatively easy) or one with a higher IQ (maybe impossible) also be outlawed? If so, *by whom*? If not, who shall decide?

Those who are most fearful of the slippery slope, and of the complex decisions involved with amniocentesis, point out that there are alternatives, that amniocentesis is not the only way of intervening to affect the genetic composition of the future person. People can affect the heredity of their offspring by having their genes tested in high school, and then avoiding what might be a genetically unsound marriage. For example, a match between a man and woman who each carry the sickle cell trait produces a one in four chance that their children will have sickle cell anemia. Alternatively, people may wish to rely on artificial insemination either to avoid the risks their own genes carry or to rely on hopefully healthier genes contained in a donor's sperm (or, soon, the donor's egg). Again, people may

wish to complete their families while they are young, because the incidence of genetic illness rises with the age of the mother. Should people to whom less risky procedures like these are available to steered away from amniocentesis?

A QUESTION OF AUTHORITY

All of these "catches" raise—directly or indirectly—a question of authority. Who speaks for society? Who decides what people are told or not told? What steps are recommended? What interventions are to be discouraged?

Most doctors argue that all these decisions are best left in their hands. They tend to view these issues as technical-medical questions best handled by "experts," and they feel they can adapt their advice to the individual patient and judge how much information she or he can cope with and act upon. At least, the doctors say, if they go as far as to bring the patient into their decision, doctors should retain the right to render the "ultimate decision."

I say that the roles should be reversed: the doctor should *advise* the patient; the patient should make the ultimate decision. Of course, if the doctor's own values conflict with the procedure, for example, if it entails abortion, he or she should not be expected to perform it. All they need to do is inform the patient and refer her to doctors who will. If people are allowed to have abortions that do entail a risk without accounting to anybody, I fail to see why amniocentesis is any different—unless of course future studies show a much higher ratio of serious consequences than now is known.

So far it is quite simple. It's not the doctor's values but those of the people whose lives are affected that should prevail. But there are some additional complexities. First, who should be the authorizing "parent"? The prospective mother? She *and* her spouse? Should not a woman have the final say over her body? Should one risk the well-being of a fetus without consulting the husband-father? It is too easy to say that both man and woman should decide, because a couple may not agree between themselves. Should a doctor refrain from action unless both parents agree? Is a wife liable to her husband if she endangers their fetus, without consulting him, by telling the doctor she is single?

If one endorses a basically libertarian view, as I do, that an informed adult should make up her or his own mind as long as there is no clear and present aggregate danger to society (and ultimately to the individual) from these decisions, there still remains the question of whether the test should be promoted (or even required) because of potential societal *good*. Take mongolism, which costs us \$1.7 billion a year. Many people who have mongolid children don't raise them; they abandon them to public institutions where they decay and die. One can quickly

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reject the idea of requiring the test, because of the horror of forcing women to be tested and perhaps undergoing abortion. But why not at least *promote* the test? Why shouldn't public-health departments advertise: If you check your fetus, you'll get a normal child, and we will all share the billion saved? Should health officials arrange tours for prospective parents of institutions in which mongoloid children are kept? Couples could thus get a realistic feeling for what such children are really like, rather than relying on antiseptic brochures and clinical explanations of physicians in their offices. Fine, one might say, but what if the same authorities start to promote the breeding of "normal" kids?

The answer to all the varied and complex questions raised by the introduction of amniocentesis, which is just one tool of genetic engineering and forerunner of many to come, is to be found, in part, in a new institution, and, in part, in new politics.

**Needed:
a modern
tribal council**

If we are not to repeat the mistakes of industrialization, when new technologies forced their way into society and made it adapt to *their* needs, we must review, examine, screen and guide the new biological techniques. To scrutinize these new techniques, we require, first of all, the modern equivalent of a tribal council of wise people to reflect on these matters and pronounce their recommendations. They may, for instance, urge the public-health departments actively to promote the use of amniocentesis to combat mongolism; suggest that doctors consult both spouses, not just the wife, when amniocentesis is indicated; ask for greater tolerance for its use for sex choice, and so on. The council's advice should not replace or constrict individual choices but rather seek to inform the individual. Thus, the ultimate decision would continue to rest with each person. But she (and her husband, if any) will be made aware of the opportunities, risks, catches and considerations pointed up in the careful deliberations of a wise body.

This modern equivalent of the tribal council will have to include not just scientists but also humanists, theologians, and social scientists. Such a wide representation will help to assure that the whole person, not just specific individual needs, will be taken into account. Furthermore, such deliberations must be backed up by a research staff. Many of the issues involved require a command of empirical data. Kidney machines are often not provided for young children when their kidneys fail because they tend to react against the tough routines involved. This rule, based on empirical observation, is followed by many ethics committees who allot access to the machines. Thus, if we suggest that amniocentesis not be used for sex choice because it will cause a gender imbalance (parents, data suggest, will order more boys than girls), we are making certain empirical assumptions, and need to gather more empirical data about the severity of the societal dislocations such an imbalance creates. And so on. Mod-

ern value deliberations require data input. Since the empirical input will not "just happen," an authority must be established to make sure that necessary data are collected.

INFORMING THE PUBLIC

The deliberations should be public, so that—like Congressional hearings on other topics—they will generate a wide-spread public debate on the issues involved. Without it, the recommendations to emerge from the deliberations will probably not be supported by the public, and the development of new mores will not take place. Thus, for example, without public hearing on why so few people donate their organs (so after they die, they can be used to save other lives), without bringing into the open the emotional resistances and anxiety accompanying such an act, the issue will not be dealt with effectively. New definitions must be evolved to deal with such questions as when life actually begins (e.g., to allow for amniocentesis and abortion after four and a half months of pregnancy, which many people still emotionally oppose) and when it ends.

Senator Walter Mondale has suggested that such an authoritative body be set up as a Congressional Commission. The Senate, at one point, unanimously endorsed the idea, but the House did not act, and the Commission is now in limbo. It should not be.

Others have suggested that ethics classes dealing with such issues be required in medical schools, that they be offered in college and high-school curricula, that local ethics boards be formed to back up a national ethics commission and apply its guidelines to local cases.

All these suggestions are important, but they leave one with the feeling that the problem would not be adequately handled. What is missing?

On the face of it, the libertarian answer may seem to provide a sufficient response. "Let each person make up her or his mind; let society—through a council of wise persons—inform the public and alert it to the issues involved, so decisions will be educated. There is no place for Government control in these matters."

On second thought, the issue becomes more of a political concern, because our personal decisions are not made in a social-political vacuum. Thus, we may be all in favor of amniocentesis, but in many parts of the country, it is still difficult even to get an abortion, especially in a public hospital. We might favor waiting longer to "pull the plug" on a terminally ill patient, but the soaring cost of hospitalization may make such delays a luxury only the affluent can afford. We may favor sex choice, but if the AMA labels this (or any other such practice) "unsound," doctors may then very well lack protection in case

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In short, what we can do as citizens in regard to our bodies, is, unfortunately, not just a personal question between us and our families, us and our physicians. The whole legal, economic, political, institutional continuum has to be dealt with. And whether we like it or not, the road to personal liberties passes through many civic intersections; we must participate in shaping the *conditions* of our lives so that we will be able to be masters of our own bodies. Only when we devote more attention, time and energy to study and to act on these public aspects of our personal lives, will the political force necessary to counter-vail the technocrats, bureaucrats, and the research-*über-Aller* cult, be formed.

As war is too important to be left to the generals, our bodies are too vital to be left to genetic engineers and doctors.