

Pragmatism and Human Genetic Engineering

by
Glenn Edwards McGee

ISBN: 1-58112-020-6

DISSERTATION.COM



1998

© Copyright by Glenn Edwards McGee 1994
All Rights Reserved

PRAGMATISM AND HUMAN GENETIC ENGINEERING

By

Glenn Edwards McGee

Dissertation

Submitted to the Faculty of the
Graduate School of Vanderbilt University
in partial fulfillment of the requirements
for the degree of

DOCTOR OF PHILOSOPHY

in

Philosophy

August, 1994

Nashville, Tennessee

Approved:

John Lewis
Richard W. Ziegen
Jean Bethke Elshani
Dirk W.
Richard Lewis

Date:

July 13, 1994
July 13, 1994
July 13, 1994
July 13, 1994
July 13, 1994

© Copyright by Glenn Edwards McGee 1994
All Rights Reserved

PRAGMATISM AND HUMAN GENETIC ENGINEERING

GLENN EDWARDS MCGEE

Dissertation under the direction of Professor John Lachs

William James and John Dewey insisted that pragmatic philosophy finds meaning in its struggle to deal with emergent social problems. Ironically, few have attempted to use pragmatism to articulate methods for ameliorating social difficulties. This dissertation attempts to do just that by putting James' and Dewey's philosophy to work on the moral and scientific problems associated with genetic engineering and the Human Genome Project. The intention is to demonstrate the usefulness of a pragmatic approach to applied ethics and philosophy of biology.

The work of proponents and critics of genetic engineering is examined, including LeRoy Hood, Hans Jonas, Leon Kass, Robert Nozick, Jeremy Rifkin, Robyn Rowland, and Paul Ramsey. It is concluded that excessive optimism and pessimism about genetic engineering rests primarily on two errors. The first, basic to the Genome Project, is that organisms are essentially determined by their genes, and that the expression of genes is identical across human populations. I draw both on Richard Lewontin and on Dewey's Logic: The Theory of Inquiry to argue that the formation of

human natures is instead the result of a fluid and interpenetrative relationship between hereditary information and varying environmental conditions. Organisms express DNA in different ways under different circumstances, and DNA itself is modified by exposure to mutagens.

The second error prevalent in the literature is the belief that genetic engineering is uniquely problematic, requiring a new kind of ethics. To counter the received view, I detail numerous cases in the history of biology and philosophy in which humans have faced moral choices similar to those present in the new genetics. In addition, I resituate new reproductive decisions in the context of everyday problems faced by parents in society, arguing that the hopes and choices of parents provide a matrix within which genetic decisions can be made. I caution against the expansion of genetic diagnosis, and detail some of the greatest real dangers present in positive genetic engineering. Finally, I suggest pragmatic alternatives to positive genetic engineering, including education and health care reform.

For Ethan McGee

ACKNOWLEDGMENTS

There are many individuals who aided in the successful completion of this project. John Lachs gave me patient, insightful, and never constraining guidance. The ideal mentor throughout these three years, he helped me find new courage, and showed me that stale boundaries can never contain American philosophy. Richard Zaner walked me through an investigation of medicine, phenomenology, and genetics, yet ceaselessly insisted that I actualize my own ideas. Shannon Baker encouraged and supported me, as she and I began our own journey of parenthood. Our families were helpful to us during those three years.

Lisa Bellantoni, Martin Dillon, Jean Bethke Elshtain, Stuart Finder, Mark Fox, Anthony Graybosch, Michael Hodges, Eric Juengst, Jacqueline Kegley, Dick Lewontin and John McDermott each gave time, energy, and ideas to the project. Jeffrey Tlumak was an invaluable sources of support and encouragement, as were Christie Allen, Micah Hester, Phillip McReynolds, Pat Shade, and Jennifer Thompson.

This project would not have been possible without the support of several organizations. The Vanderbilt Center for Clinical and Research Ethics provided travel and research support, as well as the opportunity to teach an Ethics & Genetics segment to medical students, through a Fellowship in Clinical and Research Ethics. The Vanderbilt Program in Social and Political Thought provided an Enhancement Award,

which made it possible for me to really engage the literature of other disciplines. Harvard Widener Library provided space and support, and the Vanderbilt Graduate School provided a Dissertation Enhancement Award so that I could expand my research on the biotechnological industry, screening, and philosophy of biology. A May term grant from the Department of English enabled intensive study of clinical questions in ethnicity during 1992. Finally, the Dewey Archives at Southern Illinois University made possible research into Dewey's correspondence concerning Soviet genetic experimentation.

Parts of this work have appeared elsewhere. Portions of Chapter I-V were presented as the 1994 Distinguished Visiting Professor address at California State University Chico in February 1994. An earlier draft of Chapter III was presented to the 8th Annual Comparative Literature Symposium at the University of Tulsa as "Engineering Valuation: Pragmatism Reads Human Genetics." Segments of Chapter IV are adapted from "Method and Social Reconstruction: Dewey's Logic: The Theory of Inquiry," in the Spring, 1994 *Southern Journal of Philosophy*. Other segments of Chapter IV were presented to the 1994 Society for the Advancement of American Philosophy Annual Meeting and the 1993 Central States Philosophy Association meeting. Portions of Chapter V were adapted from a presentation, "The Ethics of Genetic Screening for Health Insurance," given at the Mid-South Philosophy Conference in February, 1993. The argumentation concerning education in

Chapter 6 was adapted from a presentation on "Law, Education and Genetics," at American Bar Association Law Day, January 1994.

THE PERFECT BABY:

A Pragmatic Genetics

I. THE HUMAN GENOME PROJECT	1
The Study of Human Heredity	1
Application of the Study of Human Heredity	7
Eugenics	7
The Social Context of Reproduction	
Before and Beyond Eugenics13
The Human Genome Project20
Conclusions32
II. INCREDIBLE HOPES35
Negative Interventions:	
New Genetic Diagnoses and Cures35
A Much Better Baby42
Political and Economic Changes51
Keeping Supply Lines Open:	
The Necessity of 'Pragmatism'53
Conclusions54
III. PROFOUNDTEST FEARS56
Jeremy Rifkin's <i>Algeny</i>56
Genetic Patriarchy62
Hans Jonas' New Ethics67
Playing God72
Against Pragmatism: Leon Kass74
Conclusions77
IV. TOWARD A MORE EFFECTIVE PLAN OF ACTION79
The Usefulness Test79
The Philosophical Roots of the Problem:	
"Applied Ethics" as Method82
A Pragmatic Critique86
How New a Power88
A Biological Garden of Eden94
Idols of the Body	102
A Pragmatic Reconstruction	110
Biology	111
Culture	118
Common Sense	123
The Perfect Baby	125
Conclusions.	129

V. NEW CHOICES, OLD HOPES: HEALTHY BABIES	131
An Appropriate Goal	131
Old Pressures and New Medical Technologies	135
Fetal Surveillance and the Social Meanings of Illness	141
The Clinico-Pathological Correlation.	142
Genetics, Disease, and Illness	149
Markers	151
Alleles and Causality.	152
Environments and Causality	155
Genetic Causality and the Discourse of Disease	157
Alternative Emphases on Illness	159
Cultural Pressures and Genetic Choices.	162
The Molecular Scalpel	174
A Variety of Options: Resituating Genetic Therapies	176
Interventions	183
The Enlargement of Pathology	195
Conclusions.	195
VI. NEW CHOICES, OLD HOPES: POSITIVE INTERVENTIONS.	197
Healthy Babies?	199
An Appropriate Goal	207
The Danger of Biological Myopia	210
The Danger of Reasonable Choices.	220
The Danger of Excessive Hopes in Parenthood	225
The Danger of Lack of Foresight	227
The Danger of Hasty Choice.	232
The Danger of Pessimism.	235
Recontextualizing Genetics: A Range of Interrelated Choices	237
BIBLIOGRAPHY	239

CHAPTER I

THE HUMAN GENOME PROJECT

The Study of Human Heredity

Inquiry into human heredity is as old and as pervasive as inquiry itself. The biological and cultural horizons of parenthood have been put into question for a variety of personal, social, and political purposes. Moreover, we have often pondered distinctions between natural and learned identity. Why do we look, and act, like our parents and ancestors—and in what sense are we ever free of our heritage? Cultures have developed extensive and intricate ways of thinking and talking about heredity, as well as folkways that acknowledge the importance of biological parenthood to culture.¹

These efforts began with the cultivation of crops at least 10,000 years ago.² Human domestication of animals, through the elimination of weaker cattle and the exploitation of selective breeding, was used on sheep, goats, oxen, camels, and other animals on the African continent.³ Assyrian records indicate that as early as 5000 B.C. the use of artificial fertilization was common in the cultivation of

¹L.C. Dunn, *A Short History of Genetics* (New York: McGraw-Hill, 1984), pp. 6-123. Cf. L.C. Dunn, "Cross Currents in the History of Genetics," *American Journal of Human Genetics* 14 (1962): 1-13.

²M.I. Ryder, "The Evolution of Fleece," *Scientific American* 256 (1987): 112-119.

³See H. Stubbe, *History of Genetics: From Prehistoric Times to the Rediscovery of Mendel's Laws* (Cambridge: MIT Press, 1972).

date palms. Gradually, "genetic manipulation of animals and plants coevolved with many features of human society, and became the base of economic prosperity."⁴ For example, the city of Troy depended on a vigorous horse breeding program, which substantially advanced its wealth and reputation in the region.

Study of *human* heredity has historically been linked to social and medical concerns. Diverse traditions maintained that "blood" is of importance in illness, and in social and familial affairs. The Jewish *Talmud* makes mention of the inheritability of hemophilia. Members of the tribe of Levi exclusively inherited the Jewish priesthood. Hindu castes are based on the assumption that "both desirable and undesirable traits are passed from generation to generation."^{5 6} Several Native American tribes held that the maintenance of tribal integrity hinged on the restriction of inter-tribal marriages.

Western theory of human heredity began with the Greek doctrine of "pangenesis," which asserted that sperm carries hereditary information from father to offspring. All parts of the male body send particular portions of sperm down into the gonads, where the conglomeration is stored. Aristotle disputed the notion that females also form sperm, and held that traits acquired by parents during their lifetime might

⁴Michael R. Cummings, *Human Heredity: Principles and Issues* (St. Paul: West Publishing, 1988), p. 2.

⁵*Ibid.*, p. 3.

⁶See A. Corcos, "Reproductive Hereditary Beliefs of the Hindus, Based on Their Sacred Books," *Journal of Heredity* 75 (1984): 152-154.

be passed to offspring. The theory that experiences acquired during life could be passed to offspring helped Greeks account for strange differences in appearance among parents and children. For example, Aristotle postulated that a child whose eye color differed from both parents might have acquired the traits from parental experiences.

In post-Baconian modern science, several new ways of investigating the components and workings of human heredity emerged. The social resources and energy devoted to the pursuit of these studies has multiplied many times during the last 200 years. The practical power to effect changes in a human organism through genetic technologies has also advanced. Humanity has begun to acquire enhanced powers over relatedness and family, powers that involve the social and biological identity of children and their families.

The explosion in molecular and microbiological investigation of heredity began in the early 1800s. Biological research in that century primarily focused on the problems of inheritance in plants: how do the offspring of a flower come to retain the structures and appearance of their lineage? To answer such questions, scientists sought to uncover an essential "stuff" of biology, a unit shared by all organisms. The basic unit scientists sought would operate under the simple laws of biology, yet execute complex instructions that would make sophisticated structural development possible. Biologists held that this basic unit would be necessary to facilitate the hereditary expression of

organisms. By the 1860's, many concluded that plants and animals were made up of *cells*. Cells seemed to provide a kind of matrix for biological life, comprised of independent nodules of activity bustling within every living organism. It remained impossible, though, to explain the role of heredity in cellular functioning. How and why do cells divide?

In 1869, Frederick Miescher discovered "nuclein" (today's *DNA*) while working on white blood cells. Nuclein could be distilled from the nuclei, a gray precipitate that seemed essential to the nucleus of cells. E. Zacharia and Walter Fleming began to make connections between heredity and this material; Fleming observed that the material is also present in fused sperm and egg cells. By the 1890's, nuclein, or "chromatin" (later "chromosomes") was thought to contain the basic instructions for hereditary traits.

Gregor Mendel's experiments with garden peas began a discipline called *genetics*, which concerned itself with the relationship between traits in the parent and traits in the offspring. Mendel fertilized hybrid peas and observed differences effected by mixing and matching. He identified certain traits, such as height and color. Mendel noticed that a "recessive" trait would vanish from the second generation of plant offspring, then reappear in the third generation in a ratio of one out of four. He postulated that a biological explanation for observable differences in

offspring must exist, and called that foundation the "formative element."⁷

While Mendel, Miescher, and those who evaluated and contributed to their work forged ahead in the laboratory search for a set of relations that could be validated and would be useful, zoological investigation into "formative elements" in heredity was catalyzed by Darwin's *Origin of Species*. Darwin crafted an elaborate explanation of the role heredity plays in the production of whole organisms. He constructed an account of the relationship between cellular biology and the purposive activity of animals.

Darwin formulated the principle of "natural selection." He observed that most animals "produce more progeny than can reasonably survive."⁸ Differences among offspring make them more or less suited to survival in a particular environment. The principle of natural selection dictates that organisms with traits more favorably suited to the environment will reproduce more frequently, and more of the offspring will survive—preserving traits that are conducive to survival in a particular environment. Over time, substantial changes may be required for survival. Aggregations of favorable traits may produce a distinctly new kind or *species* of creature.

A fundamental part of natural selection is the drive, supposed by Darwin, of each organism to continue its *kind*.⁹

⁷C. Stern, *The Origin of Genetics: A Mendel Sourcebook* (San Francisco: Freeman Press, 1966). Also described in Cummings, p. 6-7.

⁸Kenneth Corey, *The Essential Darwin* (Boston: Little, Brown, and Company, 1984), p. xvii.

⁹As becomes clear later, John Dewey understood this advance to be central to the success of future philosophy: the naturalization of the notion of

This drive is expressed in the competition among individual organisms to survive and to reproduce.¹⁰ At the same time, the entire population of any given species is subject to the demands of the environment. If several lizards of a coloration that blends with their environment are generated in a population of predominantly bright lizards, the success of the new trait will be tested by the ability of the camouflaged lizards to survive and reproduce. If the new lizard can blend into the environment, perhaps he can evade predators. If the coloration of the environment changes, perhaps he will not live to reproduce. The lizard will attempt, in any case, to reproduce and to evade predators. The existence of these behaviors seemed, for Darwin, to validate the theory of natural selection.

Natural-selection theory was just one step toward developing a theory of genetics that linked animal and human traits to biological heredity. By applying the principles of Mendelian genetics to traits and behaviors observed in animals, Darwin was attempting to bridge the gap between theoretical biology and botany, zoology, and human social theory. But Darwin was "pointing along a route which he could not yet trace. For example, in the absence of a theory of the *gene*, Darwin could not explain the maintenance of

species was, for Dewey, a step toward acknowledging the relationship between experience and nature, heredity and morals. But Dewey did not celebrate the emphasis in later Darwinian thinking on a determinate structure of competition. Where later Darwinism emphasized the cutthroat power of kill-or-be-killed competitiveness, Dewey emphasized the value and power of cooperation and of democracy.

¹⁰Though Darwin did not write as a social theorist, he was deeply influenced on this point by the Scottish economists and Thomas Malthus.

inherited variation that was essential for [his] theory to work."¹¹

Nonetheless, Darwin's work encouraged the interdisciplinary study of heredity, particularly as that study intersects social and political life. Darwinian thought also catalyzed the application of Mendelian and Miescherian genetics to human heredity.

Application of the Study of Human Heredity

Eugenics

One immediate implication of Darwin's interdisciplinary research on genetics was *eugenics*. In a series of key texts, eugenicists articulated a specific, prescriptive application of natural selection. The eugenics movement was named at the turn of the century by Darwin's cousin Francis Galton, who argued for "the science of improving human stock" in his work, *Hereditary Genius*. Galton envisioned a "better race of men," produced by a series of "judicious marriages over time."¹² Though Galton coined the term 'eugenics', the social application of biological knowledge to decisions about the embodiment of future generations is much older than the confluence of Darwin and Mendel at the turn of the century. Humans have always exercised a measure of control over reproduction in social groups: it takes two to reproduce, and

¹¹Richard C. Lewontin et al., *Not in Our Genes: Biology, Ideology, and Human Nature* (New York: Random House, 1984), p. 57.

¹²Daniel J. Kevles, *In the Name of Eugenics: Genetics and the Uses of Human Heredity* (Los Angeles: University of California Press, 1985), p. 4.

those two choose each other partly for personal reasons and partly under the influence of family and community values.

In the years prior to the discovery of molecular genetics, eugenics could be employed through three overtly clinical techniques, each of which was designed to prevent reproduction: infanticide, abortion, and sterilization. These three techniques are distinguished from a host of others in two ways. First, agreement to terminate or forestall pregnancy is achieved by a political or social instrument, such as a law sanctioning sterilizations or a medical protocol for therapeutic abortion. Second, the techniques involved surgical intervention into the bodies of citizens, rather than through verbal coercion.

Non-clinical techniques could be just as effective, and were also available, such as social control over who reproduces with whom. History reports numerous cases in which societies employed both clinical and non-clinical techniques. Clinically, the Spartans left their unwanted offspring to the elements. Non-clinically, Plato wrote in the *Republic*: "those of our young men who distinguish themselves...[should receive]...more liberal permission to associate with the women, in order that...the greatest number of children may be the issue of such parents." The *Talmud*, in recognizing the hereditary nature of hemophilia, required the sterilization of hemophiliacs.¹³

¹³Ibid.

Francis Galton's work suggested similar comprehensive controls on reproduction. In particular, he had in mind the application of Darwinian principles to governmental controls on immigration and sterilization. Thus, Galton's eugenics was a particular kind of social modification of reproduction. It is the attempt, systematically, to apply knowledge of hereditary processes to reproduction for some social purpose, such as the elimination of a disease or the improvement of intelligence. These modifications were in service of preserving the "best" traits in the community through intrusive social actions.

Hereditary Genius persuaded many Americans that eugenic techniques would improve society and halt disease. In his *In The Name of Eugenics*, Daniel Kevles chronicles the rise of eugenics: within a year of the publication of Galton's work, geneticists persuaded Galton to speak to university and public audiences. Galton, then 78 years old, helped a eugenics movement flourish in Britain and the United States. Talk of "a not-so-eugenic" marriage was not uncommon, and social pressure to have a "more eugenic" child emerged.

Social momentum generated enough interest to form a public interest group for eugenics, which began to take account of the nation's hereditary profile. A Genetics Records Office was set up at Cold Springs Harbor in New York. Thousands were strongly encouraged to mail descriptions of their ancestry for filing with the office. Over time, as hereditary information was acquired, family records were to

be used for the improvement of communities. If a family incurred too many cases of chronic alcoholism or consumption, they would be counseled to avoid reproduction. Before marrying, a young man would be advised to consult the records.

Eugenics in the United States was more than a harmless fashion. The major universities offered courses in "genetics and eugenics," and "geneticists warmed easily to their new priestly role."¹⁴ Writing in popular journals, these geneticists preached the doctrine of sterilization. The public was encouraged to begin to purge mental disability and criminality from the population. In order to accomplish this mammoth task, reproduction of the retarded would have to be halted. Scientists would need to canvas social institutions that hold the criminal and insane, and prevent the reproduction of those traits. After the sites of "bad genes" were roughly categorized, American use of sterilization began.

Sterilization received a quick legal affirmation by the Supreme Court: in the landmark *Buck v. Bell*, the Court upheld Virginia's sterilization of a 17 year-old third-generation "moron," effectively licensing state sterilization policies. Thousands of institutionalized Americans were sterilized during the 1930s to prevent what Justice Holmes termed, "generations of imbeciles." With assistance from the Cold Springs Eugenics Records Office, The American Eugenics

¹⁴Ibid., p. 69.

Society, and the popularized Eugenics Education Society, laws regulating reproduction, and sterilization were passed not only in the coastal states, but in the midwest and southeastern United States, as well. Federal immigration laws were also strengthened, and members of certain races (e.g., Asians) were prohibited from moving to the United States.¹⁵

Eugeneticists, eager to find clinical and scientific credibility through universities and hospitals, and power through the government, spoke of a "feebleminded menace of some 300-400,000" in the United States. Eugeneticists began graduate training programs in most major universities, and their graduates helped communities—particularly on the east and west coasts—to systematically sterilize the mentally retarded. By 1935, around 20,000 had been sterilized in the United States. Britain's eugenics program had sterilized perhaps twice that number.¹⁶ These numbers, though, were to be dwarfed by German programs.

The Nazi endeavor is the most infamous example of massive social planning concerning heredity. In 1933, modeling his statute on existing American sterilization laws, Adolf Hitler promulgated a Eugenic Sterilization Law. It was broadened in 1934 to include a variety of "feeble" people:

¹⁵Though, of course, many of these eugenic measures were really just a cover for economic interests. Fear of the impact of Asian immigration was rampant at the time. Ibid., 104.

¹⁶Ibid., p. 112.

Going far beyond American statutes, the German law was compulsory with respect to all people, institutionalized or not, who suffered from allegedly hereditary disabilities, including feeblemindedness, schizophrenia, epilepsy, blindness, severe drug and alcohol addiction, and physical deformities that seriously interfered with locomotion or were grossly offensive.¹⁷

The counselor of the Reich Interior Ministry "called it an exceptionally important public health initiative... 'we go beyond neighborly love; we extend it to future generations,' he wrote."¹⁸ Under the Nazi law, physicians reported all "unfit" persons to Hereditary Health Courts, established to determine the sorts of persons who ought not to procreate. Decisions could be appealed to a "supreme" eugenics court, whose decision was final—and could be carried out by force. "Within three years, German authorities had sterilized some two hundred and twenty-five thousand people, almost ten times the number so treated in the previous thirty years in America."¹⁹

Disillusionment blunted the Eugenics movement in the wake of the second world war. At the heart of anti-Nazi propaganda was an attack on the eugenic nature of Nazi expansionism, with its emphasis on "purifying" the "Aryan" race. Moral condemnation haunted Nazi physicians, as accusations of eugenic experimentation became a badge of shame. The association with Nazi practices temporarily spoiled Galtonian eugenics in America— notions of a "eugenic

¹⁷Ibid., p. 116.

¹⁸Ibid., p. 117.

¹⁹Ibid., p. 117.

marriage" now carried new and dangerous associations with fascism. Americans became unwilling to countenance the sterilization of the mentally retarded, and Court decisions gradually narrowed immigration restrictions. Still, the underlying conviction—that complex human behavioral traits could be controlled by social attention to molecular heredity—had been entrenched in biology departments. There, the focus on training human geneticists produced a number of eugenic theories during the 1940s and 1950s.

The Social Context of Reproduction: Before and Beyond Eugenics

Social institutions have long exerted control over parenthood. Before Galton's treatise on the implementation of Darwinism by society, a variety of social orders had utilized policies designed to promulgate some trait in the population, or to eliminate an undesirable characteristic from the culture. We noted that from Hindu, Jewish, and Greek cultures to the marital practices of Native Americans, numerous societies prefigured Galton's "revolutionary, new" eugenics. Thus it comes as no surprise that, after World War II, the weakening of the eugenics movement did not sound a death knell for social influence on reproduction. In fact, as biological and medical practices have advanced at an exponential rate, more and more sophisticated means of social control over reproduction have become available.

During the 20th century, new medical technologies were gleaned from advances in the study of molecular biology.

Amniocentesis, ultrasonography, and *chorionic villus* sampling make it possible to look into the womb at a fetus' condition. The development of a birth control pill, "the pill," expanded reproductive control, but carried new risks and ways of choosing whether or not to have children.²⁰ With the 1973 Roe decision, legalizing abortion, diagnosis of a fetal anomaly entailed the new option of therapeutic abortion. These enlarged the region of reproductive control for families, physicians, and the community. Parents and healthcare providers were able to participate in social decisions about the traits that are acceptable in a child. As the perceptiveness of reproductive diagnosis has improved, the embryo has been more and more open to genetic testing. The presence of a *marker*, which associates a disease with information in a particular region of a chromosome, presents a difficult option for parents. Without the possibility of an immediate therapy, and perhaps without the possibility of any therapy at all, parents must decide whether or not to have a second or third trimester abortion. Society exerts influences on parents as they make their decision.

Hereditary information is also available to institutions, such as corporations and the insurance industry. Industries whose workers are exposed to chemicals (such as Eastman Kodak and DuPont) routinely screen for hereditary sensitivities to a particular chemical in the work

²⁰Though, curiously, birth rates had been falling continuously in the United States since about 1950, and it is not clear that the birth control pill measurably accelerated the decrease.

environment.²¹ Insurance companies have begun to discuss the use of detailed genetic screening of applicants for coverage.²² The fetus of an insured person may not be eligible for insurance, due to pre-existing (hereditary) conditions. For example, in 1989 a pregnant woman's fetus was tested for cystic fibrosis because the woman's first child had cystic fibrosis. When the test was positive, the insurance company, "decided that because the child had a pre-existing condition identified by [a] test before birth, it would not provide medical coverage for the child...Under pressure from the [hospital] staff, the [insurer] eventually backed down."²³ Though no sterilization or immigration policies were involved in this case, it could be said to constitute the *moral equivalent* of eugenics. Social institutions have increasing interests in the sorts of children that parents have, and have expressed those interests in eugenic ways.

And insurance companies will doubtless go further.²⁴ Though some have placed informal moratoria on the explicit use of genetic testing to determine eligibility for

²¹We will treat this issue in detail in Chapter V. See Dorothy Nelkin, *Dangerous Diagnostics: The Social Power of Biological Information* (New York: Basic Books, 1989), esp. pp. 11-24, 164-170.

²²It may be that present practices condone this screening: for example, if a patient visits a physician for a genetic test, that patient will have to disclose the visit if he or she changes insurance companies and fills out an application. The insurance company requests, on the application form, that the patient divulge results of each visit to a physician. If the genetic screen results in a positive indication, the patient might have to reveal that she tested "positive for disease X" on the application form, resulting in exclusion of a pre-existing condition—or denial of insurance.

²³Larry Thompson, "Gene Screening May Alter Future," *Portland Evening Express*, October 12, 1989, pp. 1,6. Emphasis is mine.

²⁴See *The Los Angeles Times*, March 24, 1994, p. 1A.

insurance, financial pressures to use accurate pre-existing condition testing are strong. Every insurance company competes to provide the lowest rates, which require that the pool of insureds carry the lowest risks. Within 2-5 years, regular genetic screening will most likely be conducted for insurance/employment purposes. National health reform may not ease this pressure, either. While universal health care coverage would demand that all be insured, national (even governmental) pressures on parents to utilize genetic tests will increase in direct proportion to rising health costs.

Parents are also making difficult and socially suffused decisions about making babies. They make good and bad choices about how and when to have children, with whom, and under what circumstances. Parents may elect to have an abortion because of overt social pressures concerning, for example, Down's Syndrome. A television documentary or a conversation with a doctor or accountant may convince them that the difficult option of abortion is preferable. They may also, though, make the same decision for reasons unrelated to the eugenics movement—they may be unprepared to care for such a child. In either case, where choices exist, parents must make decisions. To choose against abortion is still to choose—thus parents cannot avoid decisionmaking concerning reproduction. These decisions draw on their personal wisdom, learned from years of inculturation and formal education, and on the advice and consent of their friends, leaders, and family. Parents are situated within

their community, sharing its values and languages. They apply these highly social values to their decisions, exerting social influence on reproduction.

Regardless of whether or not social institutions or parents consciously deliberate about the best outcomes for the human species, the decisions concerning which children will be born (at what time, to whom), are made within the ethos of the community. Thus we can conclude that *parenthood is social*. Parents are influenced by the values of the community in profound ways. Babies are not constructed by rational calculators, they are made by human beings saturated with culture. The saturation of culture—social and political—is evidenced in the elaborate problem of choosing and consummating a relationship with another human being.

The process of choosing a mate is so complex and diffuse that it is difficult to assign values to the various areas of concern or methods of decision. Thus a 'special theory on mating' can likely not be developed. As Jean Bethke Elshtain points out, there is as much theoretical confusion about the creation of children as about any part of human life.²⁵ Freud and Skinner, Betty Friedan and the Pope articulate very different accounts of the purposes and parameters of reproduction: it is poetry or politics, biology or free choice, *Eros* or the furtive machinations of baby-making machines. Louise Erdrich writes of this confusion:

²⁵Jean Bethke Elshtain, *The Family in Political Thought* (Amherst: University of Massachusetts Press, 1982), p. 288.

We conceive our children in deepest night, in blazing sun, outdoors, in barns and alleys and minivans. We have no rules, no ceremonies; we don't even need a driver's license. Conception is often something of a by-product of sex, a candle in a one room studio, pure brute chance, a wonder. To make love with the desire for a child between two people is to move the act out of its singularity, to make the need of the moment an eternal wish. But of all passing notions, that of a human being for a child is perhaps the purest in the abstract, and the most complicated in reality. Growing, bearing, mothering or fathering, supporting, and at last letting go of an infant are powerful and mundane creative acts that rapturously suck up whole chunks of life.²⁶

Human beings do invest tremendous amounts of energy in the discussion and practice of ritualized, sophisticated mating. We subject ourselves to fashions and folkways that are uncomfortable and awkward. Many of these folkways are transmitted in institutional narratives about proper mating: churches and municipalities authorize the practice of marriage; laws regulate the age at which mating is consensual—and with whom (brother and sister may not marry, nor father and daughter); corporate regulations acknowledge distinctions among kinds of relationships (co-workers must carefully separate romantic and business relationships). Long-standing social habits become laws, practices, and mores, thoroughly "socializing" the decisions that humans make about individual reproductive choice.

Beyond the laws and boundaries set by society concerning sex and reproduction are the myriad pressures exerted by humans on other humans. More than three dozen teen magazines

²⁶"A Woman's Work," *Harper's Magazine* (May 1993): 35.

present stereotypical notions of female flourishing, designed to show girls all of the techniques necessary for membership in one of several "classes" of alluring young women. Read in this way, teen magazines—and much of youth entertainment—circumscribe the boundaries of reproductive success for a variety of cultural groups. Women's magazines promise to help lure the right man. Men are encouraged to dress, think, speak, and perform sexually in ways that will be most conducive to finding a "right" person. The drive to reproduce in America is utterly suffused with social values.

From the choice of a hairstyle to the choice of a mate, from the moment of pregnancy to the day a daughter moves away from home, trends and pressures create social goals and restrictions. The parent is subject to the community, and the child subject to the community and to its parents. Competing values and rules make decisions about reproduction difficult.

New genetic technologies, including those resulting from the Human Genome Project, have advanced the study and application of hereditary information for parents. These technologies portend a shift in the use of genetic information. Where genetic information used to be employed only to make a simple but agonizing decision about the termination or forestalling of pregnancy, it now enables us to devise interventions into human molecular biological makeup. The new technologies present difficult choices.

The Human Genome Project

In 1953, James Watson and Francis Crick published "Molecular Structure of Nucleic Acids: A Structure for Deoxyribose Nucleic Acid," in *Nature*. In that 900 word article, Watson and Crick argued that deoxyribonucleic acid has a structure, the now well-known double-helix. This was of enormous importance, because, it was thought, the structure of genetic information would help explain the way that cellular heredity functions and replicates. It is to this twisted structure, they argued, that four kinds of repeating nucleotides attach.²⁷ These four "bits" of genetic "information," Adenine, guanine, cytosine, and thymine (A, G, C, T), are decoded into amino acids by the machinery of each cell. Combinations of these bits, termed *base pairs*, make up a single *gene*; a total of 50-100,000 of these *genes* comprise the nucleus of each of the body's 10 trillion cells.²⁸ Within the cells, genes are organized in structures called *chromosomes*. Each human cell contains an arrangement of 46 chromosomes (23 from each parent, paired together). Altogether, some three billion nucleotide "bits" comprise the hereditary information, arranged in chromosomes, along the double-helix.²⁹

Genes contain instructions for the creation of proteins. These *proteins*, "long necklaces of simple amino acids,"³⁰

²⁷See Neil A. Holtzman, *Proceed with Caution : Predicting Risks in the Recombinant DNA Era* (Baltimore: John Hopkins University Press, 1989).

²⁸*Ibid.*, p. 17.

²⁹*Ibid.*, p. 15.

³⁰Jerry E. Bishop and Michael Waldholz, *Genome* (New York: Touchstone, 1990), p. 24.

control the metabolism of cells. Within each cell, particular instructions facilitate the specific sort of metabolism that is appropriate to the function of the cell. Bone cells become bone cells through enzymatic actions, specified by genetic information. As a fetus progresses from one cell to some 2 trillion cells at birth, the specialized metabolism of cells converts food, fed to the fetus through the umbilical cord, into organ systems and bodily structure.

Though all cells in a given individual have the same genetic information, there is enormous specialization among cells in the body. This is possible because each cell is somehow able to distinguish the particular part of the genetic information which corresponds to its function in the body. For example, a retinal cell is disposed to be sensitive to a certain sort of stimulus because a part of the genetic code enables an appropriate metabolic process within the cell to take place. Groups of human cells, each having the same genetic information, perform different tasks, such as the functions of the liver, or muscle, or hair follicle.

The discovery of the "double helix" helped to explain the way that genetic information operates within the metabolic structure of the cell. It facilitated a particular kind of description of the mode of genetic inheritance from organisms to their progeny. But absent the series of important biological discoveries made during the 1970s, study and control of the information of heredity was limited. Researchers could draw inferences about specific gene

expression only from the living or dead whole of the organism. The problem is a foundational one: What is the nature of the relationship between *genotype*, the genetic constitution of an organism, and *phenotype*, the observable physical or biochemical characteristics of an organism? It was not yet possible to discuss the way that the genetic code, present in each cell, enabled specialization and function. Like Mendel, researchers were limited to the visible evidences of heredity. It was not yet possible to see the way that genetic information operated within the cell, or to link that operation to a genetic pattern for the whole organism.

But new procedures were created. Perhaps the most important was a protocol that allowed the *splicing* of genetic information. The splicing process has been likened to a genetic sewing machine. The idea is to take genetic information from one source, mount it atop a delivery mechanism, and insert it into another source. First, DNA is clipped out of the source. Second, a *vector*, which will be used as the delivery mechanism, is constructed of special DNA from a plasmid or virus. The vector has a special mechanism that allows it to insert the source DNA into the cells of the destination organism. Third, the chromosome of the destination organism is then modified by the source DNA. The modified cell begins to follow the instructions of the new DNA, taking as its purpose the duplication of a particular

enzyme structure. And, as it duplicates itself, it begins churning out copies of the modified gene.³¹

Using enzymes as a sort of chemical razor blade, biologists were able to isolate and remove specific segments of chromosomal information. When Cohen and Boyer successfully implanted chromosomal information from one bacterium into another bacterium, it was an important step toward using the new technologies of genetic information. They had catalyzed the process of genetic engineering, and soon human genetic information would be spliced into bacterial and yeast cells, producing gallons of insulin and other useful compounds.

From a theoretical standpoint, the production of human insulin by yeast cells seemed to validate the connection between genotype and phenotype. If human cellular identity could be reduced to genetic code, then Xeroxed by a yeast cell, it would seem that much of what is essential about human biology is located in the genetic information used to create enzymes. It was assumed that what is true for insulin is true for every part of the human body—there are “codes” for each human function. This foundational assumption characterizes the body as an amalgamation of codes, placing genotype causally prior to phenotype.

As important as these technologies were for the contemporary biomedical sciences, they pointed to a future in which genetic information would be modified for the purpose

³¹Ibid., pp. 26, 75-79.