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The Ethics of Genetic Control ENDING REPRODUCTIVE ROULETTE

Foreword by Joshua Lederberg

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FOREWORD

Joshua Lederberg

Dilemmas about new knowledge, especially about our own bodies, touch deep-rooted anxieties about man's perception of himself and of the gods that he invents or are revealed to him. Mary Shelley, who created Dr. Frankenstein, subtitled her own work The New Prometheus, as witness to a mythical link that spans more than two millenniums. Most of her successors are pale imitators: No great wit is needed to fantasize the mad scientist and the unpredictable outcome of his tampering with the forces of nature. And it is a story line that always sells.

Far harder is it to address the problems of new uses of biology, as Joseph Fletcher does here, in a reality-oriented fashion that exposes the underlying problems of human values. Today instead of Dr. Frankenstein we have physicians and scientists who have dedicated their energies to the relief of disease. The "natural" outcome of a bad hand of genetic cards, or of many other of life's mishaps and misfortunes, is a level of pain and distress that cries out for artificial relief; just as we build fires and weave clothing to keep out nature's chills. And we must learn how not to burn or suffocate ourselves in the process. To outlaw fire may not be man's best path—although Dr. Fletcher reminds us how Prometheus was indeed punished for defying

the gods' interdiction. In his plays, Aeschylus tested his fellow Athenians' ethical convictions with far greater authenticity than we can experience from most contemporary debate about technological progress. With his even temper and honest exposure of the premises of his ethical arguments, Dr. Fletcher sets a new standard—and one hopes a precedent for further debate.

Dr. Fletcher comments how quickly things change. Indeed, this book may already be overtaken by changes in the process of science and the bases for its public support that are taking place right now. The fifties and early sixties were a time when the United States was especially conscious of science in the aftermath of Sputnik. Then one might have argued that knowledge in some branches of genetics was doubling every two years. The climate is very different today. National policy makers insist that we already have an excess of scientists and refuse to support training more Ph.D.s; they question long-term needs for more doctors. Research budgets have plateaued, and in some fields the dollar levels are more than overtaken by inflation. Demographic predictions point to a shrinkage of demand for higher education, and with this in the number of places needed for teacher-investigators at the universities.

Real concerns for the welfare of human subjects and a mania for bureaucratic regulation of research in the drug industry are also tempering the rate of advance. In particular it is no longer true that there is a negligible time lag between "the theoretically possible and the clinically feasible." On the contrary, for some drugs, that lag may be as long as ten or fifteen years, with many opportunities for afterthoughts, changes of standards, and the discovery of adverse information that may prolong that lag indefinitely. Whether or not

public policy is sounder for this tempering of new introductions, it is certain that we are entering a new phase of built-in resistance to innovation in many spheres.

Some of the more irrational components of this reaction may have been softened if Dr. Fletcher's wisdom had been more widely available sooner. At the moment of this writing, the California state legislature is acting on bills to prohibit research on human fetuses, and the U. S. House of Representatives has already passed such a bill with such an amendment added on the floor. The subject may well be worthy of legislative attention; my complaint is that these bodies have refused to hold open hearings to discuss the complex sets of values that may be at stake. In the wave of emotion, language may become law that includes such phrases as would prohibit "conception outside the womb," as if a test tube could be pregnant.

The most insidious features of these laws is how they imply that experimentation is inherently suspect. They would explicitly forbid certain acts if done for experimental purposes that the law would not touch if done out of malice, or for profit, or for entertainment! Whatever principles underlie these prospective laws, they are a far cry from the existential ethics that Dr. Fletcher advocates. There is of course a political explanation. The public's existential concern for its own welfare and happiness has been expressed on the abortion issue, against the deep-felt convictions of a religious minority. Experimental observations on fetuses can be a symbolic sacrifice to those minority convictions without touching the immediate interests of more than a few investigators. The long-term costs of denying to society the medical information that might be gained by studies on fetuses-including possible ways to treat fetal disease that might result in healthier babics, and the avoidance of some abortions that are now inevitable—these are too remote and too arcane to be widely understood.*

Besides these laws, which focus on experimentation itself, many other social controls limit what can be done on the course of research. The investigator has no license to invade the security of other persons or their property. Besides the informal sanctions that we call common decency, he must, like every other citizen, respect laws on criminal assault and civil recourse to damages for injury. Although a few citizens are thieves, most of us are not obliged to prove in advance that we are innocent of stealing; increasingly, investigators are facing a presumption of guilt, and the demand for more elaborate procedures to prove their innocence.

It is true that a researcher who is also a physician may be in conflict about his obligations to his patients—whose health is his primary obligation. In practice, research already exposes a doctor to special liability for malpractice suits in the event of harm. Even so, legislators can point to unredressed abuses that may justify still more elaborate procedures to protect the rights of uninformed and unconsenting patient-subjects. At the present time, even verbal psychological inquiries that would go unquestioned if done for commercial or

^{*} Furthermore, any steps that will make the medical observation of the fetus criminally suspect might help to influence public attitudes in favor of rehabilitating the civil status of the fetus even at the expense of its mother. Advocates of this status, who call themselves "for life," should ponder on the quality of life that would result if genetically damaged fetuses were in fact given legal privileges to exist. We would face the moral obligation of active steps to salvage innumerable creatures whose nurture would be an intolerable burden to themselves, their families, and the social order. It should be more widely known that one fourth of all conceptions now abort spontaneously, but could in principle be saved to protect the right to life of the worst of nature's mishaps.

for administrative purposes must be formally justified before review panels. In many instances these require certificates of the subjects' consent, before they can be pursued in a university research program. These are important instruments of social control of experimentation (contra many assertions that these do not exist); and they must be kept in mind in forecasts about the rate and directions by which fundamental new biological knowledge can be developed in man, and applied to human problems.

Dr. Fletcher takes care to point out that the time frame is unimportant, that many ethical problems are very properly introduced by the phrase "just suppose." There is much argument among biologists about the time frame in which the developments he discusses will become tangible realities, when their application to man poses individual ethical or aggregate social problems of decision. I agree about the value of the metaphor "just suppose"; but when this is not understood we may have a panic reaction to fantasied urgencies, of which legislation intended to prohibit studies on the human egg is an evident example. My personal prophetic intuition agrees with the foresight of many new opportunities for applying biological science; but the experience of the last two decades suggests that the most important applications will come from entirely new directions, most of them now foreseen and quite different from the Frankenstein's monsters that are painted today. For example, even ten years ago, hardly anyone would have predicted that prenatal diagnosis of disease would develop to the status it now enjoys, while many people were already sciencefictionizing about genetic surgery and cloning, which are still speculations.

The boldness of Dr. Fletcher's thinking is to be seen in the directness with which he develops concrete,

moral principled answers to many of the dilemmas we can easily spin. This is terribly important, whether or not we agree with his basic ethical principles, for he has exposed these for all to see. There will be conflict about these; much less about the inexorable logic by which he draws humane conclusions-for humane-ity is his logic. His liberality of outlook will inspire many demoralized and confused people, especially parents who have been beset by doubts as to their responsibilities to themselves and to their hoped-for children. He has wise counsels also for many people who in one way or another are involved in biological research and in medical care, and whose technical expertise confers unavoidable moral responsibilities. Those who disagree will at the very least be challenged to re-examine their fundamental beliefs about the validity of moral imperatives that have been invented for man, and which are sometimes in conflict with common-sense measures based on human pain and delight.

My admiration for Dr. Fletcher's work does not, of course, imply that I agree unswervingly about many of the complex issues he has raised here. I have my doubts that we can always measure the human well-being that should be the touchstone of our efforts. Human selfevaluation of right and wrong, of pleasure and pain, is not always autonomous, but itself developed within a social ethos-else why would others persist so passionately in what appears to us to be wrong thinking! Should we not encourage children to defer immediate gratification for the sake of higher pleasures and rewards? In the framework of the social contract, we may all get more freedom by sacrificing some. Can we be oblivious to another's self-injury in contexts like drug abuse or motorcycling without a helmet, without at the same time becoming more callous about their welfare and resenting having to share the medical bills?

The utilitarian principle itself must respect absolute restraints to avoid the tyranny of the majority: For example, we cannot ethically exploit a few people, without their consent, for high risk medical experiments, simply because of the great benefits to the many. It is impossible, then, in my view to avoid some categorical imperatives; but I am with Dr. Fletcher in demanding that we start, rather than finish, our ethical inquiries from such principles; and that, above all, it is the human consequences by which we must judge our acts.