BIOTECHNOLOGIES OF THE SELF

BIOTECHNOLOGIES OF THE SELF:
THE HUMAN GENOME PROJECT AND
MODERN SUBJECTIVITY

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ABSTRACT

Recent research in human genetics has sparked popular interest in genetic explanations for all human phenomena. In turn, bioethicists have been busy responding to their own call for stringent guidelines for the use of genetic information. But bioethicists in general fail to attend to deeper considerations of the nature of scientific knowledge and its role in the transformation of human subjectivity. For this reason, bioethicists are accessories after the fact to that transformation, and hence in order to study that change we must displace bioethical analyses of the Human Genome Project -- that is, displace virtually *all* of the literature on the HGP. In this thesis, I offer a different and more radical interpretation of the role of scientific knowledge in altering our conception of what it is to be a human being.

Physicians, genetic counsellors, and other experts in our gene culture offer fundamentally questionable and yet practically unquestioned genetic explanations of who and what we *really* are. These genetic experts, by virtue of their prestigious position in our economy of knowledge, impute needs only they can satisfy, impart a vocabulary only they are invited (and certified) to understand, and draw us into new networks of administration and control at the subcellular level. Drawing on the work of Duden, Foucault, Illich, and Poerksen, I argue that our attraction to technoscientific understandings of our "essence" is dangerous and disabling, and I sketch a strategy of resistance.

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TABLE OF CONTENTS

LIST OF ILLUSTRATIONS

From philosophy comes the displacement and transformation of the limits of thought, the modification of received values and all the work done to think otherwise, to do something else, to become other than what one is ... It's a way of asking oneself: if such is the relation that we have with truth, then how should we conduct ourselves?

- Foucault

On the critical side -- I mean critical in a very broad sense -- philosophy is precisely the challenging of all phenomena of domination at whatever level or under whatever form they present themselves -- political, economic, sexual, institutional, and so on. This critical function of philosophy, up to a certain point, emerges right from the socratic imperative: "Be concerned with yourself, i.e., ground yourself in liberty, through the mastery of self."

- Foucault

Chapter One -- Displacing Bioethics

Recent research in human genetics, beginning in 1953 with Watson and Crick's suggestion of the double-helix as the shape of the molecule for deoxyribonucleic acid (DNA), and continuing through the 1990s with Dean Hamer's work on sexuality genes, has rendered DNA-talk very popular. One cannot, in 1996, listen to the radio news, watch the CBC, read the newspaper or any magazine (from the *New York Times* to the *Hamilton Spectator*, and from *Time* to *Cosmopolitan*), tune in to a sitcom, or go to the cinema, without becoming aware of new genetic explanations for this or that disorder (be it Duchenne's muscular dystrophy, schizophrenia, ageing, risky behaviour, or obesity), and for our own very existence. And the popular book media have recently begun riding the wave of the "genetic revolution", with new titles appearing almost weekly. In fact, it might well be the case that the only way to avoid genetic talk is to isolate oneself entirely from popular culture.

On the radio and in television newscasts, we hear about genetics in the courtroom and elsewhere, especially in the aid of law enforcement agencies. Given the opacity of statistical discourse, seemingly endless hours are spent interpreting DNA findings for a jury, and then legal analysts drone on interminably interpreting those same findings for the public. There are also television specials dealing with DNA: social mothers vs. genetic mothers in custody battles; adopted children searching for their genetic roots; the story of Watson and Crick's role in representing the structure of DNA.[1] Television talk-show hosts hold panel discussions and offer experts who attest to whether your child is a serial killer, whether "badness" is in the blood, and whether you carry the "alcoholic gene".[2]

In 1992, *Newsweek* ran a cover story entitled "Is This Child Gay?", the question emblazoned on the face of an infant. Similar stories ran in *Scientific American* and *The Atlantic Monthly*. *Time* headlined a story on the genetic causes of criminal behaviour "Chromosomes and Crime"; 1985 saw the *Washington Monthly* run a story on the same topic, entitled "Born to Rob?". "Alcoholic Genes" were covered in *Omni* in 1989. In 1995, we were witness to a number of stories in magazines such as *Popular Science* and *Discover* dealing with the "fat gene"; this theme was already apparent

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[1] Sarah Franklin reports on the BBC docu-drama *Life Story*, a tale in which the biographies of Watson and Crick are inextricably linked to their discovery of the double-helix -- their discovery of life. See Franklin, "*Life Story*: The Gene as Fetish Object on TV," *Science as Culture* 3 (1988).

[2] The references in this section are to be found in Dorothy Nelkin and M. Susan Lindee, *The DNA Mystique: The Gene as a Cultural Icon* (New York: W.H. Freeman, 1995).

in a *New York Times* story in 1992 headlined "Where Fat is a Problem, Heredity is the Answer". Smoking has recently been identified as having a genetic element; the story was covered in the *New York Times Magazine* in 1992, and further evidence presented in the *Globe and Mail* in 1995. But not only are these "disorders" genetic in origin; some of our finest human attributes are genetic in origin as well: stories abound which comment on the genetic basis of poetic skill, intelligence, chess-playing ability, and good taste.[3]

With the Human Genome Project (HGP), the multibillion dollar effort to map and sequence all the genes in the human genome, the popular press is working overtime to process the advances made in genetic-testing techniques and the isolation of problem genes. To translate the technical language of science, a number of metaphors are used: DNA as text and code, the human body as machine, the human body as amenable to mapping. These metaphors appear

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[3] On poetry, see the *New York Times*, 26 May 1991, for Barbara Delatiner's story "For Brothers, Poetry Is in Their Genes"; on chess, see Bruce Weber, "Chess Moves Are Planned, Birthdays Happen", in the *New York Times*, 5 August 1992; see Maria Terrone and Sharon Johnson, "Fashion's Nature vs. Nurture Debate, Or Is Good Taste in the Genes?", *New York Times*, 12 April 1992. On the genetic basis of intelligence, there is a huge literature. See for example the work of Richard J. Herrnstein and his critics. For further evidence of the popularity of genetic explanations for all sorts of behaviours and disorders, see the listings under "Genetics" and related headings in, for example, the *Canadian News Index*.

in the titles of popular books intended to decrypt the scientific language of genetics. We have for instance *The Book of Man* (Bodmer and McKie), *The Human Blueprint: The Race to Unlock the Secrets of Our Genetic Script* (Shapiro), Bishop and Waldholz's *Genome: The Story of the Most Astonishing Scientific Adventure of Our Time: The Attempt to Map All the Genes in the Human Body*, Lee's *The Human Genome Project: Cracking the Genetic Code of Life*, and *Mapping the Code: The Human Genome Project and the Choices of Modern Science* (Davis).

These books, and the press stories in circulation popularizing the importance of the gene, offer genetic explanations of just about every observable (and imagined) phenomenon. Sometimes these explanations turn out to be the products of scientists' fantasies, or to have been conjured up through the press' misinterpretation or manipulation of scientific findings. More often, however, these explanations take their urgency from our willingness and expectation to hear of technoscientific discoveries which explain everything, and make the impossible possible.[4] In the 1990s, against the backdrop of the HGP, everything is laid bare to genetic and genomic scrutiny; hence, we are ready for genetic explanations of all human phenomena, in

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[4] The term "technoscience" is from Bruno Latour, *Science in Action* (Cambridge, MA: Harvard UP, 1987).

sickness and in health.

Genetic explanations are omnipresent and seemingly omnipotent. GENESIS, the computer program which compiles the human genome from gene fragments submitted electronically from all corners of the globe, is hailed, along with other databases such as GenBank, as the library of life. Once the library is stocked, the books ordered and shelved, everything there is to know about a human being will be conveniently available.

The promise is clear, and is made evident by no more than a brief survey of the recent literature. We will learn, through the HGP, about the hereditary basis of any number of genetic disorders, including cystic fibrosis, Duchenne's muscular dystrophy, multiple sclerosis, Huntington disease, Alzheimer's disease, diabetes mellitus, retinoblastoma, neurofibroblastoma, phenylketonuria (PKU), and many others. Some think "it is only a matter of time before DNA-based methods replace much of the surgery now practiced by physicians".[5] Not only will we be able to deal with known diseases, we will be able to solve the problems of homelessness and crime, and "aid the poor, the infirm, and the underprivileged";[6] and we will "have the

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[5] Karl A. Drlica. *Double-Edged Sword: The Promises and Risks of the Genetic Revolution* (Don Mills: Helix Books/Addison-Wesley, 1994) 74.

[6] Daniel Koshland, Jr., Editorial, *Science* 246 (1989): 189.

chance to improve the sexual orientation of our children".[7] In short, through the HGP we will have discovered "the instruction set according to which all humans are made. And when we learn how to read its pages and chapters we will have obtained information relevant to the understanding of most diseases, individual differences in behaviour, and a new awareness of our own history and evolution."[8]

Such is the promise of the Human Genome Project and of the genetic revolution in twentieth-century molecular biology. Yet, if we are indeed successful in the construction of a library of life through the HGP, who will be the librarian, and who will be granted a library card? To whom will borrowing privileges *mean* anything, and why? What can the lay-public expect to gain from the government-funded mapping of the human genome?

These questions are being asked by philosophers, policy analysts, and sociologists, as well as by some scientists, especially within the fora provided by the Ethical, Legal, and Social Implications Working Group (ELSI) struck by the organizers of the HGP in the United States. ELSI has identified three principal ethical, legal, and

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[7] Comment made by Dr. Ed Manier at the conference entitled "Controlling Our Destinies: Historical, Philosophical, Social and Ethical Perspectives on the Human Genome Project", University of Notre Dame, 5-8 October 1995.

[8] Sir Walter Bodmer and Robin McKie, *The Book of Man* (Toronto: Viking/ Penguin, 1994) 11.

social implications of the HGP for initial study: the privacy of genetic information, the protection of individuals from genetic discrimination, and the safe introduction of genetic tests into clinical medicine.[9] At present, the bulk of research into the HGP and human genetics in the humanities and social sciences deals with questions of new reproductive technologies and genetic engineering.

For instance, historians, sociologists, and bioethicists, among others, are concerned primarily with the eugenic possibilities inherent in genetic research.[10] Some epidemiologists and biologists, as well as some philosophers, are interested in questions of reductionism and determinism in biology and genetics.[11] Still other scholars are concerned about the impact of genetic testing, genetic engineering, and biological reductionism on women.[12] Almost all commentators, including both HGP enthusiasts and critics, have concerns about privacy, and

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[9] Elke Jordan, "Invited Editorial: The Human Genome Project: Where Did it Come From, Where Is it Going?" *American Journal of Human Genetics* 51 (1992): 4.

[10] See for example the bibliographic references under Caplan, Degler, Duster, Kevles, Paul, Proctor, and Wilkie.

[11] See the listings under Keller, Lewontin, Lippman, Ruse, and Shuster in the bibliography.

[12] See the bibliographic listings for Boetzkes, Charo, and Lippman, for instance.

about genetic discrimination.[13]

Since these are not my central concerns in what follows, let me briefly explain some of these bioethical and social policy issues in order to demonstrate how my project differs from and displaces these analyses. There is a concern about eugenics, a concern that Nazi-type politics will come in through the backdoor. We will not likely see eugenic legislation passed by Parliament, although we might see the advent of tailor-made children and voluntary sterilisation aimed at preventing further pollution of the gene pool. Of course, there is some evidence that the state may implement eugenic policies. For instance, the U.S. Office of Technology Assessment reported in its 1988 *Mapping Our Genes* that "new technologies for identifying traits and altering genes make it possible for eugenic goals to be achieved through technological as opposed to social control". And the 1927 *Buck v. Bell* decision (on the constitutionality of the Virginia sterilization law) has not been struck down in the U.S.: the justice in that case wrote that "it is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who

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[13] But see in particular Paul R. Billings *et al.*, "Discrimination as a Consequence of Genetic Testing," and Neil A. Holtzman and Mark A. Rothstein, "Invited Editorial: Eugenics and Genetic Discrimination," both in *American Journal of Human Genetics* 50 (1992).

are manifestly unfit from continuing their kind".[14] Enforced sterilization is a good example of a policy of negative eugenics, given that it is a practice destined to decrease future representation of undesirable genotypes by reducing the birth rate of the "least fit" members of the population.[15]

One recent example of enforced sterilization in the United States is the controversial case of Norplant, a surgically implanted contraceptive effective at preventing pregnancy for five years through the release of hormones.[16] The U.S. Food and Drug Administration approved Norplant on December 10, 1990. On December 12, the *Philadelphia Inquirer* printed an editorial headlined "Poverty and

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[14] United States Office of Technology Assessment, *Mapping Our Genes. Genome Projects: How Big, How Fast?* (Washington: OTA, 1988) 84; 274 U.S. Supreme Court 200; see discussion in Holtzman and Rothstein, George J. Annas and Sherman Elias, "The Major Social Policy Issues Raised by the Human Genome Project," and Patricia A. King, "The Past as Prologue: Race, Class, and Gene Discrimination," both in Annas and Elias, eds., *Gene Mapping: Using Law and Ethics as Guides* (New York, Oxford UP, 1992).

[15] Negative eugenics is understood in contrast with positive eugenics, the assigning of members of the population to parentage in order to increase the future representation of desirable genotypes. For more on this distinction, see for instance Peter R. Wheale and Ruth M. McNally, *Genetic Engineering: Catastrophe or Utopia* (New York: St. Martin's Press, 1988) 262-7.

[16] I am here drawing extensively on Nelkin and Lindee's re-creation of the Norplant controversy, 185-7; for other examples of negative eugenics at the policy level, see Ruth Hubbard and Elijah Wald, *Exploding the Gene Myth: How Genetic Information is Produced and Manipulated by Scientists, Physicians, Employers, Insurance Companies, Educators, and Law Enforcers* (Boston: Beacon, 1993) 25-7.

Norplant -- Can Contraception Reduce the Underclass?" The editorial, arguing that economic concerns required such a measure, came under heavy criticism, yet three weeks later *Newsweek* concurred with the message. Then in January 1991, a California judge ordered a welfare mother and child abuser to have the contraceptive implanted; in return, she would receive a shorter jail term.[17]

Sixty-one percent of respondents to a *Los Angeles Times* poll in 1991 favoured requiring Norplant for drug-abusing women of child-bearing age. Many states in the 1990s have tabled (but not yet passed) mandatory sterilization laws. While the justification for such laws is almost always economic, the eugenic impetus remains alive. A 1992 book endorses the use of Norplant to prevent the weak and unhealthy from reproducing. The author's justification is couched in terms of ecological concern -- an unharnessed population threatens to overwhelm the earth's

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[17] Norplant is convenient, but enforced use of birth control is hardly restricted to such a practical device. Jennifer Terry reports that on May 25, 1988, a Phoenix judge ordered that an eighteen-year-old mother, who had pleaded guilty to two counts of felony child abuse, remain on birth control for the rest of her child-bearing years; the terms of her lifetime probation require her to provide regular evidence to her probation officer that she is using contraceptives; see Jennifer Terry, "The Body Invaded: Medical Surveillance of Women as Reproducers," *Socialist Review* 19.3 (1989): 13. Terry refers to a 26 May 1988 *New York Times* article headlined "Woman's Sentence is Birth Control".

resources.[18]

When the media attach a popular cause -- child abuse, drug abuse, teenage pregnancy, the environment -- to state eugenic policies, the policies often enjoy mass popularity. Yet the major force of neo-eugenics lies not with the state, but rather with a commonly held "set of ideals about a perfected and 'healthy' human future". It is less likely that negative eugenics will be legislated than that, as Duster has put it, we will open the "backdoor to eugenics" by means of popular conceptions of health and fitness. As Hubbard and Wald suggest, "the idea of 'race purity' may have died; the idea of building a strain of supermen may have died; but the idea that it is more beneficial for certain people to have children than others, and that a vast range of human problems can be cured once we learn how to manipulate our genes, remains very much with us". People concerned that they have genes associated with alcoholism or Huntington disease may abstain from procreation in an effort to clean up (or at least not further infect) the human gene pool; this surely is already the case with certain congenital diseases. People "at risk" will either avoid procreation altogether or practice

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[18] The book is *Life Child: The Case for Licensing Parents*, and the author is Randall Fasnacht of the Life Force Institute (the publisher of the book). See Nelkin and Lindee 187.

therapeutic abortion, or they might take advantage of the wide range of new reproductive technologies (NRTs), circumventing the defective sperm or ovum.[19]

Some analysts are also concerned with the issues of reductionism and determinism. One argument is that with the recent emphasis on genetics, we risk overemphasising the role of genes in human behaviour. The HGP depends on the theoretical primacy of genes for its popularity and funding; but many have quarrelled with the reduction of complex human phenomena to genetic coding. A further argument is that with reductionism comes determinism, the view that the characteristics of the phenotype (individual people) are innate and essentially unchangeable. The correlative view in molecular biology and sociobiology is that "biology is destiny", and turns on the reduction of human and social problems to questions about "the chemical underpinnings of human existence".[20]

Two criticisms of determinism and reductionism are of particular interest. The first is that of Richard Lewontin, who maintains that the new determinism and reductionism debates are, in many ways, the old sociobiology

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[19] Nelkin and Lindee 191; Hubbard and Wald 25.

[20] James Watson, "The Human Genome Project: Past, Present, and Future," *Science* 248 (1990), as cited by Evelyne Shuster, "Determinism and Reductionism: A Greater Threat Because of the Human Genome Project?" in Annas and Elias, eds. 115.

debates. In sociobiology, not only is biology *human* destiny, but also *social* destiny: according to sociobiologists, "human life is pretty much what it has to be and perhaps even ought to be". The ideology of biological determinism says that genes make culture: genes make individuals with particular preferences and behaviours; the collection of these preferences and behaviours make a culture; so, human society is genetically determined. And yet, while we are reduced to our internal drives and compulsions, the environment remains apart from us. We arrive, via reductionism and determinism, at what Lewontin calls "the false dichotomy of nature and nurture", whereby we are victims of both our internal and external worlds.[21] Lewontin challenges this view, arguing instead for an interactive view of nature and nurture, concluding with Simone de Beauvoir, that a human being is "l'être dont l'être est de n'être pas".[22]

Abby Lippman also challenges the ideologies of reductionism and determinism. She fears the proliferation of what she calls "geneticization". This is an important concept, and her explanation is worth citing at length:

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[21] Richard Lewontin, *Biology as Ideology: The Doctrine of DNA* (Concord: Anansi, 1991) 63, 14, 81, 83.

[22] Lewontin *Biology* 97: "The being whose essence is not to have an essence." I return to Lewontin's arguments in chapter two.

> [Geneticization is] an ongoing process by which differences between individuals are reduced to their DNA codes, with most disorders, behaviours and physiological variations defined at least in part, as genetic in origin. It refers as well to the process by which interventions employing genetic technologies are adopted to manage problems of health. Through this process, human biology is incorrectly equated with human genetics, implying that the latter acts alone to make us each the organism she or he is.

The argument is that when DNA is responsible, *we* are responsible: the root cause of problems lies within us (genetic defects), and not in the environment (toxic exposure, say). Moreover, Lippman contends that genomic maps will provide evidence of genetic variations of unknown significance, at the expense of other research. "Costly attention to these variations can limit exploration of the micro- and macro-environmental factors that influence expression of genes that are, perhaps, more important for human health". Thus, geneticization leads our attention away from environmental influences, fostering neglect of external factors and blaming individuals for their problem DNA.[23]

This notion of individual responsibility for genetic health is especially troublesome for women, as fertile women are seen as having, in the jargon of tort law, the last

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[23] Abby Lippman, "Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities," *American Journal of Law and Medicine* 17.1-2 (1991): 19, 45; "Is Genome Mapping the Way to Improve Canadians' Health?" *Canadian Journal of Public Health* (September-October 1990): 398; see also "Led (Astray) by Genetic Maps: The Cartography of the Human Genome and Health," *Social Science and Medicine* 35.12 (1992), and King 107.

clear chance to propagate or stifle a genetic trait. But, as Charo asks, "should women be held accountable for the size, health and demographic makeup of future generations? The question is asked in terms of women's accountability because in the end it is they who conceive, who gestate, and who give birth to these generations".[24] One is unsurprised to hear Los Angeles radio talk-show host Jane Norris judge local television news personality Bree Walker Lampley morally depraved for daring to have a second child while cognizant of the possibility of passing on ectrodactyly. Some callers responded to Norris' comments by claiming that Lampley's decision was up to her. Others claimed Lampley was being irresponsible and unfair, that her decision was a "horribly cruel thing". One caller complained that Norris' question ("Is it fair to pass along a genetically disfiguring disease to your child?") "smacks of eugenics and selective breeding". Norris responded: "What's your problem, you have a problem talking about deformities?" To another critic, she said, "I think we have enough imperfections that we don't need to perpetuate".[25] Here we

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[24] R. Alta Charo, "Effect of the Human Genome Initiative on Women's Rights and Reproductive Decisions," *Fetal Diagnosis and Therapy* 8 (suppl. 1, 1993): 148.

[25] This case is documented in Nelkin and Lindee 175-6, and in Hubbard and Wald 31. The National Film Board documentary "On the Eighth Day: Making Perfect Babies" concludes with a rebroadcast of Norris' show.

have a striking example of backdoor eugenics, with women left holding open the door.

Eugenic concerns are also apparent in discussions of privacy and genetic discrimination. A number of surveys of clinicians and patients have demonstrated the possibility for, and pervasiveness of, discrimination against individuals or families based on an apparent variation from the "normal" human genotype. In one of the situations studied by Billings *et al.*, a couple with one child suffering from cystic fibrosis were under the care of a Health Maintenance Organization (HMO). When the wife became pregnant a second time, she underwent some prenatal diagnostic tests, one of which showed the fetus to carry two copies of a mutation associated with cystic fibrosis. The couple decided, against conventional wisdom, to proceed with the pregnancy, at which point the HMO threatened to reduce the family's access to health care benefits for refusing to abort the fetus. The HMO backed down when threatened with legal action, but the case reminds us of the problems that may arise with the popularization of genetic testing.

Perhaps the most interesting area of concern is that of the so-called asymptomatic or healthy ill, members of a biological underclass possessing a deformed genotype but a normal phenotype: healthy, but treated as if disabled or chronically ill. The asymptomatic ill are individuals who have been identified as carriers of a mutant gene, or diagnosed with either a late-onset disease, susceptibility to a genetic condition, or a condition that as yet presents no symptoms. Often, physicians, insurers, and employers deal with these individuals as if they are seriously ill, as if they manifest all the symptoms of some disabling disease. For instance, in one case, an individual who applied for a government job was turned down because his brother had Gaucher disease, an autosomal recessive condition (a condition, such as cystic fibrosis, that is clinically apparent only when both copies of the responsible gene are deformed). The job-seeker was a heterozygote for the condition, an asymptomatic carrier with only one mutant gene. Yet he was denied the job on the basis of his carrier status.

One popular strategy for avoiding genetic discrimination has been to reinforce notions of privacy. "Be careful who you tell" is one of the mottos of a gene civilization.[26] Keep genetic information private to protect family secrets, and to protect yourself from employment and insurance discrimination. The issue of the

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[26] Francois Gros uses the phrase "gene civilization" to refer to twentieth-century molecular biology's colonization of medicine and agriculture, from the theory of heredity through plant physiology to embryology and the neurosciences. See Gros, *The Gene Civilization*, trans. Lee F. Scanlon (Toronto: McGraw-Hill, 1992).

privacy of biological information has been in the public eye for a number of years. In the early 1990s, the television drama *L.A. Law* featured a character who, in order to qualify for the firm's group insurance and because of her family history of Huntington disease, was asked to undergo genetic testing. Several episodes focused on her initial resistance and eventual acquiesence to the procedure. She tested negative, thus avoiding a situation of overt discrimination.

In 1992, the March of Dimes Birth Defects Foundation reported the results of a survey on the privacy of genetic information. Nelkin and Lindee summarize the findings: "most Americans believe genetic information is public property and that those with a right to information about a person's genetic characteristics include not only those family members who could be immediately affected, but insurers and employers as well".[27] A number of commentators thus propose, in addition to the injunction to keep genetic data private, stringent confidentiality regulations to prevent discrimination on the basis of genetic variation.

All of these various analyses (of eugenics,

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[27] Louis Harris and Associates, "Genetic Testing and Gene Therapy: National Survey Findings", March of Dimes Birth Defects Foundation, September 1992; Nelkin and Lindee 167-8.

discrimination, and so on) fall under the heading "bioethics". As a discipline, bioethics assumes that there is a profound difference between science and so-called subjective disciplines like philosophy. Science examines objective relationships, and reduces complex phenomena to simpler, quantitatively verifiable relationships. Philosophy examines humanity's subjective relation to the objective world, attempting to discern rational values. Grisolia maintains that "philosophy cannot create a realistic system without recourse to the findings of natural science", and yet the astounding progress of science in the twentieth century has created a crisis in values:

> In Western cultures, the triumph of the scientific, objective viewpoint has left philosophy and other value-oriented disciplines far behind. Science has advanced too quickly for our values to assimilate the new information into a coherent world-view, either at a formal or a popular level. As the reductionist paradigm is applied to increasingly complex human phenomena, our sense of self is correspondingly fragmented, our values and sense of meaningfulness correspondingly eroded. The Genome Project could be viewed as the ultimate reduction of mankind to a chemical formula, the ultimate triumph of science and technology over humanity. Instead, by carefully integrating molecular genetic perspectives into psychology and the social sciences, we may create a bridge from the objective world of natural science to the subjective world of values.[28]

Grisolia's perspective is troublesome, as it is both wrong and popular. He assumes, for instance, that the

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[28] James Santiago Grisolia, "The Human Genome Project and Our Sense of Self," *Impact of Science on Society* 161 (1991): 47-8.

natural sciences are value-neutral, and argues that all that philosophers can hope to do is weave the truths of science into the stories we tell. None of the bioethical or social policy analysts of the HGP subscribes to a view of science as value-free, yet, notwithstanding this obstacle, these analysts share with Grisolia a felt *need* to integrate science into philosophy. Philosophy is worthless unless it understands scientific findings.

Even many of those who view science as value-laden cannot escape the privileging of scientific knowledge, for the objective-subjective dichotomy is firmly entrenched in the mind and heart of the modern world. Sure, science isn't value-*free*, but it is still more neutral than the blatant subjectivity of disciplines like philosophy. This, I think, is to misunderstand scientific findings. The findings of science are less discoveries than inventions, artifacts of the techniques that purport to evidence their discovery.[29]

Those who see science as value-laden but nonetheless more realistic (and hence objective) than any other discipline, are in the vast majority. Hence the force of the popular general view Grisolia -- regardless of his errors -- represents: the humanities and social sciences must reckon with the findings of the natural sciences; non-

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[29] For an elaboration on this point, see Barry Allen, "The Soul of Knowledge," ms 11-13. See also the work of Ian Hacking and Bruno Latour.

scientists must go the extra mile to keep pace with scientific and technological advances. But beware, nonscientists: science is ready and able to overwhelm humanity should you fail in your efforts to find, quickly, a place for science in your ethical systems.

The ethical and social literature on the HGP largely concerns the task of integrating science into bioethics, of trying to establish ethical guidelines for dealing with the new technologies before it is too late. The problem is that it may already *be* too late, at least for that kind of analysis.

The questions I shall ask in this thesis are premised on the assumption that in Western society a scientific pronouncement is always already a political statement. Instead of looking at issues of privacy and informed consent, we ought to look at the governmental and disciplinary impact of seeing our selves and our bodies as essentially genetic.

A brief history of bioethics will clarify the metaethical position I am trying to establish as my starting point.[30] The discipline of bioethics came into being around 1970. "Bioethics" is a broad heading covering any

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[30] The discussion to follow draws on Michael A. Grodin, "Introduction: The Historical and Philosophical Roots of Bioethics," *Meta Medical Ethics: The Philosophical Foundations of Bioethics*, ed. Grodin, *Boston Studies in the Philosophy of Science* (Boston: Kluwer, 1995).

application of ethical theory to the intersections of biology and human affairs. So bioethics touches on both nonmedical (say, ecological) and medical (say, genetic) affairs. Bioethics, although formalized only twenty-five years ago, has a long history. We might look at Hippocrates, or at Aquinas' views on the practice of medicine. We might look at more modern codes of ethics, such as Percival's 1803 *Medical Ethics*, or we might skip ahead to the Nuremberg Code of the late 1940s.

But for most scholars, "bioethics" refers to "contemporary bioethics", a discipline preoccupied with medical paternalism, unsafe and unethical animal and human experimentation, definitions of life and death, personhood, abortion, and the rights of Jehovah's Witnesses to refuse blood transfusions. Contemporary bioethics also focuses on the macro- and microallocation of scarce health-care resources, a phenomenon unheard of and unfathomable before 1970.

Bioethics is not identical with medical ethics; the latter is a sub-field of the former, governing topics such as the "diagnosis and treatment of disease, health promotion and disease prevention, the relief of pain and suffering, and the care of the ill".[31] Medical ethics itself

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[31] Grodin 7.

subdivides into two categories, clinical and philosophical ethics. Clinical medical ethics seeks practical advice within the context of clinical practice. So-called philosophical normative ethics, those theories and principles formulated by philosophers removed from clinical settings, is subject to criticism from within the establishment for failure to be amenable to clinical contexts. Debates rage over the justifiable application of philosophical ethics, as well as over the moral expertise of clinicians, and much metaethical literature is devoted to resolving these problems.

The major traditional principles of bioethics, of both the clinical and philosophical variety, are respect, autonomy, beneficence, non-maleficence, and justice. These have recently been the subject of a revolt against "principlism" waged by communitarians, virtue ethicists, casuists, hermeneuticists, phenomenologists, and feminists. When I say I am seeking to "displace bioethics", I mean that there is something about bioethical discourse *in general* (notwithstanding any bioethical in-fighting) that I think we must reject.[32] Let me elaborate.

Contemporary bioethics, ideally situated as it is at the intersection of science and society, is nonetheless

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[32] However, some recent work in feminist and phenomenological bioethics escapes my criticism.

incapable of offering knowledge genuinely useful to real human beings. Partially because bioethicists fetishize "life" and "health" (notions I examine in chapter three), and partially because bioethicists assume with Grisolia that we must after-the-fact make policy recommendations to reckon with the natural progress of science and technology, bioethics as a discipline is profoundly disabling.

Disciplinary bioethics is, as I will demonstrate with twentieth-century molecular biology, implicated in the transformation of modern human subjectivity. To perform bioethical analyses of the HGP is always already to assume that the HGP has something very important to tell us about ourselves, something that must be managed else it will overwhelm us. Bioethical analyses of the HGP beg the question of science's role in the invention of modern human beings by assuming that scientists discover our nature, generating knowledge which ought to be somehow controlled.

Am I suggesting that we ought to revert to the pre-1970 era, the golden age of theological medical ethics? No, for theologians no less than philosophers and clinicians fetishize "life",[33] warn against the dangers of some kinds

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[33] See Ivan Illich, "The Institutional Construction of a New Fetish: Human Life," *In the Mirror of the Past: Lectures and Addresses 1978-1990* (New York: Marion Boyars, 1992) 218-31.

of esoteric scientific knowledge,[34] and yet use scientific knowledge when it suits them.[35]

Am I arguing, then, that we ought to endorse unethical medicine? Of course not. There is obviously *some* place for ethical guidelines. I am instead suggesting that bioethics as we know it is irrelevant to human existential aliveness while it nonetheless creates a semblance of virtue and responsibility in our endeavours, biological and otherwise. Bioethics wears the cap of rationality and the gown of clinical experience; yet under that guise it is fully incapable of promoting its aim: human well being.

In the literature on the HGP there are some interesting arguments that fall under the heading of "bioethics". Yet these are the exceptions. The bulk of bioethical questions merely *seem* important to pose, while masking those questions really worth asking. Only by displacing bioethics can valuable analyses of science be undertaken.

In what follows, I consider the social and ideological processes that are transforming the genetic code

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[34] See Vatican, Congregation for the Doctrine of the Faith, "Instruction on Respect for Human Life in Its Origin and on the Dignity of Procreation," *The Ethics of Reproductive Technology*, ed. Kenneth D. Alpern (New York: Oxford UP, 1992) 83-97.

[35] See Barbara Duden, *Disembodying Women: Perspectives on Pregnancy and the Unborn*, trans. Lee Hoinacki (Cambridge, MA: Harvard UP, 1993) 21-24.

into a powerful political trope, turning the subcellular elements of the human body into a site of disciplinary control. Further, I want to examine what sort of people we make ourselves into when we think that to know ourselves we have to know what the HGP promises to tell us. I seek to displace bioethical work on the HGP, characterizing it as disabling in the same ways as recent molecular biology. Rather than concerning myself with scientifically informed bioethics or lamenting the lack of ethical concerns in science, I am concerned with science as an agent in the transformation of modern subjectivity. The bioethical literature on the HGP attempts to plot a course between the medical and scientific benefits of the HGP and the spectre of a dawning Brave New World. What are the benefits of the new genetics? What are the attendant threats? Are we opening Pandora's box by mapping the human genome? How do we maximize the benefits of the new genetics, while minimizing the harms? These are the concerns of bioethics; they *seem* very important, but they are not the fundamental questions we should ask of the genetic revolution. I seek to temper the apparent urgency of such questions by attending to and challenging -- instead of integrating -- biology's claim to facilitate human self-understanding. The stock concerns of bioethics too often take for granted the leading role of scientific knowledge. This knowledge sets the agenda, and the ethical concerns follow. That is precisely the perspective I want to displace, by offering a different and more radical interpretation of the role of such knowledge in changing our conception of what it is to be a human being.

The genetic revolution issues a series of genetic injunctions: take stock of your stock; get tested; chart your genetic inheritance; use screening and abortion to strengthen families both physically and mentally; submit to "the new biology to assure the quality of all babies".[36] These imperatives are framed in terms of a new vocabulary to describe ourselves, a new set of criteria against which to measure ourselves, a new series of practices in which to engage to promote our health and happiness -- in short, a new subjectivity, a new way of understanding (and being) a human being. Genetic injunctions, issued by disciplinary experts and circulated in the media, clinics, and in daily conversation, produce a new kind of subject, a new form of subjectivity, what I shall call *Homo geneticus*.

In this thesis, I shall be offering an analysis of the social and existential impact of the new genetics in terms of (bio)power/knowledge. Sociologists in particular

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[36] Bentley Glass, "Science: Endless Horizon or Golden Age?" *Science* 171 (1971). Glass continues: "No parent will have the right to burden society with a malformed or mentally incompetent child."

have recently begun to document the rise of surveillance society.[37] The HGP represents biomedical surveillance of the human body at the subcellular level. This surveillance generates, through the reciprocity between power and knowledge focused on life, *Homo geneticus*. We suffer from a conceptual and existential dearth in describing and understanding in the terminology of the new genetics what we are doing to ourselves.

In chapter two, I examine the relation between particular genomes and the genome being mapped and sequenced through the HGP. I raise a series of objections to the rationale for the HGP, and set the stage for my analysis in chapter four of our modern genetic govern-mentality. In chapter three, I introduce a number of concepts that I require for that analysis, including ideas from Barbara Duden, Michel Foucault, and Ivan Illich. I also discuss Uwe Poerksen's conception of "plastic words", especially as they relate to expert discourse, and I introduce the notion of "disabling knowledge".

In chapter four, I examine an ethnographic study of the culture and politics of genetics, as well as a study of prenatal testing, with a view to grasping the cultural

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[37] See Oscar Gandy, *The Panoptic Sort: Towards a Political Economy of Information* (Boulder: Westview, 1993), and David Lyon, *The Electronic Eye: The Rise of Surveillance Society* (Minneapolis: University of Minnesota Press, 1994).

status of the gene and its role in the shaping of human subjectivity.

My thesis is that physicians, genetic counsellors, and the media offer fundamentally questionable and yet popularly unquestioned genetic explanations of all human phenomena, of who and what we *really* are, imputing needs only they can satisfy, introducing a vocabulary only they are invited (and accredited) to understand, and creating new networks of administration and control at the molecular level. The terminology of genetics is impoverished when removed from its proper sphere of technicality, yet we employ that terminology, often in highly misleading or ambiguous formulations, when contemplating important life-decisions. I conclude that our attraction to scientific understandings of our "essence" is dangerous and disabling. Let us smash the idols of our gene civilization, and reaffirm our aliveness.

Chapter Two -- My Genome and "The" Genome

A genome is the set of DNA molecules, genes, we receive from our parents at conception. The human genome consists in a chain of about three billion nucleotides distributed into DNA filaments arranged randomly yet fixedly over our chromosomes. At conception, we receive twenty-three pairs of chromosomes (numbered 1-22, plus the sex chromosomes: XX [female] or XY [male]), one copy of each chromosome contributed by our mother, and the other by our father. Our genes are located in these chromosomes. Genes are composed of DNA, which is in turn composed of nucleotides. There are four kinds of nucleotides: adenine, cytosine, guanine, and thymine (A, C, G, and T). The nucleotides are said to be strung successively in a lengthy linear sequence, comprising the DNA molecule.

In 1953 Watson and Crick suggested the double-helix as the structure of this molecule. Two strands of DNA are wound together in a helical shape, corresponding to the complementarity that obtains between the nucleotides: A pairs with T, and C with G. The double-helix offers an elegant explanation of how DNA reproduces: the coupled strands unwind, and new strands are built up in accordance with the principle of complementarity. The two new DNA molecules are thus identical to the original, given that one strand in each is just the old strand, and the new strand in each is determined by the pairing of Cs with Gs and As with Ts.

A typical human gene might consist of ten thousand nucleotides. Given that there are four types of nucleotide, and hence four distinct possibilities for each position in the DNA molecule, the number of different types of genes is represented by 1 followed by 6,020 zeros. In this practically infinite variety, DNA specifies the organism by specifying the proteins which comprise organisms. DNA codes for proteins, which are made up of long strings of amino acids.

There are twenty amino acids, each specified by a triplet of nucleotides (AAC, AAT, GAC, and so on). Since there are more possible triplets ($4^3=64$) than there are amino acids, several triplets represent the same amino acid -- the code is said to be "redundant". For example, the amino acid leucine is specified by both AAT and AAC.

While one part of the DNA code specifies the protein to be made, another part determines where and when the manufacture of a protein will be "turned on" or "turned off". So the DNA "creates" the organism by specifying the production of particular proteins at particular times and in particular places. As Richard Lewontin puts it, the role of DNA is to bear information "that is read by the cell machinery in the productive process".[1] So then, my particular human genome just is the set of DNA molecules, the genes, I received from my biological parents at conception.

Samples of human DNA are usually extracted from white blood cells, sperm, or hair follicles. Every cell in the human body contains the full complement of that individual's DNA. Due to DNA's role in specifying protein production, different genes have different effects on the organism. The genes related to the development of white blood cells (the number of genes in question here is 2,164) are not the same as those involved in the development of the liver (2,091 genes), the brain (3,195 genes), or the salivary gland (17 genes).[2] A map of a human's genome would indicate the relative location of genes along that person's chromosomes; the sequence of nucleotides in that individual would be the order of the nucleotides in her or his DNA; ideally, the map would also indicate which genes are implicated in which aspects of development.

When molecular biologists talk about mapping and sequencing the human genome, they refer to a three-step

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[1] Richard Lewontin, "The Dream of the Human Genome," *The New York Review of Books* (28 May 1992): 33.

[2] Nicholas Wade, "Giant Steps in DNA Mapping," *The Globe and Mail* (7 October 1995): D8; figure 2.1 reproduced here is the illustration accompanying Wade's story.

process: the production of a high-resolution genetic map depicting the chromosome on which, and the exact point on that chromosome at which, the gene is located, relative to other genes. Another map, the physical map, represents an ordered collection of tens of thousands of DNA fragments covering the genome. These two maps will be used to help construct the sequence of nucleotides in all the genes on all the chromosomes in the human body. The sequence, scientists tell us, stored in central databases, will serve as a reference point: a composite genome to which our own genomes can be compared in efforts to locate mutant genes implicated in disease or antisocial behaviour. The genome sequenced through the HGP is an *abstract genome*; it does not belong to any human, living or dead. This abstract genome ostensibly bears some relation to the genome of each specific individual member of the human species. But it is not the genome *of* any specific individual human. As the United States National Institutes of Health (NIH) explains, "the first complete human genome to be sequenced will be a composite of sequences from many sources, most of these being cell lines that have existed in laboratories all over the world for some time. The sequence will be a generic sequence representative of humans in general and not of any particular individual". So the HGP is sequencing the genome of an abstract human (see Figure 2.1), yet scientists claim

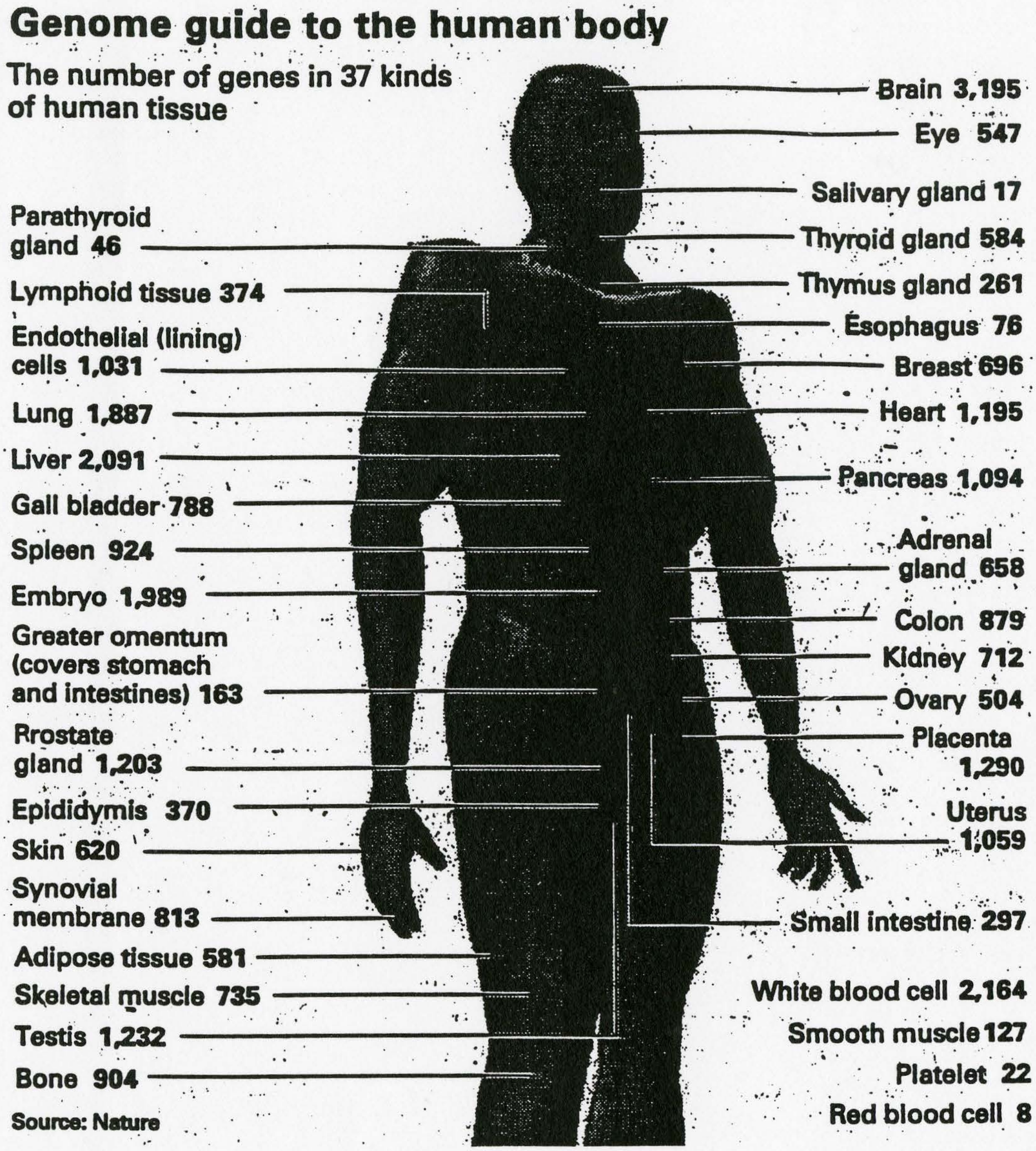

Figure 2.1 "The" human (equipped with a uterus *and* a prostate gland, ovaries *and* testes) whose genome will be mapped through the HGP -- truly an "abstract individual".

that this genome will contain data useful in studying particular genomes of specific humans.[3]

We can talk in the abstract of a composite human genome, but given my basic description of DNA and the constitution of particular genotypes, the deeper question to answer is how my particular genome relates to the abstract composite genome. Following the NIH, the relation between my genome and that genome will not be one of identity: the abstract genome is instead a genetic mosaic of a hypothetical average or prototypical human corresponding to no one in particular. Scientists claim that sequencing this abstract genome ("the" human genome) is the path to, among other things, human health and the understanding of the development of the individual human. But how? How is my human genome related to "the" human genome?

We might fine-tune our characterization of "the" human genome: it will have to be male, for only males carry the Y sex-chromosome (females are XX while males are XY). Further, "the" human genome will likely be French, as the Centre d'Etude du Polymorphisme Humain in Paris maintains a database of high-quality DNA from sixty families, and distributes segments of this DNA to researchers around the

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[3] United States National Institutes of Health, *Understanding Our Genetic Inheritance. The US Human Genome Project: The First Five Years, FY 1991-1995* (Washington: NIH, 1990) 10.

world.[4] So "the" human genome is French and male; yet it still belongs to no one.[5]

The question of the relation between particular genomes and "the" genome is glossed over in the literature. Writers describe the promise of the HGP within the universal category "human". The HGP will surely provide a scientific characterization of species-being: scientists claim that the HGP involves the "acquisition of complete knowledge of the genetic information which characterizes our species". "The" genome is "the instruction set according to which all humans are made". The HGP represents the recipe for human beings, a complete parts list for humans, the key to what makes us human. But there *is* no "instruction set" according to which *all* humans are made. Characterizations of the HGP neatly sidestep the question of individuality and human diversity in favour of homogeneity and a purely hypothetical species-being. Yet the HGP, if it is indeed the path to human health and the perfection of our species, as scientists

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[4] See Jerold M. Lowenstein, "Whose Genome Is It, Anyway?" *Discover* (May 1992): 31; Mary Rosner and T.R. Johnson, "Telling Stories: Metaphors of the Human Genome Project," *Hypatia* 10.4 (1995): 108; and Jean-Michel Claverie, "Deciphering the Human Genome: A Computer Scientist's Challenge in Biology," *Impact of Science on Society* 156 (1989): 308.

[5] A further question involves the *ownership* of "the" human genome. Several researchers have sought patents for sequenced fragments of human DNA; some critics have argued that of *all* things, surely the human genome is the property of all humankind, and of no one in particular. Since my concern is more with correspondence than ownership, I will not pursue this debate.

promise, must produce a species-genome against which *individual* genomes can be measured. It is not as if individuals are of no interest or relevance to the HGP; scientists maintain that they will identify individual deviations from "the" genome, isolate those defects, and fix them. Thus the road to health must be paved with genomic deviance.

The question of "the" genome's relation to my genome is at base one about diversity and variability. That is, "the" genome, as a composite of genetic information from tens or hundreds of human individuals, represents both the homogeneity of human beings but also our individuality. "The" genome, scientists say, will be 99.9% identical to my genome; and the 0.1% variation will explain the immense diversity among human beings. But every human genome is different from every other: that 0.1% translates into about three million nucleotides of difference. Further, while my maternal DNA differs by 0.1% from my paternal DNA, and my own DNA differs from that of any other individual by 0.1%, it is not the case that there is a certain part of my genome which is 99.9% identical with every other human's genome. Although we humans share 99.9% commonality, there is nothing absolutely common to all of us. There is no genetic lowest common denominator.

One-tenth of one percent, then, is no trivial matter. Human beings differ genomically from chimps by no more than 1.2-1.6%. Given that one normal human individual differs from another by 0.1%, the question of whose genome will be mapped, and how we each will be related to that genome, is an important one. If *variation* is the norm -- as the immensity of human diversity and the lack of a lowest common denominator would suggest -- then we are each singular variants of "the" genome. This observation points up the abstract and utterly hypothetical quality of "the" genome, and undermines its authority as a norm deviation from which would imply disease or abnormality. But this claim seems to contradict the rationale for the HGP. Scientists justify the HGP by claiming that it provides a normative reference against which we can compare individuals. This justification ignores the problem of human diversity.

Richard Lewontin suggests that one problem with the HGP stems from the supposed dichotomy between nature and nurture. Scientists claim that genes represent nature; nature means genetic means unchangeable. So by mapping and sequencing a normal human, we solve for nature. Then we hold nature constant while solving for nurture. Bodmer and McKie offer just such an explanation of the value of the HGP: "by learning about how our genes affect our bodies and minds, we can subtract that influence from our equations and learn more about the others".[6] But are we justified in believing natural=genetic=unchangeable, and so in solving for nature before even considering nurture?

Lewontin contends that the contrast between gene and environment, between nature and nurture, is not a contrast between fixed and changeable. Genes and environment interact in complex ways to produce each individual organism, and we cannot (apart from a very few cases, such as blood type) assign separate causal roles to these internal and external forces. Moreover, each organism is in a state of continuous development throughout its life, development influenced by the mutual interaction of nurture and nature. Lewontin underscores the importance of not separating nature and nurture as independent causal forces. Genes influence the organism's sensitivity to environments, while environment affects the relevance of genetic difference. There is no absolute genetic norm. "When an environment changes, all bets are off."[7]

Genes code for the production of proteins at particular times and at particular places within the organism. But in "turning on" or "turning off" the manufacture of a given protein, gene action is directly

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[6] Bodmer and McKie viii.

[7] Lewontin *Biology* 30; see also Lewontin, *Human Diversity*, 2nd ed. (New York: Scientific American Library, 1995) 97*ff*.

responsive to environmental stimuli. Further, "the complex development and metabolism of the whole organism put it into constant interaction with the external world". The continuous mutual interpenetration of nature and nurture produces the organism.[8]

Henry Plotkin makes a similar point in a lengthy passage worth quoting:

> the conception of genes as discrete entities neatly arranged along the lengths of chromosomes -- sometimes referred to as the "beads-on-a-string" idea of genetics -- has had to be relinquished. Genes are chemical structures of great complexity which are smeared across the chromosome rather than being neatly and linearly packaged. They can only be properly understood if seen as entities with significant internal structures and grouped in complicated ways into sometimes spatially widespread functional units called multi-gene families; and if it also be realized that genes are not simply passive providers of information that retain their structure across generation, but reactive complexes that are in constant and dynamic interaction with their carriers, the organism. That is, the structure and function of genes in body cells can be altered by these gene-phenotype interactions.[9]

If Plotkin is right, then the promises of the HGP are wildly overinflated, so much so that the project verges on the fraudulent.

Gould supports the claims of Lewontin and Plotkin, arguing that the concept of *emergence* demonstrates the

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[8] Lewontin *Diversity* 97.

[9] Henry Plotkin, *Darwin Machines and the Nature of Knowledge* (Toronto: Penguin, 1994) 39. I thank Barry Allen for drawing my attention to this passage.

falsity of any dichotomy between nature and nurture. Emergence requires the nonadditive interaction of the components and factors that build it. If I can make a larger entity D by adding A, B, and C, then the process is additive -- nothing about D is emergent, and I can explain D by reducing it to A, B, and C. But if to build D I need interactions between A, B, and C that are not inherent to these components when considered in themselves, then D has emergent features and I cannot explain D by reducing it to A, B, and C. Gould argues that organisms have emergent properties: "genes and environment interact in a nonadditive way, yielding emergent features in the resulting anatomies, physiologies, and behaviors". Since the interaction between genes and environment is nonadditive, we cannot meaningfully solve first for genes and then for environment,[10] as many HGP scientists have suggested.

Lewontin argues that at any moment in its life a living organism

> is the unique consequence of a developmental history that results from the interaction of and determination by internal and external forces. The external forces ... are themselves partly a consequence of the activities of the organism itself as it produces and consumes the conditions of its own existence. Organisms do not find the world in which they develop. They make it. Reciprocally, the internal forces are not autonomous, but act in response to the external.

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[10] Stephen Jay Gould, "The Confusion Over Evolution," *The New York Review of Books* (19 November 1992): 48 n2.

> Part of the internal chemical machinery of a cell is only manufactured when external conditions demand it.

Therefore, genes are not static entities, but rather dynamic; not self-motivating, but externally motivated; not unchanging, but rather subject to important alterations in the development of the organism. Each individual's genome is thus at any moment part of a process of continuous life-long development.[11] The relation between my genome and "the" genome seems less clear than ever.

A further problem with "the" genome compounds the question of its relation to my genome. Any bit of DNA that is sequenced will likely contain a number of defective genes. These defects may be masked by the presence in the strand of DNA of a normal copy of the gene (recall that we receive two copies of each gene, one from either parent). Had both copies been mutant, the result may have been a genetic disease. But the presence of only a single mutant copy makes us carriers (or what I called in chapter one the healthy sick). We are all carriers of some mutant genes. No genome, including "the" genome, is free of mutations. Lowenstein notes that a large portion of "the" genome "will be derived from people with genetic diseases", as "finding the basis of the diseases with the eventual hope of curing them, is one of the major justifications for all the effort

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[11] Lewontin "Dream" 34.

and money".[12] But when scientists compare the DNA of a person with a disease to the DNA of "the" genome, it might well be impossible to determine which, if any, of the differences is implicated in the disease. The only way to determine if "the" genome contains sections of mutant DNA is to compare it with the DNA of large populations of normal and diseased people. But such studies of polymorphism are not part of the HGP proper, and attempts to include them have been rebuffed.[13]

Sometimes, even such polymorphism studies are of no use, as in the case of diseases with multiple causes. Among congenitally abnormal live births, approximately twelve percent of the abnormalities are caused by single mutant genes. Twenty-four percent stem from multiple genetic causes, and sixty-four percent are multifactorial. If we ignore for a moment multifactorial diseases and focus on those caused by chromosomal or multiple-genetic aberration, we are faced with the situation of different people who have

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[12] Lowenstein 31.

[13] Recently, a number of scientists (including Luca Cavalli-Sforza) have succeeded in securing a small amount of funding for the Human Genome Diversity Project (HGDP), which might address some of the criticisms levelled here, although they are more concerned with the history of human evolution. Yet many scientists deem the question of polymorphism irrelevant, funding for the HGDP is but a fraction of that for the HGP, and the HGDP has already run into difficulties concerning the patenting of the DNA of a Panamanian Guayami Indian. For further discussion of the HGDP, see Margaret Lock, "Editorial: Interrogating the Human Diversity Genome Project," *Social Science and Medicine* 39.5 (1994).

the same disease but for different reasons. In the case of haemophilia, haemophiliacs and those whose blood clotting is normal differ by any one of 208 distinct DNA variations. For thalassaemics, there are "at least 17 different defects in different parts of the haemoglobin gene, all of which result in a reduction in the amount of haemoglobin produced. We would look in vain for a particular nucleotide that differed between [those with] thalassaemia and normal people".[14]

One begins to see why Lewontin suggests that a standard normal sequence of the entire human genome will be of no use. His argument depends on the claim that we cannot separate nature and nurture, that genes are variable throughout an organism's development and so cannot be meaningfully grasped and mapped, and that the value of the HGP is diminished by the lack of polymorphism studies. It seems that while every human has *a* human genome, there is no such thing as *the* human genome. Instead, we have "the" human genome, an artifact, a mosaic, a composite of the DNA of several human individuals, complete with mutant genes and an XY chromosome. The question is: why is *that* jury-rigged contraption supposed to be normative? Why must individuals match up to *that* or be judged genetically abnormal, "at

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[14] Wheale and McNally 224; Lewontin *Biology* 50.

risk", deviant, and so on?

The relation between my genome and "the" genome is anything but straightforward. Genes are constantly determined by environments and cell machinery, while simultaneously affecting both cells and environments; the dynamics of the interpenetration of nature and nurture preclude any meaningful mapping of nature in pristine seclusion from "external" factors. Further, the question of not being able to determine which of the multiple genetic differences between the DNA of a diseased person and "the" DNA is responsible for the disease, calls into question the medical value of a purportedly normal sequence.

Why then are so many scientists offering "the" human genome as the Holy Grail of biology, the key to what makes us human? Why has the U.S. government budgeted *three billion dollars* over fifteen years to map and sequence "the" genome? Why are Watson and Crick and countless other famous, powerful, extremely intelligent scientists convinced of the value of the HGP? Lewontin offers two suggestions. First, he wonders if so-called pure science is the motive. Perhaps, he suggests, the promises of HGP proponents are a cover for interest in "the hermeneutics of biological scripture": if we view DNA as the "Book of Life", and the quest for this text as the search for the "Holy Grail of Biology", then perhaps the mapping and sequencing of "the" genome is really an arcane exercise in textual interpretation. Geneticists are in the monastery of the laboratory, pondering the meaning of life as ciphered in multiple sequences of AGAATTTCGGTCA. At least one scientist, Robert Sinsheimer, one of the pioneers of the HGP, has argued in a letter to *Science* that the genome deserves sequencing "because it is there". But given the criticism I have sketched above -- that "the" genome is an artifact and not "just there" -- perhaps there is another motivation for the HGP. Lewontin suggests fame and fortune. Great careers will be made through participation in the HGP and subsequent projects. Nobel prizes, honourary degrees, prestigious professorships, and immense funding for high-tech laboratories are all at stake. Underlying the "mystical guise of pure science and objective knowledge", Lewontin argues, is political and economic ideology.[15]

Biotechnology is a major industry and recently has become a magnet for venture capital. In Canada in 1993, biotechnology produced $1.7 billion in revenue; in Japan in 1992, the estimated revenue was nearly US$300 billion.[16]

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[15] Lewontin "Dream" 35; Sinsheimer, letter to *Science* 249 (1990): 1359, as cited by Robert Proctor, "Genomics and Eugenics: How Fair Is the Comparison?" Annas and Elias, eds. 57; Lewontin *Biology* 57.

[16] These figures were presented by Dr. Andrews at the McMaster Society of Arts and Science Students' interdisciplinary forum on genetic engineering, 27 March 1996.

The rise of biotechnology along with advances in the study of human genetics have made possible the commercialization of tools and methods by private firms, even though the research and development have often been partially publicly funded. However, this is not a case of industry stepping in and capitalizing on academic advances. In 1982 Ruth Hubbard noted that almost all the scientists active in the field of genetic technology have large economic investments in related commercial enterprises. Lewontin reiterates this claim, arguing that no prominent molecular biologist of his acquaintance is without a financial stake in a biotechnology firm.[17]

Aside from the crassness of the motivations Lewontin suggests, I think there is a further, deeper reason that scientists justify the HGP: the translation of the gene -- the real thing -- into an ideological fetish. What everyday people -- and scientists when discussing genetics with everyday people -- mean by "gene" is not that which specifies the sequence of amino acids in a protein. We have created a gene culture, a world in which the gene is the key to humanity, the essence of identity, the source of social and economic difference; in short, the gene has become "the

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[17] Ruth Hubbard, "Embryo and Gene Manipulation," *Society* (May-June 1982); Lewontin "Dream" 37.

secular equivalent of the human soul".[18]

The human genome has become "the" human genome. That we all have a human genome has become the basis for evaluating variation from some supposedly normal sequence. If Lewontin's arguments about diversity and variability are valid, then there is no clear relation between my genome and "the" genome. "The" genome fails to refer to anything significantly real. While the scientific promise of the HGP may be fraudulent, and while the HGP may itself be scientifically misguided,[19] we have nonetheless built a gene civilization in which the HGP somehow makes sense to scientists and non-scientists alike. This event has significant repercussions. My goal in the remainder of this thesis is to analyze the fetishization of DNA, and to sketch strategies of recovery.

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[18] Nelkin and Lindee 198.

[19] For another set of criticisms of the HGP compatible with those offered in this chapter, see Alfred I. Tauber and Sahotra Sarkar, "The Ideology of the Human Genome Project," *Journal of the Royal Society of Medicine* 86.9 (1993).

Chapter Three -- Biopower and the Fetishization of Life

To facilitate my analysis of the fetishization of DNA, I will introduce in this chapter a number of distinct yet related ideas. These ideas stem from Barbara Duden's work on pregnancy, and Ivan Illich's work on institutionalized values, the rise of management society, and the correlative fetishization of "life". I also draw on Uwe Poerksen's conception of "plastic words", words removed from their proper scientific context and replaced in the vernacular. In this shift they lose their denotative force, and instead take on the character of infinite connotative malleability. Finally, I discuss Michel Foucault's work on discipline and governmentality, and his notion of the reciprocity between power and knowledge in the formation of human subjectivity.

Using these concepts, I set the scene for a confrontation with human genetics, the HGP, and the practice of genetic counselling. In the final chapter of this thesis, I describe our present gene civilization, and challenge the primacy of the new form of human subjectivity I call *Homo geneticus*.

Barbara Duden has written two books. One is a detailed examination of the casebooks of the eighteenth-century German physician Johann Storch, who wrote an eight-volume study on the diseases of women. Her other book documents the sociogenesis of the modern body, as distinct from the eighteenth-century body described by Storch and his patients. In studying Storch's patients, Duden notices not only body-experiential differences between herself and them, but also a difference, compared with today, in the practice of Storch as a physician. "The fact that Storch treats women does not make him a 'gynecologist', since he is concerned with the entire life history of a woman (her bios)". He was, etymologically, a *bio-logist*: he recorded lives, and his thinking, "oriented toward details and analogies, drove him to gather stories, for the body which he pursued all his life apparently had no norm, it was never complete". Duden further suggests that the women's words were especially important to Storch in a way nearly unfathomable today, especially compared with the then unimportance of a physical examination.[1]

Only rarely did Storch touch his patients, let alone probe their innards with a speculum or some other technical instrument; this practice is significant in considering the

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[1] Barbara Duden, *The Woman Beneath the Skin: A Doctor's Patients in Eighteenth-Century Germany,* trans. Thomas Dunlap (Cambridge, MA: Harvard UP, 1991) 28, 149, 153, 157, 68, 83.

relatively recent scientific notion of pregnancy, as distinct from the older idiom of "quickening" and "being with child". For Storch, pregnancy remains doubtful until the woman's story includes mention of quickening. Only the woman herself confirms the fact of pregnancy by reporting her quickening, a report with normative status in both medicine and law. Now, of course, the fact of pregnancy is in the hands of physicians and laboratory technicians -- only they can definitively establish that fact. But it was not always so: "In the history of pregnancy, women were pregnant and at some point they were pregnant with child -- after quickening, in the second part of pregnancy. But there was just no basis for a political or public discourse. Now the unborn is named as a foetus to which is imputed personhood, rights, patienthood, and so on and so on". Duden argues that women had to be skinned in order to open the space for this discourse.[2]

The "skinning" of women is Duden's evocative phrase for the discourses and practices which render the pregnant woman's body *transparent*. The clinical gaze objectifies bodies and opens the door for penetrating, interventionist medical investigation. Anatomy, physiology, and the new clinic of the nineteenth century were necessary components

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[2] Duden *Disembodying Women* 87, 93; Duden, interview, "History Beneath the Skin," by David Cayley (*Ideas*, CBC Radio, 7-8 October 1991) 7.

in making the body transparent. She contrasts this body to those Storch examined, opaque live bodies whose interior is visually unavailable.

For Duden, the demand to render the body transparent is most clearly exemplified by the use of ultrasound: "The ultrasound picture gives the appearance -- when a woman sits in front of a real-time ultrasound scanner -- that she sees the interior of her womb. That is an illusion, because what she sees is the electronic mapping of physically defined matter as it is being defined in physics ... [S]he buys into the necessity of having something visually represented that in fact she can grasp herself with her senses".[3] This technique of visualization represents, to Duden, evidence of a historical, cultural movement away from other forms of sensation toward sight, what she calls the attitudinal shift from *hapsis* to *opsis*, from the priority of kinesthetic sensation to that of a visual representation.

Duden uses "haptic hexis" as a term with which to describe a former, now long-lost way of "being, feeling, and sitting within oneself that is oriented not primarily by visual reference but by touch, taste, the sense of space, the feel for atmosphere". This feeling is put into ordinary words for a doctor like Storch, who records his patients'

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[3] Duden "History" 8.

speech largely verbatim, without translating it into the specialist language of medicine. Duden argues that we have moved from this form of sensation to one characterized by *opsis*, defined by "representation, imagination, or graphics", and "shaped by pictorial techniques".[4] The priority of this new sensation-language-representation nexus is required to explain the prestige of ultrasound as well as other aspects of a modern, thoroughly medicalized pregnancy.

Duden makes a quasi-technical use of the term "life", one she derives from the work of her colleague Ivan Illich. For Duden, the shift from kinesthetic sensation to visual representation is characteristic of a move from "aliveness to life". By "life", Duden means an understanding of existence characterized by the loss of the primacy of feeling in favour of management, standardized health, proper nutrition, the necessary amount of sleep, and the body as a system. "Life" is a resource, something to manage. Your or my "aliveness" is not. For Duden, the focus on "life" displaces individual autonomy in favour of deference to experts.

As I mentioned above, Duden argues that throughout the history of pregnancy, a woman's confirmation of

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[4] For the quotations, see Duden *Disembodying Women* 91. See also Chapter 14, "*Hapsis* and *Opsis*". For a similar perspective on the "scopic drive", see Rosi Braidotti, "Organs Without Bodies," *Differences* 1 (1989).

pregnancy by reporting her quickening was the only way (both in medicine and law) to verify the pregnancy. Today, there is a very broad, multidisciplinary public discourse surrounding pregnancy, focused on the notion of "life" as beginning at conception. The fertilization of the egg is operationally verifiable and today women are incapable of feeling their quickening -- or even if they do feel it, this sensation has no status, no authority, no meaning. Women who think they may be pregnant must have their pregnancy confirmed medically. Duden argues that this development displaces feeling, emphasizing instead the medical determination of "life".

Duden is not nostalgic, not urging the return to quickening as confirmation of pregnancy. Instead she is documenting a change in our collective interpretation of bodily experience. *How* we feel our flesh, and *what* we feel *as* our flesh, is subject to historical variation. The way modern medical discourse encourages us to sense our body is visually mediated, at the expense of autonomous kinesthetic sensation. Duden suggests that "there is a fundamental difference between what I feel, or what a woman feels inside -- what she knows, say, through her interior senses -- and what you can see on a screen on the outside". When what is on the screen is more important, more legitimate, than what we feel -- and when we can no longer feel our body in autonomous ways, but only as mediated by scientific categories -- the visual has eclipsed personal significance.[5]

The emergence of "life" is, in itself, an interesting topic. Duden's recent work, as well as some of the work of her colleague Ivan Illich, has focused on this phenomenon. So, too, has the work of Foucault. Before the eighteenth century, "life" did not exist. Instead, aliveness was the human condition: we felt and experienced because aliveness was our condition. For Foucault, as well as Duden, this way of being was replaced beginning with "the entry of life into history".[6] Duden suggests that "life" is a scientifically established state imputed to us by the current experts,[7] and that the loss of aliveness is a significant loss.

There is a profound difference between deferring to someone who honestly knows more about a certain problem than

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[5] Duden "History" 7.

[6] Foucault means by this phrase the eighteenth-century admission of phenomena peculiar to the life of the human race into the interplay of power and knowledge. "For the first time in history, no doubt, biological existence was reflected in political existence; the fact of living was no longer an inaccessible substrate that only emerged from time to time, amid the randomness of death and fatality; part of it passed into knowledge's field of control and power's sphere of intervention." (Foucault, *The History of Sexuality, Volume I: An Introduction*, trans. Robert Hurley [New York: Vintage, 1978] 142; for elaboration, see part five of *HS*.)

[7] Duden *Disembodying Women* 53.

we do, someone who can genuinely help us, and deferring to an expert because deference is the only survival skill we know, and because experts manage us as "lives" from (in Illich's nice phrase) conception to organ harvest.[8] To lose weight, one need not visit a dietician or a nutritionist (or visit a genetic counsellor for the latest information on the OB gene!),[9] although one may want to have one's scale calibrated by someone versed in weights and measures. The former, I will contend below, is disabling; the latter is simply the condition of being alive. For now, I will return to "life".

Ivan Illich elaborates on the new conception of "life" by drawing on Uwe Poerksen's notion of "plastic words". Such words "connote self-important enlightenment, social concern and rationality without however denoting anything we ourselves could taste, smell or experience". For Poerksen:

> Words have *auras*. In her work on connotation, Beatriz Garza Cuaron compares denotation, that is, the designation of a thing, with the first wave that forms when a stone falls in the water; connotation, or the feelings, associations, and valuations the thing evokes, she compares with all the following waves. Plastic words seem to be composed only of the ring-like

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[8] Illich "Institutional" 230.

[9] The OB gene was regarded in 1995 as the solution to obesity: "Make a drug that can get rid of fat, and Americans will waddle slowly but resolutely to your door." See Shawna Vogel, "The Mouse on the Left Needs Leptin," *Discover* (January 1996) 34.

> connotations, which move outward from wave 2 to infinity. The stone and the first wave have disappeared.

Building on this metaphor, Illich describes a plastic word as "a stone thrown into a conversation -- it makes waves, but it doesn't hit anything. It has all these connotations, but it does not designate anything precisely".[10] Part of the reason for this lack of precision derives from the words' *travels*.

As Poerksen suggests, "plastic words either begin in the sphere of science or pass through that sphere", and they dock in the vernacular; "science is totally altered in a vernacular context. It becomes contradictory, doctrinaire, and imperialistic. Just as mathematics is deformed in the vernacular, so is vernacular language deformed when it is mathematized". Plastic words "merge with the everyday and soon seem commonsense", yet they retain an aura of authority derived from their scientific lineage:

> A crust of science and technology has hardened over our common language and given it an authoritarian ring. But this language only seems technical. It is made to appear so by the ad hoc use of composite terms, by the use of neutral, objective, and impersonal expressions; and by the addition of abbreviations and numbers. This practice colors the language of politics, of

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[10] Illich "Institutional" 223; Uwe Poerksen, *Plastic Words: The Tyranny of a Modular Language*, trans. Jutta Mason and David Cayley (University Park: Pennsylvania State UP, 1995) 8; Poerksen's reference is to Beatriz Garza Cuaron, *Connotation and Meaning*, trans. Charlotte Broad (New York, 1991); Illich, "A Cosmos in the Hands of Man," *Ivan Illich in Conversation*, with David Cayley (Concord: Anansi, 1992) 253.

newspapers, and of public discussion.[11]

Recently the word "life" has undergone this transformation, becoming a plastic word. At the same time we have begun to sacrifice aliveness, to demote it, downgrade it, forget it in favour of the abstract idea of *life* as a resource demanding rational management. When we focus on "life", we render aliveness irrelevant. Paul Rabinow has suggested that we are moving away from an earlier notion of the subject as "the suffering, meaningfully situated integrator of social, historical, and bodily experience". We are moving instead toward the conception of "life" as "something precious, endangered, scarce" -- something "amenable to institutional management, something which calls for the training of ever-new specialists from lab scientists to therapists and professional caretakers". Thus "life" has something to do with what other people know and the rest of us do not. "Life" seems to say everything, but in the vernacular it denotes nothing; the stone and the first wave have disappeared.[12]

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[11] Poerksen 8, xviii, 1, 73.

[12] Rabinow's comment is at 243 of his "Artificialities and Enlightenment: From Sociobiology to Biosociality," *Incorporations: Zone 6*, eds. J. Crary and S. Kwinter (New York: Urzone, 1992), as cited by Emily Martin, *Flexible Bodies: The Role of Immunity in American Culture From the Days of Polio to the Age of AIDS* (Boston: Beacon, 1994) xvii; Illich "Institutional" 218-9.

"Life", as a resource to be rationally managed, necessitates deference to experts. The management of "life" is a major modern Western industry. This management is insidious, especially because it does not appear primarily in the places where our traditions of political philosophy urge us to look for the exercise of power: the sovereign, the state, capital, the ruling class. The management of "life" is a management *through* life, from the fertilized egg to the moment of organ harvest, from sperm to worm.[13] The management of "life" is not a *dominating* power but a *disciplinary* power, exercised over us all by our ready compliance with the new idea of life as a crucial resource. This is what I mean by the fetishization of "life". To go into this point further, I want to say something about Foucault's concept of "biopower".

In the first volume of *The History of Sexuality,* Foucault argues against the conventional wisdom that since the Victorian era the modern West has repressed sexuality. Instead, we have taken it to a high science, encouraging and perpetuating sexual discursivity, situating sex in a field of discursive knowledge. The so-called repressive hypothesis suggests that we were, and still are, constrained by taboo and silence on the subject of sexuality. Foucault

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[13] Duden *Disembodying Women* 101.

argues that, on the contrary, the repression of sexuality is not historical fact, and that the category of repression is not useful for describing the fate of sexuality in the West. Instead of being silenced, we have been incited to discourse on the topic of sexuality. For Foucault, the society that "emerged in the nineteenth century -- bourgeois, capitalist, or industrial society, call it what you will -- did not confront sex with a fundamental refusal of recognition. On the contrary, it put into operation an entire machinery for producing true discourses concerning it".[14] The incitement to discourse is not a state policy, but rather a product of micropowers; it is not initiated by the sovereign, but by disciplinary experts; and it is not forced, but rather compelled.

Foucault's greatest contribution to political philosophy is his focus on micropowers instead of state power. Micropowers are not invested in the sovereign or the law, but have as their vehicle the persons of those well-positioned in our economy of knowledge. These forms of power are exercised by bureaucrats, administrators, public health nurses, teachers, physicians, genetic counselors, psychotherapists, statisticians, economists. The political government of individuals is effected through special

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[14] Foucault *HS* 69.

competence and disciplinary credentials.[15] With his focus on micropowers, Foucault documents a new power over life, distinct from the right of the sovereign. He calls this power over life "biopower", and it operates on both individuals and populations.

Biopower functions through "power/knowledge", Foucault's term for the reciprocity that arises from a political regime's efforts to legitimize certain ways of seeking, authorizing, employing, and disseminating knowledge, which in turn enhances the efficiency, effectiveness, and rationality of the power that produces it.[16] Power and knowledge are not identical, but mutually constitutive and reinforcing. Beginning in the nineteenth century, with the entry of life into history, power/knowledge has focused on all aspects of life: sexuality, reproduction, health, heredity, child-rearing, and so on.

Biopower is a strategy of government. Foucault has a quasi-technical understanding of the term "government", derived from its sixteenth-century meaning:

> "Government" did not refer only to political structures

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[15] For an elaboration, see Barry Allen, "Disabling Knowledge," ms, forthcoming in *The Ethics of Postmodernity*, ed. Gary Madison and Marty Fairbairn (Evanston: Northwestern UP).

[16] Michel Foucault, *Power/Knowledge: Selected Interviews and Other Writings 1972-1977*, ed. Colin Gordon (New York: Pantheon, 1980) 51-2.

> or the management of states; rather it designated the way in which the conduct of individuals or states might be directed: the government of children, of souls, of communities, of families, of the sick. It did not cover only the legitimately constituted forms of political or economic subjection, but also modes of action, more or less considered and calculated, which were designed to act upon the possibilities of action of other people. To govern, in this sense, is to structure the possible field of action of others.[17]

Government in the modern West is effected increasingly in terms of knowledge operating in reciprocity with micropower. For example, Illich maintains that our experience of our bodies and our health is increasingly coming under the sway of medical concepts, and the activities and perceptions of the experts who employ them. We have witnessed, especially in the last fifty years, the medicalization of society (the making of medicine relevant to new and more aspects of human existence), and the rise of medicine as management (the intensification of administration, the primacy of actuarial thinking, the focus on risk, the notion of predictive medicine). Physicians now manage populations and individuals, not in the name of virtue or legitimacy, but in the name of health. Physicians are the managers of the medicalized society.[18] In the case

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[17] Michel Foucault, "The Subject and Power," *Michel Foucault: Beyond Hermeneutics and Structuralism*, ed. Hubert Dreyfus and Paul Rabinow, 2nd ed. (Chicago: University of Chicago Press, 1983) 221.

[18] Ivan Illich, "Twelve Years After *Medical Nemesis*: A Plea for Body History," *Mirror* 213; Irving K. Zola, "Healthism and Disabling Medicalization," *Disabling Professions*, Illich *et al.* 41-2. On

of sexuality, the major strategies of biopower included the medicalization of women's bodies and a psychiatrization of deviant sexuality. I am claiming that the very idea of "life" as a scarce resource belongs in the same historical ensemble.

Physicians typically do not employ force or coercion on their patients. But that does not mean that the relation is free of power. Instead, it means that we have to question the old idea that force and threat are the essence of power. We must turn our attention to the production of knowledge as itself an instrument in the exercise of power. The imputation of needs is an ideal example for appreciating this shift of focus.

Illich argues that the power of management "to name norms of health, education, psychic balance, development and other modern idols" is no less important than its power "to actually create the social context within which a default in

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medicalization, see Zola 51-61; see also the World Health Organization's 1948 definition of health as "a state of complete physical, mental, and social well-being and not merely the absence of disease and infirmity". On increased administration, see Barry Allen "Foucault and Modern Political Philosophy," ms, forthcoming in *The Later Foucault*, ed. J. Moss (London:Sage) 6, and Nelkin and Lindee 195; on actuarial thinking, see for instance Nancy A. Press and Carole H. Browner, "Collective Silences, Collective Fictions: How Prenatal Diagnostic Testing Became Part of Routine Prenatal Care," *Women and Prenatal Testing: Facing the Challenge of Genetic Technology*, ed. K.H. Rothenberg and E.J. Thomson (Ohio State UP, 1994) 201. On the emergence of the risk society, see Gandy; see also Jonathan Simon, "The Emergence of a Risk Society: Insurance Law and the State," *Socialist Review* (1987). On the rise of predictive medicine, see the work of Lippman, and my discussion of this concept below.

regard to these 'values' is experienced as a *need* which in turn translates into an entitlement". The target of this criticism is the power of experts to impute needs which only they can satisfy, thereby consolidating and further extending their power.[19] The reciprocity of power/knowledge in the person of the expert -- not the state, the sovereign, or the bourgeoisie -- necessitates an examination of the authority of experts.

To repeat, Foucault is concerned not with coercive force but with the unforced force of knowledge (or what passes for knowledge). It is this gentle coercion which compels us to defer to expertise and follow expert-issued injunctions. He is concerned with "governmentality", his term for the particular combination of *government*, the power to direct conduct, and the modern *mentality* that everything is (or ought to be) subject to management, administration, and regulation by authority.[20]

Why this govern-mentality? Why must everything be somehow managed by experts? Why do we participate in extending and justifying the unforced force of power/knowledge? Foucault argues that "power is tolerable only on the condition that it mask a substantial part of

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[19] Illich "Institutional" 222.

[20] Allen "Foucault" 17.

itself. Its success is proportional to its ability to hide its own mechanisms". Perhaps the best masking strategy is to have those constrained believe there is something about them which *requires* constraint. As Prado puts it, "the most effective way to ... get people to believe their very own nature calls for regulation is to promulgate a scientific conception of human beings as having a specific objective nature, one that is replete with possibilities for unnatural and deleterious expression".[21] We see the modern human body not as a *production*, the historical work of a contingent configuration of power and knowledge, but as the truth. What we feel as our flesh is the product of nature, always and everywhere the same. We are systems, with human DNA in our cells. All of this is completely self-evident and hence irrefutable. But Foucault and others maintain that the modern body was invented and not discovered, and the origin and extent of this invention is masked through our deep internalization of what presently passes for the truth about our flesh.

To account for our govern-mentality and our deference to expertise, Foucault borrows Jeremy Bentham's model of the Panopticon, which offers a schema for understanding how we internalize what we take to be

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[21] Foucault *HS* 86; Carlos G. Prado, *Starting With Foucault: An Introduction to Genealogy* (Boulder: Westview, 1995) 100.

knowledge about our flesh. The Panopticon is a central tower surrounded by a ring-like structure; the peripheric structure is divided into cells, each with two windows, one interior and one exterior; the exterior window has the effect of backlighting the inhabitant of the cell; the interior window offers visibility from the tower of the cell's inhabitant. The cells "are like so many cages, so many small theatres, in which each actor is alone, perfectly individualized and constantly visible ... Visibility is a trap".[22]

The principle of panopticism is "that power should be visible and unverifiable": the prisoner can see the tower, and yet never knows whether s/he is being watched. The result is the "automatic functioning of power": "He who is subjected to a field of visibility, and who knows it, assumes responsibility for the constraints of power; he makes them play spontaneously upon himself; he inscribes in himself the power relation in which he simultaneously plays both roles; he becomes the principle of his own subjection". The Panopticon is not only an instrument of observation, it is also productive, inducing self-observation as well as knowledge of and conformity to norms. "Thanks to the techniques of surveillance, the 'physics' of power, the hold

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[22] Michel Foucault, *Discipline and Punish: The Birth of the Prison*, trans. Alan Sheridan (New York: Vintage, 1979) 200.

over the body, operate according to the laws of optics and mechanics, according to a whole play of spaces, lines, screens, beams, degrees and without recourse, in principle at least, to excess, force or violence. It is a power that seems all the less 'corporal' in that it is more subtly 'physical'".[23]

Foucault seems here to be dealing exclusively with power. But since power is seldom entirely external to knowledge, the panoptic microphysics of power is at the same time and reciprocally as important for the production of knowledge: "The Panopticon functions as a kind of laboratory of power. Thanks to its mechanisms of observation, it gains in efficiency and in the ability to penetrate into men's behaviour; knowledge follows the advances of power, discovering new objects of knowledge over all the surfaces on which power is exercised". Cellular power bequeaths cellular knowledge, and the reverse, as well.[24]

The knowledge/powerful examination -- observation coupled with a normalizing judgement -- is integral to the automatic functioning of the panoptic machine. The normalizing gaze "introduces the constraints of conformity" -- it "compares, differentiates, hierarchizes,

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[23] Foucault *DP* 200-1, 202-3, 177.

[24] Foucault *DP* 204.

homogenizes, excludes"; it is the *sine qua non* of the "disciplinary society". This normalizing gaze -- as the notion emerges in Foucault's *The Birth of the Clinic* -- is also the *sine qua non* of the *medicalizing* society. I will quote a long passage from Duden summarizing the significance of the gaze and the examination in the iatrogenesis of the modern medical body:

> It was only toward the end of the eighteenth century that the modern body was created as the effect and object of medical examination. It was newly created as an object that could be abused, transformed, and subjugated. According to Foucault, this passivity of the object was the result of the ritual of clinical examination. The clinical, investigative gaze fixed and crystallized as "the body" that which it perceived. The gaze of the doctor was like a dissection; the sick patient was now treated in a way that once had been conceivable only with dead bodies. Foucault repeatedly pointed out that the impact of this new clinical discourse about the body can be seen in two ways by the historian: it repressed, censored, masked, abstracted, and alienated modes of perception; at the same time it had the power to create new realities, to constitute new objects, to introduce new, inescapable, rituals into daily life, rituals whose participants became epistemologically dependent on the newly created objects.

The normalizing gaze of the Panopticon, explains our deep internalization of what pass as the truths of our flesh.[25]

One of my concerns in this thesis is to problematize the taken-for-grantedness of the body. How we sense our bodies, and what we sense as our bodies, in the modern era has recently been investigated by Duden (in terms of

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[25] Foucault *DP* 184, 183, 209; Duden *Woman* 3-4.

pregnancy) and Martin (in terms of the immune system). Both studies shore up my contention that clinical discourse is colonizing the vernacular, reinventing our experience of ourselves from the perspective of operational verifiability and with the aid of plastic words. At the interface between technical science and popular discourse, the agent of this colonization is the expert.

Like physicians (indeed, physicians *are* experts), experts enjoy a privileged location in Western economies of knowledge. Nelkin suggests that the authority of experts "rests on assumptions about scientific rationality".

> [I]nterpretations and predictions made by scientists are judged to be rational because they are based on "objective" data gathered through rational procedures, and evaluated by the scientific community through a rigorous control process. Science, therefore, is widely regarded as a means by which to de-politicize public issues. The increasing use of expertise is often associated with the "end of ideology"; politics, it is claimed, will become less important as scientists are able to define constraints and provide rational policy choices.[26]

The flaw in the picture Nelkin provides (and later criticizes from a perspective other than that which I offer here) is that rather than de-politicizing public discourse, expertise micro-politicizes it. What I mean is that Foucault's concern with micropowers located at an entirely different level than state or sovereign power should make us

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[26] Dorothy Nelkin, "The Political Impact of Technical Expertise," *Social Studies of Science* 5 (1975) 36.

attentive to new sites of power and knowledge: the public school, the modern hospital, the prison, the genetic counselling clinic, the laboratory. The scientific penetration of society is not a formula for the end of ideology but rather for an unprecedented politicization of society at the microlevel.

Part of this process of micropoliticization -- of the deployment of biopower -- is, as I mentioned above, the plasticization of scientific discourse, science's colonization of the vernacular. The role of the expert is essential to the enterprise. Poerksen goes so far as to characterize the expert and the plastic word by the same template or prototype. Some of the elements of Poerksen's composite image of the expert are as follows: due to his position in our economy of knowledge, the expert silences the outsider or lay person and recreates everyday life through the concepts and the vocabulary of the scientific world. This language has a very wide radius of application and displaces locally meaningful signs. The expert reduces diversity to a common denominator. The expert also dispenses with the question "good" or "bad" in favour of the question "progressive" or "backward" and always appears on the side of the Enlightenment. Further, the resonance of the name "expert" and the social function he fulfils are more important than what he actually does. The expert awakens limitless needs, whose "naturalness" become an imperative through him, and he institutionalizes himself and the need for his help through his technoscientific plastic language.

The expert, so described, is what Poerksen calls a "functionary who makes reality" through plastic language; and this expert has a privileged place in the modern West. Experts make no use of threats, violence, or coercion. Instead, prestigious discourse and discursive authority constitute the expert, and recreate the rest of us as unknowledgeable audience and as consumer. "Wherever there is a profession there must be a clientele; wherever there is a disciplinary profession otherwise free or indifferent clients become a laity."[27]

Consider one relevant example. Poerksen argues that prior to the colonization of the vernacular by medical discourse on health, the word "health" is rarely mentioned, let alone used as the name of something that has to be managed. When it *is* mentioned, it refers to an absence: it means "uninjured". But now the lack of health has "been implanted in everyday consciousness":

> When the concept of health gets loose in the vernacular, it generates new forms of deviance. Originally, it was a rather unobtrusive idea, but that was before it was authorized and sanctified by experts.

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[27] Poerksen 88-9; Allen "Disabling" 12-3.

> Now it introduces arbitrary boundaries into the continuum of experience, erecting a barrier between "healthy" and "sick", and specifying a norm that has been set ever higher, so that ever more people are identified as sick. The new norm quickly takes on the appearance of being natural; its origin in the past is forgotten.

In addition to the plasticization of "life", we are witnessing the plasticization of "health". And we have only ourselves, and knowledge, to blame. In the West, we have a medicalized society relying on a popular definition of health mediated by expert discourse, subject to expert management, and productive of a body unlike anything ever felt before: "a body more than ever *lived and felt* according to prescripts of medical gnosis".[28]

Why blame ourselves? Because we are active participants in the government of all and each through (bio)power/knowledge. We are not forced by threat or violence into certain self-understandings; rather, we are gently urged by the unforced force of what passes for expert knowledge to understand our bodies and our selves in particular ways. When we subscribe to certain recent conceptions of who we are, taking those conceptions as self-evidently true, we are actively complicitous in the deployment of (bio)power/knowledge.

Must we not also blame *knowledge*? It has been

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[28] Poerksen 74; Allen "Disabling" 22-3.

suggested that we are witnessing "the appearance of an enigmatic counterproductivity of knowledge", that "knowledge turns from a morally neutral source of technical power to a strategy of political government that disables and stupefies those whom it is supposed to serve". Illich uses the term "paradoxical counterproductivity" for the process by which institutions, in the normal course of operation, subvert the very purposes for which they were created, while simultaneously delegitimizing alternative means to similar ends. For example, a city designed around wheels is inappropriate for feet, yet urbanized people spend 17% of their time as passengers. This is too long, and an embarrassment to the experts responsible for modernizing the city, and for finding ever new technological solutions to this technologically created problem. Illich argues that beyond a threshold point in the substitution of commodities (goods or services) for self-produced use-values, the commodities become destructive nuisances to the satisfaction they were meant to provide. It is in this sense that goods and services can have paradoxical disabling effects. The extended claim is that the same goes for knowledge itself.[29]

One of the major disabling effects of knowledge is the

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[29] Allen "Disabling" 2, 4; Ivan Illich, "Disabling Professions," Illich *et al.* 28.

imputation of needs, prescribable and satisfiable only by accredited experts. The political impact of such knowledge results in dependence on authority, what might be called "learned stupidity" or "disempowering deference".[30] When we resign ourselves to not knowing enough about ourselves, and defer to experts who have that knowledge and use it to satisfy imputed needs, we learn to be stupid, and our deference is entirely disempowering. Such stupidity and deference obviously contribute profoundly to our general pattern of complicity in the fetishization of "life" and the plasticization of "health".

The question to ask about knowledge is not whether it is true or properly scientific, but whether it is *good*. But surely *knowledge* is good! Not unconditionally, for when knowledge is not only disabling but stupefying, when knowledge reaches the stage of counterproductivity, its value becomes questionable. The good of knowledge must be demonstrated, and not uncritically assumed.[31]

I have been arguing that in the twentieth century we have witnessed the eclipse of kinesthetic sensation by visual representation, the latter requiring mediation by experts. These experts translate mortal needs for care into

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[30] Duden *Disembodying Women* 29.

[31] Allen "Disabling" 24.

imputed needs patients or clients would otherwise never have dreamed of, and which require resource-intensive satisfaction. The imputation of needs is a function of a society characterized by a peculiar govern-mentality operating through the arbitration of experts. Experts are poised between the language of science and the vernacular, and translate, primarily by means of unacknowledged metaphors, scientific terminology into lay-language. We think we understand it, but the lay-terminology fails to designate anything in particular. At most it vaguely connotes self-importance, enlightenment, and rationality. We incorporate these now-plastic words, and the metaphorical baggage they carry, into our own self-understandings, as well as into public discourse and political decision-making. The HGP and the haze of lay-genetic discourse that envelops everything said of it, is one example.

Now I must make a further point. In his later period, Foucault developed the notion of "technologies of the self", strategies designed to facilitate our care for our selves. Such technologies "permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality".[32] Western history since Greek times has seen a whole series of such techniques, from the dietary counsel of the Hippocratic treatises to ideas of Christian discipline and the modern work-and-consumption ethic. In his last works, Foucault provided a grid or schema for analyzing the manner in which we constitute and conduct ourselves as ethical subjects. This relationship to oneself has four components: the determination of the ethical substance, the mode of subjection, the ethical work we perform on the ethical substance, and the telos or goal of the ethical subject.[33] I think that it would prove fruitful to plot what I am calling *biotechnologies of the self* according to Foucault's grid.

It is easiest here to begin with the telos. Of course, the aim of biotechnologies is "health" -- public health, individual health, ecological health, a healthy economy, tomatoes that do not go mouldy, a disease-free gene pool, and (by some accounts) racial hygiene. Biotechnologies aim

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[32] Michel Foucault, "Technologies of the Self," *Technologies of the Self: A Seminar With Michel Foucault*, ed. Luther H. Martin, Huck Gutman, and Patrick H. Hutton (Amherst: University of Massachusetts Press, 1988) 18.

[33] See Michel Foucault, "On the Genealogy of Ethics: An Overview of Work in Progress," *Michel Foucault: Beyond Structuralism and Hermeneutics*, 2nd ed., Hubert Dreyfus and Paul Rabinow (Chicago: University of Chicago Press, 1983) especially 237-43; and Michel Foucault, *The History of Sexuality, Volume II: The Use of Pleasure*, trans. Robert Hurley (New York: Pantheon, 1985) especially 25-32.

at healthy bodies and healthy populations. Moral conduct leads to "a mode of being characteristic of the ethical subject" -- and that mode of being is the token of a pristine species, every last member of which is "healthy".

The ethical substance is what Foucault defines as that part of oneself one designates as the prime material of his or her moral conduct. Biotechnologies of the self, aiming at "health", must have either a corporeal or govern-mental ethical substance. I think however that our governmentality is our mode of subjection, and so the ethical substance must be somehow corporeal. Foucault means by "ethical substance" the material to be manipulated by ethical practice. This substance, in a gene culture characterized by "life" as a scarce resource demanding rational management both for its own sake and for that of "health", must be that part of our existence touched most intimately by biology. It must be our health-oriented lifestyle: our attention to minimum daily adult requirements of vitamins and minerals, the Canada Food Guide, "Participaction", the requisite amount of sleep, low levels of "bad" cholesterol, over-the-counter medications, condoms, spermicidal foam and jelly, the body as a system, the body as a temple (housing the secular soul, the genome). The ethical substance proper to biotechnologies of the self is fitness.

The mode of subjection is, as I mentioned above, our peculiar Western govern-mentality that envisions the world and everything in it (real or unreal) as in need of rational, responsible management. This mentality sets up the oppositions necessary to biotechnologies of the self (expert/laity, technoscientific discourse/vernacular) and fosters the satisfaction of imputed needs as the major industry of the management society. Deference to expertise disables and stupefies us, experts' disciplinary credentials disqualify lay reservations, and we are reduced to silence. But in a world in which there seems to be "something scandalous about a possible activity that is not subject to authoritative control" -- our world, our govern-mentality -- we are accustomed to expert-intervention, for our own good.[34]

The ethical work we perform on ourselves as biotechnologists of the self in order to transform ourselves into ethical subjects is best characterized by the phrase "take stock of your stock". I will expand in chapter four on the notion of "genograms", family trees of disease and disorder meant to help us comprehend our genetic inheritance. For now, I will offer the genogram as one example of the self-forming activity of biotechnologies of

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[34] Allen "Foucault" 18.

the self.

The mechanics of genogram-drawing are as follows: begin by identifying males and females by squares and circles respectively. List children from left to right in order of birth; record age and cause of death; start by "looking for anything abnormal" (including deficient lactose digestion, very short stature, hypertension, retinal tumors, gout, delayed sexual development, and muscle weakness in adults). Having noted anything conceivably abnormal, next "assume that you do not know what to look for. Thus you will need to record everything". Then make a separate copy of the genogram for each disorder, and use solid squares and circles to identify afflicted family members. Finally, search for clear patterns of inheritance (autosomal dominant single-gene disorders, autosomal recessive single-gene disorders, X-linked single-gene disorders, and multifactorial and chromosomal disorders), or have yourself tested if you see something that seems just to "run in the family".[35]

Drawing a genogram is supposed to make us acutely aware of the dangers that await us should we be "unlucky". With a genogram in hand, we might endorse the practice of

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[35] Drlica 177-80.

predictive medicine:[36] we might submit to specific genetic tests when worried that we are at risk, avoid procreation so as not to infect the gene pool any further, visit a genetic counsellor for more putatively mortal information, or alter our lifestyle so as to reduce the probability of triggering a multi-factorial disease to which we are genetically predisposed. These are examples of the ethical work we perform as biotechnologists of our selves.

To summarize, then: the ethical substance is the fitness-oriented lifestyle; the mode of subjection is our modern Western govern-mentality; taking stock of our stock and, acting responsibly on that information, is biotechnological asceticism; the telos, of course, is "health". The plasticization and fetishization of "life" generate new kinds of techniques of the self, biotechnologies of the self. These biotechnologies ignore, degrade, downplay, and render irrelevant the human *aliveness* integral to facing pain, anguish, life, and death. The

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[36] Abby Lippman uses the term "predictive medicine" to refer to the search for genetic markers that identify disease and predisposition to disease. The rationale is that we will be able either to prescribe the best program to decrease future risk after birth, or to abort those susceptible to genetic conditions. Both options fall under the heading of "predictive medicine". Lippman's concern is that there are often preventive measures we might take, many more effective than the alternatives provided by predictive medicine, the thrust of which is to emphasize how the *individual* must act to reduce the probability of later disability. See Lippman, "Prenatal Diagnosis: Reproductive Choice? Reproductive Control?" *The Future of Human Reproduction*, ed. Christine Overall (Toronto: Women's Press, 1989).

implications of these new biotechnologies are ethically and politically dubious. Biotechnologies of the self are in fact paradoxically counterproductive, sufficiently foreign to existential human reality as to be utterly ineffective at achieving anything remotely resembling their purported aim: a state of "happiness, purity, wisdom, perfection, or immortality". When we fail to see this -- when we fetishize "life" and become biotechnologists of our selves -- the practical and existential consequences are overwhelmingly disabling: we produce *Homo geneticus*.

I want to be very clear about one crucial point here: biotechnologies of the self, as I describe them here, are not bringing an end to other techniques of the self. Those techniques inspired by the genetic revolution are merely the most recent in a long succession of such technologies. "It is worth recalling that most techniques of the self -- meditation, confession, exercise, diet, exemplary role models -- are as old as the old codes, but the ways they are employed may differ from generation to generation." The new biotechnologies of the self are not of a separate class than other techniques of the self, but they exercise, promote, and are in turn reinforced by the rhetoric of twentieth-century molecular biology (a rhetoric I showed in chapter two to be wildly overinflated and irresponsible). They make sense because of our peculiar governmentality, our faith in scientific progress, and our undying quest for (what experts deem) the good life. "At present rhetoric about the good life is almost always based on some claim to know the truth about desire, about vitamins, about humanity or society. But there are no such truths to know."[37] The moment we think there are, we are complicitous in the creation of new biotechnologies of the self. These techniques are, I am urging, powerfully disabling.

In the next chapter, I show how the concepts I have introduced here are helpful in understanding the emergence of *Homo geneticus*. In particular, I urge that we understand the HGP as a strategy of biopower crucial to the production of *Homo geneticus*. I suggest that bioethical analyses of the HGP are hindered by an uncritical acceptance of the value of "health" and "life", plastic notions which say everything -- that is, nothing at all. In order adequately to challenge our complicity in the new form of subjectivity I call *Homo geneticus* we must resist biotechnologies of the self and reinvest human existence with some notion of personal significance.

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[37] Ian Hacking, "Self-Improvement," in David Couzens Hoy, ed., *Foucault: A Critical Reader* (Oxford: Basil Blackwell, 1986) 236, 239.

Chapter Four -- Biotechnologies of the Self

It has been suggested that the overarching aim of the Human Genome Project is to construct a "consensus genome", a "genetic standard of reference" produced by means of inscription, consensus, and conscription. Inscription refers to the graphical representation of DNA through, for instance, karyotypes, genetic (linkage) maps, physical maps, sequencing instrumentation, and the documentation of DNA in gene libraries. These are labelled as inscription devices.[1]

The human genome is being mapped at research laboratories around the world, though the research is coordinated through central databases. Thus inscription is

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[1] Michael J. Flower and Deborah Heath, "Micro-Anatomo Politics: Mapping the Human Genome Project," *Culture, Medicine and Psychiatry* 17 (1993): 37 n3. For detailed discussion of karyotypes, see *The Human Genome Project: Deciphering the Blueprint of Heredity,* ed. Necia Grant Cooper (Mill Valley: University Science Books, 1994) 11, 334; see also Rosner and Johnson 118-9. For discussion of physical maps and linkage maps, see especially Cooper 86-93, but also Claverie for discussion of the nature of and relations between the different maps. I have recently discovered how to access these maps through the Internet. One source is "Online Mendelian Inheritance in Man", and is a catalogue of all known genetic traits, along with information on mapping techniques and associated diseases. Another source is the complete physical map published in December 1995 by the Whitehead Institute in Cambridge, MA, and Généthon in France; the map can be viewed at http://www-genome.wi.mit.edu/cgi-bin/contig/phys-map. On gene libraries, see Flower and Heath 30; Claverie 309-10, and Cynthia Keleher, "Translating the Genetic Library: The Goals, Methods, and Applications of the Human Genome Project," *Bulletin of the Medical Library Association* 81.3 (1993).

both dispersed (through a capillary-like global system of laboratories) *and* centralized (the capillaries are linked by a computer network to the Genome Data Base at Johns Hopkins University in Baltimore and GenBank at Los Alamos National Laboratories, among others). The individual inscriptions are compiled and the genome generated by a computer program called GENESIS.[2]

As I argued in chapter two, "the" genomic sequence, arrived at through the HGP, is an artifact, a fictive, composite, generic signifier of the species. Notwithstanding the problematic relation of individual genomes to "the" genome, scientists as well as employers, insurers, and genetic counsellors, envision eliminating disease and disorder by measuring individuals against this human genome, identifying deviant genes, isolating them, and altering them. For this procedure to make some sense there must be consensus, "the establishment of agreement in a realm of inquiry". The genome generated by GENESIS is "the consensus sequence, a reference standard for detecting the genomic location and nature of genetic variants".[3]

The third process involved in the HGP is

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[2] Flower and Heath 30-1; Keleher; Dorothy Nelkin and Laurence Tancredi, *Dangerous Diagnostics: The Social Power of Biological Information* (New York: Basic Books, 1989) 14.

[3] Flower and Heath 29, 28, 30, 28.

conscription, the "deployment of consensually supported fact in the service of institutionalized power". Conscription involves the government of conduct, and this is precisely the rationale and goal of the Human Genome Project. The HGP represents the drawing of individuals into a new set of institutional power relations within which practices of administrative control find new ways to take hold of the body and "invest it, mark it, train it, torture it, force it to carry out tasks, to perform ceremonies, to emit signs".[4]

With the HGP we witness the literal penetration of the body at the molecular level; the result is a new spin on the "cellular" power/knowledge of which Foucault wrote. With the HGP and the late-twentieth-century discourse on human genetics we are witnessing the emergence of a new form of power/knowledge operating through "life" by penetrating our bodies at the microlevel from conception through organ harvest; we now have cellular knowledge of our cells. Expert discourse on genetics transforms the genetic code into a powerful political trope, as our individuality disappears in an aggregate of coded sequences subject to documentation, administration, and manipulation. Cellular power/knowledge thus creates the macromolecular examination.

It might be argued that the examination is best

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[4] Flower and Heath 28, 29; Foucault *DP* 25.

exemplified by -- or at least most easily observable through -- the proliferation of genetic testing and screening. Flower and Heath suggest that "the multiplicity of differences -- "deviations" from the consensus sequence -- may, following Foucault and his notion of disciplinary 'dividing practices', become the target of a dispersed yet centralized governmentality that categorizes, stigmatizes, and medicalizes human groups and individuals".[5] In this suggestion Flower and Heath are, I think, correct, yet they tell only one side of the story. The dividing (individualizing) practices are also at the same time homogenizing (totalizing) practices. Moreover, we should attend to our own complicity in practices of both sorts.

As I indicated in chapter three, this complicity can be explained by our "deep internalization of a carefully orchestrated value-laden understanding of the self". That this understanding is "orchestrated" indicates that we are not its sole author; yet we are not forced or coerced into any particular self-understanding except, of course, by the unforced force of truth and knowledge. The truth, supposedly, is that we are each tokens of a generic, genetic type. The official, HGP-generated sequence of genes reveals what we *really* are. We share some underlying genetic

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[5] Flower and Heath 35.

humanness (totalizing), and we are understood, and encouraged to understand ourselves, in terms of deviations from this institutionally generated norm. And it is not just being done to us. We as agents are complicitous in our conscription in the HGP, submitting to "the truth of norms and chances: the expert's truth concerning what is average or deviant, safe or dangerous, same or different".[6]

Our submission to these truths is guaranteed both by the suasive power of the norm and by what is said to lie in the balance: our health, freedom from disease, perfectibility. Since it is beyond culture, outside of time, we are led to believe that DNA is something of permanent or inherent significance. The genome becomes the truth behind phenotypic appearances; the body is thus compelled to confess its genetic truths to science, for health's sake.

It is not surprising to find, as the logo for the joint Department of Energy-National Institutes of Health publication *Human Genome News*, a circle containing a silhouette of a human figure entwined within two ribbons of DNA. Inscribed around the figure are the following words: Chemistry, Biology, Physics, Mathematics, Engineering (see figure 4.1). Nelkin and Lindee offer the obvious

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[6] Barry Allen, "Government in Foucault," *Canadian Journal of Philosophy* 21 (1991): 428.

interpretation: "The twisted double helix of DNA surrounding the figure suggests the imprisonment of the human being, who will be released through scientific knowledge". The truth will set us free. But how? If my genome bears only an insignificant resemblance to "the" genome, and yet employers, insurers, genetic counsellors, and physicians are intent on managing me through my cells, even (and perhaps

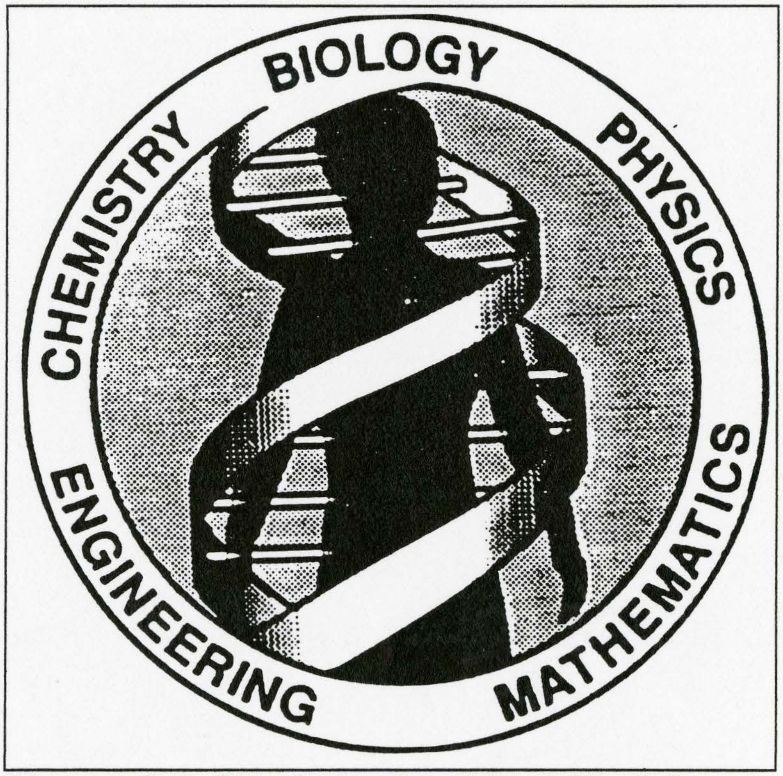

Figure 4.1 The logo for the DOE-NIH publication *Human Genome News*.

especially) if I adopt genetic terminology to describe myself, and really try to understand it, surely I am not *free*. Rather than a contribution to my liberty, I have merely cooperated in the effort to remake me along the lines of a new ground plan of modern subjectivity -- what for short I shall call *Homo geneticus*.

Flower and Heath's most important contribution to the study of the culture and politics of genetics is their observation that through inscription, consensus, and conscription in the HGP we develop a new understanding of what it means to be human. The political technologies that invest the body at the level of DNA seek to guarantee the deep internalization of the view that we each have a distinct, objective genetic nature that is subject to any number of dangerous imperfections identifiable by reference to the normal human genotype. The inscribed genome is the consensual generic species-signifier; the conscripted individual is the complicitous singular variant, *Homo geneticus*.

Homo geneticus could have been invented only in a disciplinary, normalizing society, "the historical outcome of a technology of power centered on life".[7] I mentioned above that one obvious example of the strategy of

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[7] Foucault *HS* 144.

inscription, consensus, and conscription in the new genetics is the proliferation of genetic testing and screening. Testing has historically been directed at individuals identified as members of high risk groups for the propagation of genetic deformities. Some have argued, however, that at least in the case of pregnancy, prenatal diagnosis has undergone a shift in emphasis, from risk-based testing toward population-wide genetic screening.

California is presently the only U.S. state to require that a prenatal diagnostic screen be offered to *all* pregnant women.[8] The procedure, known as the maternal serum alpha-fetoprotein test (AFP), is simple, inexpensive, and noninvasive, requiring only a blood sample from the pregnant woman.[9] AFP testing indicates the presence in the fetus of neural tube defects such as anencephaly or spina bifida. AFP is currently being refined in order also to screen for chromosomal abnormalities such as trisomy-21 (Down's

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[8] While not technically a genetic screen, the example of AFP is offered as an instance of the culture of testing, what Harvey Bender has called "the cultural appeal of genetic testing". The problem is that the sort of ethnographic work that Press and Browner are doing is entirely anomalous in the literature on screening and testing; appropriate anthropological studies of genetic testing and screening are unavailable (although Rayna Rapp serves as an exception; see her "Chromosomes and Communication: The Discourse of Genetic Counselling," *Medical Anthropology Quarterly, New Series* 2.2 [1988]).

[9] As distinct from amniocentesis, which requires a sample of the fluid in the amniotic sac (retrieved by means of inserting a hollow needle into the uterus), or chorionic villus sampling, which requires a tissue sample of the embryonic membrane surrounding the fetus.

syndrome, previously known as mongolism).[10]

Press and Browner carried out a long-term ethnographic study of three southern California sites of a Health Maintenance Organization (HMO). They questioned the clients concerning their understanding of the AFP test and the significance of the screening program. Their data point to an interesting observation. Both the booklet given to all prenatal clients and the information provided by HMO staff leaned less toward informing the women (ostensibly their purpose), more toward persuading them to take the test -- in other words, tending implicitly to make the test standard. Part of the reason for blurring the distinction between "information" (required for informed consent) and "persuasion" is the threat of litigation; making the screen seem standard removes this threat by contributing to the high rate of AFP acceptance that Press and Browner observed.[11]

The authors were also able to document the clients' low levels of test-comprehension. For instance, of the 75% who claimed to have read and remembered the information in

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[10] Nancy A. Press and Carole H. Browner, "Collective Fictions': Similarities in Reasons for Accepting Maternal Serum Alpha-Fetoprotein Screening Among Women of Diverse Ethnic and Social Class Backgrounds," *Fetal Diagnosis and Therapy* 8 (suppl. 1, 1993): 97; "Risk, Autonomy, and Responsibility: Informed Consent for Prenatal Testing," *Special Supplement, Hastings Center Report* 25.3 (1995): S9; "Silences" 202.

[11] Press and Browner "Fictions" 100.

the booklet, none could explain adequately the various conditions that might yield a positive test result. Further, only 30% of the respondents recognized the term "neural tube defect", and two-thirds of those who did recognize the term (20% of total respondents) had no idea what it might be. Several even confused "neural tube defect" with "tubal" (or ectopic) pregnancy. As for spina bifida, 60% of the respondents recognized the name, but only half of them could define it. Some guessed, based on the name of the condition, that it was a spinal disease. Finally, fully one-third of the respondents thought the test was mandated by the State -- that is, they believed they were obligated to give a blood sample (*not* that the health-care providers were obligated to offer AFP as a service to their prenatal care clients). Not surprisingly, test acceptance was around 85%.[12]

Yet Press and Browner, having interrogated the manner in which the official State booklet is written and the information provided to the women by HMO staff during intake interviews, and having recognized the litigious nature of the U.S., suggest that there is yet another factor contributing to the high rate of test acceptance and low level of comprehension. The clients and the HMO staff

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[12] Press and Browner "Silences" 209-10; "Fictions" 103; "Silences" 216 n10; "Fictions" 100.

collectively promote the screen as a *routine* part of prenatal care.[13]

Blurring the inform/persuade distinction promotes AFP as the standard of care. It is presented as a routine part of the HMO's prenatal care package. And it is received by the clients as such, not through coercion or imposition, but rather through its status in our economy of "health" knowledge, and through its neat fit with the women's own understandings of the value of prenatal care. The women's participation in the creation of the collective fiction of AFP-as-routine is evident in the comments of a large number of respondents: they underwent the test "just to be safe", "because I wanted to make sure my baby would be the healthiest that it could be", because "I wanted to do anything that could help me or my baby". If AFP is routine, then ostensibly everyone takes the test. No one is taking the test specifically because she is *at risk* for giving birth to a deformed child; were *that* the case, the prospect of abortion would be discussed up front. But the routinization of AFP neatly sidesteps the question of selective abortion (and its neoeugenic implications). In fact, Press and Browner note the formation of a "collective silence" regarding what is to be done in the case of a

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[13] Press and Browner "Silences" 210; "Fictions" 103.

positive test result: "abortion" or "termination of pregnancy" was mentioned by the client or the HMO staff member in only 2 of 40 intake interviews. And why shouldn't the women regard AFP as routine, given the "broadly shared, contemporary American beliefs about the value of scientific knowledge and medical care"?[14]

The conclusion I draw from Press and Browner's work is this: routinization does not "come from above" but is the result of our expecting the best health care available, and the biotechnology industry's endorsement of genetic testing as the core of predictive medicine -- the best medicine money can buy. The U.S. government seems to agree with the biotechnologists: the Department of Health and Human Services announced in 1991 that its goal, as part of the Healthy People 2000 initiative, is to "increase to at least 90 percent the proportion of women ... who are offered screening and counselling on prenatal detection of fetal abnormalities".[15]

The media are also interested in the promotion of what is glibly termed "the best health care available". Rennie notes that genetic testing is the fastest growing

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[14] Press and Browner "Silences" 206; "Fictions" 101; Lippman "Prenatal Diagnosis" 189; Press and Browner "Silences" 213; "Fictions" 105.

[15] United States Department of Health and Human Services, "Healthy People 2000: National Health Promotion and Disease Prevention Objective" (Washington: USDHHS, 1991) 382-3.

area in medical diagnostics: according to the Office of Technology Assessment (OTA), the number of genetic tests will increase 10-fold over the next decade. 'Potential new genetic tests roll off the conveyor belt of the Human Genome Project almost once a week', remarks Norman Fost of the University of Wisconsin-Madison Medical School". Testing is expensive, yet Bodmer and McKie urge that "[s]creening -- both in terms of money invested by the state, and in terms of demand and uptake -- is unequivocally a benefit to society". Rennie's article concludes by saying that "genetic testing can immeasurably improve the quality of life for individuals, even entire families. To ignore the good it can do would be an act of immoral blindness and cowardice". Why expand the practice of screening as far as it can go? Because "people want it ... The urge to have healthy children is an extremely powerful one". This is also an eminently *collective* urge, one felt by some of us, and enforced upon the rest by others.[16]

A woman who resists routine prenatal care is committing "the unforgivable antisocial act":

> Inevitably, she then exposes herself to a series of criticisms. Some will see her as "primitive" who deprives herself and her infant of the benefits of

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[16] John Rennie, "Grading the Gene Tests," *Scientific American* (June 1994): 90; Kathleen Nolan, "First Fruits: Genetic Screening," *Special Supplement, Hastings Center Report* 22.4 (1992): S2; Bodmer and McKie 233; Rennie 97; Bodmer and McKie 234.

> modern medicine. Others will see in her the romantic who places good will, emotions, and irresponsible trust above the certainties of modern institutionalized reality. And others will dismiss her as utopian.

If she's afraid, bring in the genetic counsellor to explain away her fear. If she doesn't understand, we had better redouble our efforts at bringing the HGP to the people. Get her to believe that she has an objective nature which is operationally verifiable at the level of DNA; convince her that we're here to help. Use talk and charts and graphs and photos and films and numbers to get through to her. Initiate her into genetic culture. Inscribe her, conscript her.[17]

The HGP represents modern Western (bio)power/ knowledge, and its major strategy is the production of new kinds of individuals on the plan of what I have called *Homo geneticus*. As I mentioned in chapter one, we are nowadays bombarded with genetic injunctions that create and entrench a new vocabulary of self-description, a new set of criteria against which to measure ourselves, a new collection of practices designed to promote our genetic fitness (and that of our progeny) -- in all, a new mode of human subjectivity.

The discourse of the new genetics is a discourse about fitness -- good and bad genes, normal and abnormal

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[17] Illich "Disabling Professions" 31; Duden *Disembodying Women* 54; Keleher; Drlica; Rapp; Alex Robinson, "Genetic Diagnosis: Present and Prospects," *Canadian Medical Association Journal* 150 (January 1994).

genotypes. Franklin maintains that this discourse "introduces a whole new language about genetic defects, abnormal genes, genetic predispositions, genetic selection, genetic screening, genetic therapy, genetic counselling, etc. This is a language about the surveillance of individual pathology. It is a powerful and privileged language, produced and guaranteed by the authority of science and the expertise of the medical profession". This powerful and privileged language is a product of experts. "Genetic predisposition" is a notoriously difficult phrase to pin down, invoking as it does both necessity and contingency. The scientific concept of genetic predisposition is a "statistical risk calculation", but statistics implies a level of mathematics that is probably beyond most health-care clients. In the popular discourse on genetics the scientific notion of predisposition reappears as "prediction". A genetic predisposition becomes a genetic *cause*; a predisposition to alcoholism, for example, becomes an "alcohol gene". A person predisposed to or "at risk" for schizophrenia, Alzheimer's, or multiple sclerosis becomes a member of the genetically ill (the asymptomatic or healthy ill), perceived as in need of differential treatment long before the presentation of symptoms.[18]

Hubbard and Wald suggest that when we speak of genes "for" this or that trait, we "convey an aura of inevitability which limits us".[19] In order to overcome that limitation, we are urged to increase our control over our genetic tendencies by submitting to screening and diagnostic procedures and following genetic injunctions to the letter, thereby producing new ways of behaving, new ways of being, or what I have been calling a new mode of subjectivity.

A lack of mathematical aptitude, coupled with popular discourse on genes "for" such and such, creates the necessity of genetic counselling. The linguistic and social differences between counsellor and client (in terms of schooling, comprehension of statistics, and so on), in addition to the ethos of medicine-as-management, combine to produce easy targets for imputed needs: the need for biological information (that which makes us who we are), the need for genetic counselling (to have that information interpreted for us), the need for selective abortion (to eliminate genetic abnormality, to clean up the human gene

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[18] Sarah Franklin, "Essentialism, Which Essentialism? Some Implications of Reproductive and Genetic Techno-Science," *If You Seduce a Straight Person, Can You Make Them Gay? Issues in Biological Essentialism Versus Social Constructionism in Gay and Lesbian Identities* (Binghampton: Harrington Park Press, 1993) 35-6; Rapp 148; Nelkin and Lindee 165; Rapp 148; Nelkin and Lindee 166; Nelkin and Tancredi 38; Nelkin and Lindee 166.

[19] Hubbard and Wald 12.

pool) -- in short, the need for the whole genomic truth about ourselves. As one physician observes, many people "can't fathom the differences between carrying a gene that could lead to a disease and having it. And some don't understand fractions, which makes explaining risk estimates difficult". But explain them they must, for as another physician concludes, "physicians will have done their patient a disservice if they deny the patient the benefit of this new knowledge".[20]

As I argued in chapter three, experts impute needs which are then interpreted as entitlements (for instance, to "the best health care available"). We take such entitlements very seriously. "There is little doubt that within a few years most of us will need expert help in making genetic decisions". But it is crucial to underscore that this need -- and the correlative entitlement -- is not in any sense *basic*, vital, simply given, "just there" to be satisfied or not. This need has been actively created and imputed by the relevant experts (clinicians, physicians, genetic counsellors), through such means as the routinization of prenatal care and genetic testing. "We are entering the age of the infinite examination", and the

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[20] Both comments are cited by Robinson: Dr. Linda Surh's at 51, and Dr. Judith Hall's at 50.

examiners are all experts.[21]

Expert discourse on genetics is communicated in a variety of ways: through the media, in a physician's office, by genetic counsellors, and so on. Indeed, given the increasingly mandatory character of prenatal care and the continued normalization of genetic screening as a routine part of such care, genetic counsellors are the key experts in our new gene culture. Genetics employs an esoteric language which "needs to be explained to the ordinary person by those who are especially knowledgeable and who can intervene between everyday life and mysterious sources of understanding and knowledge".[22]

A 1989 Ontario Ministry of Health (MOH) publication explains the benefits of genetic counselling, the discipline best-situated to answer the pamphlet's leading question: "Why is it that *normal* healthy parents can have babies with birth defects?" Genetic counsellors provide information about genetic factors in diseases, disorders, and birth defects; ascertain and explain the chances of particular diseases affecting the patient and her/his family; and discuss alternative lifestyles and behaviours to help reduce

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[21] Illich "Institutional" 222; Drlica 3; Foucault *DP* 189.

[22] Lewontin *Biology* 7.

genetic risks.[23]

The pamphlet identifies those who may benefit from genetic counselling: those who have, or think they might have, a genetic disorder; those with a family member with a possibly genetic disorder; those who are members of ethnic groups with increased representation of particular disorders; those closely related to their partner; those women who have had three or more miscarriages, a stillbirth, or who think they may have been exposed to a drug, chemical, or radiation during pregnancy.[24]

The pamphlet also indicates that six percent of Ontarians have or will develop a serious genetic disorder, and that three percent of all newborns in Ontario have a serious defect.[25] And, of course, we know that pregnancy does not occur in a vacuum: until smoking is banned completely, household hazards entirely eliminated, spousal abuse eradicated, or pregnant women hospitalized from conception until birth, the possibility of miscarrying or being exposed to a drug or chemical is very real. The bottom line, it seems, is that genetic counselling will

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[23] Ontario Ministry of Health (MOH), "More Is Known About Genetics: Can Counselling Help You?" (Toronto: Queen's Printer for Ontario, 1989) 1, 6 (emphasis added).

[24] MOH 7.

[25] MOH 5.

benefit us all -- or at least that we will all at some point soon have recourse to the services of genetic counsellors.

Ideally situated between technical language and the vernacular, charged with translating the discourse of genetics into popular and putatively useful terms, genetic counsellors are the new paradigm of "experts as functionaries", making reality through their one-sided mastery of a highly prestigious discourse.[26]

As I have stressed throughout this thesis, we are ourselves complicitous in the fabrication of our social world, not only by supporting the ethos of medicine-as-management, but by appropriating scientific language we do not understand, laundering it of its denotative content, and integrating it into the vernacular. The experts help us along in this. In a genetic counselling session, for instance, "meanings are actively and interactively produced by patients and counsellors together", and so the exercise of expert-power is masked to a significant degree (a condition of its tolerability). Our complicity in this arrangement is guaranteed by the experts' imputed belief that human beings have an underlying objective nature (the genome), "replete with possibilities for unnatural and deleterious expression". Acultural and timeless, DNA is

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[26] Rapp 143; Poerksen 72.

said to be of permanent significance; managing problem DNA is becoming the standard medical task.[27]

The terminology of genetic discourse operates in two separate spheres: scientific and lay. How "gene" is defined depends not only on which of the two spheres we are operating in, but on the particular speaker as well. As Hubbard and Wald point out:

> To molecular biologists, a gene is a stretch of DNA that specifies the composition of a protein and may affect whether and at what rate that protein is synthesized, as well as sometimes affecting the synthesis of proteins specified by nearby genes. To geneticists, genes are parts of our chromosomes that mediate heritable characteristics or traits. To population biologists, genes are units of difference that can be used to distinguish various members of a population from each other. To evolutionary biologists, genes are historical records of the changes organisms have undergone over time. All these definitions overlap and complement each other, and which one a particular scientist focuses on simply depends on her or his interest.[28]

These varied meanings, when exported from science into the vernacular or popular realm by the "explanations" of experts, amalgamate; "gene" says everything and means nothing when exported from science. In the vernacular, "gene" fails to denote. Ordinary speakers do not really have much if any idea what they are speaking of when they use it. But use it they do, and the word has powerful

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[27] Martin (1994), p. 249; Rapp, p. 146; Prado, p. 100; Nelkin and Lindee, p. 60.

[28] Hubbard and Wald 11.

connotations for ordinary people's efforts to understand what happens to them when they go to the doctor, are asked to take a test, and so on.

In their study of genes as cultural icons, Nelkin and Lindee suggest that "the gene of popular culture is not a biological entity. Though it *refers* to a biological construct and derives its cultural power from science, its symbolic meaning is independent of biological definitions. The gene is, rather, a symbol, a metaphor, a convenient way to define personhood, identity, and relationships in socially meaningful ways".[29] Discourse on human genetics oscillates from the technical and denotative to extreme generality and amorphous connotation. Even though biologists define "gene" in a wide variety of ways, its connotative scope is constrained by a certain denotative precision. However, at the level of popular culture, the nature of the gene is entirely opaque.

What are genes? What is DNA? Popular metaphors abound: "the genetic blueprint of life", "the building blocks of nature", "an encylopaedia containing many definitions". The human genome is referred to as "the Book of Life", "the Book of Man", "the code of codes", "the key to what makes us human". The HGP promises to provide "a

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[29] Nelkin and Lindee 16.

complete recipe for a human being" and "a complete parts list for a human being"; there are "more than 100,000 genes that contain instructions for building a human being". When we start thinking of ourselves in the ways suggested by these metaphors, we lock ourselves in a conceptual prison. We adopt ways of thinking about ourselves using concepts that say everything and mean nothing. There is an irony here: the infinite connotative malleability of the unacknowledged metaphors used to explain (artifactual, plastic) DNA are meant to represent its purity, stability, authenticity, and permanence. The practical consequences are profound. With the HGP and the science and industry of biotechnology, we are witnessing the birth of the genetic prison. We become confined to, and thereby limited by, our cells. We allow ourselves to become "victims of a molecule, captives of our heredity",[30] and subject to innumerable strategies of management in the quest for what we vaguely call health, life, liberty, and happiness.

We acquire a new conception of "health", a new understanding of what constitutes a healthy human being, in genetic terms, through mutual interaction with experts and popular media. Further, the new norm appears natural (a discovery, not an invention), and it is objectified. Human

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[30] Nelkin and Lindee 129.

sickness is not an objective, timeless category. "Disease and disorder are identified according to an underlying vision of health and humanity, of what kinds of being we are, and what can go wrong with us".[31] What we in the contemporary West deem an illness -- a deviation from the ever-elevated norm of health -- is contingent on the way we view our bodies and our selves, as mediated by supposedly scientific notions of what is good and right.

So, for instance, the Diagnostic and Stastical Manual (DSM) used by psychiatrists contains entries on such disorders as multiple personality and battered-spouse syndrome -- disorders unheard of until very recently. It is not that one or two centuries ago these disorders were "out there" awaiting scientific or medical notice, but that there was no way to *be* a multiple personality or a battered spouse. Of course, personality splitting and domestic violence might well have taken place in the eighteenth or nineteenth century; but that multiple-personality disorder and battered-spouse syndrome are now seen as *disorders* depends on a particular economy of knowledge.

When geneticists and molecular biologists claim that alcoholism, homosexuality, aggression, criminality, and homelessness are medical disorders, we simply cannot presume

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[31] Ian Hacking, *Rewriting the Soul: Multiple Personality and the Sciences of Memory* (Princeton: Princeton UP, 1995) 13.

that this has always been and will always be so. Diseases are artifactual, invented not discovered. In our gene civilization, disease has become operationally verifiable at the subcellular level, while simultaneously being ahistoricized. We quickly forget that "definitions of health, disease, and illness ... are not entirely objective, rational, value-free, and culturally neutral",[32] and instead adopt a variety of practices to discover and ensure our genetic integrity, and that of our offspring.

Driven by the media as well as by our conscience and the advice of physicians, we flock to those offering genetic diagnostic tests. And we hope that we are not "unlucky" (Kitcher's[33] euphemism for those with abnormal genotypes). Recently, because of privacy concerns, some people have begun to decline genetic testing; once appropriate legislation is passed, however, this minor trend should reverse itself.[34]

We consume at an unprecedented pace published material aimed at bringing genes to the people, and we govern our lives according to what we learn. Drlica, in a

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[32] Judith P. Swazey, "Those Who Forget Their History: Lessons From the Recent Past For the Human Genome Quest," Annas and Elias, eds. 46.

[33] Philip Kitcher, *The Lives to Come: The Genetic Revolution and Human Possibilities* (Toronto: Simon and Schuster, 1996).

[34] Tim Beardsley, "Vital Data," *Scientific American* (March 1996): 100.

text intended to keep readers abreast of recent developments in the genetic revolution, offers a series of "practical considerations" at the end of each chapter, and a number of appendices in order to get us started in our formal initiation into our genetic culture. In some instances, the practical considerations double as lists of genetic injunctions for the biotechnologist of the self: one can tick off those to which one has subjected oneself. Here is a sample:

> Older expectant mothers are advised to have fetal cells checked for chromosomal damage
>
> Before elective genetic testing, consider risks of uncovering an incurable disease
>
> Keep genetic data private
>
> Avoid testing children for diseases having no cure. Placing a stigma on a child can be very disruptive to a family
>
> If pregnant, begin assessing your baby's risk of genetic disease by making a family tree that lists early deaths, diseases, miscarriages, and other problems.[35]

The notion of a family medical history is not new, but now the family tree of disease and disorder is said to be

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[35] Drlica 18, 74, 75, 18, 74, 141. The injunction to make a "genogram" -- a family tree of the physical and mental ailments of our relatives -- is also to be found in Nancy Shute, "How Healthy is Your Family Tree?" *Hippocrates* (January-February 1988). Deirdre Boetzkes has informed me that the drawing of a genogram is one of the methods advocated by the School of Social Work at McMaster University. And the MOH pamphlet indicates that genetic counsellors are able to draw genograms should clients not have already done so.

invaluable, both to us and to our children and grandchildren (who will, of course, have access to more refined and sophisticated screening and diagnostic techniques). Drlica provides an appendix entitled "Family Analysis", explaining how to collect the appropriate medical information about one's family. Further, he introduces the notion of patterns of inheritance so as to ensure the cartographical accuracies of our maps. Ready, set, chart your genetic inheritance!

Drlica justifies his procedure in terms of the good to be derived from the knowledge it makes available: "knowing as much as possible about your genes is one way to prepare for future developments in molecular genetics".[36] This injunction to self-knowledge is, of course, a very old one. Here we see the new form it takes in our genetic culture. But what sort of self is a genetic self? What kind of selves do we make ourselves into when we think that to know ourselves, we have to know what the HGP promises to tell us?

We make ourselves into *Homo geneticus*. The mapping and sequencing of the human genome is the route to discovering what makes us human -- who we really, essentially, are. More and more, we see ourselves as the product of our genes. But in wandering about in the world,

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[36] Drlica 176.

the last thing one will encounter or experience in any way is a gene. Of course, one might see a picture of a gene, courtesy of an electron micrograph, or see a karyotype showing a set of chromosomes. Both of these are representations *of* the body *as abstracted from* the body, showing "the body as a mosaic of detachable pieces",[37] and suggesting that the knowledge of these pieces is crucial to our self-understanding: micrographs and karyotypes provide a glance at what we are *essentially*.

A teacher in her twenties gives an astounding answer to the following interview question:

> [Q:] When you see these kind of photos [electron micrographs], I mean at the really micro, micro level, and you think about them in terms like this, does it change the way you think about your body?
>
> [A:] Yeah. I think you forget what's really going on in there. What you're really made up of, it's awesome. I mean it's fascinating to me. It's awesome. It makes me realize how incredible the human body is, you know, what's really going on in there. You walk around every day, you exist, but what's really happening to you?

This woman suggests that what is happening at the level of the genome is what is *really* happening; for her, our autonomous aliveness is merely our existence, our walking around every day. The objective displaces the subjective -- in fact becomes the secret truth of the subjective, to be known at all costs.

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[37] Braidotti 152.

The interviewee judges everything that happens to her, that she sees, hears, feels, loves, experiences, hates, and so on, to be considerably less important than what might be happening within her cells. Everything that she *can* understand is subjugated to those things she will *never* understand. She has faith in science to tell her the truth of her very being (as many have faith in religions for the same purpose). My concern is that those things that will not enter her life story in any meaningful way are those things she values most dearly, and she degrades, downplays, and devalues the stuff of her real life. Above her daily existence, above her fleshy worldly experience, above the condition of her aliveness, she favours the truth as represented in electron micrographs. This is the loss of aliveness, in favour of knowledge of "life".[38]

Illich urges that we celebrate aliveness as the opposite of "life".[39] "Life" is morbid and macabre, rife with survival chances, statistical risk calculations, and pollution in the gene pool. Aliveness, in contrast, just is our human condition unmediated by medical and statistical expertise. But I am not as nostalgic for the innocence of

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[38] The interview is part of Martin's ethnographic study of popular understandings of the immune system. The quotation is at 176. See also Duden *Disembodying Women* 100.

[39] Illich "Cosmos" 282.

aliveness as I am fearful of the disabling deference characteristic of the "life" we so readily embrace. I am concerned to reinvest our human condition with personal significance not derived from the human and natural sciences.

Let me head off one possible (and very good) objection. When I say experience "unmediated by medical and statistical expertise", I might be read as claiming some *natural* state of experience, some sort of experience in a social vacuum. But instead I am suggesting that when we live according to the precepts of medical gnosis, we fail to live according to our own evaluations of what is important to us based on our life-experiences. We fail to answer the question "Do I want to be the sort of person who would (would not) do this?" Rather, we are drawn into seeing ourselves as responsible for "life", which I have argued throughout this thesis is not a suitable target for our psychic and social energy.

The knowledge of "life" is devoid of existential significance; it may be true, but is it good, and good for whom? Does its value serve to justify the devaluing of human aliveness in favour of something operationally verifiable? Is the genomic injunction to self-knowledge anything *but* disabling and stupefying?

NIH director Francis Collins admits that "we're all at risk for something". Lippman points out that as more and more "susceptibility" genes are mapped and tests for them developed and applied we will each necessarily be found to be "at risk" for something.[40] The future target of genetic tests and screens, then, is the entire human species. I suggest that this brings genetics very close to the point of paradoxical counterproductivity. Population-wide genetic screens, replacing specific tests intended for and useful to those at risk, become counterproductive when "the" normal human defines *everybody* as at risk. Further, the *knowledge* generated by the HGP is paradoxically counterproductive: genetic knowledge stupefies us and renders us impotent as a laity subject to experts' sermons and need-imputation. Geneticists do not address mortal needs, though they claim to. Yet paradoxical counterproductivity has not stopped the rise of modern medicine; in fact, it has called for further expert technological intervention. Paradoxical counterproductivity alone will not stop the HGP.

The rise of *Homo geneticus* would not happen without our complicity, our endorsement of what I have been calling biotechnologies of the self. As I argued in chapter three, the critical difference between biotechnologies and the technologies of the self described by Foucault is that

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[40] Collins is quoted in Beardsley at 102; Lippman "Led (Astray)" 1472.

biotechnologies ignore, and render irrelevant, the aliveness essential to facing pain, anguish, life, and death. We must derive knowledge of ourselves from *caring for ourselves* instead of endorsing institutional knowledge of "the" genome as the secret truth (as if there were one) of our being.

When we follow genetic injunctions, and adopt ways of perceiving and interpreting ourselves as essentially genetic entities, we engage in biotechnologies of the self, refashioning our subjective identity along lines sketched out and offered to us by our contemporary biotechnical ethos. When we endorse medicine as management and the provision of standardized "health", we engage in biotechnologies of the self. When we think that the most significant things that can happen to us happen at a subcellular level, we engage in biotechnologies of the self. When we feel a *need* for genetic information, and see genetic counsellors as satisfying that need, we engage in biotechnologies of the self. Once we fetishize "life", "health", and DNA, we are fully fledged biotechnologists of the self.

We must challenge the ethical substance, practice, goal, and mode of subjection characteristic of biotechnologies of the self. Instead of heteronomous, expert-defined and -managed "health", the telos of any alternative to biotechnologies of the self must be human aliveness. We might achieve that goal by any of the following modes of asceticism: reinvest health with existential significance by deinstitutionalizing the provision of health care; question the value of scientific knowledge rather than accept it as true and hence necessarily good; deprofessionalize our autonomy.

The substance on which those ethical practices work is our autonomy or, more specifically, our mode of self-perception and -construction: not learned stupidity, not disempowering deference, but autonomous existential conviviality. The ethical substance of any alternative to biotechnologies of the self must be our acts of self-constitution. The mode of subjection required for working on those acts must be the opposite of deference to expert-management; it must instead be the rejection of our peculiar modern govern-mentality.

We must begin to challenge the technocratic elite, the managers of "life" whose increasingly biotechnological solutions to biotechnologically generated problems lock us in our cells. We must learn to think differently about health, and about our aliveness. Science may not cure all our social ills, but the solution is not to reject science. Nor as I have argued is the solution to integrate into our value systems whatever scientists tell us. We must begin by evaluating science as an agent in the transformation of our bodies, our selves, and our self-concepts.

Only by refusing the optimization of health and performance where no obvious defect exists and smashing the idols of *Homo geneticus* -- DNA, management, health, biotechnology -- might we speak with Duden an unconditional NO to "life", thereby recovering our own existential aliveness.[41]

The irony of the deployment of *Homo geneticus* is in having us believe that self-knowledge, our liberation from disease and infirmity, and the perfection of the species is in the balance.

The danger of the deployment of *Homo geneticus* lies in a cycle of continuous deference at the expense of autonomy.

Our faith in a paradoxically counterproductive science threatens to render insignificant whatever it might mean to be human.

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[41] Drlica 150; Duden *Disembodying Women* 110.

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