

The Code of Codes: Scientific and Social Issues in the Human Genome Project.

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Theologians often debate issues of personal freedom and human capacities. For example, do human beings have the ability to choose to believe? Most catechisms attest that some human beings receive or experience salvation, but not all do. Is the difference a matter of individual choice, or is a deterministic force at work? And how does one account for the fact that some people appear to have a larger propensity for religious belief and devotion than others? Is being religious like being intelligent, sensitive or musical? "God must simply have thrown darts," an abbot once told me when trying to explain why some are drawn to the monastery and others are not. It isn't that the others do not have the chance (though this may be true too) but rather that they are not so inclined.

Until a few years ago, it was possible to explore most of these issues in a thoroughly speculative manner. Now all aspects of the debate must be re-examined in light of the Human Genome Project and its attempt to identify the "code of codes" by means of which genetic identity can be discerned. The project was launched in 1988 and is intended to be a long-term venture. But already scientists have been publishing preliminary reports of findings. The startling likelihood is that if the genetic structure is discernible it must also be alterable, and if alterable it can be corrected and directed toward previously inconceivable human achievement.

Such issues are explicitly addressed in these essays collected by Daniel J. Kevles and Leroy Hood. The majority of the essays were first delivered as lectures at the California Institute of Technology in Pasadena (where both Kevles and Hood teach) during the 1989-90 academic year. The editors recognize the highly controversial nature of their subject, and they ask that readers resist science-fiction style speculation. Moreover, they affirm that the most compelling and durable implications of the project require tutored and shared judgments between scientists and practitioners of the humanities.

Kevles, a professor of the humanities himself, provides a history of the project from its birth in the science of eugenics. His survey includes a discussion of the work of Nazi SS doctors and the 1927 U.S. Supreme Court decision *Buck v. Bell*, which affirmed sterilization in the case of three generations of developmentally disabled individuals. Kevles documents the growth of predictive (and not simply preventive) medicine whose primary purpose is "to protect individuals from the kinds of illnesses to which they are genetically most vulnerable." Such protection sometimes requires preventing the transmission of genetic susceptibilities to succeeding generations.

Hood in his essay examines the relatively new field of biotechnology, which involves

interdisciplinary cooperation between molecular biology and computer science. Biotechnology aims to improve both the diagnostic and therapeutic capacities of medicine. The former is achieved through identifying genes that predispose individuals to disease. The latter involves the circumvention of the limitations of defective genes (by manipulating the immune system, for example), new techniques in molecular pharmacology, environmental factors and, in the future, the substitution of good genes for defective ones.

Along with Kevles's and Hood's essays is an impressive assortment of chapters by scholars and authorities who approach the subject from virtually all relevant perspectives. Most of the authors - including Eric S. Lander, director of MIT's Center for Genome Research, and James Watson, director of the NIH genome project - are directly involved in genome project research, having been primarily trained as biochemists or molecular geneticists. Others offering insights and judgments include Henry T. Greely, a health-law policy specialist, and Evelyn Fox Keller, a historian and philosopher of science. Kevles and Hood provide in the concluding essay an outline summarizing the proposals of these expert witnesses under the simple title "Reflections."

The essays themselves include responses to the charge that the project is merely speculative and is draining precious resources (financial and technological) away from useful endeavors, and also careful forecasts of the project's development. The authors and editors want to downplay fanciful extensions of the project and judge it on the basis of what it is best able to do - produce an abundance of genetic information. Alzheimer's disease, Huntington's chorea, muscular dystrophy and cystic fibrosis involve specific and identifiable genetic defects. Manic depression and schizophrenia most likely carry specific genetic predispositions. And there is some arresting evidence that susceptibility to coronary disease, high blood pressure, arthritis and allergic reactions is triggered genetically. Establishing such links is crucial for devising and prescribing effective treatment.

But this last move raises difficult questions. For instance, if genetic susceptibility is known in advance, should such information be made available to potential employers? While this information might contribute toward the employee's being placed in the most appropriate position or line of work, the same information could also be used to discriminate against the employee. A subsequent question: since genetic identification can be known only through genetic testing, should such testing be voluntary or involuntary? Does society have the right to know the genetic makeup of each of its citizens? Mandatory genetic testing might violate human rights and individual freedom. On the other hand, since some people's genetic profiles place others at risk, such information might help the otherwise unsuspecting to avoid or mitigate such risk. Who would be responsible for regulating and monitoring genetic testing? If it is the government, then the Big Brother fears of George Orwell's 1984 will have surely come to pass. That is, if there is a national regulatory agency for all genetic testing, this agency would have more threatening information at its disposal than has ever been assembled by the FBI or the KGB.

The implications for life and health insurance are equally serious. Can insurance companies insist on knowing genetic identification before providing insurance? If the answer is No, then can insurance companies initiate litigation against those they have insured who, either deliberately or passively, have withheld vital genetic information? Or if the answer is Yes, do insurance companies then have the right to refuse to insure in cases where known risks are exceedingly high? Perhaps in the future only the genetically sound will have access to full insurance.

Another large set of questions focuses on reproductive choice. To what extent should genetic predispositions be a factor in choosing a mate or having children? Should two individuals who know that their combined genetic identities will adversely affect their offspring have unlimited freedom to make reproductive choices, or should they be encouraged (and by whom?) to consider

alternatives? But wouldn't reproduction undertaken for offspring advantage invite all of the perils of a "eugenics mentality"? And such preknowledge accompanied by permissions, warrants and sanctions could create a hostile living environment.

The shifts and adjustments we must make in imagining and evaluating the Human Genome Project are monumental. The invention of the computer was possible by mastering the thinking process and transferring these sequences from the brain to technological instruments. The genome project takes such corroboration a significant step further. Not only is thinking committed to definitive modalities, but so also is the entire range of behavioral patterns and psychological traits. That is, via genetic identification the secrets of behavior and emotion are technologically accessible, and their consequences can be halted or redirected.

There are several theological responses to these issues. We can argue that such developments remain in the human realm, not the divine. That is, God's ways and ours are too distinct to be challenged by any increase in our knowledge of human makeup and behavior. Another theological response, however, is to view the project as part of our continuing disobedience to God. Humans have once again partaken of a forbidden fruit that deceptively promises knowledge. Or, alternatively, we can affirm that whatever we learn about our genetic makeup will only increase our respect for creation and the Creator.

Fundamental paradoxes surface in any theological reflection on the project. The discovery of a code of codes would seem to reinforce the powers of determinism, yet the same knowledge works to increase and encourage human freedom, creativity and responsibility. We are not yet in a position to fathom the outcome of genetic research. But it is already clear that the project presents extraordinary moral challenges as well as exciting and sobering prospects for theological understanding.

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