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Justice and the Human Genome Project

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Introduction

Most of the essays gathered in this volume were first presented at a conference, Justice and the Human Genome, in Chicago in early November, 1991. That conference was sponsored by the U.S. Department of Energy and the University of Illinois at Chicago. The goal of the conference was to consider questions of justice as they are and will be raised by the Human Genome Project, that ambitious, multi-national effort mapping and sequencing the entire human genome. In opening the conference, Gerald S. Moss, Dean of the University of Illinois College of Medicine at Chicago noted: "It is not the gene which directs what we do with the knowledge of susceptibility or vulnerability to illness and disease. Only human judgment and consideration can make these choices." To achieve its goal of identifying and elucidating the challenges of justice inherent in genomic research and its social applications, the conference drew together in one forum members from academia, medicine, and industry with interests divergent as rate-setting for insurance, the care of newborns, and the history of ethics.

The essays in this volume address a number of theoretical and practical concerns relative to the meaning of genomic research. Whether the authors are concerned with the history of eugenics, the meaning of individual differences or access to health care, they are all united in

their concern about the impact of genomic research on individual persons. If there is a common goal underlying the analyses here, it is the protection of individual persons from unjust social prejudices and arrangements, prejudices and arrangements that would burden individual choice or degrade the worth of certain groups defined in detrimental ways. It is perhaps a measure of the age that we express as much anxiety as hope expressed in regard to the Human Genome Project. It is the goal of this volume to underline the legitimate hopes of the genome project and to resist inappropriate anxiety by offering moral analysis which resists facile and corrupting uses of genomic research but which nevertheless emphasizes the scope and significance of genomic research.

While many of the concerns raised about the genome project have a fantastic quality to them, Timothy F. Murphy, in "Genome Mapping and the Meaning of Difference," nevertheless cautions against certain subtle effects of a coordinated scientific project whose goal is a characterization of the human genome. By reason of the conforming forces involved in carrying out a centrally coordinated program of research and the inevitable influence of a "standard" human genome in biomedical thinking, genomic research may have the effect of working against incentives to scientific progress and tolerance of human diversity. In a cautionary vein, he notes, then, this paradox of science: even as it advances the realm of human knowledge and offers ways to alleviate human suffering, it may have the effect of foreclosing avenues of scientific novelty and of raising barriers to acceptance of moral and human diversity.

Perhaps part of the special moral concern that has been expressed about genomic research belongs to the decidedly problematic history of eugenics movements. In "Eugenics

and the Human Genome Project: Is the Past Prologue?", Daniel J. Kevles addresses this concern, noting the way in which eugenics movements in American and world history have been linked to invidious moral judgments about the worth and worthlessness of individuals. Despite the many dark moments in the history of eugenics, Kevles does not see that the current genome project is vulnerable to the kind of tendentious distinctions drawn by eugenicists in the past because of the democratic nature of our social institutions, because there are now powerful anti-eugenic constituencies, because we now better understand that desirable and complex human traits are not amenable to simple-minded genetic interventions, and because we now better appreciate the horrors of past eugenic brutalities.

Arthur L. Caplan likewise notes the way in which the future of genomic studies is often discussed in terms of the villainy of recent genetic history and politics. But, he argues, genomic research need not fall victim to the prejudicial ideologies of the past, especially if public debate protects people whose social circumstances may be made vulnerable by genomic studies. In a kind of thought experiment, Caplan outlines certain scenarios that might occur in the future, scenarios that point out ways in which genomic profiling can generate dilemmas about identity, affirmative action, privacy, immigration and reproductive choices. The history of genetic study may not confine genomic research, it becomes clear, but neither will genomic research be free of troubling social choices as to its fair and equitable use.

In "Public Choices and Private Choices," Lori B. Andrews reviews certain legal and policy precedents that frame the context in which decisions about genetic testing will be made in the future. She pays special attention to genetic testing in reproduction, noting ways in

which the law either permits, forbids, or requires certain forms of reproductive testing and choices, and noting too the ways in which individual desires may conflict with social objectives. She concludes this review by observing that genetic testing may well threaten, as other forces have, that traditional and comfortable distinction we have long drawn between the private and the public.

Kenneth L. Vaux, in "Perspectives on Genetics from Religious Ethics," cautions against seeing all human circumstances as problems to be solved by biomedicine. He notes ways in which problems of mind and heart have been addressed in the past and how genetic research poses challenges to religious values of hope, faith, love, and justice, and how these same religious values may, when properly appreciated, guide an understanding of the purposes and benefits of genomic research.

Robert J. Pokorski, in "Uses of Genetic Information by Private Insurers," identifies an issue of genomic research that is of central concern to the insurance industry: access to the genomic profiling of individuals genome research is expected to make possible. The use of genomic profiling is of special concern to a society in which the burdens of health care (and life insurance) are left to individual resources and employers. Although there may be a fear that genomic profiling will be used prejudicially against persons at risk of genetic disease, Pokorski argues that insurers need access to such information in order set insurance costs according to the actual degree of risk that belongs to given individuals. Access to genomic profiling will preserve the principle of equity that Pokorski thinks essential to the ability of insurers to protect not only their own solvency but also their continued ability to provide insurance benefits in ways that do not unjustly burden persons less at risk of genetic

disadvantages.

By contrast to this position, Norman Daniels raises an important philosophical question by asking to what extent it is fair to let people benefit from personal advantages when those advantages have their origin in a random genetic distribution. One's genetic disposition to disease or health, after all, is a matter of biological accident. Daniels therefore argues that the standards of equity inherent in current insurance programs violate certain moral standards and do not protect equality of opportunity in health. He therefore rejects the view that health advantages or disadvantages should be treated like mere economic assets and argues instead for a view that requires the protection of health in ways independent of its genetic origin. He also notes some implications of genomic research for public understandings of the nature of responsibility for health, especially since genomic research may elicit either fatalism or hypercaution as regards the relationship between genes and health.

In "Just Genetics: A Problem Agenda," Leonard M. Fleck addresses the matter of emerging genetic technologies, those technologies which may both eliminate genetic disabilities or enhance genetic superiority. While he rightly argues that there is sometimes an unclear line between what constitutes disability and enhancement, nevertheless he thinks that genetic technologies which aim at the elimination of clear genetic deficits ought to have moral priority over other biomedical interventions. Fleck thinks that from a disinterested point of view people would assign priority to the development of genetic technologies over other biomedical technologies--such as artificial hearts--since genetic disabilities end in profound disabilities and premature death for which there is no other means of avoidance, social remedy or recompense. Moreover, such a priority would also respect the principle of

arranging social benefits so as to favor those who are least well off.

Looking at an idea which has a central importance in American political and social thought, George Annas considers the implications of "gene banks" for privacy. Gene banks would ostensibly store genetic samples or genomic profiles of individuals, and Annas proposes that certain respected liberties can only be maintained in the age of gene banking through considered and swift deliberation of rules governing the collection and storage of genetic materials. Toward that end, he proposes certain rules for consideration, rules which require public notice as regards the establishment of gene banks, informed consent in their policies, and restricted use on their samples.

In the essay closing the volume, Marc Lappé points out ways in which genomic research will raise and sharpen questions of social equity not only in regard to screening and employment but also to questions of compensation. Genomic profiling can be expected not only to establish differences between individuals but also differences between groups, raising thereby questions of social equity in the way we value and disvalue heritable traits. He notes, too, ways in which genomic differences may extend questions of moral equity to domains we at present believe belong to accidents of nature.

All the essays raise issues that are likely to continue as matters of debate and concern even as we advance further and further into the genomic era. Part of what makes this volume unique is what has made the Human Genome Project unique from its inception: its consideration of the ethical, legal, and social implications of genomic research before that research has completed its tasks, before genomic applications have begun to alter social and institutional arrangements and policies. The Human Genome Project will be no secretive

Manhattan Project whose hidden research ultimately changed the political fate of the world forever and whose influences are still being measured to this day. The Human Genome Project is by design self-conscious: its design anticipates and subjects the future to deliberation. This kind of planned moral and social deliberation--and the funding it was given--is without precedent in the history of scientific research. These essays must not be seen then as only a contribution to the ethical, legal, and social studies of the genome project. These essays are also themselves part of a grand experiment in attempting to assess in advance the signficance of scientific research for the moral and political concepts by which we define ourselves. The challenge then of these essays is twofold: to illuminate the genome project itself and to justify the hope placed in study of this kind that science and society can be joined in equitable relations. It is in the spirit of this challenge that we offer the essays that follow.

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The Genome Project and the Meaning of Difference

Timothy F. Murphy

In many ways, the current project to map and sequence the human genome appears to be that very kind of encyclopedic enterprise that Francis Bacon recommended in 1620 as part of his proposed "Great Instauration" of science.[1] Against a science he saw mired in and confounded by philosophical speculation, Bacon advocated a painstaking study of the material--not the metaphysical--properties of the world. He thus recommended exhaustive accounts of rainbows, frost, floods, birds, sleep, dreams, drugs, baking, bodily growth, medicine, wine, and so on for page after page. Given the magnitude of the studies he foresaw, it is not surprising that Bacon, Lord Chancellor under James I and VI, pleaded for state funding of research, giving him the distinction thereby of being the father of the federal research grant. He thought the costs of the "natural histories" he proposed would be well justified because they would lead to human power over the world, a world in which human interests were freed from the vicissitudes of fate and protected and promoted by human knowledge.[2] The goal of human study, he said, was "the knowledge of causes, and secret motions of things; and the enlarging of the bounds of human empire, to the effecting of all things

possible."[3] And a society devoted to these pursuits would be, in the end, a "New Atlantis."

The human genome project appears to be Baconian enterprise ("big science" we call it today) not only in its ambitions, its enormous costs and the necessary involvement of government, but also in its capacity to offer knowledge about the secret motion of things biological. There are questions, of course, whether this initiative will or should lead to the effecting of all things possible, and there are questions about whether these ambitions, costs, and outcomes will advance our own society toward its New Atlantis. The New Atlantis described by Bacon, after all, was a harmonious, homogenous utopia protected from the strife of the world by its remote distance from world events. It was a society dedicated to a single religion. Our own society, by contrast, is in many ways a society at the mercy of events wherever they might occur in the world. It is also a society deeply marked and divided by religion, race, economics, natural resources, culture, politics, and disease.

There is already a growing body of moral analysis that has attempted to characterize the quandries and challenges of the genome project, and this analysis has raised many of the relevant questions even if it has not been able to offer definitive answers. Some of this analysis has been at pains to point out undesirable consequences of possible uses of genomic data especially in discriminatory social practices. While it is important to be aware of these outcomes, it seems to me that what moral philosophy can also profitably contribute to the discussion

is something other than prophesies of possible, objectionable use of genomic characterizations. Health care workers, insurance analysts, attorneys, and others are often better situated than philosophers to predict unhappy consequences of the genome project. What philosophers can contribute seems to me to lie in another vein: in interpreting the meaning of the project and its uses. I therefore want to identify here some of what I consider to be the main moral problematics of the genome project itself, issues that have to do with the nature and consequences of our commitment to this project. I also want to consider the genome project insofar as it raises philosophical questions about the nature and meaning of difference. This is a difficult task and one which I only begin here, but it is one that tries to get at the question of what it means that we are now engaged in a project to map and sequence the human genome and to ask, secondly, in what ways will the genome project work for or against human difference and alter the way in which we understand the worth of the individual in relationship to the social order.

MORAL ASPECTS OF THE GENOME PROJECT

Alexander M. Capron has observed that the genome project itself has proved of little ethical interest: "My personal sense is that persons assigned to discuss the ethics of genome mapping quickly find themselves discussing related subjects, because the topic-in-chief is regarded as pretty thin gruel."[4] Like most analysts, Capron therefore underlines the importance of analyzing

the uses of the information the genome project is expected to generate.[5] In particular, in an Emory Law Journal article, he expresses concern about ownership and control over knowledge generated by the project. Capron is surely right in noting the way in which commentators have shied away from discussing "the topic-in-chief." Indeed, most ethical analysis of the genome project typically shies away from any suggestion that the project itself is morally problematic.

But is it true that there is little or no moral substance in the genome project itself? I think such a conclusion should be resisted; on the contrary, there are some important moral problematics to be considered. There are, first of all, questions about whether this venture is something that a society ought to undertake given other pressing needs. To what extent, after all, should a society undertake a project whose beneficiaries, in the main, exist in the future? James D. Watson and Robert Mullan Cook-Deegan have said that the primary objective of the human genome project is to aid in the assault on disease.[6] But that assault will not, for the most part, benefit living persons, and a financial commitment of the kind involved with the genome project may mean, probably means in some cases, that care will not be offered to actually existing persons who here and now suffer from various diseases or natural or social ills. While it may be wise to prepare a future in which genetic diseases do not cause the damage they do now, it is not clear that there is anything but a supererogatory duty to do so. And so the question of the genome project may be put into relief this

way: what is the moral argument to be offered that the suffering of persons here and now may be sacrificed to expected benefits in the future?

In this vein, it is also worth considering whether and to what extent the genome project may amount to an evasion of contemporary social and medical problems, problems that we could address might be able to overcome if only we chose to. Should we, after all, be trying to develop methods to identify and eradicate the genetically defective through prenatal and neonatal genetic testing (and possibly abortion) rather than undertaking social accommodation of genetically disadvantaged persons, finding what way we can to offer such persons hope and happiness? Of course, there will be no relief for some of the genetically disadvantaged, but still it is worth wondering to what extent the living don't have priority over the future-living.

To the extent that there are possible answers to these questions, still the genome project may be problematic from another quarter. The genome project is "big science" and even bigger consequences are expected from it, but insofar as the project represents a coordinated plan of study, the potential exists for its functioning as an scientific and moral ideology because committed to a single way of representing genetic information and carrying with it the seeds of its own moral authority. The genome project, therefore, has the potential of functioning as an ideology with all the undesirable effects of ideology in conforming people and their expectations.[7]

Though there have been other government-sponsored programs

of scientific study before it, the genome project has special moral significance insofar as it may suggest a precedent that future scientific study is properly a matter of large-scale, federally financed, centrally coordinated projects. It is not wrong, of course, that the government undertake such projects of scientific study; the question is whether or not this kind of undertaking is the best way for science and scientists to proceed. With its economic supports, the federal government, for example, has in effect created a scientific orthodoxy, and it is worth wondering whether this approach will have the effect of counterproductively suppressing the element of novelty so important to scientific advance. It is important to keep in mind, after all, that every time there are converts to a scientific project, voices of dissent capable of correcting and advancing human knowledge and wisdom may be lost.[8]

But perhaps these questions do not seem essential or significant as matters relevant to the genome project itself. Maybe they are not, but perhaps there is another explanation why these questions have not been raised with special urgency. Perhaps it is because we commentators and analysts of the genome project already have and share common answers to such questions; our assumptions in common belie deep divisions of opinion. Perhaps there is no dwelling on moral aspects of the genome project per se because there are no disputants to conduct a debate about the project, this because the nation's intelligentsia has almost to a person already and predictably come down on the side of the project. In an age entirely

comfortable with the promises and priorities of science, we do not have the sense that science (as against its uses) is morally problematic. Except for research which may jeopardize persons without their consent, we seem to have lost the sense that there can be research that "goes too far." We seem to have adopted as our own that single, internal imperative of science: to know everything. We are prepared to wait until after the work of science is done to deal with any unhappy consequences it may make possible, and we have faith that our social institutions can absorb limitless advances in biomedical, physical and social science. Far from being without moral interest, therefore, it seems to me, that the genome project is remarkable as evidence of our collective and uniform moral and scientific expectations.

There is no reason, of course, why serious arguments against the genome project could not be raised on grounds of resource allocation, scientific openness, limits of inquiry, and possibly for religious reasons as well. That they have not says more about us than it does about the nature of the genome project itself. That there is no chorus of voices raised against the genome project per se does not mean, to be sure, that the project is itself without moral significance. The silence here is more likely the result of our society's homogenous views as regards the morality of scientific inquiry in general or perhaps the result of the erroneous view that scientific inquiry is itself value-free and only morally significant as regards its consequences. Given approximately equivalent educational opportunities and social ideals we perforce share common moral

views, which is to say that our moral assumptions and conclusions can be hidden by their very virtue of their pervasive nature. I am not suggesting that we object to the genome project for the kinds of reasons raised above; I am merely observing that what passes as a question without moral significance may simply represent pervasive moral consensus. It is different views, different interpretations, different observers that, after all, make moral values obvious and open to debate.

It is evident, therefore, that at least one major meaning of the genome project is that we as a society continue our commitment to academically orthodox science. We continue to place our hopes for the production of knowledge, and the economic and health opportunities it will make possible, in the hands of federally sponsored scientific researchers even to the extent that we cannot foresee the extent to which such knowledge will affect our social institutions and mores. We continue to have fairly unlimited optimism about the beneficence of science, this despite all the objectionable episodes that have occurred in research and in spite of the problems scientific research generates in its uses. We continue, that is, to draw a clear distinction between science and its sins.

MARKING AND INTERPRETING DIFFERENCE

Beyond the moral significance of the project itself, the genome project does indeed raise many interesting individual moral questions, questions related to the use of the tests and

information it will produce. For example, it will be necessary to consider the ways in which resultant genetic probes should be used in matters of employment, insurability, money lending, reproduction, counselling, and so on. Genetic characterizations will also create a new class of health costs, and the question of how these costs will be met and ranked in the nation's social priorities will need to be addressed. There will also be questions of how experimentation in correcting genetic defects should be carried out and with what priority. Perplexing questions of equitable access and informed consent in such therapies will arise.

One of the major expectations of the genome project is that its information will offer people better health. But genetic characterizations are one thing and successful medical interventions to correct genetic dysfunctions are another. It is likely that there will be considerable lag time between the identification of genetic dysfunctions and interventions which can successfully alter them. It is also unclear at the present time whether widespread use of genetic characterizations (and possible treatments) will significantly improve the health of a nation's population. After all, we already know what it is that it would take to improve a considerable portion of the nation's health; it's just that we ignore the counsels against smoking, alcohol, failure to exercise and so on.[9] Moreover, the use of genetic characterizations will not necessarily modify the course of the most socially significant diseases, communicable diseases, for example. They may prove useful, on the contrary, for fairly

rare occurrences that will not therefore significantly alter the general distribution of non-genetic disease or the costs associated with such disease. These questions all deserve considerable attention as we shape policies and practices around genomic data.

But such questions do not themselves directly get at an underlying question that, to my mind, haunts the genome project. The ancient art of haruspicy attempted to divine the future through the examination of animal entrails. In our own time, are we now trying to foretell the future through the examination of genetic entrails? Certainly, we hope at least to be able to foretell the genetic future of particular individuals. Such a hope raises important questions regarding identity and difference. To what extent will the genome project generate new classes of human inferiority? Will the genome project generate a theoretical subjugation of the genetically atypical persons, born and unborn, and thereby establish difference as disease or disability? Will the genome project mark difference as an undesirable trait and justify its eradication?

The goal of the genome project is to produce a characterization of the human genetic complement in the way that anatomy produces a representation of the structural components of the human body, in the way physiology represents bodily function. This genomic characterization will not, therefore, identify the genome of a single person any more than anatomical or skeletal characterizations represent a given individual. Nevertheless, the genome project will offer a model by which to understand the

functioning of genes and their relationship to particular organismal traits. And it is the existence of this model that lays the foundation for the interpretation of desirable and undesirable traits. The moral significance of the project may prove, therefore, to lie in its significance for the interpretation of health and disease, normalcy and difference.

There are many ways to represent the nature of human beings, and none of them is value-neutral. Even a genomic characterization is already always determined by our social and conceptual background. What we see, therefore, in a genomic characterization of human beings will depend on what we are accustomed to and interested in seeing, this for both the species as a whole and an individual in particular. There is no escaping, of course this immersion in the social and conceptual preconditions of observation, representation, science and language; we cannot ever hope to achieve the position of an entirely unconditioned, uninterested observer. The moral question at issue here, therefore, is not whether we can produce a value-neutral representation of human genetics but whether we can protect people from invidious interpretations of the representation the genome project will offer.

There are many reasons to be cautious here. German philosopher Friedrich Nietzsche once observed "<u>What one knows of oneself.</u> -- As soon as one animal sees another it measures itself against it in its mind, and men in barbarous ages did likewise. From this it follows that every man comes to know himself almost solely in regard to his powers of defence."[10]

Coming as it does from a philosopher who was acutely aware of the importance of individuality and difference, this observation might even be interpreted to mean that marking differences in order to assert and establish superiority is even the primal form of thought itself. And the history shows that difference is often the pretext for vilification and destruction of those marked in ways others are not.

It seems to me, therefore, that if there is a central moral issue at stake in the genome project, it is whether its characterizations will permit the erosion of difference in favor of genetic uniformity, whether its characterizations will offer yet another standard of "normalcy" to be used as a justification for the extermination of difference. And it is in this regard that one needs to see and consider the nature of genome mapping. Will we, in finding new ways in which to mark the differences between people, invite new theories of personal and social worth, theories that presuppose standards of superiority and inferiority. There are already differences enough between people that are used as pretexts for their subjugation and villification. Will the genome project enlarge the power we already have in that regard?

Given their relative accessibility, the genetic characterization of newborns and fetuses would be one of the most likely venues for the identification and extinguishing of genetic defect/difference. It is perhaps, then, worth recalling that the United States and not just National Socialist Germany has had its own significant eugenics history.[11] Prior to World War II, the

United States had its own very healthy eugenics movement. In advancing the cause of birth control, Margaret Sanger freely availed herself of language that bespeaks eugenic goals. She constantly spoke of the great number of children who should never have been born, those children who will pollute the race and drain the world of its resources.[12] If there was a central task facing the nation, Sanger thought it was the task of breeding a better race: "The noblest and most difficult art of all is the raising of human thoroughbreds." Accomplishing that goal required preventing the mass birth of inferior populations who were, in her view, responsible for the "ever-widening margins of biological waste." The goal should be to resist, therefore, "the ever increasing, unceasingly spawning classes of human beings who never should have been born at all," in which category she puts feeble sows' ears, the mentally and physically defective, degenerate stock, morons, the dregs of the human species, the blind, the deaf-mute, the degenerate, the nervous, the vicious, the idiotic, the imbecilic, the cretins, the epileptics, the feeble-minded, and in general the dead weight of human waste.

After the defeat of National Socialist Germany, the formal eugenics movement collapsed almost without a trace in the United States. But the concern about the defective children and adults lingers on in different form. Whereas the eugenics movement offered its counsels in the language of preserving the race and husbanding resources, concern about the lives of the defective today is offered primarily in the language of "the best interests of the child." Fetuses are aborted and certain newborns are let

to die, according to those making the decisions, because that course of action is in their best interest. Defective children who survive are, moreover, sometimes said to be the victims of "wrongful birth," even "wrongful life."

Of course, genetic characterizations cannot predict with complete certainty which children will and will not express genetic disease, this because of the roles human variability and environmental differences play in the expression of disease. Genetic characterizations will, however, highlight <u>possible</u> differences even where that difference may not be destined to occur. In an effort, to avoid even the <u>possibility</u> of disorders, some parents may wish to abort or let die those children whose genomic characterizations are ambiguous. The moral question worth taking away from considerations of this kind is this: will the genomic project cast a hermeneutic of suspicion over all people and especially children? How many tests, after all, will a man have to pass in order to be judged fit for employment and the social and personal benefits available that way? How many tests will a woman have to pass in order to buy health or life insurance? How many tests will a child have to pass in order to be wanted, born, and loved?

One other aspect of the question worth considering here is whether or not the genome project will offer a way to conform people to the existing social order. This longstanding concern about the "engineering" of people is surely relevant to the genome project if people themselves are viewed as burdens when it may be that it is the design of society's institutions that is at

fault in meeting social needs, in meeting the needs of people as they actually exist with all their diseases, defects, and differences. The question is whether the genome project will be put to the use of establishing genetic difference as personal fallibility rather than as a shared aspect of human finitude.

Regardless of the use of genomic characterizations and reproductive interventions, what of persons with genetic liabilities who are born nevertheless? Will they be seen as failures of the system, as an incentive to expand the use of genetic profiling prenatally or at birth? as an incentive to routine even compulsory genomic profiling? Will they be seen as indictments of the nation's health policy? Will they be further stigmatized as drains on society and failures in themselves because, after all, their birth/defects were in principle avoidable? And how, in such circumstances, can the presumption of social equality be preserved?

And it is not only in these ways that people's lives and differences are stake here. The question of the moral responsibilities of parents is also implicated insofar as the existence of genetic characterizations might also raise the threshold of responsible parenthood. How, for example, should parents who decline or resist such testing for eliminable or treatable genetic disease be seen? Will they be seen as exercising rights properly their own or as misguided people punishing their own children in order to advance their own private beliefs? Will their actions invite legislatures and courts to impose standards of care here? It is also worth

wondering whether the availability of genomic characterizations will widen the gap between have and have-not parents. Will genetic disease become another affliction of the poor?

All these issues implicate the question of how we will understand and interpret difference. The self is bordered by differences that are essential to individuation; marking difference is an irreducible component of individuation. And it is the meaning of difference that I regard as a central moral question of the human genome project. The question is whether we will find in genetic characterizations differences that divide us further even as we lift the burden of genetic suffering. To be sure, I do not wish anyone to suffer from genetic disease for the mere sake of maintaining difference; but I do hope that we can preserve the lessons of those differences as lessons otherwise unlearned.

CONCLUSIONS

In 1660, French philosopher and mathematician Blaise Pascal wrote an essay called "Prayer to Ask God for the Right Use of Sickness."[13] The title here is problematic to contemporary consciousness. The right use of sickness? What could this signify? that if there is a right use of sickness there is also a wrong use of sickness? that there is a purpose to sickness at all? However strange the questions might appear to us today, in Pascal's view, sickness could be put to the use of personal transformation and it was useful in guiding one to correct moral

priorities.

It is fair to say, by contrast, that the operational interpretation of contemporary biomedicine, reflecting our own pervasive social judgment, is that disease and suffering are evils to be resisted, threats to our happiness, events without meaning that we would do better to extinguish and avoid in what ways we can because there is nothing to learn from then, no purpose, no achievement in their endurance. But whatever else it may or may not be, suffering and other marks of difference teach us lessons not otherwise available about the nature and meaning of our lives. There is, of course, absurd suffering and pointless difference. But it is also true that we do not know what our lives are worth if we do not countenance the price we would be willing to pay for them, the difference we would be willing to endure for them.

The question before us then is one Pascal would have understood: what is the right use of the genome project? Will it be used to prop the existing scientific status quo and perhaps thereby impede the aims of science? Will it be used in a campaign against difference or will it be used to map the fullness and plenitude of existence? Will it be used as a strategem by which to create a new kinds of inferiority? Or will we be able to understand the way in which genomic characterizations represent one possible map of a small corner of the vastness of existence? Will the goal of biomedicine be the levelling of all genetic difference in order to accommodate the social requirements of the time?

It seems to me that we should not lose sight of some of the fundamental paradoxes of science as we consider judgment on the genome project. Even as it offers some answers science also creates uncertainty, even as it conquers some social evil it also be evasion of social problems, while it opens vistas of the world to our experience it also imposes standards of conformity in scientists and what they study, it not only offers an explanation it also advances a cause.

As a matter of moral analysis, it seems important to make the case that the differences identified by genomic mapping should not be used as a pretext for vilification whether that vilification is couched in the language of racial impurity or human health, that the social needs of the day not be mistaken as ultimate human needs, and that we do not demand answers from the genome project to questions for which it has no authority. I hope instead that we continue to recognize that difference in persons is a rare and important good, that the genetically atypical are important scientific and moral resources, that there is in individual human and social life a plenitude of difference that should be preserved, that there are lessons in difference and suffering it would be unwise to bypass.

In the Pensées, Pascal remarked that "Knowledge of physical science will not console me for ignorance of morality in time of affliction, but knowledge of morality will always console me for ignorance of physical science."[14] I take Pascal to have meant that a knowledge of, for example, the genetic molecular processes of humans or any assemblage, however large, of simply factual

information must necessarily fail in telling us what it is that we are worth, what it is that we ought to seek, how after all we should live. Moral philosophy is crucial therefore because it concerns the standards by which we judge the nature and significance of our actions. The genome project will significantly enlarge the bounds of human empire, increasing our genetic knowledge ten-million fold. It will eventually offer insight into the secret motion of things. It is dubious, though, whether the genome project will enable us to effect all things possible. But given the lessons of history, it is not even clear that we should aspire to the effecting of all things possible. I think that we should not effect, even if it were possible, the extinction of difference. On the contrary, moral philosophy seems to me to require that we find what ways there are in the use of research projects and their consequences to preserve the lessons of difference for it is only individual difference that can throw the moral order of the universe into relief, that can let us know who in fact we are.

Notes

1. Francis Bacon, The New Organon (New York: Liberal Arts Press, 1960).

2. Francis Bacon. The Advancement of Learning and New Atlantis (London: Oxford, 1974).

3. Francis Bacon, The Advancement of Learning and New Atlantis (London: Oxford, 1974), p. 228.

4. Alexander M. Capron, "Which Ills to Bear? Reevaluating the 'Threat' of Modern Genetics," Emory Law Journal 1990 (39): 665-696. This quote, p. 679.

5. See Loane Skene, "Mapping the Human Genome: Some Thoughts for Those Who Say There Ought to be a Law On It," Bioethics 1991 (5): 233-249).

6. James D. Watson, Robert Mullan Cook-Deegan, "The Human Genome Project and International Health," Journal of the American Medical Association 1990 (263): 3322-24.

7. Paul Feyerabend, Against Method, Outline of an Anarchist Theory of Knowledge (London: Verso, 1975).

8. Paul Feyerabend, Against Method: Outline of an Anarchistic Theory of Knowledge (London: Verso, 1975).

9. Leon R. Kass, Toward a More Natural Science (New York: Free Press, 1985), p. 176.

10. Friedrich Nietzsche, Daybreak, Thoughts on the Prejudices of Morality, R.J. Hollingdale, trans. (Cambridge: Cambridge University Press, 1982), p. 134.

11. See Daniel J. Kevles, In the Name of Eugenics: Genetics and the Uses of Human Heredity (New York: Knopf, 1985).

12. Margaret Sanger, The Pivot of Civilization (Elmsford, NY: Maxwell Reprint, 1969 [originally published, 1922]).

13. Blaise Pascal, "Prière de Blaise Pascal pour demander à Dieu le bon Usage des Maladies," Oeuvres, Vol. IX (Paris: Librairie Hachette, 1914), pp. 319-340.

14. Blaise Pascal, Pensées, A.J. Krailsheimer, trans. (London: Penguin, 1966), p. 36.

Eugenics and the Human Genome Project: Is the Past Prologue?

Daniel J. Kevles

In April 1991, an exposition opened in the hall atop the great arch of *La Défense*, in Paris, under the title: *La Vie en Kit*--Life in a Test Tube--*Éthique et Biologie*. The biological exhibits included displays about molecular genetics and the human genome project. The ethical worries were manifest in a catalogue statement by the writer Monette Vaquin that was also prominently placarded at the genome display:

> Today, astounding paradox, the generation following Nazism is giving the world the tools of eugenics beyond the wildest Hitlerian dreams. It is as if the unthinkable of the generation of the fathers haunted the discoveries of the sons. Scientists of tomorrow will have a power that exceeds all the powers known to mankind: that of manipulating the genome. Who can say for sure that it will be used only for the avoidance of hereditary illnesses?[1]

Vaquin's apprehensions, echoed frequently by scientists and social analysts alike, indicate that the shadow of eugenics hangs over any discussion of the social implications of human genetics but particularly over consideration of the potential impact of the human genome project. People wonder whether the eugenic past forms a prologue to the human genetic future.

Eugenic ideas go back to at least to Plato, but in its modern version, eugenics originated with Francis Galton, a younger first cousin of Charles Darwin and a brilliant scientist in his own right. In the late nineteenth century, Galton proposed that the human race might be improved in the manner of plant and animal breeding--that is, by getting rid of so-called undesirables and multiplying the so-called desirables. It was Galton who named this program of human improvement "eugenics": he took the word from a Greek root meaning "good in birth" or "noble in heredity." Galton intended eugenics to improve human stock by giving "the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable."[2]

Galton's eugenic ideas took popular hold after the turn of this century, developing a large following in the United States, Britain, Germany, and many other countries. Eugenic organizations were formed, including, in 1923, the American Eugenics Society, which, among other things, annually mounted eugenic exhibits at state fairs. The backbone of the movement was formed of people drawn from the white middle and upper middle classes, especially prominent laymen and scientists, particularly geneticists and often physicians. Eugenicists declared themselves to be concerned with preventing social degeneration, whose abundant signs they found in the social and behavioral discordances of urban industrial society. For example, they took crime, slums, and rampant disease to be symptoms of social pathologies, and they attributed them primarily to biological causes--to "blood," to use the term of inheritable essence popular at the turn of the century.[3]

To eugenically-minded biologists, the causes of social degeneration were understood as matters to be rooted out, which led some of them to pursue research in human heredity related to eugenics. As a result, the human genetics research program of the day included

the study of medical disorders--for example, diabetes and epilepsy--not only for their intrinsic interest but because of their social costs. A still more substantial part of the program consisted of the analysis of traits alleged to make for social burdens--traits involving qualities of temperament and behavior that might lie at the bottom of, for example, alcoholism, prostitution, criminality, and poverty. A major object of scrutiny was mental deficiency--then commonly termed "feeblemindedness"--which was often identified by intelligence tests and was widely interpreted to be at the root of many varieties of socially deleterious behavior.

In the hope of explaining these pathologies biologically, eugenic researchers resorted to Mendel's laws of heredity, which had been rediscovered in 1900, fastening on the idea that biological characters were determined by single elements--which were later identified with genes. Their research was pervaded by the fundamental assumption that not only could such physical characters as eye color or disease be explained in a Mendelian fashion but that so also could characteristics of mind and behavior. Charles B. Davenport, the prominent American biologist, eugenicist, and head of the biological laboratory that, in 1918, became the Carnegie Institution of Washington's Department of Genetics, located at Cold Spring Harbor, on Long Island, New York, searched for Mendelian patterns of inheritance in many behavioral categories, including the inheritance of what he called "nomadism," "shiftlessness," and "thalassophilia"--the love of the sea that he discerned in naval officers and concluded must be a sex-linked recessive trait because, like color blindness, it was almost always expressed in males. A chart displayed at the Kansas Free Fair in 1929, purporting to illustrate the "laws" of Mendelian inheritance in human beings, declared, "Unfit human traits such as feeblemindedness, epilespy, criminality, insanity, alcoholism,

pauperism, and many others run in families and are inherited in exactly the same way as color in guinea pigs."[4]

Some eugenic investigation into human heredity proved to be meritorious, revealing, for example, that Huntington's chorea results from a dominant gene and albinism from a recessive one. However, much of it was recognized in the end to be worthless. Combining Mendelian theory with incautious speculation, eugenic scientists often neglected polygenic complexities in favor of single-gene explanations. They also paid far too little attention to cultural, economic, and other environmental influences in their accounts of mental abilities such as low scores on IQ tests and social behaviors such as prostitution. Like Davenport's behavorial categories, many of the traits that figured in eugenic research were vague or ludicrous.

Class and race prejudice were pervasive in eugenic science. In northern Europe and the United States, eugenics expressed standards of fitness and social value that were predominantly white, middle class, Protestant--and identified with "Aryans." In the reasoning of eugenicists, lower-income groups were not poor because they had inadequate educational and economic opportunity but because their moral and educational capacities, rooted in their biology, were inadequate. When eugenicists celebrated Aryans they demonstrated nothing more than their own racial biases. Davenport, indulging in unsupportable anthropology, found the Poles "independent and self-reliant though clannish"; the Italians tending to "crimes of personal violence"; and the Hebrews "intermediate between the slovenly Servians and the Greeks and the tidy Swedes, German, and Bohemians" and giving to "thieving" though rarely to "personal violence." He expected that the "great influx of blood from Southeastern Europe "would rapidly make the American population "darker in pigmentation, smaller in stature, more mercurial . . . more given to crimes of larceny,

kidndapping, assault, murder, rape, and sex-immorality."[5]

Eugenicists like Davenport urged interference in human propagation so as to increase the frequency of socially good genes in the population and decrease that of bad ones. The interference was to take two forms: One was "positive" eugenics, which meant manipulating human heredity and/or breeding to produce superior people. The other was "negative" eugenics, which meant improving the quality of the human race by eliminating biologically inferior people from the population. The elimination might be accomplished by discouraging biologically inferior human beings from reproducing or entering one's own population.

In practice, little was done for positive eugenics, though eugenic claims did figure in the advent of family-allowance policies in Britain and Germany during the 1930s, and positive eugenic themes were certainly implied in the so-called "Fitter Family" competitions that were a standard feature of eugenic programs at 1920s state fairs. These competitions were held at the fairs in the "human stock" section. At the 1924 Kansas Free Fair, for example, winning families in the three categories--small, average, and large--were awarded a Governor's Fitter Family Trophy, which was presented by Governor Jonathan Davis, and "Grade A Individuals" received a medal that portrayed two diaphanously garbed parents, their arms outstretched toward their (presumably) eugenically meritorious infant. It is hard to know what made these families and individuals stand out as fit, but some evidence is supplied by the fact that all entrants had to take an IQ test--and the Wasserman test for syphillis.[6]

Much more was done for negative eugenics, notably the passage of eugenic sterilization laws. By the late 1920, some two dozen American states had enacted such laws. The laws were declared constitutional in the 1927 U.S. Supreme Court decision of Buck v.

Bell, in which Justice Oliver Wendell Holmes delivered the opinion that three generations of imbeciles were enough. The leading state in this endeavor was California, which as of 1933 had subjected more people to eugenic sterilization than had all other states of the union combined.[7]

The most powerful union of eugenic research and public policy occurred in Nazi Germany. Much of eugenic research in Germany before and even during the Nazi period was similar to that in the United States and Britain, but during the Hitler years, Nazi bureaucrats provided eugenic research institutions with handsome support and their research programs were expanded to complement the goals of Nazi biological policy, exploiting ongoing investigations into the inheritance of disease, intelligence, and behavior to advise the government on its sterilization policy. Fischer's Institute, the staff of which included the prominent geneticist Otmar von Verschuer, trained doctors for the SS in the intricacies of racial hygiene and analyzed data and specimens obtained in the concentration camps. Some of the material--for example, the internal organs of dead children and the skeletons of two murdered Jews--came from Josef Mengele, who had been a graduate student of Verschuer's and was his assistant at the Institute. In 1942, Verschuer succeeded Fischer as head of the Institute (he would serve postwar Germany as professor of human genetics at the University of Muenster).[8] In Germany, where sterilization measures were partly inspired by the California law, the eugenics movement prompted the sterilization of several hundred thousand people and helped lead, of course, to the death camps.

* * *

Since the opening of the DNA era, observers have wondered whether new genetic knowledge will be deployed for positive eugenics, for attempts to produce a super race or at

least to engineer new Einsteins, Mozarts, or athletes like Kareem Abdul-Jabbar (curiously, brilliantly talented women--e.g., Marie Curie or Nadia Boulanger or athletes like Martina Navratilova--are rarely if ever mentioned in the pantheon of superpeople). Conferences on the human genome project almost inevitably produce expressions of fear that the state will seek to foster or enhance a variety of highly valued human qualities or characteristics.

The apprehensions are not entirely unfounded given certain recent events. In Singapore in 1984, for example, Prime Minister Lee Kwan Yew deplored the relatively low birth rate among educated women, contending that their intelligence was higher than average and that they were thus allowing the quality of the country's gene pool to diminish. Since then, that government, embracing a crude positive eugenics, has adopted a variety of incentives--for example, preferential school enrollment for offspring--to increase fecundity among such women and provided similar incentives to their less educated sisters who would have themselves sterilized after the birth of a first or second child.[9]

However, it is doubtful that advances in genetic knowledge will lead to a revival of attempts to produce a super race. While the human genome project will undoubtedly accelerate the identification of genes for physical and medical traits, it is unlikely to reveal with any speed how genes contribute to the formation of those qualities--talent, behavior, personality--that the world admires. Equally important, the engineering of designer human genomes is not possible under current reproductive technologies and is not likely to grow a lot easier in the near future.

Many more commentators--for example, the late Nobel laureate biologist Salvador Luria or advocates of rights for the disabled such as Barbara Faye Waxman--have cautioned that the human genome project is likely to foster a revival of negative eugenics. Since it will

in principle be easy to identify individuals with deleterious genes of a physical (or presumptively anti-social) type, the state may intervene in reproductive behavior so as to discourage the transmission of these genes in the population. Indeed, in 1988, China's Gansu Province adopted a eugenic law that would--so the authorities said--improve "population quality" by banning the marriages of mentally retarded people unless they first submit to sterilization. Since then, such laws have been adopted in other provinces and have been endorsed by Prime Minister Li Peng. The official newspaper Peasants Daily explained, "Idiots give birth to idiots."[10]

Negative eugenics appeared to motivate the European Commission when in July 1988 it proposed the creation of a human genome project for the European Community.[11] Called a health measure, the proposal was entitled "Predictive Medicine: Human Genome Analysis." Its rationale rested on a simple syllogism--that many diseases result from interactions of genes and environment; that it would be impossible to remove all the environmental culprits from society; and that, hence, individuals could be better defended against disease by identifying their genetic predispositions to fall ill. According to the summary of the proposal: "Predictive Medicine seeks to protect individuals from the kinds of illnesses to which they are genetically most vulnerable and, where appropriate, to prevent the transmission of the genetic susceptibilities to the next generation."[12]

In the view of the Commission, the genome proposal, which it found consistent with the Community's main objectives for research and development, would enhance the quality of life by decreasing the prevalence of many diseases distressful to families and expensive to European society. Over the long term, it would make Europe more competitive--indirectly, by helping to slow the rate of increase in health expenditures; and directly, by strengthening

its scientific and technological base. To the end of fostering European prosperity by creating a "Europe of health," the Commission proposed to establish a modest Community human genome project, providing it with 15 million ECU (about $17 million) for the three years beginning January 1, 1989.[13]

Economics may well prove to be a powerful incentive to a new negative eugenics. Undoubtedly, concern for financial costs played a role in the eugenics movement. The social pathologies of the early twentieth century were said to be increasing at a costly rate. At the Sesquicentennial Exposition in Philadelphia, in 1926, for example, the American Eugenics Society exhibit included a board that, in the manner of of the population counters of a later day, revealed with flashing lights that every fifteen seconds a hundred dollars of your money went for the care of persons with bad heredity, that every forty-eight seconds a mentally deficient person was born in the United States, and that only every seven and a half minutes did the United States enjoy the birth of "a high-grade person . . . who will have ability to do creative work and be fit for leadership." Thus it was reasoned, eliminate bad genes from the gene pool and you would reduce what are nowadays called state and local welfare costs, by reducing public expenditures for "feeblemindedness" in its public institutional settings--that is, state institutions and state hospitals for the mentally deficient and physically disabled or diseased. Perhaps indicative of this reasoning is that, in California and several other state, eugenic sterilization rates increased significantly during the 1930s, when state budgets for the mentally handicapped were squeezed.[14]

In our own day, the more that health care in the United States becomes a public responsibility, payable through the tax system, and the more expensive this care becomes, the greater the possibility that taxpayers will rebel against paying for the care of those whom

genetics dooms to severe disease or disability. To be sure, the more that is learned about the human genome, the more will it become obvious that we are all susceptible to one kind of genetic disease or disability; we all carry some genetic load and are likely to fall sick in one way or another. Since everyone is in jeopardy of genetically based illness, then everyone would have an interest in a well-financed public health program--national health insurance--and everyone would have a stake in extending its benefits universally. However, not everyone's genetic load is the same; some are more severe and costly than others. It is likely that, on grounds of cost, even a national health system might seek to discriminate between patients, using the criterion of how expensive their therapy and care might be. Public policy might feel pressure to encourage, or even to compel, people not to bring genetically affected children into the world--not for the sake of the gene pool but in the interest of keeping public health costs down.

All this said, however, a number of factors are likely to offset a scenario of socially controlled reproduction let alone a revival of a broad-based negative eugenics. Analysts of civil liberty know that reproductive freedom is much more easily curtailed in dictatorial governments than in democratic ones. Eugenics profits from authoritarianism--indeed, almost requires it. The institutions of political democracy may not have been robust enough to resist altogether the violations of civil liberties characteristic of the early eugenics movement, but they did contest them effectively in many places. The British government refused to pass eugenic sterilization laws. So did many American states, and where they were enacted, they were often unenforced. It is far-fetched to expect a Nazi-like eugenic program to develop in the contemporary United States so long as political democracy and the Bill of Rights continue in force. If a Nazi-like eugenic program becomes a threatening

reality, the country will have have a good deal more to be worried about politically than just eugenics.

What makes contemporary political democracies unlikely to embrace eugenics is that they contain powerful anti-eugenic constituencies. Awareness of the barbarities and cruelties of state-sponsored eugenics in the past has tended to set most geneticists and the public at large against such programs. Most geneticists today know better than their early-twentieth-century predecessors that ideas concerning what is "good for the gene pool" are highly problematic. Then, too, handicapped or diseased persons are politically empowered, as are minority groups, to a degree that they were not in the early twentieth century. They may not be sufficiently empowered to counter all quasi-eugenic threats to themselves, but they are politically positioned, with allies in the media, the medical profession, and elsewhere, including the Roman Catholic Church--a staunch opponent of the eugenics movement--to block or at least to hinder eugenic proposals that might affect them.[15]

An anti-eugenic coalition rose up in response to the European Commission's proposal for a human genome project for predictive medicine after it went to the European Parliament for consideration. In the Parliament, primary responsibility for evaluating the genome proposal was given, on September 12, 1988, to the Committee on Energy, Research and Technology, which considered it in several meetings and, by late January 1989, was ready to vote on a report concerning the matter.[16] The drafting of committee reports in the Parliament is guided by a member--a rapporteur--who is designated for the purpose and who can exercise enormous influence over the position that the committee eventually adopts. The rapporteur appointed for the genome proposal was Benedikt Härlin, a Green Party member from what was then West Germany. Opposition to genetic engineering has been widespread

there, and it has been especially sharp among the Greens, a disparate coalition united mainly by a common interest in environmental protection. The Greens' desire to preserve nature has been suffused with distrust of technology and suspicions of human genetic manipulations. The Greens had helped impose severe restrictions on biotechnology in West Germany and raised objections to human genome research on grounds that it might lead to a recrudescence of Nazi biological policies. As James Burn, a Scottish expert on biotechnology and a longtime resident of West Germany, once told a reporter, "Germans have an abiding and understandable fear of anything to do with genetic research. It is the one science that reminds them all of everything they want to forget."[17]

The Härlin report, insisting that the European Community remember, raised a red flag against the genome project as an enterprise in preventive medicine. It reminded the Community that in the past eugenic ideas had led to "horrific consequences" and declared that "clear pointers to eugenic tendencies and goals" inhered in the intention of protecting people from contracting and transmitting genetic diseases. The application of human genetic information for such purposes would almost always involve decisions--fundamentally eugenic ones--about what are "normal and abnormal, acceptable and unacceptable, viable and non-viable forms of the genetic make-up of individual human beings before and after birth." The Härlin report also warned that the new biological and reproductive technologies could make for a "modern test tube eugenics," a eugenics all the more insidious because it could disguise more easily than its cruder ancestors "an even more radical and totalitarian form of 'biopolitics.'" Holding that the primary function of a European health and resarch policy must be "to block any eugenic trends in relation to human genome research," the report judged the proposed program in predictive medicine "unacceptable" as it stood.[18]

Härlin actually wished to make it acceptable, not to reject it. ("You can't keep Germany out of the future," he later said about his own country's involvement in genome research.[19]) On January 25, 1989, the energy committee voted twenty to one to adopt the Härlin report. It thus urged Parliament's endorsement of the European Commission's proposal as it would be modified by thirty-eight amendments contained in the report, including the complete excision of the phrase "predictive medicine" from the text. Collectively, the modifications were mainly designed to exclude a eugenically oriented health policy; to prohibit research seeking to modify the human germ line; to protect the privacy and anonymity of individual genetic data; and to ensure ongoing debate into the social, ethical, and legal dimensions of human genetic research.[20]

In mid-February, 1989, the Härlin report whisked through a first reading in the European Parliament, drawing support not only from the Greens but also from conservatives on both sides of the English Channel, including German Catholics.[21] The Parliament's action prompted Filip Maria Pandolfi, the new European Commissioner for Research and Development, in early April 1989 to freeze indefinitely Community human genome monies. The move was believed to be the first by a commissioner to block one of Brussels' own technological initiatives. Pandolfi explained that time for reflection was needed, since "when you have British conservatives agreeing with German Greens, you know it's a matter of concern."[22]

The reflection produced, in mid-November, a Modified Proposal from the European Commission that accepted the thrust of the amendments and even the language of a number of them. The new proposal called for a three-year program of human genome analysis as such, without regard to predictive medicine, and committed the Community in a variety of

ways--most notably, by prohibiting human germ line research and genetic intervention with human embryos--to avoid eugenic practices, prevent ethical missteps, and protect individual rights and privacy. It also promised to keep the Parliament and the public fully informed via annual reports on the moral and legal basis of human genome research.[23] On December 15, 1989, The Modified Proposal was adopted by the European Community Council of Ministers as its common position on the genome project. On June 29, 1990--the Parliament having raised no objection--the common position was promulgated by the Council as the human genome program of the Community, authorized for three years at a total cost of 15 million ECU, seven percent of which was designated for ethical studies.[24]

* * *

The eugenic past is prologue to the human genetic future in only a strictly temporal sense--that is, it came before. Of course, the imagined prospects and possibilities of human genetic engineering remain tantalizing, even if they are still largely the stuff of science fiction, and they will continue to elicit both fearful condemnation and enthusiastic speculation. However, the near-term ethical challenges of the human genome project lie neither in private forays in human genetic improvement nor in some state-mandated program of eugenics. They lie in the grit of what the project will produce in abundance: genetic information. They center on the control, diffusion, and use of that information within the context of a market economy, and they are deeply troubling.

The advance of human genetics and biotechnology has created the capacity for a kind of "homemade eugenics," to use the insightful term of the analyst Robert Wright--"individual families deciding what kinds of kids they want to have." At the moment, the kinds they can

select are those without certain disabilities or diseases, such as Down's syndrome or Tay-Sachs. Most parents would probably prefer just a healthy baby, if they are inclined to choose at all. But in the future, some might have the opportunity--for example, via genetic analysis of embryos--to have improved babies, children who are likely to be more intelligent or more athletic or better looking (whatever those comparative terms mean).

Will people pursue such opportunities? Quite possibly, given the interest that some parents have shown in choosing the sex of their child or that others have pursued in the administration of growth hormone to offspring who they think will grow up too short. Benedikt Härlin's report to the European Parliament on the human genome project noted that the increasing availability of genetic tests was generating increasingly widespread pressure from families for "individual eugenic choice in order to give one's own child the best possible start in a society in which heredity traits become a criterion of social hierarchy." A 1989 editorial in Trends in Biotechnology recognized a major source of the pressure: "'Human improvement' is a fact of life, not because of the state eugenics committee, but because of consumer demand. How can we expect to deal responsibly with human genetic information in such a culture?"[25]

The increasing availability of human genetic information challenges individuals with wrenching decisions. Purely for personal reasons, people may not wish to obtain their genetic profiles, particularly if they are at risk for an inheritable disease for which no treatment is known. Still, genetic testing, prenatal or otherwise, can be liberating if it reveals to individuals that either they or their newly conceived children are free from some specific genetic doom. A young woman tested and found to be without the gene for Huntington's declared, "After 28 years of not knowing, it's like being released from prison.

To have hope for the future . . . to be able to see my grandchildren."[26]

The problems and opportunities of individual choices aside, the torrent of new human genetic information will undoubtedly pose challenges to systems and values of social decency. Much of the discussion on this point has rightly emphasized that employers may seek to deny jobs to applicants with a susceptibility--or an alleged susceptibility--to disorders such as manic depression or illnesses arising from features of the workplace. Life and medical insurance companies may well wish to know the genomic signatures of their clients, their profile of risk for disease and death. Even national health systems might choose to ration the provision of care on the basis of genetic propensity for disease, especially to families at risk for bearing diseased children.

Many analysts have contended that individual genomic information should be protected as strictly private. However, a great deal more thought needs to be given to the rights of individuals to withhold and the rights of insurers to demand such information. Insurance, and insurance premiums, depend on assessments of risk. If degree of risk can be concealed, it is not insurance companies as such that will bear the costs but other policy holders. In short, it could be that classes of people with low risk will be compelled to subsidize classes of others at higher risk. Thus, insisting on a right to privacy in genetic information could well lead--at least under the system of insurance that now prevails in the United States--to inequitable consequences.

The eugenic past has much to teach about how to avoid repeating its mistakes--not to mention its sins. But what bedeviled our forebears will not necessarily vex us, certainly not in the same ways. In human genetics as in so many others areas of life, the flow of history compels us to think and act anew. It is important not to become absorbed with exaggerated

fears that the human genome project will foster a drive for the production of superbabies or the callous elimination of the unfit. It is essential to focus on the genuine social, ethical, and policy issues--some of them already evident--that the human genome project raises, and to respond to them by creating codes of law and/or regulation for the use of human genetic information by geneticists, the media, insurers, employers, and the government itself.

Notes

1. La Vie en Kit: Éthique et Biologie (Paris: L'Arche de la Defense, 1991), p. 25. "Aujourd'hui, stupéfiant paradoxe, la génération qui suit le nazisme donne au monde les outils de l'eugénisme au-delà des rêves hitlériens les plus fous. Comme si l'impensé de la génération des pères hantait les découvertes des fils. Les scientifiques de demain auront un pouvoir qui excède tous les pouvoirs connus dans l'humanité: celui de manipuler le génome. Qui peut jurer qu'il ne servira qu'à l'évitement des maladies héréditaires?"

2. Francis Galton, Inquiries into the Human Faculty (London: Macmillan, 1883), pp. 24-25; Karl Pearson, The Life, Letters, and Labours of Francis Galton (3 vols. in 4; Cambridge: Cambridge University Press, 1914-1930), IIIA, p. 348.

3. Historical accounts of eugenics, which itself produced a vast literature, have multiplied in recent years. For treatments of the subject in the United States and Britain, see Daniel J. Kevles, In the Name of Eugenics: Genetics and the Uses of Human Heredity (New York: Alfred A. Knopf, 1985) and G.R. Searle, Eugenics and Politics in Britain, 1900-1914 (Leyden: Noordhoff International Publishing, 1976). For Germany, see Benno Müller-Hill, Murderous Science: Elimination by Scientific Selection of Jews, Gypsies, and Others, Germany, 1933-1945 (New York: Oxford University Press, 1988); Robert N. Proctor, Racial Hygiene: Medicine Under the Nazis (Cambridge: Harvard University Press, 1988); Sheila Faith Weiss, Race Hygiene and National Efficiency: The Eugenics of Wilhelm Schallmayer (Berkeley: University of California Press, 1987); and Paul Weindling, Health, Race and German Politics between National Unification and Nazism, 1870-1945 (Cambridge: Cambridge University Press, 1990).

4. Kevles, In the Name of Eugenics, p. 62; Kenneth M. Ludmerer, Genetics and American Society: A Historical Appraisal (Baltimore: Johns Hopkins University Press, 1972), p. 60.

5. Charles B. Davenport, Heredity in Relation to Eugenics (New York: Henry Holt, 1911), pp. 216, 218-19, 221-22.

6. Kevles, In the Name of Eugenics, pp. 61-62.

7. Ibid., pp. 107-112, 114-16; *Buck v. Bell*, 274 U.S. 201-207 (1927).

8. Proctor, Racial Hygiene, pp. 44, 292. 307.

9. Steven Jay Gould, The Flamingo's Smile: Reflections in Natural History (New York: W. W. Norton, 1985), pp. 292-95, 301-303;

10. [author, title], New York Times, Aug. 15, 1991, p. 1.

11. The Commission is the Brussels-based executive arm of the European Community (the term has come to replace the phrase European Communities, meaning the European Economic Community, the European Coal and Steel Community, and the European Atomic Energy Community). It described its proposal as "a European response to the international challenges presented by the large-scale biological research projects in the United States . . . and Japan (Human Frontier Science Programme)," adding, "Although it is a programme of basic precompetitive research, both new information and new materials of potential commercial value will result; new technological processes will also be developed. These will all contribute to the development of Europe's biotechnology industry --often based in small and medium-sized enterprises." Commission of the European Communities, Proposal for a Council Decision Adopting a Specific Research Programme in the Field of Health: Predictive Medicine: Human Genome Analysis (1989-1991), COM (88) 424 final-SYN 146, Brussels, 20 July 1988, p.1.

12. Ibid., p. 3.

13. Ibid., pp. 10, 12, 20, 30.

14. Kevles, In the Name of Eugenics, pp. 62-63; Philip R. Reilly, The Surgical Solution: A History of Involuntary Sterilization in the United States (Baltimore: The Johns Hopkins University Press, 1991), pp. 91-93. The last state eugenic sterilization law was passed in 1937, in Georgia, partly in response to conditions of overcrowding in the state's institutions for the mentally handicapped. Edward J. Larson, "Breeding Better Georgians," Georgia Journal of Southern Legal History 1991 (1): pp. 53-79.

15. The Roman Catholic Church took an official stand against eugenics in 1930, in the Papal Encyclical *Casti Connubii* (Kevles, In the Name of Eugenics, p. 119). The Church's well-known opposition to abortion sets it against the kind of eugenics that spokespeople for the handicapped currently fear, since such a eugenics can be accomplished at the moment only by the abortion of fetuses determined to be "defective" by amniocentesis, ultrasound, or some combination of the two.

16. European Parliament, Committee on Energy, Research, and Technology, Report Drawn up on Behalf of the Committee on Energy, Research and Technology on the Proposal from the Commission to the Council (COM/88/424-C2-119/88) for a Decision Adopting a Specific Research Programme in the Field of Health: Predictive Medicine: Human Genome Analysis (1989-1991). Rapporteur Benedikt Härlin, European Parliament Session Documents, 1988-89, 30.01.1989, Series A, Doc. A2-0370/88 SYN 146, p.3. Auxiliary opinions were also requested of the Committee on Budgets and the Committee on the Environment, Public Health, and Consumer Protection (Ibid.).

17. [author, title] Financial Times [London], May 10, 1989, p. 18; Joel Davis, Mapping the Code: The Human Genome Project and the Choices of Modern Science (New York: John Wiley, 1990), p. 175; Michael Specter, "Petunias Survive German Debate over Biotechnology," International Herald Tribune, April 12, 1990. The German fear of genetics and eugenics would intensify, leading some activist groups on a number of occasions to intimidate and even suppress debate on biomedical subjects in universities using methods reminiscent of the Nazis (Peter Singer, "On Being Silenced in Germany," The New York Review of Books, Aug. 15, 1991, pp. 36-42).

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Handle With Care: Race, Class and Genetics

A.L. Caplan

I. Race, Ethnicity, Class and Genetics--A Grim and Dismal History.

Discussions of the consequences of increased knowledge concerning the composition and structure of the human genome for public policy often leaves geneticists and others involved with research or clinical care in the domain of human genetics surprised and angry. They are often taken aback by the high level of ethical concern expressed about their work. Why is it, they wonder, that knowledge of human heredity so often becomes the center of controversy and protest? Why is it that in some nations, such as Germany (Kahn, 1992), talk of genetic engineering or gene therapy elicits heated political protests, strict legislative controls, and, sometimes outright bans on certain types of research? There can be no disputing the fact that the subject of genetics evinces a great deal of concern and worry. The reason why this is so is to be found in the past.

Human genetics has a problematic history and, sadly, minorities and the poor have not fared well in that history. Genetics, race, and ethnicity have sometimes proven to be an explosive and even fatal mixture. In Germany, for example, racial and ethnic minorities paid with their lives when developments in genetics were used in the service of a science of racial hygiene whose leaders gave enthusiastic and vocal support to Nazism (Lifton,

1986; Müller-Hill, 1986; Proctor, 1988; Kater, 1989; Caplan, 1990; Caplan, 1992). Groups such as Jews, Gypsies and Slavs were targeted for extermination on the grounds that their genes posed a threat to the overall health and reproductive well-being of the German people.

Some dismiss Nazi science as merely mad science or bad science (Biagioli, 1992; Caplan, 1992). But, the involvement with Nazism of many mainstream authorities and leaders in medicine, public health and science in a technologically and scientifically advanced nation cannot be dismissed as merely 'fringe' or 'peripheral'. The road to Dachau and Auschwitz runs too straight through the eugenic institutes and genetic courts of pre-World War II Germany (Weindling, 1985; Proctor, 1988; Seidelman, 1988; Pross, 1991; Caplan, 1992; Lerner, 1992) to be considered nothing more than a inexplicable detour.

Obviously, there is no inherent connection between the science of genetics and a public policy of murder and euthanasia based upon race hygiene. Nazism or genocidal policies cannot be deduced or inferred from facts about human heredity and it would be dangerously false to suggest otherwise. But, genetics, at least in the form that prevailed in Germany during the 1920s and 1930s, served as a powerful source, tool and buttress for racist ideology--an ideology that took a terrible toll in terms of human lives.

It is worth noting that the majority of the biologists, social scientists and physicians who used their beliefs about human heredity to support the Nazi cause were not forced to do so. Some had arrived at racist conclusions long before the Nazi party came to power (Caplan, 1992). They lent their support

because they believed that their scientific beliefs were consistent with Nazism not because the Nazis demanded that they fit their science to suit an ideological purpose (Lifton, 1986; Proctor, 1988, Seidelman, 1988; Kater, 1989; Pross, 1991; Biagioli, 1992; Caplan, 1992; Lerner, 1992; Burleigh and Wipperman, 1992). Neither biomedical science in general nor genetics in particular were responsible for the rise of the Third Reich or the Holocaust but, some scientists and physicians used their skills and authority to create a 'scientific' foundation for the racism which was a pivotal factor in legitimating Nazism and in bringing about the Holocaust (Caplan, 1992).

The case for the tie between mainstream genetics and racist social policy is bolstered by the fact that efforts to link genetics and social policy were not confined to Germany. For example, in the United States for much of the first half of this century the mentally ill, the retarded, alcoholics, recent immigrants and those thought to be sexually promiscuous, especially if they were members of minority groups and poor, became the object of government sponsored sterilization efforts inspired by scientific testimony and expert opinion aimed at preventing the spread of 'bad' genes to future generations (Proctor, 1988; Reilly, 1991). Restrictive immigration laws, forced sterilization, and prohibitions on interracial marriage were in part a legacy of mixing genetics, race, and class in the United States and many other countries.

The use of genetic information to guide American social policy continued through the nineteen sixties and seventies with mixed results. Attempts to conduct mass screening programs to detect carriers for diseases such as sickle cell, thalessemia and Tay Sachs, led to much confusion, misunderstanding

and stigma (Bergsma, 1974). One state enacted a law requiring any child found to be a carrier of the sickle cell gene to be vaccinated before admission to public school even though this would have no possible prophylactic effect! Companies and government agencies such as the Department of Defense enacted discriminatory policies which excluded African Americans from jobs or promotions based on flawed and confused misunderstandings about the genetic basis of disease (Lappé, 1984; Duster, 1990). Efforts to create mass screening programs aimed at particular groups in an atmosphere of uncertainty about the meaning of genetic information as well as prejudice and bias resulted in a great deal of confusion, harm and misunderstanding.

Inquiry into behaviors such as criminality, intelligence, aggressiveness, homosexuality, altruism and mathematical skill and their prevalence in various ethnic or racial groups have been and continue to be the source heated debate within and outside the scientific community in the United States and many other nations. While careful inquiry into these subjects is certainly appropriate, it is also the case that the results of such inquiries must be handled with great caution since racism and prejudice are still with us. For example, many women continue to this day to have abortions upon learning that the fetus they are carrying a child who is 47XYY, a condition which some geneticists maintained more than a decade ago was causally responsible for criminal conduct. While the evidence for the 'criminal chromosome' has proven weak the consequences for procreative decisions have proven to be very resilient. There are many genetics screening programs in India, Canada and other nations which will provide prenatal screening and testing services to couples seeking to abort any fetus which is female, no questions asked (Kumar, 1985). There is no evidence from the realm of genetics that

demonstrates that being female is a disease. Nonetheless, genetic information can have direct and dire consequences for female fetuses if it is simply dumped into the public arena where bias and prejudice are allowed to mix with information about heredity.

Racism, prejudice and genetics have made for a socially combustible and often deadly mix. The mixture has proven so toxic that a strong case can be made that applying knowledge from the realm of human genetics to public policy has led to far more misery, confusion and suffering in the twentieth century than it has to human betterment. History suggests that there are real reasons for concern about the impact a rapid increase in knowledge about human heredity might have on current and future social policy. This is especially true in light of the fact that those who proudly espouse racism continue to invoke the terminology of genetics to support their views (Applebome, 1991).

But is it really fair to assess the implications for human groups and populations of the genome project solely on the basis of history? After all, Nazi racial hygiene, while accepted by many scientists of that era as valid, is understood today to be invalid. And the genetics reflected in Nazi social policy simply is an instance of biomedical information being applied in a political state gone mad. The eugenic dreams of some biologists and physicians concerning prophylactic sterilization that led to government sponsored programs of coercive surgery in many regions of the United States combined what we now recognize as fallacious science with overt prejudice. Why should we let the errors of the past be our guide to the ethical implications of current work in genetics when we are no longer bound by

crude knowledge concerning human heredity, the yoke of totalitarian ideologies or the overt, scurrilous prejudices of our parents and grandparents?

Ironically, the only way to understand the significance of the past with respect to justice and genetics in thinking about the implications of the human genome project for various groups and sub-populations may be to look forward into the future. By trying to imagine how our own, more sophisticated (at least hypothetically), more humane (at least arguably) and tolerant values (at least hypothetically) might combine with new less error-laden (at least hypothetically) genetic knowledge to produce a range of consequences for various groups thirty or fifty years from now, we might be in a better position to evaluate the lessons taught by historical experiences of the past.

II. The Future Implications of the Genome Project for Minorities and Groups

Imagine the year is 2030. It is ten years after the completion of the complete genome maps for human beings, fruit flies, slime molds, carp, the roundworm, the Norway rat, the dog, the chimpanzee and a large number of viruses and bacteria. Much work has been done to try and analyze the connections between structure and function in these genomes and to examine how the information contained in the genome interacts with the environment to mediate ontogenesis across a whole range of characteristics and behaviors.

Not only are a large number of 'archetypical' maps on hand for a large number of animal and plant species but, a large number of regional maps, what are called 'demic' maps, have also been compiled. These provide an overview of key areas of the genome in various races and sub-populations (demes) in animal species and in various racial and ethnic groups in the human population. The maps provide information about the precise degree of variation that exists within sub-populations at certain key loci. The X and Y chromosomes have been analyzed down to the finest detail. What sorts of policies and issues might have evolved by this point in time? What sorts of implications would this knowledge have for equity, fairness and justice? Consider six possible case scenarios that might be occupying the attention of the bioethicists of the twenty first century.

Case #1 Who is a Jew?

A certain Avram Kaplan has decided to immigrate from his home in Minnesota to Israel. He can no longer stand the sterile, artificially controlled climate of his home state and wants to go back to a land that has been preserved in a relatively pristine, natural and peaceful state by international accords. He knows that, as a Jew, he has the right to return to Israel as a citizen. But he faces a problem. His grandmother on his mother's side was not Jewish.

The Orthodox rabbinate in Israel, who set policy on matters regarding the law of return, insist that every person invoking the law of return to enter Israel as a citizen undergo genetic testing. The Israeli government maintains a large

computerized registry of demic maps obtained from the genomes of Jews from various parts of the world. Whenever an immigrant arrives, a tissue sample is taken and the genetic material from the cells is used to cross-check claims of Jewish identity with the deme maps in the registry. By examining the X chromosome it is possible to identify markers which show whether a man did or did not have a 'Jewish' mother or is of Jewish matrilineal descent.

There has been much criticism of the idea within and outside of Israel that there are ideal or 'typical' maps for different races or groups but, since these same maps are widely used in molecular anthropology, forensic biopsychology and biological archeology it is difficult to argue that the systematics used in those fields are of no utility in the realm of public policy. Many governments and the United Nations have sanctioned the use of genomic archetypes to help resolve land conflicts and ancestral ownership claims among Tibetans and Chinese, Azeris and Armenians, Serbs and Croats, and among those in Poland, Russia and the Ukraine who claim German citizenship on the grounds that they are ethnic Germans. The secular law in many nations including the United States has long recognized archetypical and demic matching as legitimate techniques for establishing individual identity.

Is it fair for genetic testing to be used for the purpose of identifying who is and is not a 'real' or 'true' member of a racial group? Should those doing tests agree to do them for non-medical, non-health related reasons? Should religious authorities in nations where ancestry is seen as relevant to the religious or social standing of a person be discouraged or encouraged to use genetic testing to remove uncertainties?

Case #2--Affirmative Action

Sally Hightower was thrilled to learn that the United States government had started a new program to try and encourage Native American people to enter the field of philosophy. The demand for teachers of philosophy had escalated dramatically with the shift in demographics toward a much older society. Sally was certain she could qualify for the scholarship since she had long been active in her tribe. She was on the tribal council, had participated in numerous interviews with anthropologists and oral historians seeking to record Native American ways of life and was one of only a handful of people remaining fluent in her tribe's language. She had long had an interest in ethics and was eager to take advantage of the opportunity to go to college.

Federal regulations required sequence matches on at least six key marker areas of one of the Native American sub-population maps in order to qualify for the program. All applicants were required to submit a blood sample for use in determining eligibility for affirmative action programs such as this one.

When Sally's DNA was extracted from the refrigerated blood sample she sent to the Bureau of Indian Identity and Affairs in Washington it failed to achieve the requisite number of matches. Unbeknownst to her, she had quite a bit of white ancestry. The government was uncertain about what to do with respect to her application since it would be politically difficult to turn down a person as prominent in Native American affairs as Sally on the grounds that she failed to satisfy the biological test requirements federal law mandated in

order to be classified as a Native American. Sally would also be uncertain as to what to make of these test results. Should she resign her position on the tribal council? Was she deceiving her closest friends if she chose not to reveal her white ancestry?

Is it fair to use information about the genetic makeup or composition of a population to establish membership in a racial, ethnic or tribal group? Should social policy allow people to define themselves on the basis of culture and behavior as belonging to a particular group or is biological inheritance a key element of membership as well? Should such tests be required for the purposes of determining eligibility for affirmative action or equal opportunity programs. Would such evidence be admitted or even required in discrimination suits?

3. The Real Scoop on Jimmy Carter

By the turn of the century so many scientists, conspiracy theory buffs, biographers and media organizations were seeking samples of Presidential tissue for genetic analysis at the Smithsonian that the National Presidential Tissue Sample Registry had been established with strict rules governing access, disclosure of findings and the collection of new materials. Some samples, such as Lincoln and Kennedy, were of enormous interest. Others, such as Chester A. Arthur and Franklin Pierce drew very little attention.

The registry had a number of thorny issue to contend with concerning the control of information about public figures. The discovery of the source of Gerald Ford's lack of balance as resulting from a congenital neurological

defect had created such a stir among his descendents that the museum felt it could no longer honor every request for cells or tissues. The decision by President Bush not to permit a tissue sample to be kept in the registry in order to protect his and his family's privacy had led the Smithsonian to call for legislation guaranteeing a fifty year ban following the death of the source of tissues before they would be made available to the general public for analysis.

But now the museum faced a very tough problem A researcher at Emory medical school who was interested in the genetics of the pancreatic cancer that had ultimately caused Jimmy Carter's death had inadvertently found a marker on a segment of Carter's DNA that suggested he might have had a distant relative who was African American. Should this information be released to the family? Should the general public be told? How should unintentionally acquired information about race or ethnicity be handled in terms of privacy, confidentiality and disclosure?

4. Immigration and human disease vectors

North American immigration authorities did not like the policy which forbid those of Haitian ancestry to enter the United States and Canada but they enforced it. When it was found, five years earlier using genome maps and genetic autopsies, that poor Haitians of African descent were especially likely to be carriers of mitochrondrial prions which had long been implicated in the transmission of degenerative diseases such as multiple sclerosis, some forms of arthritis, some cancers and lupus, governments all around the world restricted their right to freely visit or immigrate. The policy required a quick-scan, genetic screen to be run on all non-whites living outside North America

to establish racial and ethnic identity and ancestry. This took time, was costly and led to a large number of fights and arguments between immigration authorities and would-be immigrants.

The immigration authorities were not wild about having to handle and risk coming into physical contact with infected or potentially infected tissue specimens. It was not clear that the level of risk or danger to the public health would justify restrictions on freedom of movement for various groups and sub-populations within American society. Nor was there any consensus about when public health officials, technicians doctors, police or other government officials could be forced to come into contact with individuals suspected of being 'biologically dangerous'. Since these groups did not have to interact with those deemed biologically dangerous by court order except on a voluntary basis it was difficult to find a legal basis to compel interaction in the face of possible risk.

Is it possible that certain groups of people mind find themselves labelled as dangerous to others by dint of their biological makeup? What would the legacy of current disputes about the duties of health care providers and others to interact with persons known to be HIV-infected be when advances in genetics make it possible to make very precise determinations as to who is and is not likely to transmit disease?

5. Public Health and good mating practices

The newest virtual reality tapes (VRs) on marriage and child-bearing from the Minnesota Department of Health and Procreation were ready for

distribution (Lancet, 1991). They warned young people about the economic consequences for the state and for themselves of reproducing without a genome test. The public service VRs made a very persuasive case that certain groups known to be at high risk of bringing children into the world with disabling and costly disorders and defects such as diabetes, gout, deafness, migraines, panic disorders and allergies, should get a complete genetic analysis before mating and procreating. Strong reinforcement stimuli including subliminal messages were used to urge young couples to get an embryo biopsy before sending their offspring off for incubation at the fetal nursery.

Many civil libertarians were aghast at the idea that the state could coerce reproductive behavior. While no one disagreed about importance of using genetic information to encourage responsible parenting, it seemed wrong to many for the state to try and compel such behavior. Yet, since there had been no effort to create a right to privacy following the dismantling of Roe v. Wade in the mid-1990s, it was almost impossible to find a basis to protect procreative liberty against the interests of the state in protecting the public good. Mandating the provision of information about who was at risk of procreating a child with a problem and the financial consequences of an unfortunate pregnancy outcome seemed the only way to handle ethically the question of individuals and groups at risk of passing on deleterious genes.

When should the state be allowed to encourage or require genetic testing, screening or counseling? What conditions merit such activities? And what rights will individuals and families have to assert their rights to reproduce in

the face of an overwhelming state interest in minimizing the burden of disease and disability on the community?

6. Mass screening for bad blood

The National Health Insurance program announced its intent to create a screening program to detect genetic markers associated with especially high risk for high blood pressure. The burden imposed by illnesses related to high blood pressure, such as diabetes and stroke, was such that the program sought to screen all groups believed to be at higher than average risk for the disorder. Broad screening would permit early intervention using psychological as well as pharmacological methods. But the program had limited funds to carry out screening, counseling and follow-up interventions. Since it had been established in the nineteen seventies that African Americans were at especially high risk of high blood pressure (Tyroler and James, 1978; Harburg et al., 1978), the program intended to make this group the first population targeted for screening and intervention.

The federal insurance program was built on a two-step strategy. The program would provide information on stress management, relaxation, as well as free medications which could lower blood pressure with only minimal risks of side effects. Higher premiums would be charged those identified at high risk who fail to responsibly manage their blood pressure.

Would it be ethical to target a particular racial group whose membership is defined by culture and history, for genetic screening? Should such programs be undertaken if there are penalties attached for non-compliance? What will

greater information about the risks created by one's genetic makeup do to our understanding of the concepts of personal responsibility and voluntary choice?

III. What Is A 'Race' and Who Are the Members?

There are a number of issues raised concerning justice, fairness and equity for minority groups that arise from these six cases. Emerging knowledge about human heredity will have enormous implications for the use of genetic information to classify human beings, understanding the reality and legitimacy of racial and ethnic classification schemes, the purposes for which testing and screening are done, the selection of traits to screen, and the need to protect privacy and confidentiality. The extent to which beliefs about heredity and human genetics have been used, abused and misused in the past indicate how important it is that discussion begin now about the normative and prescriptive stance that is appropriate for shaping social policy in the light of rapidly expanding knowledge of the genome in the future.

Perhaps no question is more pressing from the point of view of ethnic and racial minorities than understanding the ways in which new genetic knowledge will shape their self-understanding and social standing. Should knowledge generated by the genome project be used to identify, classify or label racial or ethnic groups or to establish the boundaries of their membership? When screening programs are undertaken for groups should the traditional cultural and political definitions of race and ethnicity prevail or will--and to what extent can--biological definitions be used? Will the information generated by the genome project be used to draw new, more

'precise' boundaries concerning membership in existing groups? Will individuals who have tried to break their ties with their ethnic or racial groups be forced to confront their biological ancestry and lineage in ways that clash with their own self-perception and the lives they have built with others?

It might be argued that it is morally acceptable to use genetic information to classify groups of human beings for scientific purposes but, perhaps, not for use solely in the service of social, community or public policy goals. However, since there may be very real benefits associated with the compilation of information about the medical or psychological needs of certain groups a better principle might be to avoid testing except in so far as it is undertaken with the goal of benefitting the individual being tested or the group of which that person might be a member. Health care professionals in particular will need to be cautious about allowing themselves to be cast into the role of using genetic information for purely social purposes if they hope to retain the trust of minority group members.

While it is possible that the genome project will reveal huge amounts of variation and difference among the genotypes of those persons who are currently lumped together as being in the same ethnic or racial group based upon their phenotypes, it is also likely that some genetic information will be found to be unique or prevalent among the members of certain groups. If this is so, then the temptation to cluster groups in the light of this information may well be unavoidable. Those taking genetic tests may have to be fully informed about the possible threat to self-image and sense of personal identity that genetic testing may pose. Warnings--genomic

informed consent--about the possible impact of genetic testing and screening for an individual in terms of their self-worth, self-esteem and sense of personal security may have to become commonplace in the not so distant future.

Because of the many possible invidious uses of genomic profiling, the principles of autonomy and informed, voluntary choice will have to be used to regulate the collection and use of genetic information for the purposes of classification. If individuals have a right to their genetic privacy, then new genetic knowledge should not be used to classify those who do not wish to be classified (e.g., children from what we now term 'mixed' marriages, potential donors of organs or tissues, or those who for personal reasons do not want their ancestry known to others). Nor should genetic information be used for social policy purposes unless it is shown to be absolutely necessary as a precondition for expanding opportunities or benefits to the members of certain groups and then, only if the information is obtained and used with the express permission of the source of the genetic material. The lessons of history count as stern cautions in favor of these broad recommendations. One shudders to think what the use of genetic information based upon the genome might have meant in terms of social policy in Alabama in 1890, Germany in 1939, or South Africa in 1970.

Some attempt must be made to decide what purposes justify genetic screening and the storage of genetic information targeted toward specific racial or ethnic groups. One possible moral stance is that those in biomedical science and health care will not screen groups or populations unless it is for the benefit of those in the group or other members of the same group in the future. Non-

therapeutic testing and screening must be approached with great caution, especially in the light of the historical abuse of genetic information by those responsible for social policies in the past and the potential for abuse that will be possible in the not so distant future. Those involved in public health will need to understand their duty to protecting the interests, dignity and rights of individuals against the desire of the community or the state to obtain information that could be used to enact social or financial policies that might be advantageous to many but with a great cost to a few.

The selection of traits, behaviors and properties to identify, screen and classify should be driven by a concern to identify what is incapacitating, disabling or damaging to the members of groups rather than merely what is characteristic, distinctive or typical of a group. The classification of human beings into groups, races, sub-groups and ethnic groups must be undertaken with great care. The ethics of human systematics that will emerge is likely to become one of the greatest moral challenges to face those involved with the human genome project.

IV. Race, Class and Genetics in the Here and Now.

The hypothetical case studies raised earlier in this essay present obvious challenges to the ways in which new knowledge about heredity will impact public policy, our notions about race and the ethics of health care. But, one need not await new knowledge about genetics to see how information about biological differences influences and shapes the distribution and allocation of resources to the members of racial and minority groups. The allocation of organ and tissue transplants is currently extremely sensitive to the nature of

group-based biological differences in ways that raise important questions about the ethics of using emerging genetic information concerning human populations.

Study after study has appeared in recent years showing that access to cadaver kidneys for transplants for those in renal failure does not reflect the actual need for kidney transplants in the general population in the United States (Kusserow, 1990). African Americans are under-represented relative to the percentage of whites with renal failure who receive transplants. While many explanations have been advanced as to why the difference in rates of kidney transplantation exist between blacks and whites, including differences in the age of onset of renal failure, differences in the type and severity of the illnesses causing renal failure and socioeconomic differences which are thought to correlate with compliance and, thus, with the efficacy of kidney transplantation, one key reason for the difference in rates between the races is the reliance of many programs on antigen matching in determining who will receive priority for available kidneys.

Certain crucial biological markers have been identified in key components of the immune system, the lymphocytes, which are fairly predictive of whether or not a particular organ from a particular person will trigger a strong immunological reaction in the recipient. When a cadaver donor is identified and permission given to procure a kidney, surgeons remove the kidneys and, if possible, lymph nodes in order to maximize the chances of obtaining a sample of healthy lymphocytes in order to allow for the identification or 'typing' of antigens. Standard classification systems have evolved for categorizing characteristics markers found on well mapped areas of these

antigens. Many transplant surgeons look for the best possible match between donor and recipient on the A, B and Dr loci even though these are not the only areas governing immunologic resistance. By mixing lymphocytes with various known forms of human sera it is possible to determine the degree of biological similarity between donor and recipient on these important loci.

The reliance on tissue typing is believed by many to correlate with increased chances for successful engraftment in kidney and other forms of transplants (Vichinsky, 1990). Many studies show that significant differences, between five and ten per cent, in outcomes at one year and five years survival can be shown for kidneys transplanted between donors and recipients who are biologically similar to one another. Full matches at the A B and Dr loci, which are rarely occur due to the enormous variation that exists among the immune systems of human beings, have such marked success in terms of graft survival that the current national system in the United States and those in Europe for distributing organs mandate that a cadaver kidney always be made available to a recipient who is a full match for it.

In terms of equitable distribution of kidneys among blacks and whites, the use of antigen matching as a critical factor in allocating kidneys to those in need means those who are members of minority groups will have a lower probability of receiving a transplant. Since antigens are closely linked to race and ethnicity it is much easier to find a biological match among persons with similar ethnic and racial backgrounds than it is among any two randomly selected individuals. Using tissue matching, organs from blacks will almost always go to blacks and organs from whites will almost always go to whites. Blacks however, have a much higher incidence of kidney failure than whites.

But, since whites significantly outnumber blacks in the American population, there are still large numbers of whites waiting for organs. There are so many, in fact, that nearly every white donor is matched to a white recipient. Blacks and other minorities must rely on a much much smaller pool of kidneys. Matters for potential black kidney transplant recipients are made even worse by the fact that blacks have a lower rate of cadaver organ donation than do whites. So there is a disproportionately small share of black cadaver kidneys available for a disproportionately large group of blacks in need of kidney transplants. By deciding to use biology in the name of efficacy and, it must be added, fairness, whites wind up with a much larger number of kidney transplants then do blacks relative to the incidence of renal failure in both groups.

The reality of the dilemma that exists between between being guided by considerations of efficacy and equity in the allocation of cadaver kidneys for transplantation today is likely to become all too familiar as new knowledge about genetics points the way toward the more efficacious use of medical resources tomorrow. The challenge societies will face is deciding to what extent the values of equal opportunity and fairness justify modifications in policies which aim at the maximization of effectiveness when it is biology that influences the chances for success. Whatever the answer offered in response to situations in which biology points in one direction concerning effectiveness but notions of opportunity and fairness point in another, it is important that the answer be formulated publicly so that those whose interests are at issue can demand accountability from those who must ultimately decide.

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RULES FOR "GENE BANKS":

PROTECTING PRIVACY IN THE GENETICS AGE

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Medical information is becoming less protected and private in the United States.[1] Anne Sexton's biographer, Diane Wood Middlebrook, for example, was supplied with 300 audiotapes of sessions she had with her psychiatrist, Martin Orne. Dr. Orne not only thought it was ethically acceptable to breach his patient's confidentiality in this way, he wrote the forward to the biography itself that begins with a description of "my first therapy session with Anne Sexton."[2] Although he contends Anne Sexton would have consented to the release of her medical records, she never did during her lifetime, and in fact released only four of the tapes to the University of Texas which holds her papers.

Similarly, two days after Magic Johnson announced that he was infected with HIV, the physician who did the confirmatory blood work in New York released confidential medical information about Magic to New York Times reporter (and physician) Lawrence Altman, which information was printed without comment on the violation of privacy and confidentiality involved[3]. Four months later, when Altman wrote a front page story in the Times about Presidential candidate Paul Tsongas's treatment for cancer and prospects for continued health, he made it clear that Tsongas himself had authorized his physicians to discuss the details of his treatment and current state of health.[4]

Presidents and presidential candidates seem to have accepted the reality that they cannot claim the privacy of the average American. But the privacy of average Americans itself is

increasingly at risk, and Americans seem to know it. A Time poll, for example, found 83% of Americans believing that companies should be prohibited by law from selling medical information about individuals, and 93% believing that individuals should have to give their permission before such information could be made available.[5]

Promoters of the human genome project are not unmindful of the public's concern or of the potential for harm that unauthorized access to genomic information could produce. At an October, 1991 congressional hearing, for example, NIH Director Bernadine Healey testified that, "Like all powerful tools, genetic information can be misused and abused. Discrimination based on genotype must be prohibited as a matter of basic civil rights."[6] And James Watson added at the same hearing, "The idea that there will be a huge databank of genetic information on millions of people is repulsive."[7] Why is such a databank repulsive, and what (if anything) can be done to safeguard the genetic privacy of individuals in the genetic age?

The human genome project has the potential to radically alter our views of privacy because control of and access to the information contained in an individual's genome gives others power over the personal life of the individual. Genetic information also has its own unique privacy implications, in that much genetic information about an individual will also provide personal information about the individual's parents, siblings, and children. This potential power is so pervasive that personal

liberty can be protected only by stringent safeguards on access to and use of genomic information. Current policies and practices governing the privacy and confidentiality of medical information are woefully inadequate to protect personal privacy and liberty in the new genetics age. Therefore, new rules for "gene banks" (DNA storage facilities) are needed now to help minimize the harm to individual privacy and liberty that storage of genomic information could produce.

Current Law and Practice Involving Medical Records[8]

As society becomes more and more dependent on large information systems, two conflicting trends have emerged. The first trend, exemplified by state and federal Freedom of Information and Sunshine Acts, is to provide the public access to information held by governmental agencies. The premise is that public knowledge of the most intimate details of how government works is likely to make government more responsive to the will of the people and to prevent official wrongdoing (such as trading arms for hostages). The second trend is exemplified by state and federal laws (such as the federal Privacy Act) designed to protect information about individual citizens from public disclosure. Details remain to be worked out in many areas. There is, however, a consensus that in all personal data-keeping systems, such as credit, insurance, education, taxation, criminal, and medical, individuals have or should have a right to

examine and correct the information and, under most circumstances, to prevent its release without their knowledge and express consent.

Medical records have been the last to come under public scrutiny, perhaps because medicine has a tradition of "keeping confidences." But now that sole practitioners have become an endangered species, record keeping in medicine resembles other massive record-keeping systems. Accordingly, many of the rules applied to these other systems will likely be applied to medical records as well. The concept of confidentiality of medical records has been much more discussed than litigated, and only a few dozen cases have reached the appellate court level. The law in this area is still in its infancy, and resort to public policy arguments and analogy is often necessary.[9]

Almost all of the law dealing with access to medical records by persons other than the patient can be categorized under the headings of confidentiality, privilege, and privacy. As commonly used, to tell someone something in confidence means that the person will not repeat the information to anyone else. *Confidentiality* presupposes that something secret will be told by someone to a second party (such as a doctor) who will not repeat it to a third party (such as an employer). Relationships such as attorney-client, priest-penitent, and doctor-patient are confidential relationships. In the doctor-patient context, confidentiality is understood as an expressed or implied agreement that the doctor will not disclose the information

received from the patient to anyone not directly involved in the patient's care and treatment.

A communication is privileged if the person to whom the information is given is forbidden by law from disclosing it in a court proceeding without the consent of the person who provided it. *Privilege*, sometimes called testimonial privilege, is a legal rule of evidence, applying only in the judicial context. The privilege belongs to the client, not to the professional, although the hospital, physician or data bank may have a duty to assert it on behalf of the patient. Unlike the attorney-client privilege, the doctor-patient privilege is not recognized as common law and therefore exists only if a state statute establishes it (most states have such statutes).

There are at least four senses in which the term *privacy* is generally used. The first three describe aspects of the constitutional right of privacy. The central one, in the liberty interests protected by the Fourteenth Amendment, is the right of privacy that forms the basis for the opinions by the U.S. Supreme Court limiting state interference with individual <u>decisions</u> concerning birth control and abortion. This sense of privacy involves liberty because it specifically relates to an individual's ability to make important decisions that intimately affect one's personhood free from government interference. The second and third types of constitutional rights protect certain <u>relationships</u>, like the husband-wife, parent-child, and doctor-

patient relationships, and certain places, such as the bedroom, from governmental intrusion.

In the more traditional sense, the right to privacy has been defined as "the right to be let alone," to be free of prying, peeping, and snooping, and as the right of someone to keep information about himself or his personality inaccessible to others. In Privacy and Freedom, Alan Westin defines privacy as "the claim of individuals, groups, or institutions to determine for themselves when, how, and to what extent information about them is communicated to others.[10] He goes on to argue that, as thus defined, the concept has its roots in the territorial behavior of animals, and its importance can be seen to some extent through the history of civilization. Specific protections of privacy were built into the Constitution by the framers in terms that were important to their era. With the subsequent inventions of the telephone, radio, television, and computer systems, more sophisticated legal doctrines have been developed in an attempt to protect the informational privacy of the individual. Many diverse acts come under the heading of privacy violations, but most involving medical records are in the area generally described as the "publication [disclosing to one or more unauthorized person] of private matters violating ordinary decencies."[11]

A court can conclude that the unauthorized disclosure of medical records (including genomic information) is an actionable invasion of privacy even without a state statute that

specifically forbids it. As an Alabama court put it in a case involving disclosure of medical information by a physician to a patient's employer: "Unauthorized disclosure of intimate details of a patient's health may amount to unwarranted publication of one's private affairs with which the public has no legitimate concern, such as to cause outrage, mental suffering, shame, or humiliation to a person of ordinary sensibilities."[12]

The policy underlying the right of informational privacy is that because of the potential severe consequences to individuals, certain "private" information about them (such as their HIV status) should not be repeated without their permission. In the words of one legal commentator, "the basic attribute of an effective right of privacy is the individual's ability to control the flow of information concerning or describing him."[13] Most of the cases in the doctor-patient context alleging violation of the right to privacy have involved actions in which personal medical information has been published in a newspaper or magazine, and often the suit is against the publisher rather than the physician. In the specific case of genomic information, informational privacy, relational (family) privacy, and decision making privacy all overlap, creating arguably unique privacy concerns.

The Case of DNA Profiling and Criminal Gene Banks[14]

Medical records are the major analogy used for DNA samples, but their use as criminal records is becoming widespread as well.

The banking of DNA samples is useful primarily because of the technique of amplification, known as polymerase chain reaction (PCR), which permits small quantities of DNA to be multiplied into large quantities with relative ease. As this applies to criminal investigations, it means that DNA samples in trace materials (such as, semen, blood, hair) found at the scene of a crime can be compared with DNA samples from crime suspects. In addition, files of DNA samples could be used like fingerprints to run samples from a crime scene against. This technology is extremely attractive to law enforcement officers, and has already been used in ways that help explain why an individual might be concerned about the banking of samples of his or her DNA. DNA typing is based on the assumption that a combination of specific repetitive DNA sequences ("variable number of tandem repeats" or VNTRs) in a person is extremely unlikely to match the DNA of anyone else.[15]

A suspect may be placed at the scene of the crime in a number of ways. The most common is by an eyewitness. But eyewitnesses are notoriously unreliable, and most prosecutors prefer to have eyewitness testimony supplemented by physical evidence such as fingerprints or footprints. In violent crimes like rape and murder, the perpetrator may leave his sperm or blood behind, or carry away some of the victim's blood on his person. Using ABO blood groups, individuals can be <u>excluded</u> as suspects, because their blood types do not match the sample left at the scene of the crime. Using DNA typing, however, it has

been suggested that suspects can be conclusively identified as the source of blood or sperm. This type of identification has been hyped by law enforcement officials as the ultimate law enforcement tool, and its first use to help solve a murder case is graphically chronicled in Joseph Wambaugh's best seller, The Blooding. A California Department of Justice official predicts that "in a few years, a crime-scene sample will tell a suspect's race, eye color, hair color and even his build." Others see DNA samples as eventually being fed into a computer that will decode them and produce "an image like the kind our police artists do now."[16]

There is general agreement that DNA profiling or fingerprinting can accurately exclude individuals from being possible suspects of specific crimes, and it should continue to be so used. On the other hand, problems have been demonstrated with some of the methods used (which have not been standardized) by the country's major private testing laboratories, and ultimately there must be national standards on laboratory procedures. In addition, issues of population genetics (used to determine the probability of a match by chance) will have to be resolved, at least until actual sequencing of the samples can be performed for comparison.

U.S. courts agree that DNA profiling itself is scientifically-accepted, but are currently split on the proper evidentiary standard to use in admitting DNA fingerprinting for use by the jury in a criminal trial, although the majority admit

such evidence under either standard. A January 1992 decision by the U.S. Court of Appeals for the Second Circuit may set the standard.[17] The court rejected the traditional (and still majority) "Frye rule" in which admissability of novel scientific information is not permitted until the technique has been "sufficiently established to have gained general acceptance in the particular field in which it belongs."[18] This standard would require acceptance of population-based probability as determination as well. Instead of this "general acceptance" standard, the court adopted the newer standard of the Federal Rules of Evidence (Rule 702) which treats scientific evidence no different than any other evidence:

> If scientific, technological, or other specialized knowledge will assist the trier of fact to understand the evidence or to determine a fact in issue, a witness qualified as an expert by knowledge, skill, expertise, training, or education, may testify thereto in the form of an opinion or otherwise.

Under this rule, according to the court, it is not for the judge to decide if what the expert says is "true," only if the expert's testimony can assist the jury in discharging "its duties of weighing the evidence, making credibility determinations, and ultimately deciding the facts." The court, noting the tendency to liberalize admissibility rules and let the jury decide, concluded that it did not think "that a jury will be so dazzled or swayed as to ignore evidence suggesting that an experiment was improperly conducted or that testing procedures have not been

established." But the court decided to go much further than simply affirming the decision of the trial judge (whose procedure they concluded would also have satisfied the Frye rule) , and rejecting the Frye criteria, concluded that for future cases in the Second Circuit:

> ...a court could properly take judicial notice of the general acceptability of the general theory and the use of these specific techniques (of DNA typing) ...the threshold of admissibility should require only a preliminary showing of reliability of the particular data to be offered, i.e., some indication of how the laboratory work was done and what analysis and assumptions underlie the probability calculations.

The court went on to acknowledge the subpopulation problem, noting that "The probability data may well vary among different segments of the population," but concluded nonetheless, "affidavits should normally suffice to provide a sufficient basis for admissibility."

Some states are now conditioning parole on the deposit of a DNA sample with the police (in most cases for sex offenders only, but it seems inevitable that all felonies will soon be included, and then all crimes). The purpose, of course, is to "locate" the perpetrator of future sex crimes among former sex offenders. It will likely be seen as reasonable at some point in the future to have the FBI store samples of everyone's DNA (just as they now have a large proportion of the population's fingerprints) to make the job of law enforcement easier. Who, but criminals, could object? One problem is that this treats everyone in the U.S. (whose DNA is on file) as a crime suspect, making us a "nation of suspects."[19]

The more generic gene bank problem is that once a governmental agency has a DNA sample, it can learn much more about the individual than just whether or not their DNA "matches" that taken from a crime scene. The agency can not only discover the genetic makeup of an individual, but also, in the future, may be able to learn about genetic predispositions - the probability of an individual developing a specific (in fact, many specific) genetically-determined or genetically-influenced diseases. There are currently no standards for such criminal DNA banks. Accordingly, it seems most prudent at this point to limit the information that law enforcement officials can store on convicted felons and others to the actual sequences of portions of their DNA (digitalized for computer storage and use), and not to an actual DNA sample which can be used for a multitude of privacy-invading, non law-enforcement purposes.

DNA as a Future Diary

We can now see that gene banks contain information that is significantly more personal and private than both fingerprints and medical records. For whereas a medical record contains information about one's past, a DNA molecule contains information about one's future as well. A medical record can be analogized to a diary; but a DNA molecule is much more sensitive. It is in a real sense a "future diary" (although a probabilistic one), and it is written in a code that we have not yet cracked. But the

code is being broken piece by piece (and this is the major goal of the human genome project) such that holders of an individual's DNA will be able to learn more and more about that individual and his or her family as the code is broken.

It seems reasonable to conclude that the mere existence of the technology to "decode" one's DNA will lead us to radically alter our view of informational privacy. In the past we have put special emphasis on information that is potentially embarrassing and sensitive (such as sexually transmitted diseases), and on information that is uniquely personal (such as a photograph of one's face). Genetic information is both potentially embarrassing and uniquely personal. It seems likely that either the existence of such decodable information will impel us to take privacy much more seriously in the genetic realm than we have in the medical and criminal realms, or lead us to give up on maintaining personal privacy altogether. This latter response seems defeatist and unlikely. On the other hand, the success of TV programs like Geraldo Rivera and Oprah Winfrey, which flourish on ordinary Americans discussing the intimate details of their sex lives and family problems, evidences both a voyeuristic strain in many Americans, as well as an exhibitionistic trait in others. Is it too much to think that future guests may have their genomes "decoded" before a live studio audience, or that whole families might appear for a public genomic diagnosis for Oprah? However one answers these questions, the issue of privacy and liberty revolves around choice in exposing personal

information such as that contained in one's genome. What lessons can we learn from current information systems that might help us maintain control over our own genetic information?

Rules for Medical Information Systems

Rules about medical information are mostly state rules, and there has been very little serious study of the problems of medical record keeping systems since the early 1970s. At that time, when computerization of medical records was in its infancy, the U.S. Congress established the Privacy Protection Study Commission to study privacy rights and record keeping practices generically. Its 1977 report remains the most thoughtful and authoritative statement on large record keeping systems. In regard to the medical records, the Commission found that medical records contain more information and are available to more users than ever before; that the control of health care providers over these records has been greatly diluted; that restoration of this control is not possible; that voluntary patient consent to disclosure is generally illusory; that patients' access to their records is rare; and that there are steps that can be taken to improve the quality of records, to enhance patients' awareness of their content, and to control their disclosure. Some of the commission's major recommendations are that:

1. Each state enact a statute creating individual rights of access to, and correction of, medical records, and an enforceable expectation of confidentiality for medical records.

2. Federal and state penal codes be amended to make it a criminal offense for any individual knowingly to request or obtain medical record information from a medical care provider under false pretenses or through deception.

3. Upon request, an individual who is the subject of a medical record maintained by a medical care provider, or another responsible person designated by the individual, be allowed to have access to that medical record, including the opportunity to see and copy it; and have the opportunity to correct or amend the record.

4. Each medical care provider be required to take affirmative measures to assure that the medical records it maintains are made available only to authorized recipients and on a "need-to-know" basis.

5. Any disclosure of medical record information by a medical care provider be limited only to information necessary to accomplish the purpose for which the disclosure is made.

6. Each medical care provider be required to notify an individual on whom it maintains a medical record of the disclosures that may be made of information in the record without the individual's express authorization.[20]

Of course, it is not just the storage of information that is problematic. It is the use of such information by third parties to make decisions about the future of individuals that puts an individual's privacy and liberty interests most directly at risk. The U.S. Privacy Commission was careful to specify rules for the release of data identified with a particular individual from the data bank.

The U.S. Privacy Commission discovered, for example, that often when an individual applies for a job, life or health insurance, credit or financial assistance, or services from the government, the individual is asked to relinquish certain medical information. Although this is necessary in many cases, the commission found that individuals are generally asked to sign

open-ended or blanket authorizations with clauses such as one requiring the recipient to "furnish any and all information on request."

The American Psychiatric Association took the position that such blanket consent forms are unacceptable, since they do not provide the patient the usual informed-consent protections. The commission agreed and made the following recommendations:

> Whenever an individual's authorization is required before a medical care provider may disclose information it collects or maintains about him, the medical care provider should not accept as valid any authorization which is not:
>
> (a) in writing;
>
> (b) signed by the individual on a date specified or by someone authorized in fact to act in his behalf;
> (c) clear as to the fact that the medical care provider is among those either specifically named or generally designated by the individual as being authorized to disclose information about him;
> (d) specific as to the nature of the information the individual is authorizing to be disclosed;
> (e) specific as to the institutions or other persons to whom the individual is authorizing information to be disclosed;
> (f) specific as to the purpose(s) for which the information may be used by any of the parties named in (e) both at the time of the disclosure and at any time in the future;
> (g) specific as to its expiration date, which should be for a reasonable time not to exceed one year.[21]

Patients and former patients should not sign release forms that do not meet these criteria, and health care providers should refuse to honor requests that are not at least this specific on the grounds that the patient probably did not understand what he or she was consenting to when the patient signed the form.

Health care providers should be obligated to contact the affected individual directly if they are suspicious of the quality of the consent and, thus, the legality of the release form.[22]

If these rules are reasonable (and I think they are), they lead to some even more stringent rules for the maintenance of DNA molecules which contain an individual's probabilistic future diary.

Rules for Gene Banks

Since there are no existing rules for gene banks, and since most genetic samples are now being collected and stored either by hospital-based programs, or private clinics and corporations, it seems reasonable to suggest a moratorium on such storage until reasonable rules are developed. On the other hand, because most storage (outside of law enforcement agencies) is in private hands, it seems unlikely that any agreement on a moratorium could be enforced without federal legislation. Since this itself seems unlikely, it is probably more constructive to try to get agreement on the rules all gene banks should follow with or without legislative mandate. The following rules are suggested to protect individual privacy and liberty while permitting reasonable medical research and treatment goals to be pursued:

1. No DNA bank should be created or begin to store samples until there is:

a. Public notice that the DNA bank is to be established, including the reason for the bank; and

b. A privacy impact statement is prepared and filed with a designated public agency that is also responsible for developing and enforcing privacy guidelines for the DNA bank [alternatively, a DNA bank-licensing board should be established to license all DNA banks in the U.S. with uniform rules].

c. The burden of proof should be on the DNA bank to establish that storage of DNA molecules is necessary to achieve an important medical or societal goal.

2. No collection of DNA samples destined for storage is permissible without prior written informed consent that:

a. sets forth the purpose of the storage;

b. sets forth all uses, including any and all commercial uses, that will be permitted of the DNA sample;

c. guarantees the individual: (i) continued access to the sample and all records about the sample; and (ii) the absolute right to order the identifiable sample destroyed at any time.

d. guarantees the destruction of the sample or its return to the individual should the DNA bank significantly change its identity or cease operation.

3. DNA samples can only be used for the purposes for which they are collected. Specifically, unless agreed to at the time of storage, there may be:
   a. no waivers or boilerplate statements that permit other uses;
   b. no access to the DNA information by any third party without written notification to the individual, whose sample is being used;
   c. no access by third parties to any personally identifiable information;
   d. strict security measures, including criminal penalties for misuse or unauthorized use of DNA information.
4. Mechanisms must be developed to notify and counsel those whose DNA samples are in storage when new information that can have a significant health impact on the individual is obtainable from their stored DNA sample.

Most of these proposed rules are self-explanatory. It may seem premature to develop rules or guidelines for DNA banks, but the long history of medical record keeping, the short history of DNA fingerprinting, and the intermediate history of sperm banking, has demonstrated that standards <u>are</u> necessary. Some questions these proposals have raised merit comment. First, where is the "designated public agency" responsible for developing and enforcing privacy guidelines? The response, that

there currently is no such agency, is not satisfying. There should be one, and ideally it should be a federal agency because few, if any, DNA banks will operate soley within the confines of any one state. This agency should be as independent as possible from the funding agencies (such as NIH), and should probably be located either in the National Bureau of Standards, or as an independent agency such as Nuclear Regulatory Commission.

The requirements for "informed storage" of part 2 are not remarkable, and are analogous to both medical records storage and embryo storage. Embryos are, of course, even more important than DNA samples, since they have the potential to become children. Typical storage contracts currently require the couple to agree to such things as disposition of the embryos upon the separation, divorce, or death of one or both of the couple; as well as limiting the terms of the storage and providing for other contingencies. Even more elaborate storage agreements are used when an individual wants his entire body frozen and stored for possible "treatment" at some distant time in the future. The point is not that we should treat DNA samples like embryos or bodies, but that detailed storage contracts and consent forms are not a novel idea, and can be implemented.

Part 3 is relatively standard privacy protection language, although many researchers and commercial enterprises might object to keeping track of current addresses, and of a requirement (3.c) forbidding all third party access to identifiable information. In the research context, the practice has been to appeal to the

Institutional Review Board (IRB) for such uses; but this is very unsatisfactory. The IRB did not approve the new use when the sample was collected and, of course, the individual could not have given his or her consent (at which time it will usually be just as easy to get a new sample) unless the type of research is agreed to at the time the sample was collected. Obviously, this agreement cannot be generic (e.g., "all genetic research") but could include specific types of research not currently envisioned (e.g., "all attempts to locate CF genes").

Part 4 is the vaguest, and the rule that requires the most work to make operational. Since most new genetic tests first appear in the nation's newspapers, notification may be less important than counseling options. Each DNA bank could also have a newsletter that it routinely sends to all depositors, and any new genetic tests could be described therein. It seems unlikely that the "duty to protect" the depositor's family members will ever arise at a storage facility; although research facilities may discover a genetic condition that has serious implications for family members. If this is a possibility, the facility's policy on such disclosure should be made clear at the time of deposit, so the individual who disagrees with it can keep his or her DNA sample out of the bank.

As should be evident from this discussion, these are preliminary proposals that require additional discussion, debate, and refinement. There certainly is room for this discussion. The issues at stake, however, are privacy and liberty, and

compromises in the security of the data contained in the DNA molecule will ultimately compromise the privacy and liberty of the individuals whose DNA are stored in the DNA bank. Scientists, physicians and the public should take a strong stand in favor of privacy.

In this regard James Watson's "repulsive" comments are on target. It is, of course, not the gene banks per se that are repulsive, but the seemingly inevitable misuse of the data stored in them to the detriment of individual citizens that is repulsive. For example, we may tolerate a consulting physician to Magic Johnson discussing his HIV status in the New York Times without sanctioning that same physician running a DNA profile on Johnson to discover and then disclose any genetic conditions or predispositions Johnson might carry. Likewise, some commentators have found it acceptable for Martin Orne to discuss his therapy sessions with Anne Sexton's biographer. Nonetheless, even these commentators would likely want to prohibit current biographers of Sexton from examining her DNA to discover what genetically-determined conditions she may have suffered from. This could be either out of a concern for the future privacy of all of us, or for the current privacy of Anne Sexton's children, whose privacy would also be invaded by disclosing her DNA profile. And even in the case of Abraham Lincoln, whose relatives are all long deceased, a greater justification than simple curiosity should be required for historians to be given access to his DNA.

Most of us, of course, will not be the subject of front page news stories, biographers, or historians. It will be the police, our insurance company, our employers, and our families that are most likely to seek the information encoded in our DNA. If we are to stand any reasonable chance of keeping this information confidential, we will need early agreement on some basic rules for gene banks. Without such agreement, our two unattractive alternatives would seem to be abandoning current notions of privacy and confidentiality, or outlawing DNA banks altogether.

Although written in the pre-genomic era and with no thought of gene banks in mind, some lines of Anne Sexton's poetry provide a fitting conclusion (and a hopeful note) for this chapter:

> Each cell has a life.
> There is enough here to please a nation.
> It is enough that the populace own these goods.
> Any person, any commonwealth would say of it,
> "It is good this year that we may plant again
> and think forward to a harvest.
> A blight had been forecast and has been cast out."[23]

Notes

1. A preliminary version of this paper was presented at a workshop on "The Impact of Molecular Genetics on Society," held at the Banbury Center, Cold Sprigs Harbor, New York, Nov. 5-8, 1990. I would also like to acknowledge the comments on the proposed "rules" by the participants at a AAAS/ABA Conference on Ethical and Legal Aspects of Large Pedigree Genetic Research, Wild Dunes, Charleston, So. Carolina, March 13-15, 1992, which were of great assistance in finally completing this paper.

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13. Miller, Personal privacy in the computer age, 67 Mich. L. Rev. 1091, 1107 (1968).

14. Portions of this section are adapted from Annas GJ. DNA fingerprinting in the twilight zone. March, 1990; Hastings Center Report, 20(2):35-37.

15. The standard method of DNA fingerprinting utilizes the same restriction fragment length polymorphism analysis (RFLP analysis) used in genetic testing and screening. Restriction enzymes recognize and cut specific nucleotide sequences in DNA molecules. Since the nucleotide sequences in the human genome vary widely from person to person, the

restriction sites will also vary, and therefore the length and content of the fragments. RFLP analysis rests on the finding that two samples of DNA from the same individual will produce the same DNA fragments, whereas samples from different individuals (other than identical twins) will produce different fragments from the same site.

16. Quoted in Annas, supra note 14.

17. U.S. v. Jakobetz, 1992 U.S. App. LEXIS 322 (2d Cir. 1992), cf. States v. Two Bulls, 918 F. 2d 56 (8th Cir. 1990).

18. Frye v. U.S., 293 F. 1013 (D.C. Cir. 1923).

19. Glantz LH. A nation of suspects: Drug testing and the fourth amendment; Am J. Public Health 79:1427-31; 1989. See also P. Aldhous, Challenge to British forensic database, Nature 355:191; 1992.

20. Privacy Protection Study Commission. Personal privacy in an information society. Washington D.C.: U.S. Gov. Printing Office, 1977.

21. Ibid.

22. Quoted in Annas, supra note 8.

23. From "In Celebration of My Uterus."

PUBLIC CHOICES AND PRIVATE CHOICES

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The notion that certain diseases were inheritable predated the discovery, four decades ago, of the chemical makeup of DNA. But a new scientific endeavor is underway to uncover the specific links between genes and disease. Labeled by proponents as science's "Moon Shot" and detractors as the "Manhattan Project of Science," the $3 billion Human Genome Initiative will map (that is, determine the location of) and sequence (analyze the constituent parts of) each of the 50,000 to 100,000 genes in each human cell.[1] The ultimate goal of the Human Genome Initiative is to facilitate the development of genetic diagnostic tests and genetic treatment modalities for the nearly 4000 diseases[2] which are believed to have a genetic basis. The tests will diagnose current -- and future -- diseases that do or will affect the patient. The tests will also enable couples to determine whether their conceptus suffers from a serious genetic disease, thus providing information so that the couple can decide whether to continue or terminate the pregnancy.[3]

I don't understand this. What are you saying?

See Remarks

Even before the concentrated effort of the Human Genome Initiative, predictions about genetic risks have been possible. Family histories have been used to predict the risk of an inheritable disorder. Some genetic tests are already in use to determine whether an individual or a fetus has a particular disorder, will definitely develop a particular disorder, or has a predisposition toward illness when exposed to a particular environmental stimuli.[4]

singular

US

Blood tests and tissue tests are ~~readily~~ routinely performed on children and adults to determine if they are carriers of or are themselves affected by a particular genetic disease. Testing of the fetus is accomplished through amniocentesis[5] or chorionic villi sampling,[6] both of which are invasive procedures. But less intrusive tests are currently being developed. Genetic testing can be undertaken on a fertilized embryo ex utero before implantation. Work is also underway to develop a test that would be able to identify fetal cells that are circulating in the pregnant woman's blood, thus allowing for prenatal diagnosis through a simple maternal blood test.[7]

The range of technologies for genetic testing is thus expanding. More importantly, the types of disorders these technologies can test for is also expanding.

The types of disorders tested for will go beyond rare genetic diseases to include more common diseases such as heart disease, diabetes, and certain cancers. Moreover, genetic testing is being proposed for numerous behavioral disorders such as alcoholism, manic-depressiveness, and even "risk-taking" behavior. The test may show that the tested individual will suffer from a late onset disorder: a healthy twenty year old could be told that she -- or her fetus -- will suffer from Huntington disease, a debilitating neurological disorder, 30 or 40 years hence. Or a test may show that she is at risk of developing a particular disease when exposed to environmental stimuli.

As this type of research progresses, health care providers will begin warning patients about those aspects of the environment (diet, job, climate) that could trigger a disease. Already, some physicians are advising parents of children with a genetic propensity toward skin cancer to move to an area with a rainy climate.[8] We may be asked to plan our lives around our genes.

add to previous paragraph

James Watson, co-discoverer of DNA and head of the human genome project has said, "We used to think our fate is in our stars. Now we know, in large measure, our fate is in our genes."

Although the Human Genome Initiative will be providing us with a genetic map, it will be up to the law to determine where that map leads. The policy choices are whether use of such tests should be allowed, forbidden, or required. Even if the tests are not mandated, a policy question arises about whether people should be required to provide information from tests that were voluntarily undertaken (to employers, insurers, the government, or other entities).

At least

These policy choices are not coming before us in a vacuum. Two powerful forces in the legislatures are creating pressures that will influence the policy choices that are implemented. On the one hand, the pro-life movement is pressuring legislatures to adopt laws that discourage use of prenatal screening and forbid women from aborting even a seriously ~~affected~~ defective? fetus. On the other hand, concerns about rising costs of care of people with genetic anomalies are being used by some lawmakers as a rationale to propose laws to encourage the use of genetic screening -- and to require that genetic information be disclosed to various entities such as _____ and _____. At the extreme of this position, some commentators have suggested that genetic screening on couples or prenatal genetic screening be mandatory, and that couples should be penalized if they do not use genetic diagnosis to avoid the birth of children affected with serious genetic diseases.[9] It is in this crucible of pressures that the laws fashioning genetic testing will be formed.

[affected says nothing unless you also say by what?]

Genetics and Law: An Historical Perspective

The history of the use of genetic information in this country is a mixture of private choices and public choices. In the late 1800's, a majority of the geneticists in this country believed that one could use genetic principles not only to explain physical and mental disorders, but also to explain human behavior.[10] Traits such as feeblemindedness,[11] criminality,[12] pauperism,[13] seafaringness,[14] and prostitution[15] were thought to be single gene defects. People began to make private choices about who to marry on genetic grounds, in order to avoid having a child with a disfavored trait.[16] In 1910, a Eugenic Records Office was established in Cold Spring Harbor, New York which trained field workers to collect family histories from people around the country.[17] By 1924, data on people had been entered on around three quarters of a million cards and people made inquiries to the office about whether particular proposed marriages would be eugenically appropriate.[18]

The theories of geneticists quickly served as the basis for proposals for social and legal reform. The prime thrust of the reforms was to prevent people with presumably undesirable genes from reproducing. A Chairman of the Department of Psychology at Harvard advocated "the replacement of democracy by a caste system based upon biological capacity with legal restrictions upon breeding by the lower castes and upon intermarriage between the castes."[19] The federal and state legislatures took the teaching of geneticists to heart. They passed laws to prevent people with presumably undesirable genes from reproducing, on the grounds that the care of the unfit (such as the mentally disabled) was draining society's resources.

The first eugenics law, enacted in Indiana in 1907, provided for the involuntary sterilization of institutionalized, unimprovable individuals who were idiots, imbeciles, rapists, or habitual criminals.[20] Eventually, 26

other states followed suit,[21] and at least 100,000 people were sterilized under the laws. The Nazi misuse of sterilization did not dampen the American program. In a study of sterilization laws and their implementation, Philip Reilly found that "more than one half of all eugenic sterilizations [in the United States] occurred after the Nazi program was fully operational."[22]

The impetus for the eugenics laws was, in large measure, fiscal. In the 1870's, state governments had provided extensive funding for institutions for the care of the feebleminded, but subsequently they began reassessing this expenditure.[23] Concern for the public fisc continued throughout the eugenics movement in the United States. [In the 1920's, county fairs exhibited a display which "revealed with flashing lights that every fifteen seconds a hundred dollars of your money went for the care of persons with bad heredity, that every forty-eight seconds a mentally deficient person was born in the United States, and that only every seven and a half minutes did the United States enjoy the birth of 'a high grade person . . . who will have ability to do creative work and be fit for leadership.'"[24]] At a time when attention was focused on gangsters, the American Eugenics Society told the public that crime, a function of hereditary defects, was costing the average family $500 annually.[25]

Already quoted by Kevles in his own paper [See Remarks]

Today, health care costs are again on the public agenda. In addition, other psychological, economic, and social pressures are in place, which will influence whether people use or reject genetic technologies.

Private Choices

Restrictions on the private use of genetic testing may take a variety of forms. They may occur as outright bans -- such as a ban on embryo biopsy. They may occur as barriers to the receipt of information about the existence

of a particular genetic test. They may occur as barriers to a particular use of the genetic information -- such as a ban on abortion. Or they may occur as a result of fiscal barriers which prevent access to the information, the test, or an additional action based on test results.

Bans on Certain Prenatal Testing

In the current legal climate, the use of certain genetic tests is clearly allowed. In fact, with respect to prenatal diagnosis, physicians can be held liable if they do not advise potential parents of the existence of relevant genetic tests or if they perform such testing inadequately.[26] The gravamen of this cause of action is that people could not adequately exercise their constitutional right to make reproductive decisions (such as the decision to contracept or abort) without sufficient information.[27]

Is this really a verb with present and past and future tenses?

Although prenatal diagnosis via amniocentesis is clearly allowable, bans on other types of genetic testing are in effect in some states. The testing most affected is embryo biopsy in which a woman's egg is fertilized with a man's sperm in a petri dish. One cell of the embryo is removed, with the remaining cells frozen. The single cell is tested for a variety of genetic conditions, ~~defects~~, such as Down Syndrome. Couples then decide whether they want the embryo implanted.[28]

Two states have statutes banning experimentation on embryos in language that is broad enough to forbid embryo biopsy;[29] although, in three other states that ban embryo experimentation, there is an exception for genetic testing.[30]

Another type of law that affects the use of embryo biopsy is a law, such as a statute lobbied through by a right-to-life group in Louisiana, that does not allow embryos to be terminated.[31] Thus, if a couple does learn that their

What does this mean? Destroyed by any means?

embryo is affected with a defect, the couple would not be able to terminate the embryo. They would have three options: freeze the embryo indefinitely, donate the embryo to another couple who is willing to rear a child with that defect, or have the embryo implanted in the wife and have her undergo a subsequent abortion (since the laws against terminating in vitro embryos do not apply after the embryo is reimplanted). Each of these three options present potential financial and emotional costs to the couple that they may not wish to bear.

Prohibitions on the use of in utero genetic diagnostic tests or on embryo biopsy interfere with the couple's right to make decisions about reproduction by depriving them of the means of obtaining the information necessary to make that decision. Consequently, such laws are unconstitutional unless they further a compelling state interest in the least restrictive manner possible.

In the first case of its kind, Lifchez v. Hartigan, a federal district court in Illinois in April 1990 held that the constitutional right to privacy protects a couple's decision to use genetic diagnostic tests on a conceptus, including embryo biopsy.[32] The court struck down as unconstitutional a law that forbid experimental use of such tests.[33]

In a future case, could a state demonstrate a compelling interest in protecting embryos? Probably not. Its potential interest is not justifiable as an interest in protecting life since the conceptus has not been recognized in law as a person.[34] Rather, it is an interest in protecting the conceptus as a symbol of our high regard for human life. This symbolic protection is also thought to make it more likely that we will treat with appropriate regard certain vulnerable groups in society such as seriously ill newborns, comatose individuals and elderly patients. The underlying assumption of this view is

that the conceptus, though it may not be a person, nevertheless has a special status; it is symbolic of human life, or represents life in a way which makes its destruction symbolic of the destruction of persons. Persons who hold this view claim that harm to conceptuses may influence our attitudes toward and treatment of real people -- that we may come to treat the symbolized no better than we have treated the symbol. The notion is that proscribing procedures which are potentially harmful to conceptuses is a symbolic expression of our interest in human life, an expression which may be necessary for sustaining the level of respect persons deserve.

The protection of symbols is an important part of our legal culture, but it is not sufficient to justify infringing upon a fundamental constitutional right. There is no empirical evidence that actions toward a symbolic entity influence negatively the way actual people are treated.[35] This is particularly true in the case of early embryos, which are undifferentiated cell masses and do not resemble people, so that it is unlikely that actions toward <u>in vitro</u> embryos will shape our actions toward newborns, comatose people, elderly patients, or other persons.[36] It would be unconstitutional to ban on symbolic grounds alone the use of experimental techniques on embryos, such as embryo biopsy, that further procreative decisions. However, there may be a sufficient state interest in protecting the conceptus against pain that a fetal research law that restricted experimentation after the fetus could feel pain could be justified.[37]

Some states, which do not ban genetic testing, nonetheless have adopted statutes that eliminate tort actions against physicians for providing inadequate or inaccurate genetic testing or genetic information.[38] The constitutionality of such statutes must be scrutinized as well, however. A

person's right to privacy to make reproductive decisions includes a right to information upon which to make that decision. By not allowing courts to hold physicians liable when they fail to provide that information, states with statutes prohibiting wrongful birth actions eliminate incentives for physicians to disclose such information, thus interfering with the couple's exercise of their right.[39] In an analogous situation, the Fifth Circuit Court of Appeals recognized that when the state provides inaccurate genetic information, and an individual subsequently makes reproductive decisions based on that information, the person can sue for violation of his or her constitutional rights.[40]

The purpose of statutes banning wrongful birth or wrongful life cases is to discourage abortion in order to protect the embryo or fetus. Thus, these statutes, too, unconstitutionally infringe upon the couple's rights to privacy without advancing a compelling state interest.

Restrictions on Abortion

What about, though, direct restrictions on abortion? Although the U.S. Supreme Court's decision in Webster v. Reproductive Health Services[41] indicated a greater willingness on the part of the Court to uphold state regulations restricting abortion, the Court did not overrule Roe v. Wade.[42] Even if states were, in the wake of Webster, to adopt more restrictive abortion laws, it is likely that they would nevertheless permit abortion when the fetus suffers from a serious genetic defect. Polls of the public show that 74% of Americans surveyed approve of abortion in those circumstances.[43] Even prior to Roe v. Wade, model abortion laws promulgated by legal[44] and medical groups[45] would have allowed abortions of fetuses with serious genetic defects.[46]

Although it is likely that abortions for genetic reasons would still be allowed under state laws after an overturning of Roe v. Wade, such abortions might be restricted to instances of particularly serious disorders (such as Tay-Sachs[47]). State legislatures might ban abortions when the disorder is not rapidly life-threatening, such as when a prenatal test indicates a late onset disorder such as Huntington disease, or when the disorder can be treated after birth, as with a disorder such as phenylketonuria.[48]

Fiscal Constraints

Legal barriers are not the only, or even the most serious, constraints on access to genetic testing. Fiscal constraints figure prominently since prenatal genetic screening can cost from $500 to $1000 or more. Embryo biopsy is even more expensive since fertile couples who want to use it will need to pay the costs of in vitro fertilization as well, possibly $5000. In cases where the genetic test can only be accomplished through linkage studies, the person who wants to use such testing may have to pay for the costs of all the testing done on family members as well.

The expense of genetic tests prevents many people from using them. Prenatal diagnosis, for example, is mainly used by women from the middle and upper classes.[49] This disparity has implications for public policy far beyond the area of genetic testing per se. Prior to the advent of prenatal diagnosis, a child with a genetically-based mental or physical disability could be born into a family of any socioeconomic status. Middle class and wealthier families used resources and connections to lobby state legislatures to pass laws providing for adequate education for children with disabilities.[50] With the use of prenatal diagnosis and abortion, fewer such

children are being born to couples of a higher socio-economic status. Affected children may become -- like crack babies and boarder babies -- an issue for the poor, with many fewer protections and resources available for them.

One you don't mention: the state can find ways to pay for them.

Public Choices

In contrast to the restrictions on private choices in the use of genetic testing, there are potential public pressures in the opposite direction. There are a number of ways in which the state can encourage or mandate the use of genetic testing. It can require a particular test, it can make a person liable in tort for not undertaking the test, it can allow institutions (such as insurance companies) to condition benefits on submission to the tests. At a more subtle level, it can require that people be informed about the test, or provide financial incentives for people to take the test. To the extent that these public actions interfere with private choices, they need to be justified by a strong public interest. The types of public interests usually set forth to justify such actions are the governmental concern for safety and health, and protection of the public fisc.

Mandatory Genetic Screening

While the early genetics laws in this country focussed on mandatory sterilization, more recent laws took the approach of mandatory screening. In the early 1970's, some states adopted laws mandating carrier status screening for sickle cell anemia.[51] In retrospect, this has been acknowledged to have been a disaster.[52] Appropriate counseling was not provided, and people were psychologically harmed by the information. Societal institutions did not know

how to use the test results, and consequently, carriers of sickle cell anemia who were themselves healthy were nonetheless discriminated against in insurance and employment.

Although most sickle cell screening laws have been repealed, mandatory genetic screening is currently in effect in limited circumstances. Under an Ohio law, sperm donors must be screened for genetic carrier status for disorders such as Tay-Sachs and sickle cell anemia.[53] However, such a provision is not an untoward limitation on the sperm donor since the right to be a genetic parent alone is not as fundamental as the right to be a genetic parent who ultimately rears the child.

From the standpoint of the potential rearing parents who wish to use donated semen, they are not involved in an intimate on-going relationship with the donor where they wish to pass on the donor's personal traits. They view the donated semen in the same way they view a medical treatment; they want it to be safe and effective. In that sense, they expect it to be screened for genetic defects.

But what happens when lawmakers, unschooled in the subtle distinctions between various procreative purposes, start asking, "Why should only the children of sperm donors be healthy?" What happens when they begin passing laws to require screening of potential parents who are procreating coitally? No state laws currently require women to undergo prenatal testing, although commentators have suggested legal sanctions to force people to undergo prenatal diagnosis or to abort fetuses with serious genetic defects.[54] Most likely, lawmakers have not mandated prenatal diagnosis because the currently available techniques of amniocentesis and chorionic villi sampling are invasive and present risk to the pregnant woman[55] and risk to the fetus.[56]

However, evolving techniques -- such as embryo biopsy or, in the future, maternal blood tests for fetal trophoblast cells -- may be viewed as less risky by legislators and, consequently, laws might be proposed to require such procedures in order to provide people with information about the genetic status of their fetus. Indeed, researchers working on a prenatal test that could be performed on maternal blood have suggested its suitability for mass screening.[57]

Case law establishes that a competent adult generally has a right to refuse medical care except in limited circumstances -- primarily when the person has or is likely to develop a contagious disease that would directly harm others. Even with respect to situations in which the state has been recognized to have the power to mandate treatment, the state has been incredibly circumspect in using that power. Vaccinations have been required,[58] but the government generally has not undertaken activities to track down people who might have infections and to keep them from participating in social life or force them to be treated. With respect to AIDS, people have generally not been required to be tested against their will. Although people may put themselves at risk in decisions regarding medical services, the state has been allowed to intervene when the person had an infectious disease that put others at risk due to the possibility of contagion. Some commentators argue that mandatory screening of adults for genetic disorders is justifiable under contagious disease precedents, to prevent people from "transmitting" disease to their offspring. Under the analogy of genetic disease to infectious disease, the government could order interventions on all individuals of reproductive age (since all people carry genetic defects).

The policy concerns raised by attempts to stop the transmission of genetic diseases differ from those addressed to infectious diseases because genetic diseases differentially affect people of different races. Some commentators contest the applicability of the infectious disease model to government actions regarding genetic disorders because "[u]nlike infectious disease which [generally] knows no ethnic, racial, or gender boundaries, genetic disease is the result of heredity" leaving open the possibility for discriminatory governmental actions.[59]

Most reasonable people would be horrified at the thought of forcing people to be sterilized or undergo abortions against their will for eugenic reasons. Upon first consideration, however, they may not be as troubled by mandatory screening for genetic disorders in the absence of forced sterilization or abortion. Some may even argue that mandatory screening is not an infringement on procreative rights because it represents at most a modest physical invasion (for example, a blood test) and it merely provides information which the person can use in making decisions about reproduction.

The provision of information is not a value-free act, however. People have a right to waive information -- for example, they can decide to waive the presentation of health care information before they consent to treatment.[60] In addition, the U.S. Supreme Court has recognized that the presentation of information in the context of reproductive decisions can coerce an individual to make a particular decision. Laws have been struck down as unconstitutional that required that women be given information that tended to pressure them not to have an abortion. In City of Akron v. Akron Center for Reproductive Health, for example, the U.S. Supreme Court struck down statutory provisions that required physicians to give speculative information such as the

characteristics of the fetus, including ability to feel pain and provisions that required physicians to present "a 'parade of horribles' intended to suggest that abortion is a particularly dangerous procedure."[61]

In the subsequent Thornburgh case, the U.S. Supreme Court held that the required disclosure of even information that was medically accurate and objective could be unconstitutional because it tended to influence a person's reproductive decision.[62] The Court said that "[t]he States are not free, under the guise of protecting maternal health or potential life, to intimidate women into continuing pregnancies." The Court recognized that certain information -- no matter how objective and accurate -- is not always relevant to a person's reproductive decision, and "it may only serve to confuse and punish her and to heighten her anxiety," which is contrary to proper medical care sensitive to the individual patient's needs.

Moreover, in order to reach potential childbearers, carrier status screening of adolescents in school, people of reproductive age generally, or people applying for marriage licenses has been suggested. However, such screening measures carry psychological and social risks. In a Montreal Tay-Sachs screening program, several thousand people under age 18 were screened. The adolescents screened experienced anxiety when they learned they were carriers.[63] In another study, an American adolescent reportedly suffered a psychotic reaction when she was told she was a carrier of Tay-Sachs.[64]

Probably because, in part, they were called "carriers"

Screening of adults, too, can lead to psychological trauma. Some people have committed suicide when they learned they were carriers of Huntington disease. In fact, deaths due to suicide are four times as prevalent among Huntington disease patients than among the corresponding U.S. Caucasian population.[65]

But this is everyone in either somatic or gametic ways.

In addition to presenting a psychological risk to those individuals who learn that they are carriers of genetic disorders, screening can present a psychological risk to those who find they are not carrying the defective gene. According to Nancy Wexler, when at-risk individuals learn that they are not carriers of Huntington disease, "[m]any may suffer 'survivor guilt,' particularly characteristic of wartime soldiers who live while their buddies are killed."[66]

A National Academy of Science Committee has taken the position that genetic screening should be voluntary.[67] This comports with the individual's right of self-determination. An individual may not wish to know his carrier status. Indeed, most people at risk from Huntington disease have not come forward to be tested. Mandatory screening has also been criticized because it could lead to stigmatization of carriers. For example, discrimination against people at risk for Huntington disease has already occurred.[68] If a definitive test were made compulsory, it might be used by employers or insurers to disadvantage asymptomatic carriers. Even with respect to disorders in which carrier status leads to little or no ill effects on health (such as sickle cell anemia), discrimination has resulted in the past.[69]

In the reproductive setting, mandatory prenatal screening interferes with couples' constitutional rights of privacy to make procreative decisions. The Lifchez opinion I mentioned earlier specifically held that the right to privacy specifically covers decisions concerning prenatal genetic testing.[70] Consequently, a mandatory genetic screening law will be upheld as constitutional only if it is necessary to further a compelling state interest in the least restrictive manner possible.

There are two state interests raised to justify mandatory genetic carrier screening or prenatal screening. One is the prevention of harm to third parties; prevention of the transmission of a genetic defect is analogized to prevention of transmission of an infectious disease. The other is the protection of the public fisc by providing information which may prevent the birth of a child with serious mental or physical handicaps.

With respect to other fundamental rights, such as freedom of speech, the government has only been allowed to interfere to protect against a danger that is substantial, imminent, and irreparable.[71] Arguably, that is the sort of danger that the U.S. Supreme Court envisioned when it upheld an emergency mandatory vaccination law[72] at a time when infectious disease presented a substantial threat to the community.

Certain infectious diseases potentially put the society as a whole at immediate risk since the diseases can be transmitted to a large number of people in a short time. The potential victims are existing human beings who may be total strangers to the affected individual. In contrast to infectious disease, the transmission of genetic diseases does not present an immediate threat to society. While infectious disease can cause rapid devastation to a community, the transmission of genetic disease to offspring does not have an immediate detrimental effect, but rather creates a potential risk for a future generation in society.[73] U.S. Supreme Court cases dealing with fundamental rights have held that harm in the future is not as compelling a state interest as immediate harm.[74]

It is unlikely that the government will be seen as having a legitimate interest in preventing the birth of children who are affected with genetic disorders. Given the current state of development of medical genetics, in

among those better situated classes you mentioned before.

which effective treatment for genetic disorders is rare, screening and diagnosis prenatally generally leads to abortion of the affected fetuses.

Because the state could not show that the policy improves the health of potential children, it is likely to have to fall back on the argument that such a policy advances a state interest in saving money. However, a state interest in saving money should not override fundamental rights.[75]

Also, it is unclear that the state could prove, in a cost-benefit analysis, that screening actually would save a sufficient amount of money to justify infringement with individual choice. While aborting a fetus with cystic fibrosis may represent a savings to society of the cost of rearing that child, it may be that the overall costs of screening and providing necessary counseling and other services for the entire reproductive age population to find carriers or even just of screening prenatally would be so great that it would not offset the costs of rearing the few affected children whose births the state is trying to prevent.

It is likely that no statute actually mandating prenatal screening or treatment will ultimately be upheld as constitutional. However, it may be constitutional for the state to adopt a law that mandates that physicians inform pregnant women of the availability of prenatal screening and treatment, which the women could then choose to undergo or to refuse. This is the current approach taken in a California program that requires physicians to inform their patients about maternal serum alpha-fetoprotein (AFP) testing.[76] Another role that the government could play would be the provision of funds to subsidize voluntary prenatal screening and treatment.

OK

Newborn Screening

The type of genetic service that the states have been most willing to mandate is the screening of newborns for inborn errors of metabolism. However, even with respect to this service, most states make some provision for parental refusal. The statutes of three jurisdictions (the District of Columbia, Maryland, and North Carolina) clearly provide that newborn screening is voluntary.[77] In five states (Arkansas, Iowa, Michigan, Montana, and West Virginia), screening is mandatory and there is no provision for parental objection or refusal based on religious grounds.[78] In 31 states, the test may be refused on religious grounds only.[79] In seven states, parents may object to the test for any reason.[80] The statutes of two states allow both parental and religious objections.[81]

Allowing parents to refuse newborn screening is in keeping with parents' fundamental right to make childrearing decisions. Only when their decisions put their children at grave risk are parental decisions overridden by the state. For example, when parents refuse to allow a blood transfusion to their child, placing the child at risk of serious harm or death, a court will generally order the transfusion over the objections of the parents. However, refusal of a newborn screening test is not analogous to refusal of a blood transfusion. While there is virtual certainty that refusal of the blood transfusion will lead to grave harm to the child, refusal of a newborn screening test is unlikely to harm a particular child. Consider newborn screening for PKU (phenylketonuria). If the incidence of PKU is 1 in 12,000 to 15,000, the chance is very small indeed that a child who is not screened will actually be affected.[82] The risk is less than the risk of a false

negative from the test.[83] Moreover, the small risk of mental retardation from a refused PKU screen is far less than the risks inherent in many other decisions that parents are routinely allowed to make. For example, society allows parents to decide that their children may participate in high school athletics even though there is probably a greater risk that a child will be injured during participation in high school sports than that he or she will be affected by a metabolic disorder in the instance when parents refuse screening.

Because, in the rare instance in which an untested child is affected, the injury to that particular child is so devastating, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical Research suggested that screening might be mandated if it appeared that the number of refusals was high and the number of affected, undiagnosed children was high.[84] However, research suggests that even when a newborn screening program is completely voluntary and parents may refuse for any reason, the actual refusal rate is quite low, about 0.05 percent (27 of 50,000 mothers).[85] In addition, since a voluntary program requires the informed consent of parents, the voluntary program adds a check on the procedure. If parents are told about screening, and agree to it, but then notice that the screening has not been done, the parents can take action to assure that the baby is screened. Thus, more infants may actually be screened under a voluntary program than a mandatory one if parents point out when their infants inadvertently are not screened. Any facts on this latter point?

Although opponents of voluntary screening assume that fewer infants will be screened under that approach than with mandatory screening, this is not necessarily the case. In a 1979 study, the percentage of newborns screened

was calculated for each of 12 states.[86] The two states with the highest percentage of newborns screened (98 percent) were Maryland, which has a voluntary program, and New Hampshire, which allows parents to refuse screening for any reason. The other ten states, which all have mandatory programs that require all infants to be screened unless the parents can qualify for religious exemption, had lower percentages of newborns screened. In one of these mandatory states, the proportion of newborns screened was only 58 percent. Naturally, any voluntary program needs as its underpinning an adequate procedure for informing parents and obtaining consent. In a study of Maryland's voluntary program, most nurses reported that it required only one to five minutes to inform a mother about newborn screening.[87]

Tort Liability

Mandatory screening is not the only policy approach which pressures people to undergo genetic testing. So could the potential for tort liability. A California case, Curlender v. Bio-Science Laboratories,[88] suggested that a child with a genetic defect could bring suit against her parents for not undergoing genetic screenings and aborting her.[89] This is not without precedent. A Michigan court held that a boy had a cause of action against his mother for taking tetracycline during her pregnancy, which gave him brown teeth.[90] Subsequently, the California legislature, as well as the legislatures of five other states, prohibited suits by children claiming the parents should be liable for not aborting them.[91] Statutes prohibiting wrongful life cases against parents further the couples' autonomy in procreative decisions. As the California Supreme Court pointed out in a later case, the purpose of such legislation is "to eliminate any liability or other

similar economic pressure which might induce potential parents to abort or decline to conceive a potentially defective child."[92] While a physician breaches a legal and moral duty by not giving competent advice to allow parents to make an informed decision about whether they should continue a pregnancy, parents are exercising a legal right by choosing not to abort.[93] It is also questionable whether there is much to be gained practically by such suits. Since parents usually pay for the child's support, recovery against them rather than against a third party tortfeasor "would just shift family funds (less lawyers' fees and court costs) from one pocket to another."[94]

Conditioning Benefits

An additional policy approach to coercing testing is to allow private institutions to condition benefits on the results of genetic testing. There is no law, for example, that requires an applicant for insurance to undergo testing or to disclose information about previously-undertaken tests. However, such testing may be required by the company if the applicant wants to receive insurance. Such required testing cannot be justified on health promotion grounds because the people denied insurance may not be able to afford medical care, and their health will thus be damaged rather than promoted. The only rationale for such a policy is an economic one -- that it is unfair to let people purchase insurance when they know in advance that they will be heavy users of care. Yet the potential for adverse selection is only a problem if one accepts the current insurance system as a given -- and there is no reason to do that. Insurance is supposed to be a risk-spreading mechanism. But if people are going to be asked to pay a premium based on their actual future medical costs -- which might be predictable when genetic

testing reveals, for example, that they will later suffer from Huntington disease -- the risk-spreading benefit is lost. Perhaps the availability of genetic testing will make the current form of insurance obsolete, just as it will make some current forms of medical practice obsolete, and new forms of insurance will be found which actually do spread risks.

Currently, insurance companies do have access to a wealth of genetic information. Only a few states' laws prescribe how insurance companies should use genetic information. Two states prohibit denying an individual life insurance[95] or disability insurance[96] or charging a higher premium[97] solely because the individual has a particular genetic anomaly, sickle cell trait. A California statute prohibits discrimination by insurance companies against people who carry a gene which has no adverse effects on the carrier, but which may affect his or her offspring.[98] A related statute prohibits such discrimination by health care service plans.[99]

Similar problems exist in the employment context. Twenty-four percent of American geneticists and genetic counselors surveyed said they would disclose genetic information to employers, against their patient's wishes.[100] Employers often refuse to hire applicants with any health impairment, even a mild one.[101] A new form of discrimination is occurring in which employers screen to reject candidates (such as diabetics) who are qualified for the job, but who are more likely to use medical benefits programs.[102]

The American With Disabilities Act,[103] passed in 1990, may help contain such discrimination since it prohibits pre-employment medical examinations and inquiries designed to uncover information about disabilities unless the examination or inquiry is designed to reveal the applicant's ability to perform job-related tasks.[104] The American With Disabilities Act also

prohibits discrimination against individuals with disabilities in any terms, conditions or privileges of employment. However, the ADA does not prohibit discrimination against carriers. In addition, it is not clear whether a person with an increased risk of genetic disease, but not a definitive diagnosis he or she will get the disease, will be viewed as having a disability. A deputy legal counsel of the EEOC has stated that "characteristic predisposition to illness or disease" is not an impairment. "Consequently, the ADA does not protect individuals, who are not otherwise impaired, from discrimination based on genotype alone."[105]

Because of the sickle cell debacle[106] in the early 1970's, a few states have specifically adopted statutes to prohibit mandatory sickle cell screenings a condition of employment,[107] to prohibit discrimination in employment against people with sickle cell trait,[108] and to prohibit discrimination by unions against people with sickle trait.[109]

A broader New Jersey law prohibits employment discrimination based on an "atypical hereditary cellular or blood trait."[110] This law would seem to prohibit the use of genetic screening results in making employment decisions, since such screening reveals the pre-existing genetic traits of the person. However, it might not provide protection against the use of genetic monitoring -- which reveals damage to genetic material which arguably affects certain cells but does not make a sufficient overall change in the individual's genetic makeup to be considered a trait. In Oregon, an even more comprehensive law prohibits any genetic screening as a condition of employment.[111]

Conclusion

I've entitled my speech today "Public Choices and Private Choices," but the dichotomy between the two is not as clear as you might think. The "public" choice to mandate carrier status or prenatal screening obviously affects very private choices regarding reproduction. Similarly, a private decision to use carrier or prenatal testing has public ramifications beyond that individual couple or family. If only wealthier people tend to use screening, the current disparity between poor children and rich children will be underscored biologically as well as socially.

This is not to say that private choices in the genetic realm should be prohibited. That would not be a sound policy, nor even a constitutionally permissible course. But it does point out the need to provide additional protections -- not just geared to the use of genetic testing, but to the wide-ranging effects those uses will have. It also cautions us that any given choice about genetic testing is not one single decision, but a series of decisions -- with which all of us must live.

FOOTNOTES

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1. McKusick, "Mapping and Sequencing the Human Genome," 320 New England Journal of Medicine 910 (1989). The location of about 1500 genes have already been mapped and around 600 have been cloned and sequenced. Id. at 913.

2. V.A. McKusick, Mendelian Inheritance in Man XI (7th ed. 1986).

3. Understanding the genetic bases of disease could lead to the development of gene therapies. In September 1990, researchers at the National Institutes of Health performed the first gene therapy in humans. B.J. Culliton, "Gene Therapy Begins," 249 Science 1372 (1990). The protocol involves gene transplants into children with severe combined immune deficiency caused by the lack of the enzyme adenosine deaminase (ADA).

4. L. Andrews, Medical Genetics: A Legal Frontier 135-136 (1987).

5. Physicians employing amniocentesis insert a needle into the mother's uterus in order to remove a small amount of amniotic fluid, usually between the 16th and 19th weeks of pregnancy. The procedure can ascertain the sex of the fetus, chromosomal defects, and numerous genetic defects. See, e.g., National Registry for Amniocentesis Study Group, "Midtrimester Amniocentesis for Prenatal Diagnosis and Accuracy," 236 J.A.M.A. 1471 (1976); Simpson, Dallaire, Miller, Siminovitch, Hamerton, Miller and McKeen, "Prenatal Diagnosis of Genetic Disease in Canada: Report of a Collaborative Study," 115 Can. Med. Assoc. J. 739 (1976); Office of Technology Assessment, U.S. Congress, Human Gene Therapy: A Background Paper 64, 136 (1984).

6. Chorionic villi sampling (CVS) can be used as early as eight weeks into pregnancy. Samples are taken from the villi, which attach the fetal placenta to the uterus. Analysis of the tissue takes only about one week. The procedure has been used for prenatal diagnosis of chromosomal and genetic defects. See, e.g., G. Pescia and H. Nguyen The, eds., Chorionic Villi Sampling (CVS) (volume 15 of Contributions to Gynecology and Obstetrics (1986); M. Fraccaro, G. Simoni, B. Brambati, First Trimester Fetal Diagnosis (1984); Jackson, Wapner, Barr, "Safety of Chorionic Villus Biopsy," 1 Lancet 674 (March 1986); Knott, Ward, Lucas, "Effect of Chorionic Villus Sampling and Early Pregnancy Counselling on Uptake of Prenatal Diagnosis," 293 Br. Med. J. 479 (1986); Oehme, Jonathan, and Horst, "DNA-Diagnosis of Sickle Cell Anemia from Chorionic Villi: Possible Influence of Maternal Cell Contamination," 73-74 Human Genetics 186 (June 1986); Jackson, "Prenatal Genetic Diagnosis by Chorionic Villus Sampling (CVS)," 9 Seminars in Perinatology 209 (April 1985); Hogge, Schonberg and Golbus, "Prenatal Diagnosis by Chorionic Villi Sampling: Lessons of the First 600 Cases," 5 Prenatal Diagnosis

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393 (1985); Evans, "Chorionic Villus Sampling Detects More than 100 Fetal Abnormalities," 84 Mich. Med. 456 (1985).

7. Herzenberg, Bianchi, Schrder, Cann, and Iverson, "Fetal Cells in the Blood of Pregnant Women: Detection and Enrichment By Fluorescence-Activated Cell Sorting," 76 Proc. National Academy of Science 1453 (1979); Walknowska, Coute, and Grumback, "Practical and Theoretical Duplication of Fetal Maternal Lymphocyte Transfer," 1 Lancet 1119 (1969).

8. Hecht and McKaw, "Chromosome Instability Syndromes," in J.J. Mulvihill, R.W. Miller, and J.F. Fraumeni, Jr. Genetics of Human Cancer 105, 114 (1977).

9. See, e.g., Shaw, "Conditional Prospective Rights of the Fetus," 5 Journal of Legal Medicine 63 (1984).

10. K. Ludmerer, Genetics and American Society (1972). "Eugenics as applied to humans, was a powerful ideology during the first thirty years of this century, and appealed to a surprising diversity of geneticists, of all political persuasions." Williamson, "Gene Therapy," 298 Nature 415, 416 (1982).

11. Beckwith, "Social and Political Uses of Genetics in the United States: Past and Present," 265 Annals N.Y. Academy of Sciences 46, 47 (1976) (citation omitted).

12. Id. at 48. See also D. Kevles, In the Name of Eugenics: Genetics and the Uses of Human Heredity 100 (1985).

13. Reilly, "Eugenic Sterilization in the United States," 227, 227 in A. Milunsky and G. Annas, eds., Genetics and the Law III (1985).

14. Beckwith, supra n. 11 at 47. See also Kevles, supra n. 12 at 46.

15. Kevles, supra n. 12 at 53, 101.

16. F. Scott Fitzgerald addressed the dilemma for couples when, as an undergraduate at Princeton, he composed the song "Love or Eugenics?" Id. at 58.

17. Kevles, supra n. 12 at 54.

18. Id. at 56.

19. Beckwith, supra n. 11 at 48 (citation omitted).

20. Reilly, supra n. 13 at 230.

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21. Ruth Macklin and Willard Gaylin, Mental Retardation and Sterilization: A Problem of Competency and Paternalism 65 (1981).

22. Reilly, supra n. 13 at 235. An official of the American Eugenics Society told the media that the German sterilization plan "showed great courage and statesmanship." Kevles, supra n. 12 at 118.

23. Reilly, supra n. 13 at 228.

24. Kevles, supra n. 12 at 62.

25. Id. at 72-3.

26. See Andrews, supra n. 4 at 135 to 158.

27. Capron, "Tort Liability in Genetic Counseling," 79 Columb. L. Rev. 619, 628 (1979). There is evidence that, when faced with the information that their fetus will have a serious disorder, most potential parents choose to abort. In a large-scale study of 3000 amniocenteses, in which 113 fetuses were found to have chromosomal or biochemical abnormalities, 93.8% chose abortion. Golbus, Loughman, Epstein, et al., "Prenatal Genetic Diagnosis in 3000 Amniocentesis," 300 New Eng. J. Med. 157, 160 (1979). In a subsequent study of 7000 pregnancies in which 149 cytogenic abnormalities were detected, nearly all women with severely abnormal fetuses elected to terminate their pregnancies, while only 62% with a prenatally diagnosed sex chromosome abnormality did so. Benn, Hsu, Carlson, and Tannenbaum, "The Centralized Prenatal Genetics Screening Program of New York City III: The First 7,000 Cases," 20 Am. J. Med. Genetics 369-370 (1985).

    The advances that will be made possible through the Human Genome Initiative, however, could change the complexion of tort actions brought on the basis of inadequate or inaccurate genetic information. As more treatments become available for the fetus in utero (thus allowing a fetus diagnosed with a particular disorder to be aided), wrongful birth and wrongful life cases will be replaced by actions charging traditional malpractice.

28. At the eight-cell stage, all cells are totipotent and thus the embryo would develop normally, with no damage attributable to the removal of the one cell. For a description of the benefits of genetic screening of the embryo, see, Grobstein, From Chance to Purpose: An Appraisal of External Human Fertilization 123 (1981).

29. La. Rev. Stat. Ann. §9:121 et seq. (West Supp. 1989) Ann.; Me. Rev. Stat. Ann. tit. 22 §1593 (1980). But see Lifchez v. Hartigan, 735 F. 1361 Supp. (N.D. Ill. 1990) which held that such a statute is unconstitutional when applied to genetic screening. Some states specifically exempt

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genetic screening from their bans on embryo and fetal research.

30. Mass. Ann. Laws ch. 112 §12J (Law. Co-op. 1985); N.D. Cent. Code §14-02.2-01(2) (1981); R.I. Gen. Laws §11-54-1(b) (Supp. 1988).

31. See, e.g. La. Rev. Stat. §9:121 at seq. (West Supp 1989).

32. Lifchez v. Hartigan, 735 F. Supp. 1361, 1376 (N.D. Ill. 1990).

33. The law was also declared to be unconstitutionally vague. Id. at 1376.

34. Under the common law, an embryo traditionally was not considered to have the rights of a person. In Roe v. Wade, the U.S. Supreme Court scanned the Constitution, looking for provisions with the word "person," and found that none of the contexts "has any possible prenatal application." 410 U.S. 113, 157-8 (1973).

35. As Joel Feinberg notes, the weakness of the symbolic argument is "the difficulty of showing that the alleged coarsening effects really do transfer from primary to secondary objects." Feinberg, "The Mistreatment of Dead Bodies," 15 Hastings Center Report 31, 37 (February 1985). He observes that "[w]e can deliberately inhibit sentiment toward one class of objects when we believe it might otherwise motivate inappropriate conduct, yet give it free rein toward another class of objects where there is no such danger." Id. (footnote omitted).

36. Sissela Bok, in arguing for an examination of the reasons for protecting life, argues we cannot simply equate killing an embryo with murder. "[T]he reasons for protecting life fail to apply here. This group of cells cannot feel the anguish or pain connected with death. Its experiencing of life has not yet begun; it is not yet conscious of the interruption of life nor of the loss of anything it has come to value in life. Nor is it tied by bonds of affection to others." Bok, "Fetal Research and the Value of Life," 2-1, 2-7 in National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, Appendix: Research on the Fetus (1975). See also Bok, "Ethical Problems of Abortion," 2 Hastings Center Studies 33 (January 1974).

37. In addition, granting various protections to embryos in a way that does not infringe procreative rights (for example, by allowing suits on the embryo's behalf against third party tortfeasors) would be arguably constitutional. Without a fundamental right at issue, the legislation would be considered constitutional if it was rationally related to a permissible governmental purpose and the protection of the embryo as a symbol would likely meet that standard.

38. At least four states have statutes that prohibit parents from bringing wrongful birth suits against health care practitioners and institutions.

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Minn. Stat. Ann. §145.424(2) (West 1989); Mo. Ann. Stat. §188.130-1 (Vernon Supp. 1990); 42 Pa. Cons. Stat. Ann. §8305 (Pardon Supp. 1990) (this statute does not prohibit cases based on intentional misrepresentation); S.D. Codified Laws Ann. §21-55-2 (1987). At least eight states prohibit children from bringing wrongful life suits. Idaho Code §5-334 (Supp. 1985); Ind. Code Ann. §34-1-1-11 (Burns Supp. 1989); Minn. Stat. Ann. §145.424(1) (1990); Mo. Ann. Stat. §188.130-1 (Vernon Supp. 1990); N.D. Cent. Code §32-03-43 (1991); 42 Pa. Cons. Stat. Ann. §8305 (Pardon Supp. 1990); S.D. Codified Laws §21-55-1 (1987); and Utah Code Ann. §78-11-24 (Supp. 1987).

39. The wrongful birth cases specifically recognize that they are creating an incentive for physicians to provide genetic testing and information. See, e.g., Berman v. Allen, 80 N.J. 421, 432, 404 A.2d 8, 14 (1979). Siemieniec v. Lutheran General Hospital, 134 Ill. App. 3d 823, 480 N.E. 2d 1227, 1232 (1985) (citation omitted).

40. Avery v. County of Burke, 600 F.2d 111 (4th Cir. 1981). In that case, a young pregnant woman was erroneously diagnosed by a county health department prenatal clinic as having sickle cell trait and told that she should undergo sterilization. The health care professionals at the clinic apparently overstated the complications of sickle cell trait, telling her it made her more susceptible to numerous diseases while pregnant, it made childbirth incredibly dangerous, and that it rendered her unable to take birth control pills. Id. at 113. She underwent the sterilization, then discovered she did not have the trait. The court held that she had a valid cause of action against the clinic for violation of her constitutional rights for wrongfully causing her sterilization.

41. 492 U.S. 490, 521, 109 S.Ct. 3040, 3058 (1989) (Rehnquist, C.J., writing for a plurality consisting of himself and Justices White and Kennedy).

42. The Supreme Court in Webster noted that the facts in that case differed from those in Roe giving the Court "no occasion to revisit the holding of Roe." Id.

43. 21 National Law Journal 1264 (May 20, 1989).

44. Uniform Abortion Act Approved February 1972 by ABA House of Delegates, 58 A.B.A.J. 380 (1972) (allowing abortion if the physician has reasonable cause to believe "that the child would be born with grave physical or menial defect.")

45. American Medical Association, Proceedings of the AMA House of Delegates 40-51 (June 1967) (allowing abortions if there is "documented medical evidence" that the child "may be born with incapacitating physical deformity or mental deficiency").

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46. See Roe v. Wade, 410 U.S. 113, 141-46 (1973) for a discussion of existing and proposed laws prior to the decision.

47. Tay-Sachs disease is a recessive gene disorder most common in families of Eastern European Jewish origin. Children who have the disease exhibit early progressive and profound retardation, blindness, and paralysis with characteristic cherry red spots on the retina. Death usually occurs by age three or four. Lawyers' Medical Cyclopedia §4.10 (3rd ed. 1981).

48. See Andrews infra n. 82.

49. Golbus, et al., supra n. 27 at 158. In New York State, this disparity has been attached through a policy of state funding of amniocentesis for poor women.

50. This is not to say that poorer families did not participate in these efforts, but rather to say that the effort was easier for wealthier families.

51. P. Reilly, Genetics, Law, and Social Policy 62-86 (1977).

52. Id. at 67.

53. Ohio Rev. Code Ann. §111.33 (Baldwin 1988).

54. See, e.g. Shaw supra n. 9; Note, "Constitutional Limitations on State Intervention in Prenatal Care, 67 Va. L. Rev. 1051, 1052 (1981).

55. The primary risk is infection. Andrews, New Conceptions: A Consumer's Guide to the Newest Infertility Treatments Including In Vitro Fertilization, Artificial Insemination, and Surrogate Motherhood 59 (1988).

56. Amniocentesis presents a 1 in 200 risk of fetal death. Id. at 69. Chorionic villi sampling presents a 2 to 3 percent risk of fetal death. Office of Technology Assessment, U.S. Congress, Human Gene Therapy -- Background Paper, Appendix A at 65 (1984).

57. According to the researchers, "because the FACS procedure requires sampling of maternal blood rather than amniotic fluid, it could make widespread screening in younger women feasible . . . . Widespread screening is desirable because the relatively large number of pregnancies in women below 35 years old means that they bear the majority of children with chromosomal abnormalities despite the relatively low risk of such abnormalities in pregnancies in this age group." Herzenberg, Bianchi, Schroder, Cann and Iverson, "Fetal Cells in the Blood of Pregnant Women: Detection and Enrichment by Fluorescence-Activated Cell Sorting," 76 Proc. Natl. Acad. Sci. U.S.A. 1453, 1455 (1979).

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58. Jacobson v. Massachusetts, 197 U.S. 11 (1905).

59. C. Damme, "Controlling Genetic Disease Through Law," 15 U. Cal. Davis L. Rev. 801-807 (1982).

60. Andrews, "Informed Consent Statutes and the Decisionmaking Process," 5 J. Leg. Med. 163, 215-216 (1984).

61. City of Akron v. Akron Center for Reproductive Health, 462 U.S. 416, 445 (1983).

62. Thornburgh v. American College of Obstetricians and Gynecologists, 476 U.S. 747, 106 S.Ct. 2169, 90 L. Ed. 2d 779 (1986).

63. Id. at 2178.

64. Goodman and Goodman, "The Overselling of Genetic Anxiety," 12 Hastings Center Report 20, 24 (October 1982), citing Clow and Scrivner, "The Adolescent Copes With Genetic Screening: A Study of Tay-Sachs Screening Among High School Students," 381-393 in M. Kabach, Tay-Sachs Disease: Screening and Prevention (1977).

65. Clark, "Screening for Carriers of Tay-Sachs Disease: Two Approaches," 119 Canadian Med. J. 550 (1978).

66. N. Wexler, "A Genetic Jeopardy and the New Clairvoyance," 6 Progress in Medical Genetics 277, 298 (1985).

67. Committee for the Study of Inborn Errors of Metabolism, Division of Medical Sciences, Assembly of Life Sciences, National Research Council, "Recommendations" 1, 4 in Genetic Screening: Programs, Principles, and Research (1975). ("Participation in a genetic screening program should not be made mandatory by law, but should be left to discretion of the person tested, or, if a minor, of the parents or legal guardian.")

68. Wexler, supra n. 67 at 295.

69. Bowman, "Identification and Stigma in the Workplace," in J. Weiss, B. Bernhardt, N. Paul, eds., Genetic Disorders & Birth Defects in Families and Society: Toward Interdisciplinary Understanding, 20 Birth Defects Original Article Series 223, 225 (1984).

70. Lifchez v. Hartigan, 735 F. Supp. 1361 (N.D. Ill. 1990).

71. For example, in The New York Times v. United States, 403 U.S. 713 (1971), the U.S. Supreme Court, in a per curium opinion held that the government had not met its "heavy burden" of proving that national security required that the Pentagon Papers be suppressed. The logic of the case was

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explained further in the concurrences; the right of free speech is to be infringed by a prior restraint only when disclosure "will surely result in direct, immediate, and irreparable damage to our Nation or its people." (Id. at 730, (Stewart, J., concurring)) or when there is "governmental allegation and proof that publication must inevitably, directly, and immediately cause the occurrence of an event kindred to imperiling the safety of a transport already at sea . . ." during wartime. Id. at 726-727 (Brennan, J., concurring).

The standard of irreparability for granting an injunction against protected speech is an absolute, not a comparative standard. Even if the speech could cause great harm, that would not be sufficient. As Justice White pointed out in his concurrence in New York Times, it is not sufficient that there may be "substantial damage to public interests." Id. at 731 (White, J., concurring.) Similarly, Justice Stewart said "I am convinced that the Executive is correct with respect to some of the documents involved [i.e., they should not, in the national interest be published]. But I cannot say that disclosure of any of them will surely result in direct, immediate, and irreparable harm to our Nation or its people. That being so, there can under the First Amendment be but one judicial resolution of the issue before us." Id. at 730 (White, J., concurring).

Even if irreparable harm were a possibility, New York Times indicates that an injunction should not be issued against the press unless such harm would come about directly and immediately. The term "immediately" is easy enough to understand; it requires a present, not future, harm. The term "directly" relates to the lack of intervening influences during that time period. The irreparable harm would not occur directly if another important influence would or could intervene. Another way of expressing the immediacy and directness that is necessary is by saying the harm is "inevitable" -- it will occur within a short period of time during which nothing will or could change it or stop it.

Even when a prior restraint is not at issue, high standards are required for showing a compelling state interest when a fundamental right is at issue. Also in the First Amendment area, speech which is not false should not be the basis for subsequent punishment unless it provided an immediate threat of serious harm. (See, e.g., Bridges v. California, 314 U.S. 252, 263 (1941) ("the substantial evil must, be extremely serious and the degree of imminence extremely high before utterances can be punished")).

72. Jacobson v. Massachusetts, 197 U.S. 11 (1905).

73. Moreover, it should be noted that this risk (transmission of genetic disease to offspring) is one that society has always lived with, and seems to have flourished despite that risk.

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74. See, e.g., the discussion of New York Times v. United States, supra n. 71.

75. In U.S. Supreme Court cases, the goal of protecting the public treasury has not been found to be superior to protecting individual rights. A person's right to travel is recognized as more important than the drain on the welfare system of the state to which he moves. See, e.g., Edwards v. California, 314 U.S. 160 (1941). Due to a person's fundamental right of privacy to make procreative decisions, a state may not condition welfare on an individual's cessation of childbearing. "People are free to move and to be burdens on the state, and procreate and be burdens with their children on the state. If the consequence of a protected act means direct state support, that is the unpredictable price a free society has to pay." Weiss and Wizner, "Pot, Prayer, Politics, and Privacy: The Right to Cut Your Own Throat in Your Own Way," 54 Iowa L. Rev. 709, 733-734 (1969). Commentators Weiss and Wizner point out that the government in other ways uses its finances to support choice in the area of constitutional freedom: "Armies are raised and supported so that people may live freely. The consequent loss of income and burden on the state are the price of supporting freedoms of choice." Id. at 734 n. 113. Thus, there are valid policy reasons for not holding potential economic costs as a sufficiently compelling governmental interest to outweigh the privacy right to make reproductive decisions.

76. See, e.g., Steinbrook, "In California, Voluntary Mass Prenatal Screening," 16 Hastings Center Report 5 (October 1986).

77. D.C. Code Ann. §6-314(3) (1981); Md. Health-Gen. Code Ann. §§13-102(10) to 109(f) (1982); N.C. Gen. Stat. §143B-195 (1983).

78. Ark. Stat. Ann. §86-625 (Supp. 1983); Iowa Admin. Code §470-4.1 (136A) (1983); Mich. Comp. Laws Ann. §333.5431(1) (West 1980); Mont. Code Ann. §50-19-203(1) (1983); W. Va. Code §16-22-3 (Supp. 1983).

79. Ala. Code §22-20-3(a) (1984); Cal. Health and Safety Code §309 (West Supp. 1984); Conn. Gen. Stat. Ann. §§19a-55(b) (West Supp. 1984); Ga. Code Ann. §31-12-7(a) (Supp. 1984); Hawaii Rev. Stat. Part I §333-1 (Supp. 1983); Idaho Code §39-912 (1977); Ill. Ann. Stat. ch. 111 1/2, para. 4905(3) (Smith-Hurd 1983-1984); Ind. Code Ann. §16-8-6-1 (Burns 1983); Kan. Stat. Ann. §65-182 (1980); Ky. Rev. Stat. Ann. §214.155(2) (Baldwin 1982); Mass. Ann. Laws ch. 111, §110A (Law. Co-op. Supp. 1983); Minn. Stat. Ann. §144.125 (West Supp. 1983); Miss. Code Ann. §41-21-203 (1984); Mo. Ann. Stat. §210.065.4 (Vernon 1983); Neb. Rev. Stat. §71-604.01 (1981); N.J. Stat. Ann. §26:2-11 (West Supp. 1982-1983); N.Y. Pub. Health Law §2500-a(b) (McKinney 1972); N.D. Cent. Code §25-17-04 (1978); Ohio Rev. Code Ann. §3701.501(B) (Baldwin 1984); Okla. Stat. Ann. tit. 63, §1-534 (West Supp. 1982-1983); Or. Rev. Stat. §433.285(3) (1981); 35 Pa. Cons. Stat. Ann. §621 (Purdon 1977); R.I. Gen. Laws §23-13-12 (1976);

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S.C. Code Ann. §44-37-30 (Law. Co-op. Supp. 1983); S.D. Codified Laws Ann. §34-24-17 (1977); Tenn. Code Ann. §68-5-308 (1983); Tex. Rev. Civ. Stat. Ann. art. 4447e-1 §5 (Vernon Supp. 1984); Utah Code Ann. §26-10-6 (Supp. 1981); Va. Code Ann. §32.1-65 (Supp. 1983); Wash. Rev. Code Ann. §70.83.020 (Supp. 1982); Wis. Stat. Ann. §146.02(3) (West Supp. 1982-1983). In another state, the law empowers an agency to determine whether testing should be mandatory. In Maine, the Department of Human Services is authorized to make the program mandatory, but provision for religious objection is made. Me. Rev. Stat. Ann. tit. 22, §1522 (1980).

80. Alaska Stat. §18.15.200(f) (1981); Ariz. Comp. Admin. R. & Regs. 9-14-515 (1979) (provided testing is done with consent of parent); Fla. Stat. Ann. §383.14(3) (West Supp. 1984); La. Rev. Stat. Ann. §40.1299.1 (West Supp. 1984); Nev. Rev. Stat. §442.115(4) (1979); N.H. Rev. Stat. Ann. §132:10-c (1978); N.M. Stat. Ann. §24-1-6(A) (Supp. (1982).

81. Colo. Rev. Stat. §25-4-804 (1982), §25-4-1005 (1983); Wyo. Stat. §35-4-801(c) (Supp. (1983).

82. Fisher, Foley, and Mitchell, "Problems and Pitfalls of Newborn Screening Programs Based on the Experience in California and New England," 38, 39 in L. Andrews, ed., Legal Liability and Quality Assurance in Newborn Screening (1985).

83. Delbert Fisher presentation, Conference on Legal Liability in Newborn Screening, American Bar Foundation (October 15-16, 1984).

84. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Screening and Counseling for Genetic Conditions: The Ethical, Social, and Legal Implications of Genetic Screening, Counseling, and Education Programs 6 (1983).

85. Faden, Chwalow, Holtzman, and Horn, "A Survey to Evaluate Parental Consent As Public Policy for Neonatal Screening," 72 Am. J. Public Health 1347, 1350 (1982).

86. Sepe, Levy, and Mount, "An Evaluation of Routine Follow-Up Blood Screening of Infants for Phenylketonuria," 300 New Eng. J. Med. 606 (1979). See Andrews, supra n. 82 for an analysis of the voluntary or mandatory nature of screening in each state.

87. Faden, Chwalow, Holtzman, and Horn, supra n. 85 at 1350.

88. 106 Cal. App. 3d 811, 829, 165 Cal. Rptr. 477 (2d Dist. 1980).

89. Subsequently, California and five other states adopted statutes eliminating such a cause of action. Cal. Civ. Code §43.6 (West 1982); Idaho Code §5-334 (1990); Minn. Stat. Ann. §145.424(1) (1990); N.D. Cent.

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Code §32-03-43 (Supp. 1991); S.D. Codified Laws §21-55-1 (1987) and Utah Code Ann. §78-11-24 (Supp. 1989).

90. Grodin v. Grodin, 102 Mich. App. 396, 301 N.W.2d 869 (1980).

91. Cal. Civ. Code §43.6 (West 1982); Idaho Code §5-334 (1990); Minn. Stat. Ann. §145.424(1) (West 1989); N.D. Cent. Code §32-03-43 (Supp. 1991); S.D. Codified Laws Ann. §21-55-1 (1987); Utah Code Ann. §78-11-24 (Supp. 1989).

92. Turpin v. Sortini, 31 Cal. 3d 220, 643 P.2d 954, 959, 182 Cal. Rptr. 337 (1982).

93. Capron, "Legal Rights and Moral Rights," 221, 237 in B. Hilton, D. Callahan, M. Harris, P. Condliffe, and B. Berkeley, eds., Ethical Issues in Human Genetics: Genetic Counseling and The Use of Genetic Knowledge (Fogarty International Proceedings No. 13, 1973).

94. Id. at 236.

95. Fla. Stat. Ann. §626.9706(1) (West 1984); and La. Rev. Stat. Ann. §22:652.1(D) (West Supp. 1987). While not dealing with a genetic disorder, some states have indicated they are willing to restrict insurers from unfairly using other potentially discriminatory health information. A Wisconsin statute restricts life insurance companies from denying or restricting benefits because the insured's death was related to HIV infection. Wis. Stat. §631.93 (1990). Furthermore, it provides criminal penalties for non-authorized test disclosure. Wis. Stat. §146.025(a) (1990).

96. Fla. Stat. Ann. §626.9707(1) (West 1984); and La. Rev. Stat. Ann. §22:652.1(D) (West Supp. 1987).

97. Fla. Stat. Ann. §626.9076(2) (West 1984) (life insurance); §626.9707(2) (West 1984) (disability insurance); and La. Rev. Stat. Ann. §22:652.1(D) (West Supp. 1987).

98. Cal. Ins. Code §10143 (West Supp. 1988).

99. Cal. Health & Safety Code §1374.7 (West 1972).

100. D. Wertz and J.C. Fletcher, "Ethics and Human Genetics: A Cross-Cultural Perspective," 440 (1989).

101. Weinstock and Haft, "The Effect of Illness on Employment Opportunities," 29 Archives of Environmental Health 79, 83 (1974) ("the results of this study suggest that in the area sampled, even patients with mild illnesses, which may not increase their morbidity or mortality, are being

(cont'd.)

denied work").

102. M. Baram, "Charting the Future Course for Corporate Management of Genetics and other Health Risks," 475, 480 in A. Milunsky and G. Annas, eds., Genetics and the Law III (1985).

103. 42 U.S.C. §12101 (1990).

104. 42 U.S.C. §12112(4)(A) (1990).

105. Letter by Elizabeth M. Thorton, Deputy Legal Director, U.S. Equal Employment Opportunity Commission to Drs. Paul Berg and Sheldon Wolff, Co-Chairmen, NIH-DOE Joint Subcommittee on the Human Genome, August 2, 1991.

106. Andrews, supra n. 4 at 18.

107. This same law appears in three places in the Florida statutes: Fla. Stat. Ann. §448.076 (West 1981); §228.201 (West Supp. 1987); and §63.043 (West 1985).

108. Fla. Stat. Ann. §448.075 (West 1981). N.C. Gen. Stat. §95-28.1 (1985). La. Rev. Stat. Ann. §23:1002(A)(1) (West Supp. 1985).

109. La. Rev. Stat. Ann. §23:1002(C)(1) (West Supp. 1985).

110. N.J. Stat. Ann. §10:5-12(a) (West Supp. 1988).

111. Or. Rev. Stat. §659.227 (1989).

~~Religious Views of Genetics~~

Perspectives on Genetics from Religious Ethics

Kenneth Vaux

Peoples of the Book, those who have given civilization words like "genesis," "revelation," and the nomenclature of alchemists from Paracelsus to Francis Crick, would be expected to have a number of spiritual and ethical concerns about the genetic age in general and the human genome project in particular. Those concerns will range from hope, affirmation, and advocacy through apocalyptic dread, negation and subversion--with a spectrum of responses and actions in between. Depending on how these responses emerge, the project will be sustained and grow strong or it will bog down and falter. Evoking and elucidating the religious dimensions to genomic research are crucial to the genome project since concerns of spiritual and ethical ultimacy, which is how we define religion or god since the age of the Greeks, may prove decisive in two ways. Religions may provide the inspiration and direction of this project which is--with the possible exception of the appropriate care of the dying--the most crucial endeavor in the realm of human life, health and well-being of our time. Alternatively, if the religious voice is not heeded, the project could flounder and fail as have ventures in conception, abortion and fetal research.

Religious concerns relevant in all these regards fall under two theological terms used by the Greeks: theoria (that divine idea) and praxis. Under theoria the following issues, among others, have been raised:

- the impact of human genetics on human nature, destiny, identity, and self-worth
- our concepts of suffering
- concepts of health and defect
- the moral meaning of the pursuit of knowledge
- the meaning of freedom and determinism
- concepts of certainty, uncertainty, blame and innocence
- concepts of autonomy and solidarity

Under praxis, at least the following issues have emerged:

- prenatal diagnosis and abortion
- eugenics
- equality of access to health care
- confidentiality
- paternalism
- discrimination
- actual harm
- prevention and cure of disease
- prolongation of life.

In this essay, I will cite two specific thrusts of genetics projects in general: understanding and--if possible--ameliorating the breakdown of the heart and brain. I hope to show the way in which unfolding scientific knowledge and technique may instruct religious consciousness and conscience and, conversely, how faith and ethics might shape, safeguard and guide the scientific project. When the Psalmist spoke of our life-time allotment of seventy or eighty

years and when he affirmed that we expired at the divine exhaustion of our human spirit, he was offering a very different cosmology of life and disease, health and death than the ones we hold today. It was not envision by him that aging and organ wear-down were problems to be fixed at the depth of being we now call genotype or phenotype, what the ancients called our essence and form. The rise and fall of our biological being--body and mind--is linked to those seats of vitality and mentality--the heart and the brain, and contemplating the bearing of the genetic program on these vital centers will help us to understand the import and impact of the religious influence.

Genetics and Heart Failure

Today we are undertaking grand scale research on both sudden and gradual coronary death. We are seeking signals about what causes heart failure and seeking to develop a variety of means to counter this morbidity and mortality. Pharmacologic therapy: Laxis, Digokin, Nitroglycerine, antihypertensives, pressors, Beta and other channel blockers, and all the rest are primitive palliative but not curative agents. Cardiovascular and coronary transplant surgery is one of the medical dramas of our time. Diet, exercise, and prophylactic life-styles--especially life-styles cleansed from smoking and alcohol--are widely advised and followed. Beginning trials of mechanical assistance devices and artificial hearts have begun. Michael DeBakey, noted heart specialist, once told me that all of these interventions would one day look like primitive blood-letting or leeching when genetic diagnosis and therapy came into play.

The American Medical Association's 1991 conference in Atlanta was the venue for

the report from Emory University's Center of Genetics and Molecular Medicine and the Centre Cochin de Genetique Moleculaire in Paris. Citing their work in mitochrondrial genetics as pioneering a "new philosophy of genetics," Emory directory Douglas Wallace, described the molecular basis of heart deterioration.[1] Deprived of oxygen through hypoxemia or ischemic disease, deletions increase in the mitochondrial DNA which in turn impede the OXPHOS enzyme activities necessary for cardiac vitality. What should we do until we can prevent or ameliorate the molecular flaw? The report calls for aggressive and early surgery. The primitive response suggested by our present state of art in medicine is more angioplasty, more coronary bypass surgery and probably more heart transplant and artificial heart implantation. If we can't reverse the slowing of RUACH--the breath of life to the heart--we'll substitute not-yet atrophied tissues in auto- or heterografts or we'll use the human version of immortal devices: plastic. Later, we might even anticipate a fetal weeding-out project--another primitive stopgap measure whereby the ischemically inclined (say, beginning with the genetically hyperlipidemic) would be amniotically screened and aborted. One of the dangers of the initial phases of the genetics age in this era of the "Medical-Business, Legal" complex will be the temptation to do stupid things. Ultimately, however, we can envision in heart care an approach which will genetically modify this propensity or set in motion through genetic manipulations certain countervailing biological processes. We might begin in such a venture by controlling--through genomic research--mechanisms which control cholesterol in human pathology.

Brain Break-Down

Two recent studies represent the range of endeavors applying genetic knowledge and technique to the brain. In 1991, Dr. John Hardy of St. Mary's College and Dr. Allen Roses of Duke University reported a genetic defect that causes Alzheimer's disease.[2] This mutation involved with the amyloid precursor protein will cause brain cells to "crumble and die." At the same time, Dr. Merrill Benson of Indiana University School of Medicine showed the inheritance pattern of the Alzheimer's disease gene.[3] Dr. Gene Cohen, acting director of the National Institute of Aging, acclaimed the development as a major stride against degenerative brain disorders, loss of memory and reason, and aging per se. Then in early November, Japanese researchers reported in Nature that they may have found what has bee called the "holy grail" for brain biologists: the N-methyl-D asperate receptor, a protein related to the gene that may be involved in memory, learning, stroke, as well as various forms of brain disease.[4] This discovery in rats is seen to be the necessary precursor for human studies. If one half of the genes in the human genome are expressed in the brain as Leroy Hood has suggested earlier in this volume, the magnitude of the task of the Human Genome Initiative is obvious in its implications for study and understanding of the brain and brain therapies. An estimated four-to-ten million people in the United States are afflicted with diseases which are characterized by a relentless loss of brain cells, gradual loss of memory, and loss of the ability to reason. Afflicted persons become disoriented, cannot care for themselves, and die.

The tragedy of human aging and mortality has often been spoken of as the sorry spectacle of an alert and vibrant mind watching over the disintegration and demise of the

body beneath it. Some see it as even more tragic to witness a strong and vital body and brain with a deteriorating mind. Our definition of death as brain death and our willingness to accept as moral passive, even active euthanasia in cases where brain function is far gone betray the offense of loss of mind to our moral sensibility. When the ability to think, remember, relate and anticipate are gone we are almost willing to say with Hoch, Binding, and the old German psychiatrists and pathologists that the person is already dead and gone.

Freud called cancer the "last disease." It is not more likely, though, that diseases of the brain, mind, and soul will linger long after we have made conclusive strides against heart and vessel disease, infections and cancer? If Science is correct when it predicted a few years back that AIDS and Alzheimer's will be the dominant diseases of the twenty-first century and these two conditions are joined to suicide as major vectors of death in our time, then neurological and mental death will indeed be our "last disease." If we sustain life in the glorious and graceful bodies of our Magic Johnsons by virtue of AZT and other anti-HIV drugs only to allow neurotropic devastation in the eyes, the senses, the brain and mind, what good will we have accomplished? Have we not in the Rabbi's word gained the world and lost our soul?

A range of theological imperatives starts to come into focus as we analyses these two representative domains in which the Human Genome Initiative has relevance. Religion concerns two dimensions: faith and hope derivative of Transcending Being and love and justice derivative of Transcending Power. In an important essay contributed to Houston's Institute of Religions Project on the Genome, Austin Seminary's Jack Stotts writes that religion

> means the human attempt to affirm and to deal with, through ritual, intellectual

> actions and moral behavior, an Ultimate Power whose intention is good. By Ultimate Power I mean a force that is able to accomplish its own purposes and is finally not subject to the control or manipulation of other powers. The appropriate terminology for such an Ultimate Power is God.[5]

I wish to devote the remainder of this essay to the bearing of these religious ideas on the genetic project: hope, faith, love, and justice.

Religious Values and Their Meaning for Genomic Research

Hope. Religious understanding of the world and ultimate reality prompts Hope and faith which in return offer acceleration and caution to the genome project. Perhaps the strangest impulses in religion both oriental and occidental are disaffection from a world that is not what it should be and compassion for those who suffer. In the end, there will be sustenance for both these impulses to be found in the genome project. Those who hope in God, wrote German theologian Jurgen Moltmann, chafe against this magic and dangerous world because "The good of a promised future stabs into the flesh of every unfulfilled present." The Western scientific project was in an important sense initiated by the Benedictine hospitals and clinics whose origin belonged in the hope of biblical religion. Healing is the manifestation of an impending future drawn into the present, and millennial expectations fuel the scientific project to this very day. Religion's hope is quite specific. It does not yearn for human perfection or the superman. It does not crave cryogenic immortality. It prays and works to the end that people be as well (that is whole, holy) as they can be and that they be spared unnatural ailments and premature deaths. A spiritual challenge in this hyperpuritan age of

biotechnology is to define nature's diseases whose course we cannot alter and to receive those deaths we cannot resist. In this perspective, aging cannot be viewed as disease any more than can pregnancy, adolescence, or the furrowed brow or balding mane. Aging is the agonal crisis which is life's crowning culmination. In a glorious passage in his journal, Soren Kierkegaard writes

> What pleases God even more than the praise of angels is a man, who in the last lap of his life, when God is transformed as through into sheer cruelty and...does everything to deprive him of all joy in life, continues to believe that God is love and that it is from love that God does this. Such a man becomes an angel. And in heaven he can surely praise God. But the apprentice time, the school time, is also the strictest time. Like a man who journeyed through the whole world to hear a singer who had a perfect voice, so God sits in heaven and listens. And every time he hears praise from someone whom he brings to the uttermost point of disgust with life, God says to himself, "That is the right note!" He says, "Here it is!" as though he were making a discovery.[6]

James D. Watson, of double-helix fame, once spoke of the great keyboard that is our genome and expressed his skepticism as to whether a benign generative deity watched over us with respectful appreciation as Kierkegaard implied in his words or whether as in the Psalmist's words, "He who sits in the Heavens laughs...and has us in derision." (Psalms 2)

Appropriate hope is not eugenic, as Dan Kevles has with the force of his argument observed earlier in this volume. Hope is not to be found in growth hormone or genetic corrections of sexuality: hope please that persons simply be allowed to fulfill their God-

given endowment. PKU rudely blurs the mind, cystic fibrosis robs one of the breath of life too soon, and Alzheimer's robs us of memory and hope. But when we seek the conquest of aging we should remember the words of Henry David Thoreau at Walden Pond: "Do not think that winter with its ice and snow is a problem to be solved."

Faith. Faith is the essence of religious life--idolatry is the antithesis of faith. To borrow Jack Stotts's concept, faith is trust in that ultimate power whose will for us is good and whose will no countervailing powers can thwart. In this light, the main threat of genomic study will be the same threat that medicine and science themselves pose to divine or natural providence. The genome project in its therapeutic thrust will enable us to exchange some diseases for others. It will change the epidemiology of disease. It will redefine mortality and the vectors of mortality. It will give us power to control and remake death, which aspiration is in all faiths the ultimate hubris. It is no accident that Dr. Jack Kevorkian introduces his "thanatron" and that the state of Washington votes on proposition 119 in regard to physician-assisted suicide at the same time the federal government mandates the genome project. To take control over the morbidities and mortalities that will affect us is a tantalus in which the grape-clusters lowered to our clinging grapes now come in the form of DNA spirals. The fruits we pluck may be better or worse than those now on our table. Is Alzheimer's preferable to pneumonia? Is AIDS to be preferred to tuberculosis? To discard certain deaths and choose certain healths ultimately will require that we more deliberately choose the time, manner, and mechanism of our death. This eventuality was probably inevitable the moment our Egyptian and Hebrew forebears decided that life, not God, was God. Faith will sustain in us a serenity and solemnity in the face of death and a humility in the face of the complexity of the life-world as we are coming now to know it. Faith--as

Einstein and even Kepler before him reminded us--is integral and indispensable to science. Faith makes science sufficiently contemplative to know truth and to do right with that truth. Knowledge is terribly ambivalent as is its technologic application: it can liberate, it can destroy. The angels and fallen angels are both rubbing their hands right now as they look on the genome project.

Love. There is finally the bridge theme of compassion, bridging faith and justice. Love is the greater gift of faith and is the forebear and precondition of justice. Compassion, to suffer with another, is crucial to the biomedical enterprise. Love is at work as we seek to ameliorate the suffering to which persons are heir by bodily condition or life's circumstance. Through such compassion, we uphold the person born with Down Syndrome and with all handicaps. Love entails acceptance, non-discrimination and amelioration os that if we can't relieve suffering at least we support one another kindly as we live with disability and pain.

How might a continuum of compassion--that response ranging from acceptance to amelioration--work itself out in the genetics project? Down syndrome offers an example. Once called by the Irish dinneledia--the gift of God--in old Catholic theology, such a child became the mongoloid in Euro-American eugenic history. Then, Down syndrome became a diagnosis when 19th century pathological diagnosis came into vogue. The same condition is now known as trisomy 21 in Lejune's age of chromosomic analysis. Awe-struck observation moves to self-righteous pity, then to dissection and eradication of the amniotic project and now to the "find it, fix it or fool it" approach implicit in genomic research. Ironically, the ability to repair the biologically flawed condition diminishes our ability to care. Explanation tends to foster excommunication. The knowledge of what has gone wrong tends to make us want those with afflictions--however defined--out of sight. The one redeeming feature in this

development which might be fortuitous for the genome project is a very recent renewal of an ancient mode of compassion, co-suffering consciousness which sees the wounded and the afflicted as hero and/or pioneer. If I read social consciousness rightly, what is happening in our responses to Steven Hawkins, Ryan White or Magic Johnson is possibly a restitution of the ancient religious grace Albert Schweitzer and Johann Sebastien Bach called love.

Justice. Justice is the virtue that is born as the sense of mortality that inspires solidarity. Justice is also borne in the theological sense that the power that has given us life has also measured our span of being and will one day, in some manner, possibly with some pathological vector, culminate that work. The fact that we shall all die requires that no one shall be deliberately crushed or held down. Justice declares that no embodiment of nature ought to go unfulfilled and no destiny be thwarted. Equality and solidarity are legal and philosophical doctrines grounded in theologically created endowment shared by all human beings. Non-discrimination in policy flows from this conviction, as does the imperative of equality.

Concluding Remarks

In conclusion, what has religion to offer the genome project? The being of God inspires faith and hope that is caution and affirmation--the power of God inspires love and justice which require help while not hurting. In the end, the religious impulse commands that we not kill so that life unviolated may flourish. The genome project will enfold into our larger human tendency either to violate or liberate. It will fashion either Golem or Mensch. When we've unravelled as many as one hundred thousand genes and their billion bits we'll have

either a straw man with a tape in his mouth--a composite nobody--or a living breathing Mensch. For this reason alone, religion and technology must instruct one another.

Notes

1. [citation needed]"Researchers find molecular basis for deterioration of the heart," Chicago Tribune, October 3, 1991, sect. 1, p. 16. See also M. Corral-Debrinski, et al., "Ayproxemia is Associated with Mitochondrial DNA Damage and Gene Induction," Journal of the American Medical Association 1991 (266): 1812-1816.

2. "Studies lLink Genetic Defects to Alzheimer's" Chicago Tribune, October 4, 1991, sectl. 11, p. 3.

3. J. Murrell, et al., "A Mutation on the Ambloid Precursor Protein Associated with Hereditary Alzheimer's Disease," Science 1991 (254): 92-99.

4. "Japanese Scientists Isolate Brain Gene Used in Memory," The wall Street Journal, Nov. 7, 1991, p. B3.

5. Jack L. Stotts, "The Human: A Protestant Christian Perspective" [unpublished manuscript], The Institute of Religion, Houston, Texas, 1990.

6. Alexander Dru, The Journals of Soren Kierkegaard (Oxford: Oxford University Press, 1937), p. 603.

Use of Genetic Information by Private Insurers

Robert J. Pokorski

Because a great deal of the present concern regarding future use of genetic information by insurers stems from a lack of knowledge of the basic tenets of private, voluntary insurance, I would like to overview briefly some of the fundamental principles of private insurance before directly addressing issues associated with advances in genetic technology. It will be the goal of this essay to describe not only those principles but to argue that genetic information must be made available to insurers as a matter of equity.

PRINCIPLES OF INSURANCE

Insurance is intended to provide financial protection against unexpected or untimely events. In particular, life and health insurance are purchased not in anticipation of imminent death or illness--although it's understood that death is inevitable and serious illness is fairly common. Rather, life insurance is obtained to protect dependents or business associates from the financial disadvantages that can occur in the event of unexpected death, and health insurance is meant to provide protection in the event of a significant financial loss associated with an unanticipated illness.

How does private insurance work? Basically, policyholders pay a relatively small, affordable amount into a common "pool" and the benefits of the pool are distributed to the

unfortunate few who die (life insurance), become disabled (disability insurance) or develop illness (health insurance). In this way, the financial loss attendant to these events can be mitigated even through the events themselves cannot be prevented.

But not all people are alike. The likelihood of occurrence and magnitude of loss will vary across those differences. Some people will apply for large amounts of insurance and others for small amounts. Some will be young and others elderly. Occupations and avocations will modify the likelihood of unexpected death or illness, as will health-enhancing activities such as exercise, proper diet, and nonsmoking. And some applicants will already be in poor health or at known significant risk of developing poor health in the future. These different factors are evaluated by the insurance company through a process known as "risk selection and classification." The more common term for this process is "underwriting." Through underwriting, the insurance company determines the appropriate contribution to the risk pool by an individual policyholder.

The fundamental goal of the underwriting process is equity: policyholders with the same or similar expected risk of loss are charged the same. The higher the risk, the higher the premium. The lower the risk, the lower the premium. Note the distinction between equity and equality. With equity, premiums vary by risk; with equality, everyone--young/old, healthy/ill, and with/without associated factors that significantly increase the likelihood of experiencing an early claim--would pay the same price.

During the underwriting process, risk classifications are created that recognize the many differences that exist among individuals in order to place applicants into groups with comparable expectations of longevity and health. Although the risk presented by any single individual cannot be determined with absolute precision, if people are assigned to groups

with reasonable accuracy and the total number of insured persons is large, then the estimate of the risk of the entire group of insured people is likely to be accurate.

Traditionally, characteristics important for risk classification have included factors such as age, gender, health history, physical condition, occupation, the use of alcohol and tobacco, family history, and serum cholesterol. These factors serve to identify individuals that have a greater or lesser likelihood of premature death or illness in the future. Because of this process, costs are held down for the great majority of insurance applicants since premiums more closely match the risks taken on by the insurance company.

How are rates determined that reflect the principle of equity? Under state laws and in the opinion of most observers, rates are considered equitable when they allow the insurer to earn enough income to pay claims and expenses and generate a reasonable margin for the risks they accept. In other words, "rates should be adequate but not excessive and should discriminate fairly between insureds. They should be adequate in order to provide insurers with sufficient income. They should not be excessive, for excessive rates impose undue burden on insureds. And they should discriminate fairly so that each insured will pay in accordance with the quality of his life."[1]

The statement above reflects the rate-setting philosophy of a private insurance company--not equal but equitable treatment of all. It recognizes differences between classes of insured persons, with products priced at a level which will result in a payment by each insured of an amount which is fair. Such fairness is accomplished by equating the anticipated cost to the company and the amount of the premium.

The vocabulary of insurance can be confusing. In the context of private insurance, discrimination is not necessarily bad and equality good. For example, in accordance with the

insurance philosophy set out above, it would be inequitable to collect the same annual premium for the same life coverage from a sixty-year-old man in poor health as collected from a twenty-year-old woman in good health. To charge an equal premium would be inequitable. An insurer may--and must--discriminate to achieve equity, insofar as the discrimination remains fair. In fact, the statutes, regulations and case law which regulate the insurance industry compel discrimination; what they forbid is unfair discrimination.

Adverse selection, also known as antiselection, is a consideration that is of great importance to insurers. Adverse selection is a well known phenomenon in which people with a likelihood of loss greater than what they are charged tend to apply for or continue insurance coverage to a greater extent than do other similarly situated people. It occurs when applicants withhold significant information from the insurer and/or choose amounts and types of insurance that are most beneficial to themselves. For example, someone with a history of heart disease is more likely to apply for insurance and/or apply for a greater amount of insurance coverage than he would have otherwise done because he knows that he is likely to experience a claim in the foreseeable future. If he fails to mention this important information on his insurance application and the insurer does not otherwise become aware of it, the premium charged by the insurer will be insufficient to cover the risk involved. This premium deficit would be made up by the others in the pool who have paid their fair share. Adverse selection also occurs if the insurer is not permitted to obtain or use information that is pertinent to the risk being considered. In the example above, the premiums charged would be insufficient to cover the risk involved if the insurer was not permitted to ask the proposed insured and his attending physician about the nature and severity of the heart disease, or if this information could not be used in setting premium cost

after it had been obtained.

What would happen if the insurance company was unaware of important, unfavorable information that was known to the applicant? In these instances, serious errors in risk classification would occur. Certain individuals would receive their insurance at unreasonably low cost. More claims would be filed than were expected, and if a significant number of these risk classification errors were made, the financial status of the entire insurance pool would be adversely affected.

But couldn't premiums simply be increased across-the-board to cover the payment of these unanticipated benefits? Where permitted, an insurer could increase premiums to reflect these revised claim expectations. But this would encourage potential insurance applicants who are at lower risk to either buy from a different seller or exit the insurance market altogether. And with the individuals who had knowledge of their unfavorable risk status--individuals who had adversely selected against the insurance pool--further escalation of premiums becomes necessary. More potential applicants then decide not to apply for insurance.

Eventually, a point is reached in this upward spiral where the desired coverage becomes unavailable on any reasonable premium basis or the insurer becomes financially unsound. This "assessment spiral" is not merely a theoretical possibility. It actually occurred in some companies during the 1880s and 1990s because of poor risk classification practices. A more recent example of the effects of failing to classify risks properly is provided by the recent failure of a moderate-size casualty insurer located in Chicago.[2] The company originally specialized in individual disability income policies. In the early 1970s, new management took over the company and decided to use its casualty authority to write auto insurance.

They believed that people living in some of Chicago's neighborhoods were being charged auto premiums that were too high. Based on this belief, management ignored the actuarial statistics and evidence, and wrote author insurance for drivers in these neighborhoods at rates that would have been correct for a population with far fewer auto accidents. As a result, the company failed and everyone was hurt financially. All the company's lines of business were affected, including its disability income line. Many disabled individuals who had long depended on income payments lost those benefits.

The current risk classification system permits private insurers throughout the world to respond fairly to valid cost and experience-related differences among persons. To help guide actuaries in developing this system, the actuarial profession through the Actuarial Standards Board has adopted a risk classification standard of practice. This standard enumerates three basic requirements for an appropriate risk classification system. First, risk classification must be fair. Secondly, it must permit economic incentives to operate, and thus encourage widespread availability of coverage in the marketplace. Finally, risk classification must do its part to keep the insurer solvent. To achieve these ends, a sound classification system should be based on at least four principles as follow.

A. First, risk classifications should reflect cost and experience differences. For example, employers of coal miners would pay more for their unemployment insurance than employers of computer technicians because coal miners historically have much higher rates of unemployment.

B. Secondly, the system should be applied objectively and consistently. By this principle, for example, males of the same age with similar health histories should be charged similar rates for life insurance.

C. Thirdly, the system should be practical, cost-effective, and responsive to change. This means that there are limits on how much effort and money can be spent to classify a given risk, and risk classification systems must be dynamic. For instance, when polio was eliminated as a public health hazard, the system changed to reflect that development.

D. Finally, adverse selection should be minimized. As noted earlier, sound risk classification systems limit the ability of an applicant to take an unfair financial advantage at the expense of the insurance company or other policyholders already insured by the company.

PRIVATE AND PUBLIC INSURANCE

Many people have come to expect that private life insurance and, to a greater extent, private health insurance, is an entitlement, i.e., that all citizens have a right to expect that affordable insurance protection will be made available to them regardless of age or health. This expectation is based to a considerable degree on misconceptions regarding the nature of private and public insurance programs. A brief discussion of these two different types of insurance will help clarify their relationships.

Private (Voluntary) Insurance. Participation in a private commercial insurance plan is typically voluntary. An individual chooses whether or not to belong and determines how much insurance protection he or she would like to purchase. Since all of the funds used to pay future claims against the insurance pool are derived either directly or indirectly from premium payments, risk classification is essential in order to ensure that the premium charged is proportionate to the risk assumed. The potential for adverse selection is very real

and an important concern of the insurer. Finally, private insurance companies are businesses that are accountable to their policyholders and stockholders. They must generate a profit for those who have invested in the company. If insufficient premiums are collected, a private insurance company, like any other business in which liabilities exceed assets, will cease to exist.

Public (Involuntary) Insurance. American society has used private means to fulfill certain general social welfare needs such as payment for health care. But private health insurance has never been a completely adequate or universal method of providing access to the health care system, not has it been a perfect mechanism for covering all diseases. The poor, disabled, aged, or seriously ill cannot always be covered by private means. For this reason, society has supplemented private insurance with publicly supported programs such as Social Security, Medicaid and Medicare.

Participation in a public insurance plan is not typically voluntary. One does not choose whether or not to belong nor does one determine the extent of insurance protection. Rather, participation is mandatory and benefit amounts or entitlements are determined by the law establishing the program. Since everyone--good risks, poor risks, even those suffering from a severe or terminal illness--is automatically insured and there are no options regarding the amount of benefits that will be paid, adverse selection is not a concern. Premiums are charged in the form of income and social security taxes, or so-called "insurance premiums," but they are not and need not be proportionate to the risk assumed. Risk selection is not required and no profit motive exists.

The foregoing points are summarized in the table below.

Comparisons Between Private and Public Insurers

	Private (Voluntary) Insurance	Public (Involuntary) Insurance
Examples	Private, Commercial Insurers	Medicare, Medicaid Social Security
Participation	Voluntary	Mandatory
Amount of Insurance	Optional	Controlled
Risk Classification	Essential	Unnecessary
Potential for Adverse Selection	Yes	Unnecessary
Profit Required	Yes	No

Even given these fundamental differences between private commercial insurance and public insurance, couldn't legislators or regulators simply mandate that private insurers provide coverage--at rates appropriate for lower risks--to those individuals who have learned from their physicians or insurer that a genetic test has identified a higher likelihood of premature death or illness? Or, in an action having the same consequences, couldn't insurers be prohibited from asking applicants and their physicians for the results of prior genetic tests or order their own tests?

There seems little chance that this would work in a private, voluntary insurance industry. This mandated subsidization of unfavorable risks by good risks would be tantamount to an indirect governmental tax levied solely against insurance policyholders and stockholders. The impact of such an action may not appear significant at the outset, but its cumulative effects would be dramatic. Under such a scenario, many potential policyholders--primarily

favorable risks who would be asked to subsidize the higher, underpriced risks, and people with other health impairments such as cancer and heart disease who pay a premium commensurate with their increased risk--would realize that they are being overcharged or treated unfairly, and choose not to buy insurance because coverage has now become unaffordable for them. Why? Wouldn't the premium increase be relatively small? Although such a plan for mandated benefits probably wouldn't result in significantly higher costs at first, premiums would gradually and progressively risk as more and more favorable risks decide not to purchase insurance. The relatively large base of good (standard) risks is progressively eroded, it becomes increasingly difficult to subsidize the poorer risks, and premiums increase again. The situation worsens even more as some companies decide to stop writing this type of insurance coverage altogether since a profit can no longer be expected.

Such a legislative or regulatory mandate would force insurers to provide coverage for a large (because of the effects of adverse selection) group of people at a price that would be insufficient to cover the claims that would occur. These additional costs would be passed directly to other policyholders with a subsequent decrease in insurance affordability and availability.

INDIVIDUAL AND GROUP INSURANCE

There is yet another issue worth discussing prior to specific mention of the use of genetic test results, and that is the matter of insurance provided through employers. A brief overview of the differences between individual and group insurance is necessary in order to assess the

impact of genetic testing and the arguments regarding access to test results.

For individual life, disability, and health insurance, an applicant applies for whatever amount of insurance coverage that he or she feels is needed (within broad guidelines established by the insurance company). An application form is completed, medical questions are asked, tests may be ordered, and a physician's statement may be requested. The premium charged is based on factors such as age, gender, health history, general physical condition, and occupation.

Group life and health insurance, by contrast, is generally divided into two categories: medium-to-large size groups containing 10-25 or more employees, and small groups with fewer persons. Under a medium-to-large size group life and health insurance plan, an employer buys a single policy for his employees. All employees can elect to receive coverage if they so choose. Benefit amounts are fixed by formula and individuals are normally not subjected to the underwriting process described above with the possible exception of those who choose not to participate in the program when they first become eligible and those who withdraw from the plan and later request reinstatement. Rather, the entire group is underwritten according to factors such as the number of employees, age and gender distribution, area of the country, and prior health care costs for the entire group. Once a rate is established , it is typically adjusted ("experience rated") on a yearly basis, depending on claims experience. If claims exceed expectations, rates increase. Or rates decrease if claims are less than expected. With such a large group, it is expected that some workers will be poor insurance risks. But the majority who are good risks tend to offset these few, thus allowing the insurer to offer coverage to the entire group at an affordable rate. Typically, payment by the employer of part of the cost provides adequate

incentive for the good risks to join the insured group.

Small group life and health insurance is different. Since these groups do not have the benefit of a large number of employees among whom the less health risks can be shared, claims experience is strongly dependent on the health of the small number of individuals within the group. For example, if one individual in the group was already ill or at significant risk of becoming ill in the near future, and the insurer was not aware of this information, then the claims submitted by this one individual could far exceed the claims expected from the entire group. To guard against this possibility, in the absence of underwriting, the insurer would have to increase the premium rates for all small groups. The increased premium rates would induce groups with more good risks not to buy coverage.[5] An assessment spiral much like that described earlier for individual insurance would develop. And if such a practice occurred with any regularity, the cost of insurance to small groups would soon become unaffordable. For this reason, the underwriting of small groups shares many similarities with that used for individual insurance, e.g., the need for application forms, medical questions,, and sometimes tests and physician reports. The principle differences between individual and group insurance are summarized in the heading below. The column headed "Group" refers to medium-to-large size group plans.

Comparisons Between Individual and Group Insurance

	Individual	Group
Adverse Selection	Optional at discretion of an individual	Generally guaranteed as a benefit of employment; high participation is common
Amount of Insurance	Optional	Controlled
Individual Risk Classification	Essential	Generally not done
Potential for Adverse Selection	Significant	Minimal

Approximately 90% of commercial group health insurance--and perhaps a similar percentage of group life insurance--is sold to medium-to-large size groups. The employees within these groups are eligible for insurance coverage as a benefit of their employment. There is no individual underwriting or testing of those who sign up for the program when the group plan goes into effect or when new employees begin work. For this reason, the overall impact of genetic advances on group insurance may be expected to be minimal. For small groups, the ramifications are less certain. The effects may be more like those to be expected in individual life and health insurance. It is worth considering in this regard the nature of genetic disorders in order to see the significance of testing for these forms of insurance.

TYPES OF GENETIC DISORDERS

Genetic disorders may be divided into two broad groups: (1) disorders that follow a genetic predisposition and (2) diseases that are independent of environment.

Disorders with a genetic predisposition (or a genetic component) are those in which the presence of a gene confers an increased tendency to develop a certain disorder. The disorder may or may not develop depending on a variety of associated personal and environmental factors such as geographic location, diet, exposure to harmful chemicals or toxins, exercise habits, obesity, tobacco use, heavy alcohol ingestion, and so on. A genetic predisposition is often a factor in the development of common impairments such as cancer, coronary heart disease, hypertension, diabetes mellitus, and epilepsy. Together these disorders are responsible for much of the morbidity and mortality that is experienced in insurance claims.

Genetic disorders that are independent of environment involve a determining force so overwhelming that the disorder is expressed in a predictable manner without environmental interaction. For example, an individual who inherits the gene for Huntington's disease, or Duchenne muscular dystrophy will eventually develop the disorder regardless of other socioeconomic factors or preventive health measures. Individual genetic disease are rare compared to disorders with a genetic predisposition, but collectively they are also an important cause or morbidity and mortality.

Given the genomic profiling that the genome project is expected to make possible, physicians will probably begin to use new diagnostic tests that will be able to identify genetic diseases and predispositions to such disorder. Some of this information may be important to private insurers. Why? If this information were unavailable at the time of underwriting, then applicants who knew they were likely to experience early death or illness could buy large amounts of insurance coverage at prices that failed to reflect this increased risk. In the aggregate, this could involve disproportionately large numbers of applicants and/or very significant amounts of insurance. The ensuing claims would markedly exceed projected

losses, and everyone within the insurance pool would suffer the disadvantage.

Consider the following scenario. Suppose a man who applies for an individual life or noncancelable disability insurance policy has had a genetic test performed in the past by his physician, the results are unfavorable, i.e., the test suggests a significant likelihood of premature death or disability, and the insurance company does not learn about this result. If no other unfavorable risk factors are known in this case, the policy issued on a standard class basis.

What has happened? Essentially, the principle of equity has been violated. This applicant with an above average risk for claims has obtained insurance at standard rates. This situation would be analogous to that of an older person who misrepresents his true age and obtains insurance at the rates of a much younger person. It is important to note that he has not suddenly become a standard insurance risk because he was issued standard insurance. Rather, he is a substandard risk who has nonetheless obtained insurance at standard rates because of a failure of the underwriting process. Although the applicant would be pleased with this arrangement, the other policyholders would be equally unhappy with this sequence of events. True, he currently seems in good health, but his unfavorable genetic test clearly identified a significantly increased risk. And since his insurance coverage cannot be canceled once it has been purchased nor can the premium be increased relative to other policies issued to individuals with similar coverage, it is likely that he will be paid benefits from the pool that are disproportionate to the premiums he paid.

This kind of example is just one of the many that may be expected in the way of the genome project. Indeed, genetic advances are forcing society to confront unexpected medical, ethical, and social dilemmas. In light of the foregoing discussion about the nature

and practices of insurance in the United States, four concerns of particular interest with respect to insurers' use of genomic profiling will be considered next.

HOW WILL GENETIC INFORMATION BE USED BY INSURERS?

It may be expected that genetic descriptions of individuals would be used much like other data that is developed during the underwriting process. Current tests that may be used in that process include electrocardiograms, liver and renal function tests, blood sugar and cholesterol values, lung function tests, and urinalysis. Related data of interest are age, past medical history, geographic location, occupation, avocation, smoking habits, history of drug abuse or heavy alcohol ingestion, hypertension, family history, exercise, weight and data from a physical examination. All of these factors are evaluated, and their potential impact on longevity and health is estimated. The great majority of applicants will be found to present an average risk. Some will be at lower risk, and the risk will be higher for a small number of applicants.

Genetic information would be one additional factor that is evaluated during underwriting. For example, suppose a genetic test could identify those at lower or higher risk of coronary heart disease. Favorable genetic information would tend to offset unfavorable parameters such as a high cholesterol level or hypertension. And the converse would be true for those with less favorable genetic traits.

WILL GENETIC INFORMATION AFFECT THE AVAILABILITY OF INSURANCE COVERAGE?

It is likely that use of genetic information will not significantly affect the availability and affordability of private insurance coverage. As noted earlier, a great deal of the life and health insurance in the United States is provided on a group basis by employers. In these instances, individual underwriting is not done. Genetic information, whether favorable or unfavorable to an individual, isn't likely by itself to alter these patterns of insurance provision.

In regard to individual insurance, genetic information may improve an insurer's ability to select risks in some cases, but I doubt that it will significantly affect the number of people who obtain insurance overall. As with other data developed during the underwriting process, genetic information might identify more or fewer favorable risk factors. This information, however, would be interpreted in the context of all other available data especially since genetic diagnoses would not supplant already existing diagnostic tests and because genetic diagnoses do not always rule out insurability. Many genetic diseases, such as Down's syndrome, cystic fibrosis, and sickle cell anemia, strike very early in life and can be detected by means other than genetic tests. Having genetic tests available might not result in many additional persons being identified as being at risk for these diseases. Other genetic diseases develop only late in life, with the result that young persons who are predisposed to them may still have a long life expectancy. And if they have passed the age at which the disorder usually develops, their life expectancy might be normal.

There are some genetic disorders, of course, like Huntington's disease, for which additional genetic information might increase an individual's chance of obtaining insurance. For instance, if one parent had Huntington's disease, 50% of the children are at risk for the same condition. These individuals are very high mortality risks and may not be able to buy

individual life coverage. Even then, though, a favorable genetic test result would, however, identify those who are at virtually no risk, and insurance could be offered to them at standard rates. Many genetic predispositions involve only an increased likelihood of developing a disease, such as lung cancer, which is very uncommon in the average person. In many cases, this may not itself represent a very large increase in life insurance risk, especially if the disease is one which, like heart disease and many forms of cancer, tends to strike at relatively advanced ages.

Moreover, since genetic information may help insurers evaluate risks more precisely, there may be fewer rejections--not more--in the future than there are now. One reason for the rejections that occasionally occur now (in about 3% of individual life insurance applications) is that, in high risk cases, it is often impossible on the basis of present knowledge to make a close estimate of the level of risk. Presumably, an applicant would not accept a policy bearing a very high premium charge unless he or she had reason to believe that high though the premium might be, the insurer has nevertheless underestimate the risk. The insurer, therefore, may reject such applicants rather than make an offer on likely loosing--for the insurer--propositions. With greater precision in risk evaluation, the insurer would have less fear of accepting certain risks.

It is worth noting, finally, that private insurers--and not the government or other social agencies--have been responsible for initiating efforts to provide insurance coverage for people with illnesses that had been previously considered uninsurable. For example, at the turn of the century, diabetes mellitus was often fatal soon after its onset. After insulin was discovered, insurers were able to study the medical literature to determine the many different patterns of longevity and health among those with diabetes. Because they could analyze this

data, classify the risks appropriately and charge a price commensurate with the risk, insurers began to insure diabetics. The same can be said about coronary heart disease, hypertension, and many cancers.

WILL CONFIDENTIALITY OF GENETIC INFORMATION BE MAINTAINED?

Insurers have used genetic information in the underwriting process for a long time. Applications for insurance policies frequently seek information relative to family medical history, cholesterol, hypertension, coronary heart disease, cancer, diabetes, and many other impairments with a genetic component. Applicants' medical records, obtained in connection with some applications for coverage, may also reveal information relative to genetic impairments. Historically, insurers have used this information responsibly, protecting its confidentiality and relying upon it to make fair underwriting decisions. The lack of complaints about any breaches of confidentiality bear witness to this fact. Given this fine track record, I think the insurance-buying public can anticipate that any genetic information seen by insurers will be treated with the utmost confidentiality.

IS USE OF GENETIC INFORMATION BY INSURERS DISCRIMINATORY?

Much of the concern about use of genetic information by insurers stems from the word "discrimination." In today's world, this word often carries very negative connotations, but it's a word with several means, some negative, some positive.

As noted earlier, private insurance, by its very nature, is recognized as being discriminatory in that individuals who represent a higher risk are routinely charged a higher premium rate. Risk selection is properly performed and there is "fair" discrimination when the applicant's expected future mortality and morbidity have been properly estimated and reflected in the premium rate. "Unfair" discrimination, on the other hand, is not and should not be permitted. Unfairness in the insurance context occurs when there is no sound actuarial justification for the manner in which risks are classified.

Comments about discrimination with respect to insurers' use of genetic information highlight the mistaken impression that identifying differences in risk is somehow bad or unfair. They also indirectly express the belief that it is acceptable to "discriminate" against those with health impairments such as cancer or coronary heart disease by charging an extra premium even though these disorders are no more one's fault than are genetic impairments. Distinguishing risks is precisely what insurance companies must and, in fact, are expected to do. It is because insurers are able to identify these differences that insurance coverage can be offered to so many people at affordable rates.

Who suffers if an insurer doesn't charge an appropriate premium solely because the applicant's impairment has a genetic basis: healthy individuals paying standard insurance rates, policyholders who are making additional premium payments because of some non-genetic health problem, and, in cases involving genetic data, every applicant whose genetic information is favorable (which will probably include the great majority of applicants). All of these people would be forced to pay higher rates so that those at greater risk can pay less than would be required by an equitable estimate of their own risks. The attractiveness of private insurance for everyone, healthy and impaired, begins to

decrease under such a schema.

Insurers try to charge premiums commensurate with risk. Applicants with a greater likelihood of experiencing an early claim are asked to pay more into the insurance pool since their risk is greater. It is this probability that is important, not whether a disease has a genetic basis or whether it can be controlled. For example, an individual with coronary heart disease or a recent history of cancer has an increased risk of death and illness. An insurer doesn't ask if it is or isn't the individual's fault. Likewise, someone with a similar probability or early death or poor health due to a genetic disorder would be charged a similar amount. Again, fault or lack of control over the condition is not an issue.

Within the context of discrimination, the point is sometimes raised that society has prohibited insurers' use of certain factors over which a person has no control, notably race, gender, and religion, even though these are characteristics that would be useful to consider when trying to classify risks. Given this kind of moral precedent, so the argument goes, society should also prohibit use of genetic information in classifying risks. This is a serious issue and deserves the following response.

With respect to race, it is true that insurers are legally prohibited from basing underwriting decisions on race. It is also worth emphasizing that insurers are very supportive of this legislation. The reason is this: race by itself is not a risk factor in determining an individual's expectations for health and longevity. Differences in morbidity and mortality among races are explained by the presence of health impairments. Laws prohibiting use of race during the underwriting process are in essence a confirmation of the principle of equity: they state that risks that are equal, i.e., the intrinsically equal morbidity and mortality among races, must be treated the same. Note that they do not require that

insurers treat different risks the same, as would be the case if such a philosophy were applied to those at greater risk of death or illness because of cancer, heart disease, or a genetic impairment.

Regarding gender, epidemiologic experts have concluded that there are intrinsic gender-related differences in morbidity and mortality risks. These gender-related differences are recognized in the vast majority of jurisdictions. As of July, 1991, for example, there were not federal laws or regulations mandating unisex pricing for life or health insurance products. And only one state--Montana--has enacted unisex legislation that affects life and health insurance. This bill was passed in 1983, and there have been repeated attempts to repeal it since that time.

I don't know if insurers ever used religion to classify risks. The members of some religious groups such as Mormons and Seventh-Day Adventists have high average longevity, certainly attributable to, among other things, a principled avoidance of alcohol and tobacco use. Legislation requiring insurers to treat all religious backgrounds equally would presumably have the unintended effect of a prohibition of offering lower cost coverage on this basis.

CONCLUSIONS

Diagnostic and therapeutic advances in the practice of medicine are both inevitable and desirable. The genetic testing one may expect in the wake of the human genome project offers exactly such advances. Genetic testing will be thrust on a society that has had little experience in dealing with many of the complex ethical, medical, and social issues that will

ensue. Many facets of society--including the private insurance industry--will need to study the potential impact of this new technology and adapt. At this time insurers are no more able to answer the difficult questions concerning future use of genetic testing than is any other facet of society. In fact, most of the questions themselves are still unknown. We will continue to study the issues and await further developments. This can be the only reasonable course of action until significant technologic advances are made and the nature and use of genetic testing becomes more apparent.

What insurers fear most in the future is that people will learn of important, personal genetic information outside the context of insurance and then successfully use this medical knowledge to gain an undue advantage in the application process. This is unfair both to insurers and other applicants and policyholders who must pay higher premiums in order to issue coverage to those who failed to disclose this information. Americans choose the type of insurance system they want. If they choose a private insurance system, it must be one that makes sound decisions about which risks it will insure. A system that does not classify risks will at some point cease to be an "insurance" system. Whatever entitlement program remains will be very expensive because it will allow unrestricted access to coverage by those with very serious diseases, some of which are genetic in nature.

There are those who would suggest that genetic information not be shared with insurers, this in spite of the likelihood that this information will be favorable in the great majority of cases. As noted in a recent editorial dealing with ethics and the human genome, "A rule that insurance companies should not seek genetic information about potential policy-holders would probably be unenforceable, would be unjust to those free from defect and would probably be unconstitutional in most advanced countries."[3] The policy adopted in the past by all

countries where private insurance is sold is not to deny insurers access to medical information, but rather to require that the medical information utilized be accurate and up-to-date, and that underwriting decisions be based on sound actuarial assumptions. These same requirements of fairness are appropriate for the use of future genomic information as well.

Notes

The opinions expressed in this article are those of the author. They are not necessarily shared by any insurer or the insurance industry in general.

1. H.T. Bailey, T.M. Hutchinson, G.R. Narber, "The Regulatory Challenge to Life Insurance Classification," Drake Law Review Insurance Annual 1976 (25), p. XXX.

2. Record of the Society of Actuaries, San Francisco Meeting, Jun 14-15, 1990 Vol. 16, No. 3, p. 1362.

3. Author needed if there is one, "Ethics and the Human Genome," Nature 1991 (351): 591.

The Genome Project, Individual Differences, and Just Health Care

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The mapping of the human genome is likely to have important implications for the just distribution of health care services. Some of these implications will be the result of the new medical technologies that will be developed once we learn more about the human genome. Despite their likely importance, I will not speculate about them in what follows, nor will I comment on the way they add to the burden we already have in deciding how to disseminate and ration new technologies under conditions of resource scarcity. Instead, I want to focus on the fact that the mapping of the genome will give us specific, new **information about individual variation**. This information can be used in good and bad, fair and unfair ways, and it raises, or, I should say, refocuses, important questions about how we should distribute health care resources.

I shall address three questions of genuine philosophical interest, each of which is sharpened in some way by what we learn about human variation from the genome project. One probable outcome of the genome project is a greater ability to predict certain health risks as a result of genetic screening. We will better be able to divide people into risk groups, not only for strictly genetic diseases but also for other diseases that have some genotypic

component. This predictive ability may lead to better preventive or treatment regimens, but it also is of interest to private insurers who may want to use the information to exclude some individuals from insurance and to facilitate the risk-rating of insurance pools. The ethical question posed by the underwriting practices of insurers is this: Are people at lower risk entitled to benefit (through better access to cheaper insurance) from this sort of individual variation? More generally, which variations between individuals should be the basis for gaining advantage over others and which variations should we treat as a collective asset or liability? These questions take us deep into political philosophy.

The second question is this: Can we defend the distinction between medical therapies that **treat** and those that **enhance** in the face of new genetic information that allows us to pinpoint the genetic contributors to traits we want to alter? Imagine, for example, that we will come to identify particular genes or patterns of genes that contribute to making people very short. These do not represent pathology of the usual sort: they do not lead to growth hormone deficiency, for example. But being able to look at the microstructure underlying the "normal distribution" of height may produce strong pressures to identify a new class of "bad genes" and to suggest that people who have those genes now have a claim on others to assist them in changing their traits. This question thus has vast implications for resource allocation. Like the preceding question, it too takes us deep into political philosophy, for we are really asking which inequalities between people give rise to

claims on others and which are matters of individual responsibility?

Finally, what are the implications of knowing that an individual is at higher risk for a disease because of genotype, when the phenotypic expression of that disease also has a significant lifestyle component? Specifically, what happens to our concerns about responsibility for health and the relationship between our judgments about responsibility and our obligations to provide medical services? As we shall see, none of these questions arises solely because of the new information we gather from the genome project. Each is already an issue for us. But quantity sometimes has qualitative effects, and the prevalence of contexts forcing these questions on us will increase as a result of what we learn about human variation from the genome project.

ACTUARIAL FAIRNESS AND INDIVIDUAL DIFFERENCES: ARE HEALTH RISKS INDIVIDUAL ASSETS OR COLLECTIVE BURDENS?

Suppose that one outcome of the genome project is the development of various screening tests that allow us to predict who is at higher risk for a variety of medical conditions. These tests could be used to improve what I shall refer to as **standard underwriting practices**: denying coverage, or offering more expensive and substandard coverage, to those who have a disease or at higher risk of contracting it in the future, as determined by various medical examinations, tests, or records, or other

Why this word rather than extend?

"predictors" of risk. Is there a sound moral justification for these practices?[1]

The best strategy for insurers would be to develop a knock-down argument that showed we are **morally required** to use standard underwriting practices. Such an argument would seize the high moral ground and not simply rest on an appeal to their economic interest. Seeking such an argument, some insurers argue that it is **actuarially unfair**, and therefore morally unfair, to those at low medical risk when insurers do not exclude those at high risk from insurance pools. Thus the hybrid term, "actuarial fairness," widely used in the literature, expresses the **moral** judgment that **fair underwriting** practices must reflect the division of people according to the **actuarially accurate** determination of their risks. I shall refer to this as The Argument from Actuarial Fairness.

Let us begin by thinking solely about the risk-management aspect of medical insurance, ignoring for the moment any special moral importance we may attribute to assuring access to health care services. From this perspective, health insurance is only a way for rational economic agents to manage their risks of serious losses under conditions of uncertainty. Prudent people buy insurance because they prefer to face modest losses (premiums) on a regular basis rather than face catastrophic losses at unpredictable times. The absence of information about when losses will occur gives people an interest in pooling risks. When all parties symmetrically lack information, prudent consumers of insurance will have a common interest in sharing their risks.

The situation changes when we acquire information that allows us to disaggregate the risk and sort people into stratified risk pools. For example, suppose we can differentiate risks by using information about the construction, age, density and location of houses, as well as information about available firefighting facilities and relevant fire safety codes. Or suppose we can differentiate risks through information about individual medical histories, genetic disposition to disease or genetic disorders,[2] or lifestyle choices. Then, those purchasing insurance will come to see themselves as having distinct rather than common interests. Those at lower risk will prefer to pool their risks only with others at comparably low risk, since that will lower the cost of buying security. They may not want to subsidize security for those at higher risk. At the same time, those at high risk will seek the bargain in security offered by insurance that pools high and low risk individuals (this is called adverse selection).

Insurers must respond to these consumer preferences. They must protect themselves against adverse selection, excluding those at higher risk; then they can aggressively market insurance to those at lower risk who seek security at a lower price. The behavior of insurers thus responds to competitive forces in a particular marketing context, one that assumes health insurance has the primary function of giving individuals the opportunity to manage risks prudently.[3] This assumption, as we shall see, is far from morally neutral. Changing the rules governing insurance marketing, by making insurance compulsory, for example, or by requiring that

all insurance be community rated, would not eliminate the profit from insurance. But justifying those changes requires a different assumption about the function of insurance, e.g., that insurance is necessary to guarantee people adequate access to medical care.

The concept of actuarial fairness could be assigned a purely **descriptive** as opposed to **normative** content in the kind of "risk management" insurance market we have just been considering. Saying that a premium is "actuarially fair" would mean only that it reflects the actuarial risks the purchaser faces, i.e., that it is actuarially **accurate**. The appeal to actuarial fairness that we find in the insurance literature goes beyond this purely descriptive content, however, and carries the implication that actuarially accurate underwriting practices are also morally fair or just ones. Thus insurers defend standard underwriting practices by claiming that "Insurance is founded on the principle that policyholders with the same expected risk of loss should be treated equally...The primary goal of underwriting is the accurate prediction of future mortality and morbidity costs. An insurance company has the **responsibility** to treat all its policyholders **fairly** by establishing premiums at a level consistent with the risk represented by each individual policyholder (emphasis added)."[4] Specifically, it will be unfair to those at low risk if they are made to pay the higher premiums necessary to cover the costs of those at high risk. The remark about the "responsibility" of insurers suggests that it is an **obligation** to refuse to underwrite those at high risk.

The Argument from Actuarial Fairness confuses **actuarial fairness** with **moral fairness** or **just distribution**. These are different notions: actuarial fairness is neither a necessary or nor a sufficient condition for moral fairness or justice in an insurance scheme, especially in a health insurance scheme. To forge the link this argument does between fairness and actuarial fairness presupposes that individuals are entitled to benefit from **any** of their individual differences, especially their different risks for disease and disability. This presupposition not only highly controversial, it is false.

To get from the merely descriptive notion of actuarial fairness, which has no justificatory force, to the moral claim about fairness found in the insurer's argument, we need to add some moral assumptions. Specifically, we have to add the **strong assumption** that individuals should be free to pursue the economic advantage that derives from any of their individual traits, including their proneness to disease and disability. The strong assumption might be used in an argument that echoes some recent work on distributive justice: (1) Individual differences -- any individual differences -- constitute some of an individual's personal assets. (2) People should be free to, indeed, are entitled to, gain advantages from any of their personal assets. (3) Social arrangements will be just only if they respect such liberties and entitlements. (4) Specifically, individuals are entitled to have markets, including medical insurance markets, structured in such a way that they can pursue the advantages that can derive from their

personal assets.

This skeletal argument can elaborated, and the strong assumption it contains be defended (or attacked), in quite different ways within different theories of justice. For example, Nozick's libertarianism begins with certain assumptions about property rights and the degree to which certain liberties, such as the liberty to exchange one's marketable abilities or traits for personal advantage, must be respected even in the face of what many take to be overriding social goals.[5] Consequently, actuarially unfair schemes confiscate property without consent. Other political philosophers claim that just arrangements are the result of a bargain made by rational people who want to divide the benefits of mutual cooperation.[6] On this view, bargainers who have initial advantages in assets would only accept social arrangments that retain their relative advantages. As a result, bargainers might argue that just arrangements would preserve the advantages of those at low risk of disease through insurance markets that use standard underwriting practices.

An important objection to both libertarian and bargaining approaches is that the significant inequalities such theories justify can be traced back to initial inequalities for which there is little moral justification. To avoid this problem, Rawls imagines a "hypothetical contract" made by "free" and "equal" moral agents who are kept from knowing anything about their individual traits; they must select principles of justice that would work to everyone's advantage, including those who are worst off. Just which

individual differences should be allowed to yield individual advantage thus becomes a matter for deliberation within the theory of justice, not a starting point for it.[7] We now need an argument why this model for selecting principles is fair to all people and why we should count its outcome as justified, since we can no longer claim they are justified by appealing to the interests of actual property holders or bargainers.[8,9]

The debate about the relevance of individual differences to the just distributions of social goods thus touches on deep issues about equality that lie at the heart of the conflict between alternative approaches to constructing and justifying theories of justice. Showing that the strong assumption about individual differences is deeply controversial at the level of the theory of justice is obviously not a refutation of the Argument from Actuarial Fairness. Still, we now have good reason not to accept the assumption without a convincing argument.

As it stands, the strong assumption is much too strong. Some individual differences are ones we clearly think should not be allowed to yield advantage or disadvantage. In recent legislation in the United States, we have established a legal framework to reinforce these views about justice. For example, we believe that race or sex should not become a basis for advantage or disadvantage in the distribution of rights, liberties, opportunities or economic gain, even though these traits carry with them market advantage and disadvantage. Thus we reject, in its most general form, the view that all individual differences can be a moral basis for advantage

or disadvantage.

Though we agree that race and sex are clearly unacceptable bases for advantage, we have less agreement about how to treat some other individual differences. We allow talents and skills, for example, to play a role in the generation of inequalities, and yet we tax those with the most highly rewarded talents and skills in ways that help those who lack them, at least to some extent (though not to the extent that the worst off are made as well off as possible, as Rawls would have it). How much inequality we allow is controversial in practice, just as it is in theory. Some people, like Nozick, think that individuals are entitled to derive whatever advantages the market allows from their talents and skills, and they view income redistribution as an unjustifiable tax on talents and skills. Others, like Rawls, argue that talents and skills, such as intelligence or manual dexterity, are the results of a "natural lottery," and that it is a matter of luck, not desert, who enjoys the family and social structures that encourage traits of character, such as diligence, necessary to refine ones basic talents. On this view, redistributive schemes are a morally obligatory form of social insurance that protects us against turning out to be among those who are worst off with regard to marketable talents and skills.

Even among those philosophers who want to treat talents and skills as individual assets, only the strictest libertarians treat health status differences merely as "unfortunate" variations and believe that there is no social obligation to correct for the

relative advantages and disadvantages caused by disease or disability. [10] The moral design of health care systems throughout most of the world rests on a rejection of the view that individuals should have the opportunity to gain economic advantage from differences in their health risks. Despite variations in how these societies distribute the premium and tax burdens of financing universal health care insurance, ~~our~~ the mixed system of the United States is nearly unique in allowing the degree of risks to play such a role. Moreover, as I noted earlier, surveys show that most Americans would prefer a universal system that abolished that practice. Far from being a self-evident or intuitively obvious moral principle, the strong assumption is widely rejected, both in theory and practice.

I'm not sure what earlier point you're referring to here.

Two further points about the practice of insurers and society strengthen the claim that we do not in fact treat actuarial fairness as a basic principle of distributive justice. If insurers thought it were such a basic principle, we might expect that they would try to develop and use all possible information about variations in risk among insurees. But insurers use information about risks only when it is in **their economic interest** to do so. In effect, the principle actually underlying their practice is that we are entitled to benefit from our differences only if the market makes it profitable for insurers to provide such benefits.

This market-based entitlement can be construed as a principle of fairness only if we think the market is a fair procedure for drawing the distinctions we want to make. But, and this is the second point, we do not trust the market to draw the distinctions

we think it is fair to make in this regard. We override appeals to actuarial fairness for many reasons in both medical and nonmedical insurance contexts. For example, we condemned "redlining" in the late 1970's as an unacceptable underwriting practice, though no one questioned its utility as a (rough) predictor of risks of loss. Similarly, unisex rating is a rejection of an actuarially fair and efficient method of underwriting and pricing groups at differential risk, but we here override standard underwriting practices because we give more importance to a principle of distributive justice assuring equal treatment of groups that are the traditional targets of discrimination. Similarly, some states have established insurance pools that guarantee no one is deemed uninsurable because of prior medical condition or high-risk classification. Where such pools are funded by insurance premiums paid by low risk individuals, we simply have an enforced "subsidy" from those at low risk to those at high risk, overriding concerns about actuarial fairness. Our practice shows that we do not believe that actuarial fairness is a basic requirement of justice.

(a brief explanation. Please)

There is, however, an even more compelling argument for rejecting the view that ~~I turn now to my main argument~~ health insurance must be structured so that individuals can derive benefits from their differences in medical risks. Health care does many things for people: it extends life, reduces suffering, provides information and assurance, and in other ways improves quality of life. Nevertheless, it has one general function of overriding importance for purposes of justice: it maintains, restores, or compensates for the loss of -- in short, protects --

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functioning that is normal for a member of our species. Normal functioning is a crucial determinant of the opportunities open to an individual, since disease or disability shrink the range of opportunities that would othewise have been available to someone with particular talents and skills in a given society. Since justice requires that we protect **fair equality of opportunity** for individuals in a society, it requires that we design health care institutions, including their method of reimbursement, so that they protect opportunity as well as possible within reasonable limits on resources.[11] Specifically, justice requires that there be no financial barriers to access to care and that the system allocate its limited resources so that they work effectively to protect normal functioning and thus fair equality of opportunity. In fact, we get a rough way to assess the importance of particular health care services, namely, by their effect on the normal opportunity range. Any general theory of justice that includes a strong principle protecting fair equality of opportunity will be able to incorporate my account of justice and health care.

The view I have been sketching involves rejecting the Argument from Actuarial Fairness. A health care system is just provided that it protects fair equality of opportunity. Our system uses standard underwriting practices, but it fails to protect equal opportunity, since access to care depends on ability to pay. Therefore, these underwriting practices are not a sufficient condition for assuring the system is just. It will be clear from what follows that these practices are not a necessary condition either.

The most common way to try to meet social obligations regarding access to health care is to institute a universal, compulsary national health insurance scheme. Under social insurance schemes, prior medical conditions and risk classification can not serve as the basis for underwriting or pricing insurance coverage. Rather, because society acts on its obligation to meet all reasonable health care needs, within limits on resources, there will be subsidies from the well to the ill and from low risk to high risk individuals, as well as from the rich to the poor. The social insurance scheme thus **requires** what a private market for health insurance would condemn as actuarially unfair. This point is independent of whether the national health insurance scheme includes a sector with private insurance: The German and Dutch systems, for example, have many private insurers, but they are prohibited from using our standard underwriting practices.

From the perspective of a private insurer in our mixed system, denying coverage to those at high risk seems completely unproblematic ("You can't buy fire insurance once the engines are on the way.") But this perspective is persuasive only if the central function of health insurance is risk management. Since health insurance has a different social function, protecting equality of opportunity by guaranteeing access to an appropriate array of medical services, then there is a clear **mismatch** between standard underwriting practices and the social function of health insurance. A just, purely public health insurance system thus leaves no room for the notion of actuarial fairness.

Ironically, a just, but mixed public and private health insurance system makes actuarial fairness a largely **illusory**, perhaps even deceptive, notion. Suppose that high risk individuals are excluded from private insurance schemes in a mixed insurance system, for the kinds of reasons we have noted earlier. Since the system is just, however, these people will not be left uninsured, as many are in the U.S. today. They will be covered by public insurance or by legally mandated high-risk insurance pools subsidized by premiums from private insurance. Those lower-risk individuals left in the private insurance schemes might think that actuarial fairness has protected them from higher premiums. But here is where their savings are largely illusory. The premiums of those in the private insurance schemes will either cross-subsidize the high-risk individuals who are insured in the special high-risk pools, or their taxes will cover the costs of insuring high risk individuals through public schemes. Their actual insurance premiums are thus their private ones plus the share of their taxes that goes to public insurance.

The main point of principle in a just, mixed system is this: Low-risk individuals still share the burden of financing the health risks of high-risk individuals. Fairness requires that these risks be shared, not, as the Argument From Actuarial Fairness would have it, that they not be. In effect, health risks are not treated as economic assets and liabilities for the individual.

The genome project will generate information that insurers in our system will want to use in standard underwriting practices, not

because they are greedy but because they respond to the incentives we have built into the design of our system. The argument I have offered says that such uses will make our system **less** fair, **more unjust**. But the problem is not that new information emerges from the genome project. In a national health insurance scheme that prohibited our morally unacceptable underwriting practices, information about risks would not be used to exclude people from treatment but to improve counselling, education, and treatment. It is not the availability of the information that is bad, but how our system forces us to use it. If we fail to correct the more basic injustice in the health care system, then singling out information from the genome project for special treatment would itself seem arbitrary. The problem must be corrected at its source -- the design of our health care system -- not simply where a new symptom of the injustice arises.

CAN WE RETAIN THE TREATMENT/ENHANCEMENT DISTINCTION?

We have social obligations to treat disease and disability because of their impact on opportunity, and so we should not accept the barriers to access that follow from standard underwriting practices. Are these obligations limited to treating disease and disability? Or does any condition that creates an inequality in opportunity for welfare or advantage between individuals give rise to claims on others? In rejecting the argument from actuarial fairness, we countered an attack from the right on our social

obligations to treat disease and disability. I want to consider now an attack from the left on the way I have formulated these obligations. The attack rests on the view that our egalitarian concerns require us to eliminate inequalities between persons that arise from many conditions other than disease and disability. In effect, it is a demand for a more radical version of equality of opportunity. In the context of health care, the attack takes the form of a challenge to the distinction between treatment and enhancement.

I suggested earlier that the genome project may provide us with information that will erode the distinction we often draw between uses of medical technology for treatment of disease and disability and used that enhance human appearance or performance. This distinction is closely connected to the frequently used, but poorly understood concept of "medical necessity." Many public and private insurance schemes in the United States (and Canada) claim to provide only medically necessary services: many services that involve only enhancement (e.g. cosmetic surgery) are thus excluded from coverage on these grounds. I shall suggest in what follows that the treatment/enhancement distinction does have a moral justification, at least relative to a **standard** way of thinking about equality of opportunity. The genetic information about human variation provided by the genome project may make that distinction seem more arbitary, and to the extent that it does, it poses a challenge to the standard model and the use to which I have put it in thinking about justice and health care. Of course, this is not

a conceptually novel threat: viewed from the perspective of the attack from the left, the distinction and the standard model it depends on already seem arbitrary. But the new information may heighten that appearance, and that is the reason for discussing the issue here.

~~Medical Need and the Scope of Obligations to Treat~~

Many medical technologies, new and old, can alter people in ways they desire to be changed. When do we have a social obligation to assure that such preferences are met? Do rights to health care include entitlements to have those preferences met, resources permitting? What should insurance cover?

The most inclusive answer to these questions is that we have such obligations whenever someone desires to eliminate an unwanted physical or mental condition. This would allow subjective preferences to place enormous demands on resources, holding us hostage to the extravagant tastes of others.[12,13] Since we do not believe it is medicine's task to make everyone equally happy, we reject this view and its implication that we should have to pay for liposuction or face lifts. Instead we think obligations arise only when medical treatments address more important problems. The stance we take about medicine is compatible with rejecting, as Rawls and Dworkin do, a broad form of egalitarianism that would require us to ensure the equal welfare or happiness of all individuals.[14,15]

A less inclusive answer is that we have obligations to provide

medical care whenever people desire to eliminate conditions that put them at some disadvantage. The notion of disadvantage is meant to be objective, including some forms of suffering as well as the competitive disadvantages that result from the lack of capabilities, such as marketable talents or skills. This view has some initial ~~grip on us~~ moral appeal when disadvantages are not our fault or the result of our prior choices, i.e., they are accidents of circumstance. Our egalitarian inclinations may incline us to think we owe something toward eliminating them.[16,17] If we adopt such a radical view -- the left position I referred to earlier -- we may have to assign medicine a much greater a role as a social equalizer than we now assign it. At least currently, it is not medicine's task is to make make everyone an equal competitor, wherever possible eliminating all inequalities in the distribution of talents and skills or other capabilities.[18]

A more modest answer that tends to match a wide range of our practices, in fact including our insurance practices, is that we have obligations to provide services whenever someone desires that a medical **need** be met. Generally, this is taken to mean that the service involves **treatment of a disease or disability**, where disease and disability are seen as departures from species-typical normal functional organization or functioning.[19,20] Characterizing medical need in this way implies a contrast between uses of medical services that **treat** disease (or disability) conditions and uses that merely **enhance** human performance or appearance. Enhancement does not meet a medical need even where the service may correct for a competitive disadvantage that does not result from prior choices.

Accordingly, medicine has the role of making people **normal** competitors, not **equal** competitors; this role fits, I shall claim, with the standard model for thinking about equality of opportunity.

~~Challenges to the Distinction~~

Despite its wide appeal, the distinction between treatment and enhancement ~~is~~ may seem arbitrary in light of hard cases like these:

> Johnny is a short 11-year-old boy with documented GH deficiency resulting from a brain tumor. His parents are of average height. His predicted adult height without GH treatment is approximately 160 cm (5 feet 3 inches).
>
> Billy is a short 11-year-old boy with normal GH secretion according to current testing methods. However, his parents are extremely short, and he has a predicted adult height of 160 cm (5 feet 3 inches).[21]

These cases make the distinction seem arbitrary for several reasons. First, Johnny and Billy will suffer disadvantage equally if they are not treated. There is no reason to think the difference in the underlying causes of their shortness will lead people treat them in ways that make one happier or more advantaged than the other. Second, although Johnny is short because of dysfunction whereas Billy is short because of his (normal) genotype, both are

short through no choice or fault of their own. The shortness is in both cases the result of a biological, "natural lottery." Both thus seem to suffer undeserved disadvantages. Third, Billy's preference for greater height, just like Johnny's, is a preference that most people hold; it is not peculiar, idiosyncratic, or extravagant. Indeed, it is a response to a de facto even if unchosen social prejudice. The prejudice is what we should condemn, not the fact that they both form an "expensive taste" in reaction to it.

Cases like these raise the following question: Does the concept of disease underlying the treatment/enhancement distinction force us to treat relevantly similar cases in dissimilar ways? Are we violating the old Aristotelian requirement that justice requires treating like cases similarly? Is dissimilar treatment unfair or unjust?

~~The Treatment/Enhancement Distinction and Equality of Opportunity~~

Despite the challenge of hard cases, the treatment/enhancement distinction should play a role in deciding what obligations we have to provide medical services. To show that this distinction is not arbitrary from the point of view of justice, despite the hard cases, I shall argue that it fits better with what I shall call the **standard model** for thinking about equality of opportunity than alternatives. Of course, the standard model may itself be indefensible, a point I will return to shortly. First though I want to show that the standard model helps specify a reasonable limit on the

central task of health care.

Earlier I noted that disease and disability restrict the range of opportunities open to an individual. Health care services maintain, restore, and compensate for losses of function that result from disease and disability. They thus restore people to the range of capabilities they **would have had** could be expected to ? without disease or disability, given their allotment of talents and skills. Our **standard model** for thinking about equality of opportunity thus depends on **taking as a given the fact that talents and skills and other capabilities are not distributed equally** among people. Some people are better at some things than others. Accordingly, we assure people **fair** equality of opportunity if we judge them by their capabilities while ignoring "morally irrelevant" traits like sex or race when we place people in schools, jobs, and offices. Often, however, we must correct for cases in which capabilities have been misdeveloped through racist, sexist, or other discriminatory practices. Similarly, by preventing or treating disease and disability, we can correct for impairment of the capabilities people would otherwise have. The standard model does not call for eliminating differences in normal capabilities in general, let alone through medical enhancement.

This limitation of the standard model can appear arbitrary. As I noted earlier, our capabilities are themselves the result of a natural and social lottery, and we do not "deserve" them. We just are fortunate or unfortunate in having them. We can **mitigate** this underlying arbitrariness **somewhat** as follows. Those who are better

endowed with marketable capabilities are likely to enjoy more goods such as income, wealth, and power. If we constrain inequalities in these goods so that those who are worst off do as well as possible, considering all alternatives, then social cooperation will work to the benefit of all.[22] Still, this constraint does not eliminate all inequalities in the individual capabilities or in the resulting opportunities individuals enjoy, especially since we are enjoined to judge people by their capabilities, not their "morally irrelevant" traits like sex or race. If our egalitarian concerns require that we strive to give people equal capabilities, wherever technologically feasible, then we should not settle for mitigating the effects of the normal distribution of capabilities, as proponents of the standard model of equality of opportunity would have it.[23] Rejecting the standard model pushes us toward equalizing all differences in capabilities; from that perspective, the distinction between treatment and enhancement has no point, at least where enhancement is aimed at equalizing capabilities.

Information from the genome project might make the distinction between disease (including genetic disease) and the normal distribution of capabilities seem more arbitrary. Suppose we learn that some particular pattern of genes explains the extreme shortness of Johnny, the child who did not seem to be growth hormone deficient. We learn, that is, just which "losing numbers" in the natural lottery placed Johnny in the bottom 1% of the normal distribution for height. Identifying these genes may then tempt us to think of them as "bad" ones: they lead to Johnny's unhappiness

or disadvantage in a "heightist" world. We will then be sorely tempted to think of them very much on the model of genetic defects or diseases, especially if they work through mechanisms that have some analogy to pathological defects. We will be tempted, that is, to medicalize what we have hitherto considered normal. What, after all, allows us to treat the "bad genes" differently from genes that lead to growth hormone deficiency or to receptor insensitivity to grown hormone? If we can remedy the effects of these genes with growth hormone treatment or other treatments, including genetic tampering, we might think it quite arbitrary to maintain the treatment/ enhancement distinction.

I want to offer several points as a limited defense of the standard model and the treatment/enhancement distinction. Both versions of equality of oppportunity, the standard model and the more radical one that requires equalizing capabilities, seem to appeal to the same underlying intuition, that advantages and disadvantages resulting from the natural lottery are not themselves deserved. But they use the intuition differently. The standard model suggests we mitigate the effects of normally distributed capabilities through restrictions on other inequalities we allow. Since some inequality in capabilities is a fact of life, the task is to mitigate their effects while adopting principles that let everyone benefit from social cooperation. The criticism from the left rests far more weight on the underlying intuition: it says that wherever possible we must actually try to reduce variance in the distribution of capabilities, equalizing them wherever

possible. I believe that the standard model better captures our actual concerns about equality than the more radical version. (Of course, our actual concerns may be too limited, so this is not a conclusive argument.)

Some supporting evidence for this point derives from our moral beliefs and practices concerning health care. We regard medical services as meeting **urgent needs** when they are aimed at restoring or maintaining "normal functioning." Our consensus about where to draw the line focuses on eliminating disease and disability. We already have many technologies that can enhance functioning for individuals, even giving them advantages (beauty, athletic performance) they previously did not have. But we generally resist assimilating these cases of enhancement to cases of treatment because we do not see them as meeting important needs. Although these enhancing services alter traits that may be the results of a natural lottery, they involve optimizing capabilities that are not departures from normal functional organization or functioning.

Of course, what makes the case of Billy and Johnny problematic is that they both suffer equal disadvantage as a result of the natural lottery (and social prejudice). But there is justification for adhering to a distinction that captures and sustains social agreement on important matters, even if the distinction seems arbitrary in isolated hard cases. The line between treatment and enhancement is generally uncontroversial and ascertainable through publicly accepted methods, such as those of the biomedical sciences. Being able to draw a line in this way allows us to refer

counterfactually in a relatively clear and objective way to the range of opportunities a person **would have had** in the absence of disease and disability; it facilitates public agreement. Because of these virtues, not every hard case counts as a counter-example that warrants overturning the distinction.

The "equal capabilities" approach, bolstered by new information from the genome project, is likely to undermine agreement on the importance of meeting medical needs. According to it, we would now have many more such needs, for much of what we now take to be normal would become conditions in need of rectification. Since we are far less likely to think that it is "urgent" to correct the effects of these newly labelled "bad genes," shifting away from the standard model is likely to undermine consensus on the moral importance of health care.

Will it be possible to hold the line? Some relief may come from a more careful attempt to examine the distinction between genetic disease and normal variation. This may enable us to offer a theoretical justification, coming out of the biological sciences, for a baseline distinction. It is important to note that I am not trying to save the appeal here to a natural baseline for metaphysical reasons: there is nothing magical about a natural baseline. Nor am I violating Hume's injunction against deriving 'ought' from 'is'. Rather, the natural baseline both facilitates and reflects moral agreement about the urgency of medical care. I also believe there is moral justification for limiting in some ways the task involved in protecting equality of opportunity, otherwise

it will be discredited as too demanding an ideal. If, however, no theoretical justification is forthcoming that lets us distinguish "bad (or nonoptimal) genes" from genetic disease, then we will have to give more complex justifications for drawing the line between cases where we have obligations to provide services from those in which we do not. My claim is simply that it will be harder to reach consensus on these justifications without the ability to appeal to a natural baseline, however imperfectly drawn.

I have been offering reasons not to expand our goals in protecting equality of opportunity from the more limited ones of the standard model to the more encompassing one of equalizing capabilities. Nevertheless, our obligations to provide medical services need not derive solely from the concerns about equality of opportunity I have argued are central. For example, I think we have compelling reasons for providing public funding of non-therapeutic abortions that go beyond their importance for preventive health care. Similarly, suppose an inexpensive treatment became available for improving cognitive capabilities in childhood; administering it would greatly enhance the results of education, close the gap between poor but "normal" students and others, and contribute greatly to social productivity. We might then have compelling reasons to seek enhancement in this way, even if they differ from our standard justification for the importance of health care. Of course, we already have excellent reasons for putting more resources into education, yet we do not, despite the fact that our failure to do so results in misdeveloped talents and skills along

race and class lines.

GENES AND RESPONSIBILITY FOR HEALTH

Lifestyle choices about diet, exercise, and drug and alcohol abuse play a significant role in our risks for cardiovascular disease, cancer and trauma. Throughout the last decade, a cult of health fitness has gripped millions of Americans, though it is more prominent among the better-off socio-economic groups. There is significant media and peer pressure to reduce smoking, alcohol consumption, and fat in diets, all around the theme of "taking responsibility for health." No doubt this movement will reduce the health risks for many people. But the genome project is likely to reveal to us many genetic influences on the risks for major "lifestyle" diseases, including addictions. It will then be the case that some people who have low-risk genotypes can engage with little bad effect in what would be highly risky lifestyle choices for others. Conversely, people who are follow low-risk regimens with nearly religious fervor may reduce their risks only marginally, if they have genotypes that predispose them to be at higher risk for these conditions. What are we to say about "responsibility for health" when the effects of responsible action is so varied?

As the genetic information becomes more available it is likely to have two effects on motivation. Some people may think that the risks they face are really "in the cards" and that there is little

point to making life less pleasant when there is only a modest effect for them on overall risks. Others will draw the opposite conclusion: it will become imperative for them to devote extra effort to reducing the high risks they face. Their genes have put the ball in their court. It is difficult to say which of these effects on motivation will be greater, but there is some chance that public concern with taking responsibility for lifestyle choicees will be reduced or fragmented by the discovery of significant genetic components.

There are corollary judgments third parties will make about responsibility. Some will see the presence of a large genetic influence on risks as an excusing condition. People who do little to modify their high risks will be excused on the grounds that there was really little they could do. Their best efforts will not reduce their risks to the levels faced by those with "good" genes who can eat, drink, and be merry at low risk. How can we expect people to remain committed to being responsible for their health when so much of the effect is out of their hands? Others will say that the obligation to reduce risks is even greater for those whose genotype puts them at higher risk. It is bad enough that their genes place higher burdens on them and others; it is even worse if they know they impose those burdens and do not do what they can to reduce them. That is, there is a strong temptation to blame the victim.

Two issues of policy emerge. First, the appearance of information about genotypic contributions may tend to fragment the

public concern about responsibility for health. This is a bad effect we must try to counter. We will want to preserve and broaden the movement that encourages people to adopt healthy lifestyle choices, and that will mean educating people carefully to avoid concerning the new information into a cult of genetic determinism. Health risks are **phenotypic**; they result from the interaction of genotype and environment, including our lifestyle choices. Even strong genotypic effects can be countered by crucial environmental interventions (e.g. changing diet to reduce the effects of phenylketonuria). Though the urgency of this message may differ for people with different genotypes, and though the incentives may vary as well, there is still an effect of lifestyle choices that will have to be carefully documented and made the basis of continuing education and even incentives, e.g. through discounts on life-insurance. Of course, the effort to retain such incentives will be set back if genetic screening for life insurance produces a different set of rewards and punishments.

Second, there may be a reduction in the temptation to blame those who become ill from diseases for which there is a significant lifestyle component. This would be a positive effect of new genetic information about human variation, a modest reduction in the temptation to blame the victim. We would be less tempted to look at anyone with coronary artery disease or even alcoholism as paying the price for their lifestyle sins; we are in a weaker position to resent the burdens they impose on us, since they may have been at higher risk than average no matter what their lifestyle choices.

Whether this positive effect emerges, however, depends on facts about the structure of our health care system. If we retain a private insurance sector that is free to engage in standard underwriting practices, then, for the reasons discussed earlier, economic forces will work against our willingness to share risks and the burdens of disease collectively.

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JUST GENETICS: A PROBLEM AGENDA

Leonard M. Fleck

As I prepared to write this essay the image that forced itself upon my mind was one of those ancient maps whose known world was named with the ~~label~~ words "Terra Incognita." The more I considered the problem of justice in connection with emerging genetic technologies, the more I felt I was entering a territory that was largely unknown. Hence, this essay can be considered nothing more than a preliminary exploration of that territory. I shall feel that I have made a useful contribution if I can identify and articulate some of the distinctive problems of justice that are raised by emerging genetic technologies.

It might be useful at this point to mention the major working hypotheses that are shaping this essay. First, many of these emerging genetic technologies cannot be thought of, morally speaking, as simply another advanced medical technology competing for resources in the medical marketplace. That is, if our society were to withdraw all research funding for the development of a totally implantable artificial heart, the result being that it would be very improbable that such a device would ever come into existence, we would have treated no one unjustly in our society. But I am inclined to argue that at least for some emerging genetic technologies this would not be true. That is, there are powerful considerations of justice that would require the development and dissemination of some emerging genetic technologies.

Second, if ~~my first claim is true~~, then ~~this suggests that we~~ perhaps it is true that genetic technologies are, not morally medical technologies without claim to moral priority, ought to think about this collection of moral issues in terms of a

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"sphere of genetic justice." Here I make an appeal to Walzer's metaphor of "spheres of justice."[1] I think Walzer's pluralistic conception of justice represents a useful corrective to grand theories of justice that have a certain allure for philosophers. Deductive reasoning from any of these grand theories of justice will rarely yield moral resolution regarding, for example, problems of genetic justice. In other papers I have argued that there is a unique cast to problems of justice in the field of health care in general; and hence, we ought to think in terms of a sphere of health care justice.[2] Genetic justice might be seen as a subset of that larger sphere.

At this point I should mention that I am less than comfortable with the sphere analogy, which suggests a neatness and isolatedness which is false to both our moral practice and an adequate conceptualization of health care justice. My preferred metaphor for genetic justice would be that of an urban neighborhood, which has rougher shifting boundaries, and which is part of the urban megalopolis that is health care justice. There are lots of internal connections among the neighborhoods and suburbs that make up the megalopolis, which is to say that there are moral considerations that link up the neighborhoods of health care justice, But there are also distinctive qualities of the neighborhood or suburb that give it a character of its own. If I were to push the analogy one step further, then we might think of genetic justice as being a new suburb we are planning. Our choices are constrained by the street system and utilities that are

adjacent, and by zoning, environmental, topological, and economic considerations, among others. But there is still room for considerable creativity with respect to the layout of that suburb, and the creative possibilities are enhanced by emerging building technologies. It is similarly the case with respect to the moral judgments and moral practices that will constitute our sense of genetic justice. The large scale moral framework that seems most attuned to this analogy is that of Rawls' Kantian constructivism.[3] The slogan that best epitomizes this moral framework is that justice is political, not metaphysical. That brings me to my third point.

Philosophers have for the most part been enamoured with ideal conceptions of justice. There may be good logical and philosophical reasons why such debates are important, but these debates seem to do little by way of resolving concrete problems of medical/ moral practice and public policy. From the perspective of ideal justice all our public policy choices are morally flawed, are, in some sense, unjust. A conclusion like that is neither practically nor morally helpful. More accurately, it is pernicious if it encourages moral scepticism and indifference or arbitrariness. What I have argued for as an alternative are non-ideal frameworks of justice.[4] This is what I believe is needed if we are to address intelligently and effectively the problems of genetic justice. When we adopt a non-ideal framework, then we will be able to determine whether a specific resolution of a specific problem of genetic justice is "just enough." That is, we will be

able to judge whether our proposed resolution justifiably represents a moral improvement over the current state of affairs, which is what often will be sufficient to warrant moral approbation.

One additional methodological point needs to be made. In moral practice it is usually the case that it is more difficult to achieve agreement on what justice positively requires of us regarding some redistribution of resources, as opposed to what justice negatively requires. That is, it seems easier to achieve agreement that a certain state of affairs is seriously unjust than to achieve agreement regarding the preferred just state of affairs that must replace the unjust state of affairs. For example, there is broad agreement among health economists, health policy analysts, and moral philosophers that the large tax subsidy we provide to the middle class for the purchase of health insurance benefits is seriously unjust. In 1990 this was a tax subsidy of about $48 billion, which is what federal and state governments would have collected in additional taxes if our health insurance had been taxed as income. The injustice is that 70% of those without health insurance in our society are working, but at low wage jobs that do not offer health insurance as a benefit. That means these individuals would have to purchase health insurance with after-tax dollars, which means their health insurance, if they could afford it, would have a 40% premium attached to it. Yet these individuals, who are certainly less well off than the middle class, have helped to subsidize the middle class. It is difficult to

imagine any conception of health care justice that would see this as a just state of affairs. The point I wish to make here is that we should not minimize the moral importance of such negative moral agreement. If we can identify clear injustices with respect to the use or dissemination of emerging genetic technologies, then we will have made some moral progress.

Fourth, though the focus of this essay is on justice as a moral concern regarding emerging genetic technologies, the fact is that justice is not the only moral value that counts. One of the problems that has to be addressed is how we balance considerations of justice against other equally important moral considerations in this area. Again, my objective here will be to identify and map some of these moral conflicts as opposed to offering premature resolutions. In particular, I shall focus on possible conflicts between justice and liberalism regarding these emerging genetic technologies. Nozick and Rawls are generally viewed as offering diametrically opposed conceptions of justice, though in fact both offer what are described as "liberal" conceptions of justice. I take some of the essential features of a liberal conception of justice to be the following: (1) a strong emphasis on individual rights, (2) respect by the state for a zone of privacy and individual liberty marked out by these rights claims, a zone in which the state will not interfere, and in which individuals can make choices regarding their lives in accord with their individual conceptions of the good, (3) official state neutrality with respect to competing conceptions of the good, and (4) state commitment to expanding the

domain of liberty as much as is compatible with respect for the rights of all. As we shall see, there are a number of emerging genetic technological possibilities that will severely challenge the compatibility of liberalism and genetic justice.

I. HEREDITAS?

Would we treat anyone unjustly if, say, after we had completed the task of mapping the human genome, we decided that no more research funds would be used to continue the development of a broad range of emerging genetic technologies? ~~There is a lot of private research money funding these technologies.~~ ~~So,~~ to make this scenario somewhat plausible, we ~~have to~~ could imagine that all the large health insurance companies in America had agreed that no policies would be issued that provided coverage for such technologies to be applied in health care settings; That would effectively squelch the profit motive. If the federal government endorsed this action as a way of gaining some control on escalating health costs, could the government be justifiably accused of having acted unjustly? There is considerable evidence to suggest that roughly half the problem of escalating health costs is attributable to these expensive, emerging medical technologies.[5] Further, the claim might be advanced that no one really has a just claim to any of these emerging medical technologies, that it is a matter of social beneficence as to which, if any, of these technologies are nurtured and developed, and that so long as decisions about which technologies to support are not a product of obvious discriminatory judgment, no one has been treated unfairly.

In responding to the issue that has been raised, I want to begin by largely endorsing this last claim. That is, no one has been treated unjustly if, for example, society chooses not to develop a totally implantable artificial with the result that 350,000 people continue to die each year whose lives could have been extended by an additional five years if they had had access to that device. Having said that, however, I will also argue that at least some emerging genetic technologies belong in a special moral category because they do raise concerns of justice that must be explicitly addressed. Given limitations of space we can only make some crude distinctions here, but they will still be useful. We should distinguish, for example, emerging genetic testing technology from emerging gene therapy technology that is somatically focussed from emerging germ-line genetic technology. Further, we should distinguish genetic tests that might be applied to adults for diagnostic purposes from genetic tests that might be applied to early fetuses from genetic tests that might be applied to four-cell embryos. For reasons that will be explained later, I will argue that embryonic genetic testing and embryonic genetic engineering involve prima facie claims of justice.

What moral arguments can be given for saying that we, as a society, have not treated anyone unjustly if we refuse to provide any more funding for the development of a totally implantable artificial heart, the result being that such a device is likely never to be developed? If this means that 350,000 people each year will die from heart disease who otherwise would have had the

opportunity for five extra years of life on average, then it seems that this ought to be cause for moral concern. However, I will argue that all these deaths might be unfortunate, as is true for any premature death, but not unjust. First, for all practical purposes virtually all Americans are at risk for heart disease; and hence, failing to fund continued development of the totally implantable artificial heart does not represent arbitrary and unjustified discrimination against some identifiable group of individuals, as would be the case if a white-dominated society refused to provide any research funds for sickle cell anemia, or some other disease that was especially burdensome to some disfavored group. Second, individuals who suffer from heart disease have no special moral claims against society, as might be the case with coal miners who suffer from black lung disease. Third, if a reasonable societal objective is to use our health care system to save as many high-quality life-years as possible within a limited health budget, and if I am correct in believing that this is an objective that proponents of utilitarian or Rawlsian contractarian or radically egalitarian conceptions of justice could all endorse, then my judgment is that none of the proponents of these competing conceptions of justice would see totally implantable artificial hearts as a morally obligatory means to that end because there were too many alternative medical therapies that could save more life-years (with equal moral claim) at a lower cost.

We can complete our moral analysis on this point by turning

around our original question and asking: Would there be anything unjust about continuing funding for totally implantable artificial hearts until they are successfully developed? Here I would argue that a strong case can be made for saying this would be unjust, not intrinsically, not in some possible health care systems in some very wealthy societies, but in the actual society that we find ourselves in today with the actual health policies we have in place for financing and distributing access to health care. Two contingent facts need to be noted here. First, the total cost of implanting a totally implantable artificial heart would be in the vicinity of $100-150,000 in 1990 dollars. Second, unlike natural heart transplants, for which there are something like natural limits on the number that can be done (because it is related to the number of brain-dead head injury victims), there is no natural limit to the number of artificial hearts that might be produced. That limit would be determined by ability to pay. These are not the kinds of costs that most people could pay out of pocket, so it is reasonable to believe that the middle class would seek insurance protection through their employer-provided health benefit packages. This would drive up substantially the total cost of health care in our society, adding at least $30 billion per year to those costs. Both the middle class and businesses would try to find ways to reduce the burden of health costs to themselves, which they would do by squeezing funding for state Medicaid programs, which would mean that the poor would have less access to less adequate health care, and by squeezing hospitals for discounts, which would mean

that hospitals could not engage in traditional practices of cost-shifting so that they could provide uncompensated care to the uninsured working poor, whose access to care and quality of care would then be greatly compromised. [No one who reads this should think this is some fanciful philosophical scenario. This is essentially what is currently happening in our health care system.]

Finally, if there are increased costs for health benefits for the middle class, then this means increased tax subsidies for the middle class as well, and those subsidies will be financed in part by the working poor, who will themselves be without health insurance and without access to totally implantable artificial hearts. In conclusion, if all this is true or very nearly true, then it seems any reasonable person would conclude that such an outcome is unjust; and if the dissemination of the totally implantable artificial would cause this to happen, then that would be an unjust technology to disseminate. Even a proponent of a libertarian conception of justice would see this total state of affairs as being unjust. Certainly neither the working poor nor the very poor would autonomously ratify as fair or just the dissemination of the artificial heart in these circumstances.

II.

We may now return to our original problem: Should we think of emerging genetic technologies as being on a moral par with all manner of other expensive life-saving medical technologies? That is, social beneficence might warrant social investment in the development and dissemination of these technologies, but there are

no considerations of justice that would require this. Or, alternatively, there are a large number of life-prolonging medical technologies that are competing for limited health resources, and society is free to use whatever criteria (moral or non-moral) that seem reasonable, which is to say that emerging genetic technologies have no moral priority in this competition because they have no special moral status. As noted earlier, I will argue that considerations of justice do have relevance in this case and would warrant giving priority to some of these emerging genetic technologies. Specifically, I will argue that germ-line genetic engineering aimed at eliminating deleterious genes and replacing them with their properly functioning version would have such priority. By way of contrast, I will also argue that genetic engineering aimed at enhancing the genetic structure of an embryo makes no just claim on health resources, partially for reasons analogous to those that would disallow development of the artificial heart, partially for reasons that are peculiar to the domain of genetic justice.

I have in mind the following scenario: We have successfully developed germ-line genetic engineering. That is, we can take a four-cell embryo, place it under a very powerful microscope hooked to a very powerful computer that analyses its genetic structure, and identify those genes that are most likely to have serious deleterious effects on its future health, if it were allowed to develop and be born. If its genetic structure is very badly flawed, then it is simply discarded. But if it has ten or twenty

genes that could be replaced, then this will be done quickly and efficiently through the genetic engineering mechanisms then available.

If we wish, we can imagine two scenarios here. In scenario "A" we are very proficient in using the technology, but the cost in 1990 dollars is still about $10,000 per engineered embryo. If every birth in the United States were so engineered, then the cost would be about $30 billion per year since there are roughly three million children born each year here. In scenario "B" we can imagine that we are not quite so proficient and the cost per engineered embryo is closer to $100,000. If every birth in America were to be engineered in that more costly scenario, then total costs would be about $300 billion per year, which is about 45% of 1990 total health expenditures in the United States.

Before going on, I would like to dispense with some anticipated reader nitpicking. First, some might object that I have offered a fanciful philosopher's scenario from which we can learn nothing useful or reliable, morally speaking. In response, I would be prepared to argue that this is more a futuristic than a fanciful scenario. The seminal technology is in place that suggests that what I have described is a real world possibility.

Second, someone might argue that there is no perfectly perspicuous way to identify "deleterious" genes. I am operating with a very simpleminded and reductivist understanding of genes, failing altogether to take into account the complex ways in which genetic heritage interacts with widely variable natural and social

environmental factors. This, of course, is a reasonable criticism; and hence, I will stipulate that "deleterious genes" will refer to those genes that virtually all reasonable individuals would judge consistently cause very premature death or serious health problems that drastically compromise the capacity of an individual to carry out virtually any near-normal life plan.

Paradigm examples of the sort of genes I have in mind would be those for Huntington's or cystic fibrosis or Tay-Sachs. A paradigm example of the sort of genes I do not have in mind are those that might predispose an individual to coronary artery disease in the later stages of life. What I assume with respect to this latter example is that a predisposition is not a rigid determination, that individuals who knew themselves to be so disposed could modify their diet and lifestyle so as to minimize the actual risk of serious disease.

Third, I need to stress the fact that for now I am talking about genetic engineering with respect to deleterious genes, as opposed to genetic engineering that would enhance genetically determined traits so that they might be expressed in a superior way rather than an average way, such as might be the case with memory skills. I will concede that there is an area of conceptual mushiness here, that sometimes a genetic modification can be described in either positive or negative terms, and that we may not have non-controversial reasons for preferring one description rather than another. Still, there will be many other circumstances where it will be clear that we are talking about genetic

enhancement.

I now wish to turn to a discussion of moral issues connected with genetic enhancement. My moral judgment in this regard is that it is a lot less likely that considerations of justice would require the development or dissemination of genetically enhancing technologies. Morally speaking, such technologies are analogous to the development of totally implantable artificial hearts. Of course, someone might point out that if we are capable of eliminating deleterious genes and replacing them with their intact version, then it would require no radical technological innovation to replace a normal gene with a superior version of that gene. If this were true, then we would be faced with some serious and difficult problems of justice. The precise nature of these problems would depend upon the policies and practices in place for the financing and delivery of health care in our society. Let us consider two broad scenarios.

First, if this technology were paid for through private health insurance provided by employers and a train of consequences followed similar to those described above in connection with the artificial heart, then the same moral conclusion would follow, namely, that the uninsured working poor and the very poor on Medicaid would have been treated unjustly because the lot of those already well off had been improved at the expense of those who were already substantially less well off.

Second, we could imagine that we had in place a system of national health insurance, say, a very comprehensive system such as

they have in Canada, a system where all had essentially the same package of health benefits. Then the question would be whether to include genetic enhancement engineering as part of that package. Depending upon the cost of that technology, it would displace other possible therapeutic interventions, some of which might have a stronger claim to inclusion in that package from the perspective of justice. If it were excluded from the package, then the issue would be whether there was anything unjust about permitting those with sufficient resources to purchase the technology for their future progeny.

At first glance it might seem that this would be no more morally problematic than sending one's children to elite private universities, the result being enhanced life opportunities to which less affluent parents would not have access for their children. But on more careful inspection there would seem to be more serious difficulties from the perspective of justice. After all, at least some children from economically impoverished circumstances who are intellectually gifted and highly motivated will be given scholarships that will permit them to attend elite universities and reap enhanced opportunities and rewards. This is what allows us as a society to pat ourselves on the back morally because we are committed to fair equality of opportunity. However, in the case of privately purchased genetic enhancement technology there are no fair equality of opportunity structures. That is, no four-cell embryo has the opportunity to merit access to that technology. Rather, the actual dissemination of the technology is determined by

straight willingness and ability to pay. There are, of course, lots of goods in our society that are distributed in this way. However, we have to recall that we are talking about germ-line genetic engineering. If the technology really does enhance native abilities substantially and effectively, contributing greatly to an enhanced sense of self-esteem, then that expands greatly and fundamentally the range of opportunities that will be available to that individual, and, presumably to the descendants of that individual. This would create the very definite possibility of a genetically permanent "master class." And even if we imagined this as a benign, non-oppressive master class, as Attanasio seems to have in mind,[6] this would still represent a prima facie unjust state of affairs because fair equality of opportunity would have been so significantly compromised.

There is one final moral conundrum that needs to be mentioned under the national health insurance scenario for genetic enhancement technology. On the assumption that we would not want to be unjust in our genetic enhancement decisions, what moral landmarks would we use for assuring ourselves that we were being fair enough in our genetic enhancement decisions? Again, I will remind the reader that we are talking about four-cell embryos. As Agich[7] and DeNicola[8] point out, the normal moral reference points we use in connection with justice are entirely absent.

Does one four-cell embryo have any more of a just claim to an enhanced genetic endowment because of merit or desert or effort or productivity than any other? What about desire or respect for

individual autonomy? This latter question has no obvious meaning in connection with a four-cell embryo, so we could hardly fail to treat this embryo justly if this is our moral reference point. The parents might well have strong preferences for such genetic enhancement, but it is not obvious that this is sufficient to generate just claims for this technology.

Another common reference point for assessing just claims is need. This moral reference point does have some applicability for our discussion, but I would argue that it is in connection with deleterious genetic traits, though the connection is more indirect than direct. That is, the concept of need in health care requires some moral discipline so that needs are not just arbitrarily asserted. Callahan has observed, for example, that we tend to identify medical needs in our society in terms of whatever is at the edge of medical innovation, which is useless for purposes of asserting the justness of competing claims.[9] By way of contrast, I think Daniels has got it right for the most part when he links needs-that-have-a-just-claim-to-health-resources with the degree to which fulfillment of such needs allows an individual to access a normal opportunity range in that society.[10] Thus, there are very obvious ways in which cystic fibrosis or Tay-Sachs or a very large number of other genetic disorders effectively block an individual's access to that normal opportunity range. To return to our discussion, however, we are talking about genetic enhancement technologies, the kind of genetic interventions that might give an individual access to a superior opportunity range. That would seem

to disqualify the concept of need as a moral marker for justice in this regard.

Next, we might appeal to the concept of rights. I do not believe that a four-cell embryo has any rights at all, much less a right to an enhanced genetic endowment. But for the sake of argument and analysis, I will assume that such a right is a possibility, that it is a claim-right, and that it is rooted in some alleged interest that the embryo has in having an optimal range of life opportunities made available. Well, if such a right exists, then we would have to specify somewhat precisely what that right gives an embryo a just claim to. That is, we would have to have some way of knowing when that claim right had been satisfied. However, if we try to think this through, we will quickly find ourselves in a complete conceptual muddle.

There is no natural limit to what might count as adequate genetic enhancement. Moreover, we are not just talking about some single genetic trait. We could conceivably be talking about thousands of genetic traits. Further, I would remind the reader that this thought experiment is occurring in the context of a Canadian-style national health insurance plan, which is to say that we would have to be concerned about fair treatment of all citizens in this society, or at least all four-cell embryos that are going to be born. Presumably, all those embryos would start out as very diverse genetically speaking. If we were to protect that diversity, and there are very good biological and social and moral reasons for wanting to do that, then how would we know what counted as "fair

genetic enhancement" of these embryos relative to one another? There would be enormous diversity, and hence, incomparability in this regard. How would we know whether we had done too much or too little in the way of genetic enhancement with respect to any given individual embryo? Life was a lot simpler when there was only the natural lottery, when all of us simply had to accept the fate that God or nature had imposed upon us. But if each and every genetic endowment is a product of human choice, then it seems we have an inescapable responsibility to make those choices as fairly as possible.

One further consideration is worthy of note: Who exactly is the "we" that is supposed to have responsibility for making these choices for genetic enhancement? Do we have in mind some panel of experts who would have the moral right to shape in an absolutely fundamental and intimate way the lives of each and every future child, quite apart from the desires, preferences, or values of the parents of that child? That might be one way of assuring a high degree of impartiality, but a high price would be paid in terms of other social values. Alternatively, we could allow parents to make their own genetic enhancement choices, though this would predictably yield substantial inequalities among those future children. Would the natural lottery be morally preferable from the perspective of justice, or at least the natural lottery stripped for the most part of deleterious genes? We turn now to answering that question.

III.

What are the considerations of justice that would warrant giving moral priority to genetic technologies that would eliminate deleterious genes over other kinds of emerging life-saving or life-enhancing medical technologies? To begin answering this question we must appeal to some conception of justice that would command widespread rational assent. As we noted earlier, and as Agich and DeNicola have argued, traditional theories of justice have nothing useful to offer in this regard, the primary reason being that these theories all operate in a world in which natural assets and liabilities are assumed as given. But with the emergence of genetic technologies, that assumption is justifiably called into question. Again, what both Agich and DeNicola argue is that a Rawlsian contractarian conception of justice is the only conception of justice that gives us a handle for determining what might count as a just distribution of genetic resources.[11] The virtue of Rawls' position is that he offers a fair procedure for determining distributions, which involves assuming the original position behind a veil of ignorance. Though Rawls himself has very little to say about genetic choices (because this was a barely imaginable option at the time he wrote A Theory of Justice), and though Rawls' theory of justice tolerates a broad range of inequalities in our social life, and though Rawls is inclined to think that we ought to remedy natural inequalities through choosing appropriate social policies and practices, it is relatively easy to make a case for saying that Rawls would support the genetically engineered elimination of

deleterious genes as something required by justice. One obvious reason for saying this is that there are numerous genetic disorders that cause very premature death or profound disabilities that virtually exclude that individual from effective participation in any portion of our social life, and no amount of remedial social policy or more just social practices will effectively correct for those losses. The only effective corrective is the genetic engineering we described. Further, one of the substantive moral reference points for Rawls is the plight of those who are least well off. Changes in social policy are just only to the extent that they improve the lot of the least well off. Certainly those who are afflicted with the very serious genetic disorders that we have in mind have a legitimate claim to be considered among those who are least well off so far as health care justice is concerned.

A critic might respond that there are alternatives, such as gene therapy, that are less radical than genetic engineering. However, as I hinted earlier, gene therapy might not generate just claims in the way that genetic engineering would. This is not a moral judgment that I can make with absolute confidence because the actual facts, such as they might prove to be in the future, can make a large difference. Right now gene therapy is more like a half-way technology that corrects for a time a medical deficiency, but does not actually cure the disorder. If this were to remain true for the indefinite future, then gene therapy would have to compete on the same moral plane as a host of other half-way life-prolonging medical technologies, such as organ transplants or

dialysis. That is, gene therapy would have no intrinsic claim to moral priority over any of these other technologies. And even if it were a very successful technology, the moral question could be raised of why we would prefer this to germ-line genetic engineering, which would delete the defective gene from all succeeding generations.

There is, of course, an obvious answer to our last question, namely, that germ-line genetic engineering is not a therapeutic option for someone who is already born. For that individual the only choices are gene therapy, however imperfect it may be as a therapy, or passive acceptance of one's genetic fate, which might be very gruesome. Of course if a society had sufficient resources to completely fund both unlimited gene therapy and our genetic engineering program, then we would have bought our way out of that moral dilemma. That, however, is a fanciful scenario. There are limits to what any society can spend to meet competing, virtually unlimited health needs.

If we imagine that some sort of choice must be made between funding a very large potential demand for gene therapy, say, thirty billion dollars per year, and funding my genetic engineering program at the thirty billion dollar level, and if we have only thirty-five billion dollars to spend on these health needs, then what would count as a just allocation of these resources? This has all the appearances of a terrible and irresolvable problem of intergenerational conflict.

Daniels has one approach for dealing with what appear to be

problems of intergenerational conflict, and that is to transform them into problems of allocating health resources over the course of one's own life. He uses this approach to achieve a creative solution to the problem of what counts as a just allocation of health resources to the elderly.[12] This approach has considerable rational appeal with regard to our current problem since it seems that it would be eminently prudent to eliminate from the very beginning of our life those deleterious genetic predispositions that are most likely to seriously compromise the length and/or quality of my life later. However, the reason why Daniels' original strategy is so creative and feasible is that the current generation of the young and middle-aged are making rationing decisions for their <u>future</u> selves which contribute to the enhancement of their own current life prospects. But in the situation we are faced with, the current generation in need of gene therapy would simply be shifting resources to another generation, if they were to relinquish their claims to those resources.

At this point we might invoke Rawls' original position/ veil of ignorance argument, or a variation thereof. That is, if we were all noumenal selves who knew nothing unique about ourselves, and if we knew that at some point in our social history we would invent the genetic technology I described above, and if we did not know which generation it was that we belonged to so that, for purposes of this example, we might belong to the generation that needs (and can only use) gene therapy or we might belong to the generation that would benefit near conception from genetic engineering, then

what principles of justice would we appeal to for purposes of determining a fair distribution? I assume my readers are familiar with Rawls' principles of justice, which I do not see as offering that much by way of resolving this particular moral dispute. As noted earlier, one standard reference point is the plight of those who are least well off. Well, that is precisely what is up for grabs in this dispute since, if one side or the other receives the bulk of these resources, the result will be that the other side will be able to claim that they are now among those who are least well off health-wise.

At this point we can invoke Daniels' original strategy in thinking about problems of health care justice. That is, Daniels devises a version of Rawls' fair equality of opportunity principle which he then uses to determine what counts as a more or less fair distribution of health resources in our society. The general idea is that health resources ought to be distributed so that all have an opportunity to access a normal opportunity range in that society, that is, the range of life plans that are available in that society.[13] It is this moral perspective that gives considerable moral weight to the genetic engineering approach we have described in competition for limited health resources. Eliminating deleterious genes, more than anything else offered by medical science, would seem to assure fair access to a normal opportunity range for individuals who would otherwise be extremely deprived in the distribution of societal benefits. With this in mind we move back behind Rawls' veil of ignorance.

We have individuals who have a sense of justice, who do not know which generation it is they belong to, and whose sense of health care justice requires that they distribute health resources so that they maximize the likelihood that each individual will have a fair opportunity to access a normal opportunity range. What follows from that? We might imagine someone saying that it is unfortunate that the current generation is not able to benefit from germ-line genetic engineering, but that is not unjust since this was simply an outcome of the natural lottery over which no one could exercise much control. By way of contrast, if the current generation were to deny this future generation access to germ-line corrective genetic therapy, then that would be unjust. Therefore, this future generation has a just claim to the $30 billion needed to assure this future generation an intact genetic structure.

But then we have to remember that an integral part of Rawls' contractarian perspective is the hypothetical assent that all parties to the social contract give to the principles of justice that will govern that society, which I am extending to include the more specific principles of health care justice. I do not believe that I have that assent from the current generation to the proposed distribution. I suspect that they would have a justified claim that they were treated unjustly if this last proposal was insisted on. In order to rectify that, we have to imagine some sort of exchange of benefits between these generations. What we need to equalize is fair equality of opportunity for the members of both generations, which would include comparable exposure to the risk of

premature death. Daniels' lifespan account does offer some helpful moral clues at this point. What we need to imagine is that this future generation, which will reap very large assured health benefits from germ-line genetic engineering, would be willing to give up access to some very expensive life-prolonging medical interventions at later stages of life, by which I mean stages of life as early as middle age. After all, they have been granted from virtual.y conception protection against a very large number of life-threatening and life-diminishing genetic disorders. The willingness of this future generation to give up access to some of these future medical technologies, which some members of that generation will most certainly need because they will still be susceptible to a host of medical problems that are not genetically determined, will free up resources that the current generation may use to purchase gene therapy for its members up to that point at which the members of both generations will have roughly comparable opportunity ranges and ranges of risk for premature death. That is, individual members of each generation will end up dying prematurely or having something less than access to a normal opportunity range, but they will not be able to claim that they had been treated unfairly because this will once again be a product of the natural lottery (and a social agreement between the generations). This would strike me as a plausible and fair outcome, not to mention its being a feasible bargain between the generations. But this is not an outcome that would simply be dictated by principles of justice derived from either Rawls or

Daniels. Rather, this reflects a constructivistic approach sensitive to the moral contours of genetic justice.

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Justice and the Limitations of Genetic Knowledge

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In the next decade, the Human Genome Project will come of age, as about 100,000 different human genes and their supporting infrastructure yield to molecular inquiry. Previous commentators on the ethical issues raised by this project have often centered their analysis on the proprietary uses of genetic knowledge, confidentiality, and the requirements for protection of individuals against potential discrimination.[1] This essay will focus on the implications of the project for the treatment of human differences under certain social policies and programs.

Scope of Genetic Description

Early in the decoding of the human genome, researchers believed that genetic data would be useful primarily in a medical context. The National Center for Human Genome Research, for example, has stated that genetic information "...will provide new strategies to diagnose, treat, and possibly prevent human diseases."[2] While this objective was a major selling point for the Genome Project in the late 1980s, it is clear that benefits of this kind represent only a portion of the true scope of the genome initiative.

Even in 1992, the genome project continues to be described in limited terms. For

instance, the current brochure used by the U.S. Department of Health and Human Services to summarize the project limits its significance to medical developments and two additional areas: 1) understanding the process of embryonic development; and, 2) uncovering genomic sequences that reveal human ancestry.[3]

Despite the addition of these latter elements these kinds of descriptions still provide an incomplete and modest depiction of what will be accessible once the human genome is fully described. The scope of genetic data which will be gleaned from the genome project is almost certain to eclipse simple descriptions of single-gene associated disease, mutations that disrupt embryogenesis, or genetic markers that help us trace our ancestry. At a minimum, it is evident that genomic researchers will uncover much of the data needed to decipher the molecular code for functional genes that directly and indirectly affect the timing, sequence and operation of specific organs. Researchers will uncover the blocks of genes analogous to the "homeobox" genes in fruit flies and mice which govern embryologic development. In so doing, they will gain more than a simple understanding of embryogenesis: developmental phenomena will be subject to a new degree of biomedical analysis and control.

Most critically, the genome project teams will unveil data about the genetic predisposition to (not merely the occurrence of) disease. This is especially significant from the perspective of the distribution of societal resources (e.g., from a national health insurance pool), because it is likely that substantial, gene-based differences in human proclivities to infectious organisms or environmental agents will be revealed in advance of actual disease. Such uncovery of disease predilection has already received much attention and concern, as shown by the papers in this volume that deal with insurance and genetic screening.

As new gene sequences are revealed, it is most likely that they will be cross-

correlated with detailed interactive maps of all other genetic loci in the genome. As we have seen from the essay by Dr. Leroy Hood, this interpretation will involve complex integrative technology to compare and interpret genome sequences at great chromosomal distances from each other. With this capacity, a much more complex picture of gene action and their significance for human traits will probably become accessible. Most compellingly, polygenic traits (those associated with multiple genetic loci and environmental factors, acting in concert) will become amenable to a level of analysis heretofore not possible with standard linkage and heritability analyses.

This means that we will learn more about why individuals as well as groups differ from each other in diseases like hypertension, heart disease and cancer. Indeed, it is this very issue of group profiling that raises important questions of equity for social policy in the areas of discrimination and compensation.

Group versus Individual Differences

Even as the genetic language has proven to be universal, we have learned that the content of each person's genetic makeup is different. This uniqueness provides a basis for differentiating biological individuality and provides the starting point for a whole new field of forensic genotyping. Currently this fine, genetic differentiation is considered relevant for issues such as paternity testing, criminal identification or tissue grafting where precise gene-based matches are critical.[4] In a medical context, individual genetic profiles have proven useful primarily for identifying those families whose members express deviant genotypes sufficient to cause clinically relevant disease so that more precise counseling and/or prenatal

diagnosis may be offered. The question of how much of this data is relevant to public health has yet to be addressed fully.

A key question in this regard is to what extent if any, the genome project will reveal group differences in the frequency of major genetic loci that affect signficant human attributes. To date, this possibility has been given short shrift primarily because of the presumption that genetic material in widely distributed and rarely unique. Indeed, much of the focus on the genome has stressed its presumptive universality or extensive commonality. Emphasizing that only [sic] 2-10 million nucleotide bases (out of 3 billion) differ from person to person, Dr. Mark Guyer of the National Center for Human Genetic Research (NCHGR) has stated that "most of the information in that map will pertain to everyone."[5]

As shown by the spate of recent correspondence in Science pertaining to the overlap or lack thereof of unique genetic identifiers in forensic work, we are still uncertain whether some genetic data will prove to be unique to certain groups, or if some data may not be found in all persons of even closely related groups.[6] Marked genetic variance has been found for some rare blood group polymorphisms[7], alpha-1-antitrypsin alleles[8] and other complex loci where certain groups (e.g., the Lapps, Eskimos or certain African tribal peoples) have genes that are exclusive to their common ancestry.

The commonly held view that genetic mutations will always generate a few aberrant genes in unrelated groups (as has proven true for the genes that determine Tay Sachs disease among non-Ashkenazi Jews) and that subsequent genetic "churning" will asssure the eventual intermixing of these genes with the gene pool as a whole, may not hold up over time. Rare genotypes are rare because of their genetic isolation, and are commonly found among groups separated by long evolutionary intervals. Heterozygote selection may increase

the frequency of such genes (as is the case for the hemoglobinopathies), and Hardy Weinberg equilibria may describe their new incidence figures in interbreeding populations, but as Lewontin and Hartl emphasize such equilibria are of little value for for detecting variation among subgroups--and major genetic differences are likely to exist among historically isolated populations.[9]

By analogy to human cancer incidence data which reveals major group-specific differences in site-specific cancer rates, some major genetically-based characteristics may be found to differ systematically from group to group. There already may be such a prominent example in the gene products determined by the Lp(a) locus. Humans can have levels of Lp(a) that vary over a thousand-fold range, with most persons having very low levels. Those who have high levels are at increased risk of heart disease. However, this risk is currently limited to persons of Caucasian ancestry. Those of African ancestry appear to have other risk factors that are more important for determining cardiovascular status.

The level of this lipoprotein which is associated with either a "healthy" phenotype (little heart disease) or "high-risk" phenotype (much heart disease) is determined by the number of copies of certain sequences in this gene. People with smaller than average numbers of these duplicate regions have high Lp(a) levels and are much more likely to have heart disease than are those with multiple sequence copies whose Lp(a) levels . About thirty percent of patients whose heart disease began at an early age will have Lp(a) levels above those of the general population norms. This protein may be involved in promoting the formation of blood clots or arteriosclerotic lesions which eventually clog the heart's arteries. Most interestingly, it appears to be an independent risk factor from those traditionally linked to heart disease, like cholesterol levels or blood pressure.

Because Lp(a) also predicts the severity of heart disease, it is almost certainly going to be a candidate for clinical testing and, perhaps, for as a pre-enrollment screen for insurers as well. While the blood level of this factor cannot yet be predictably influenced by drugs or dietary regimen, it is particularly important to consider what might be gained by instituting early screening. At least one prominent human geneticist, has suggested that we may wish to institute intensive environmental measures to modify Lp(a) levels once we have uncovered the increased risk status linked to the gene.[10]

But since only the risk status of whites is presently tied-in with this gene, instituting screening and follow-up testing and prophylaxis (should that become available) to the rest of the population is problematic. Will persons of Afro-American ancestry or Hispanics benefit or be harmed by such a policy were they not to be screened? Excluding groups from presumptive prophylactic measures, of course, is potentially discriminatory. This is so because Afro-Americans who are at the same or higher risk of cardiovascular disease may be better identified by other, as yet unascertained loci and corresondingly benefitted by alternative risk-reduction measures. Instituting a genetic screening program that focused solely on Lp(a) alleles could mean that minority populations would receive fewer health benefits simply because another "white" genetic locus had been described before the comparable genes had been identified in another risk group. Of course, should adverse effects stem from such screening (e.g., employment discrimination, etc.) then Afro-Americans may in fact be better off if their competitiveness for employment is increased by the screening of other populations.

The counterargument that complete knowledge of the human genome will fill in all data gaps and eventually result in equity for all groups fails to be convincing because it

assumes that the risk profiles of groups--in terms of health risks and economic and social access--will all balance out once the full genomic complement of each group is ascertained. That is, the social costs of adverse health outcomes among groups like Afro-Americans which have certain predispositions (presumably genetically based) to illnesses like hypertension will be counterbalanced by the differential health risks carried by having a predominantly Caucasian genetic background. Such an eventuality is extremely unlikely, given the extent of genetic divergence between groups resulting from disparate selection pressures on populations that have historically had predominantly urban versus rural life styles. Were substantial, ethnic based group differences to be found in the distribution of major disease-associated genetic loci, the fact that access to health is unequal among many such groups has clear ethical implications. This especially true in a society like that of the United States which has not yet adopted any version of universal health insurance. (See, for example, the essays in this volume by Robert Pokorsky and Norman Daniels.)

Significance of Group Differences

Certain gene-associated human characteristics other than health factors may also differ among groups. Such behavioral characteristics with significant social utility or disutility--tendencies towards altruism or violence, predisposition to mental illness, mental acuity or intelligence, and maternal instinct--would require considerable rethinking if shown to be associated with a group-specific genomic profile. The traditional view is that these factors are highly conditioned and shaped by social and other environmental forces, and hence to speak about genetic determination of any measured group differences (e.g., in intelligent

quotients) as being largely or wholly "genetic" in origin is erroneous.[11] But, based on animal models from behavioral genetics, many of behvioral characteristics are undoubtedly polygenic and will prove to have a strong genetic component. These groups associations would be made even more problematic were they also to divide along socioeconomic lines.

Certain key conditions already show social gradients in their incidence. For instance, many psychiatric disorders as well as major diseases like cancer, heart disease and hypertension, are distributed along a steep socioeconomic gradient. Poor people and those with less education commonly experience a higher incidence of many diseases in these categories than do their well-to-do, better educated brethren. Because in the United States, poverty is frequently linked to ethnicity, and ethnicity in turn reflects major differences in certain gene frequencies, attempts to identify genetic components of these trends has been inherently suspect as racist and a prejudicial abandonment of egalitarian values.

However, recent studies of emigres in Israel suggest that some of the social (environmental) explanation for the high concentration of disease among low socioeconomic classes may be only partially correct. Researchers have now shown that while depression is closely associated with environmental correlates of low social status (especially in women), the concentration of cases of schizophrenia among persons in low socioeconomic groups shows a strong pattern consistent with genetic selection.[12] In the researchers' view, this disorder--and by inference others which show a steep socioeconomic gradient--can be the result of a social "sifting" of persons with genetic predisposition to poorer coping skills into the lowermost rungs of the social order where their reproduction furthers the spread of the responsible genotypes.

The assumption that the human genetic proclivity for these or any other valued or unvalued traits is unknowable or that environmental factors will always skew genetic causation--may not hold. First, it would be imprudent to believe that complexity alone will thwart the accessibility of polygenic human traits to analysis. As we have seen, the process of decoding the genome will almost certainly include a process of cross-correlation and integration of multiple loci as they interplay in shaping characteristics and features of the whole person.

We can be reasonably sure of discovering the genetic precondition of a range of complex human traits by looking at the history of other traits and disorders once thought to be intractable to reductionist analysis. A case in point is depression, a psychological disorder once thought to defy biochemical explicaton. As mentioned above, recent studies have shown that several forms of depression, including the bipolar form of manic depressive illness, fit quite nicely into biochemical and genetic analysis.[13]

The increasing scope and explanatory power of the genome project generally, and population genetics specifically, means that many of these most crucial human attributes--including the distribution of illness, senescence, learning skills and competence--may also fall to genetic explanations, at least in part. This inference is drawn from parallel studies in animals, especially mice, which show that disease susceptibility, aging, and learning ability are all controlled to some degree by multiple genetic loci.[14] Such traits clearly involve a delicate and complex interplay between environmental and genetic factors. However, a strong likelihood exists that these genes are not randomly distributed between groups of persons with disparate ancestry (ethnic origins). While the creators of the human genome

initiative see such a likelihood as raising scientifically interesting questions about human origins, the existence of group-specific differences in key human attributes has more ominous overtones: it raises the specter of eugenic policies, discrimination, and oppression. This is particularly so in light of the history of misapplications of human genetics and social theory, and the use of false science in shaping malevolent eugenic theory. What will be different after the genome project is that there will be substantial "hard" science pointing to group differences. What uses if any such data is put to for shaping social policy must be considered now.

Implications of Inequitable Genomic Distribution

When and if a given genetic sequence proves instructive about such polygenic adaptive traits as intelligence, emotionality, or attentiveness, integrating these new facts into public policy will be fraught with moral and political difficulty. The tendency will be to ignore such data for all but medical purposes. At the simplest level, this is because the formulation of equitable policies presupposes a "veil of ignorance" behind which policy is made. First expounded by John Rawls, the ignorance principle holds that policies are best made by the assumption that anyone could be in a given reference group.[15] The effect of such a principle is to prevent groups from using social policy as an intrument of their own, exclusive advantage. Because everyone must consider themselves to be potentially in the worst-off group, the tendency of policy formulations under a Rawlsian system of justice is to have persons identify with and protect the interests of those who are most disadvantaged.

In large measure, the heuristic appeal of this approach turned on the reality (circa

1971-2 when it was first proposed) that we could not know all of the salient features of persons. Nor could we know in what way the natural lottery distributed poor lots to some and good lots to others. However, ignorance of salient differences cannot be an ingredient of "just" social policies when such differences not only exist but can in fact be known and identified. It is now clear that the curve of "normalcy" which underlies virtually all significant human traits is fractured and partitioned into several very discrete polygenic domains. Just as the bell-shaped curve of human height contains individuals with both pituitary dwarfism and gigantism, so will the bell-shaped curve of normalcy for the distribution of risks to heart disease be found to be bifurcated and bifurcated again into high- and low-risk groups.

How we handle this information is as much a moral question as a political one. How should we distribute societal goods (like jobs) and support (like universal health insurance) among high-risk populations? Who should pay and how much for these benefits? Should we compensate or ignore costly gene-based predilections for disease or disability? It may prove possible to design policies which acknowledge certain gene-based proclivities towards illness as part of programs which compensate for disability rather than penalize the holders of certain traits--whether those traits are socially valued or disvalued.

The extent, if any, to which we are obliged to recognize such human differences in terms of compensating those who are disadvantaged will be put to an acid test in the post-genome years. Will we consider ourselves to be duty bound to compensate for the distribution of genetic disadvantages while at the same time accepting an obligation to respect the distribution of genetic advantages? These questions require that we rethink the question of justice, deservedness, and duties in a new light.

While many groups with genetic infirmities have attracted public empathy and support, it is not clear that the United States public is ready or willing to recognize group differences other than those that directly pertailn to genetic susceptibility to illness. (Witness, for example, the racist overtones of the I.Q./heredity debate). Answers to these questions may require a different approach to the philosophy of equity and justice. Genes for traits like intellect are almost certainly going to be found to be inequitably distributed among groups of persons as they are now know to be so distributed among individuals. Existing ethical theories about differences and their adjudication usually assume that random events contribute to this so-called "natural lottery". Once those events fall under conscious control, what comprises a "fair share" of the genetic lottery (say for intellectual traits) and what a "poor share" will of necessity become a social problem. While overt efforts to control this lottery will almost certainly be resisted (for all the reasons that contemporary eugenic measures are opposed in this country), even the simple disclosure of genetic compositions will perforce reveal human differences that warrant some attention.

The Moral and Social Challenges of the Genome Initiative

The products of the genome initiative may throw into stark relief the paradox of a society based on the premise of equal standing at creation and one which is found to be comprised of a genetically heterogeneous group of sub-populations with qualitatively different frequencies of heritable traits. As a society, we will have to ask if we can in fact collect information that reveals these individual differences, and still continue to treat all persons the same. We may wish to consider some persons, by virtue of their gene-based handicaps or predispositions, to

have greater (or lesser) claims on us for support (especially if that support is limited to job opporutinity and health coverage). Others, by virtue of their inheritance of larger-than-normal genetic loads (by virtue of their exposure to genotoxins or high inbreeding coefficients) may have claims on us for still other protections or compensations. And still others may be the genetic equivalents of the non-smoking populations in terms of their projected fitness (in a non-Darwinian sense) and therefore have certain claims on us for recognition or compensation (e.g., special insurance rates).

What is clear is that even a partial picture of the genetic landscape that defines the molecular differences between human individuals will reveal more in its non-uniformity than in its hoped for universality. This landscape is likely to be one which is jagged and uneven, broken by genetic discontinuities among cultural and ethnic groups. Genes will not be partitioned either uniformly or fairly among groups with disparite genetic heritages. This means that by its nature, the genetic lottery will show itself to be manifestly unfair. But fairness is only a valid concept when outcomes or measures to achieve a certain endpoint are under human control or dominion. We do not think that lightning strikes are "unfair": but we do think that poorly grounded cables that permit such strikes to injure persons to be unfair. In a broad sense, a similar analogy applies to genetics.

We do not think that the partitioning of the genetic lottery is itself manifestly unfair: genes are normally distributed by purely chance events of recombination and assortment. This is why the Hardy-Weinberg Law applies to universally. But once genetic loci are known with mutational "hot spots" or when individuals are indentifiable with "risky" genotypes (e.g., those who carry the genes for Fanconi's anemia, xeroderma pigmentosum, or ataxia telangietasia) the consequences of their reproductive activities for their own children

and future generations become knowable and hence controllable. Will we be able to resist the pressures to break from the past tradition of totally "neutral" genetic counseling in which non-directiveness is the goal? Or will we feel compelled to recognize these differences as being salient and important for future generations?

Clearly, we will know with much greater precision what populations will have disproportionately high gene frequencies for certain deleterious traits or predispositions--at least as those traits are now measured against present environments. Some traits which had selective advantages in past environments will be recognized as part of the genetic load for contemporary environments. Other populations which have been isolated culturally and historically from the mainstream of human affairs, will exist as genetic islands, with archaic and perhaps inappropriate genotypes for modern human environments. Many of these populations presently exist in rural, developing countries. Such persons will be unlikely to receive the same kind and degree of benefits from the genome initiative as will their more fortunate peers in developed countries, if for no other reason than that the diseases that afflict affluent populations include more disorders with genetic proclivities than do those of the rural poor.[16]

Some persons in the industrialized countries will be discovered who will prove to be unusually robust and tolerant of the stringent conditions common to the toxic environments common to some worksites. For instance, persons who can only metabolize certain chemicals slowly (so-called "slow acetylators") are at higher risk for cancers (especially bladder cancer) than are their faster-metabolizing co-workers.[17] It is still a major unanswered ethical dilemma is whether or not to use such information in genetic screening programs in potentially toxic work sites.[18] Social and political forces may ask that

those who carry a disproportionate load in terms of genetic heritage, carry a proportionately increased share of the responsibility and cost of health insurance, job-training, or other benefits. Moral reasoning may reach the exact opposite conclusions. Those who are least well-off may arguably be given certain social advantages to compensate for their otherwise unavoidable genetic infirmities, for instance by putting them into a "high-risk pool" of insurance applicants or by expanding the ambit of the present day acts to protect persons with disabilities. But in so doing, we will also be expanding the penumbra of discrimination and social stigma to groups whose infirmities used to be hidden and private matters.

Conclusions

We will still need to garnered much wisdom to know how to apply the data which we glean from the genome initiative and how to ensure that it is used morally. Among the options which will become available at each phase of the genome project are the following:

A. Accrue data and use it to establish prevalence figures ~~for key human traits~~ for key human traits

B. Put data into banks that permit access to group information

C. Use data to identify and provide counseling to individuals at risk for perpetuating serious disorders

D. Use data to redress inequalities in apparant apportionment of genes that confer disadvantages to holders

E. Use data to design eugenic strategies

These independent alternatives are arrayed in ascending order of controversy. Simple acquisition of genetic data unlinked to individuals by name or address provides a basis for establishing gene frequencies and prevalence figures. But to be truly useful in any epidemiological sense, genetic data will also have to be associated or linked to persons by virtue of their extended mating groups, geography, and health patterns. Here, issues of confidentiality must certainly come into play, or problems of potential discrimination will inevitably occur.

Using genome data for counseling purposes, or for that matter forensic work and genetic identification programs, is a logical extension of existing programs. While not without ethical problems, there are few novel issues drawn out by these applications. Using genetic data to design social programs that address the issues of inequalities is a major novel consideration. For instance, if it were shown that certain HLA markers put individuals of particular ancestry at risk for autoimmune disorders, it might be appropriate to design strategies to pinpoint the carriers of the particular markers and alert them (and their care-givers) to the possiblitiy of adverse reactions. A case in point is the genetic predisposition to silicosis and rheumatic disorders. While the responsible genetic locus is most prevalent among persons of Japanese ancestry,[19] alerting people who are potential sand blasters or other workers to their risk status would be a justifiable use of this data. Use by employers to exclude such persons from employment is a much more controversial application.

At the terminus of the applications of this data are those persons in the general population who might be at increased risk for autoimmune disease. Such persons would be potential candidates for counselling before they received breast implants or other interventions with the possibility of stimulating the immune system.

Use of genome data for eugenic purposes, whether tacitly or by policy, is the most controversial policy of all. In the past, the medical and public health communities has had to handle human differences in each extant generation as they arose and expressed themselves in predilections to disease and disability. But with advanced knowledge of the consequences of reproduction, it is inevitable that eugenic questions will be raised about supporting or not supporting certain group or individual decisions about procreation.

Even as this data becomes increasingly probative and reliable, it would be a great mistake to use such knowledge to compel, coerce or otherwise discourage procreative decision-making. The present policies which favor free reproductive choice are based on the premise of equal standing and deservedness of persons of greatly dissimilar backgrounds and makeups. Genetic data may further refine such differences, but provides no real guidance as to the deservedness of any group of individuals for support or sanction for their procreative decisions. Different policies may prove appropriate for persons who are the genetic equivalents of the non-smoking population in terms of their projected fitness. For these persons, accepting their genetic status as conferring better than normal odds of future well-being may mean nothing more than assuring that policies are not adopted which penalize them for their good fortune. Benefits, in terms of tracking, rewards, or similar incentives may not be appropriate since the genetic lottery has conferred its own reward.

We may wish to consider whether or not some persons by virtue of their gene-based handicaps or predispositions have greater claims on us for support than do those whose genetic makeup is largely "normal". This is especially true if that support is limited to job opportunity where we have determined that handicaps of this kind should not reduce the employability of otherwise qualified applicants. We may also wish to consider the

appropriateness of selective policies for those who carry larger-than-normal genetic loads by virtue of their exposure to genotoxins or socially-induced high inbreeeding coefficients. For these persons, the choice to play the genetic lottery on a level playing field has been compromised by societal actions. Arguments of justice support the claim that many such genomically impaired persons have claims on us for other forms of compensation just as did the Hiroshima maidens who came to the U.S. for plastic surgery after the war.

Knowing that the genetic lottery will not have treated all groups the same does not mean that we are duty-bound to treat such groups differently. The salient Aristotelian principle of treating like things alike assumes that we have already agreed upon what things are worthy of consideration. Those things that determine humanness and standing are most of all socially determined and fixed by circumstances of personal history and socioeconomic factors. They are least of all those things that are genetic. Even where there are genetic factors at play, as is likely to be true for schizophrenia, policies that recognize the human needs of such persons are of necessity "gene-blind" as well as color-blind. For every human infirmity that has a genetic basis, there is a "phenocopy" that is solely the result of environmental forces. So here, treating like things alike means ignoring the causal factors, and treating the person. For this reason, social policies directed against genetic impairments--real or predicted through the human genome's revelations--are almost always secondary to social policies directed against the environmental causes of human injustice. In any case, deciding how to incorporate new genetic data into social policy and how to compensate persons with important genetic differences will thus be a daunting task. Just how we will incorporate the traditional American values of justice and fair play into the genetic lottery is perhaps the largest, long-term challenge posed by the genome initiative. How we do so, will

be a measure of our humanity as well as our science.

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