

Genetic Information, Health Insurance, and Rawlsian Justice

I. Introduction and Overview

In the summer of 2000, the member countries of the Human Genome Project (HGP) completed the first draft of the human genome. This accomplishment was widely viewed as the first chapter in an epic novel, not its conclusion. Ethical attitudes regarding this feat generally consist of a mild form of approval, perhaps stemming from a blind trust in technology and a larger sense of disorientation. In the popular media, many persons unapologetically adopt a "wait and see" attitude, publicly proclaiming that they simply do not know what to think about the ethical questions raised by the coming genetic revolution.

My goal is to stake out a bit of solid ground upon which to stand concerning the moral aspects of genetics by focusing on the following question: does using genetic information for decision-making about health insurance eligibility and premiums constitute a form of morally unacceptable discrimination? ¹ In order to answer this question, we must address the larger issue of whether using genetic information bases decisions upon an arbitrary and unjust basis, and to do this, we must invoke moral and social/political philosophy.

If, for instance, we adopted a principle charging policyholders higher premiums (or depriving them of coverage altogether) on the basis of race or sex, this would clearly base decisions upon an arbitrary and unjust criterion. But if insurance premiums were affected by (e.g.) life expectancy, and in this society women on average lived several years longer than men, it is not obviously unacceptable to allow this factor to influence premiums. While life expectancy is coupled with gender, it is not gender *per se* that is the basis of the decision, and life expectancy may be a relevant factor in insurance decision-making.

While procedures such as radical gene therapy are somewhat in the future, the use of

information derived from genetic testing for insurance decisions is one of the most likely ways that the HGP will touch human lives, for better or for worse, right now. At present in the United States, anywhere from 44 to 70 million citizens are uninsured, if the figures include those persons that go at least part of a year without health coverage, and 8.7 million persons buy health insurance through individually underwritten policies. (Banja 2000, 17) The Health Insurance Portability and Accountability Act (HIPAA) of 1996 prohibits rejecting coverage for individual members of a *group* health insurance plan (such as those offered by employers) on the basis of current health status or some future disposition to a particular disease based on genetic testing. However, this law does not address the use of genetic information in the *individual* underwriting process. What this means is that persons who must pay for their own health insurance are subject to increased premiums and even denial of coverage based on information gathered from genetic testing. The argument of this paper will address the lacuna in the HIPAA regarding individual health insurance policies by providing the ethical basis necessary for determining the justice of using genetic information in health insurance decision-making.

Does genetic discrimination exist at this time? The Shriver Center for Public Health announced in 2000 the results of a survey that documents 582 cases of people who were turned down for jobs or health insurance because of genetic testing. This and other available evidence does not suggest that genetic discrimination is widespread by any means, but as genetic testing becomes available for a larger number of diseases, the possibility of this sort of discrimination continually increases. Francis Collins, director of the National Human Genome Research Institute, has summarized the current situation as follows: "Already, with but a handful of genetic tests in common use, people have lost their jobs, lost their health insurance and lost their economic well-being due to the unfair and inappropriate use of genetic information." While it is

difficult to precisely determine how often genetic discrimination occurs, since insurers do not publicize their practices and victims do not come forward in order to avoid further stigmatization, the time to consider the moral issues surrounding the use of genetic information is now.

Some (ACLI-HIAA 1991) argue that there should be full disclosure of information from genetic testing to insurance companies, while others (Murray 1992) argue that information from genetic testing should not be made available at all to insurers. I will assess the current situation and argue that using genetic information to determine insurance premiums and eligibility is an unjust practice by appealing to John Rawls' (1971, 1996) theory of justice. As we shall see, the extreme positions regarding genetic information and insurance are problematic, and a Rawlsian approach supports a defensible moderate position on the disclosure of genetic information to health insurers.

II. Preliminaries

There are several preliminary matters that need to be briefly discussed. First, throughout this discussion I will use the term 'genetic information,' yet some have argued (Holm, 1999) that there are no politically or ethically relevant differences between genetic and other health-related information. The problem, then, is how to properly define this term. For my purposes, I can simply grant that there may be no inherent difference between these two types of data. While whether a person has this or that gene on a particular chromosome may be the clearest example, is blood type an instance of genetic information? I do not know, and hope to avoid these problems by simply using 'genetic information' in a pragmatic way, as a designator for 'the results of tests on DNA and RNA and related gene testing.' The important point is that my argument does not depend upon an intrinsic difference between genetic and other health-related information; the definition itself is not used to establish any substantive conclusions.

Second, in discussing genetic discrimination as a pressing problem, the argument of this paper assumes that current forms of genetic testing do possess some predictive power regarding the existence of traits which increase one's lifetime risk for specific illnesses. It is important to keep in mind that presently this predictive power is very small, given that genetic testing is in its infancy. However, this science is progressing rapidly, and it is now possible to identify mutations causing diseases such as Huntington's chorea, Amyotrophic Lateral Sclerosis, (ALS) and mutations which predispose one to develop (e.g.) heart disease and breast, colon, and other forms of cancer. Within this paper I do not endeavor to examine the difficult notion of genetic causation,² but only rely on the simple contention that the predictive power of genetic testing will increase as the HGP progresses.

Finally, I should discuss why I have chosen to focus on exploring how a Rawlsian approach to questions about insurability would work. This paper was born out of dissatisfaction with the current literature on this topic. Much of the ethical criticism leveled against developments in the field of genetics is based solely on the existence of possible harms, yet critics provide no substantive arguments to support these claims and develop no ethical principles to establish the moral unacceptability of creating such harms. Harms arising from social practices are certainly important, yet they are not the only relevant consideration, since we also care about how a social policy is created in a democratic society when assessing whether or not a policy is just. Rawls' theory has had an enduring influence, and it provides a compelling account of the principles necessary to address these further considerations. This paper is a call to rethink a strictly harm-based method for evaluating social policy and to instead include elements of fairness and democratic process in a more well-rounded approach. This paper not only utilizes Rawls' theory to provide insight on the questions of justice surrounding insurability, but the

conclusions reached by this examination illuminate and test important aspects of Rawlsianism itself. Preliminaries aside, let us now turn directly to the debate.

III. The Health Insurers' Argument and The No Disclosure Position

Advocates for insurers present two arguments in support of the claim that they should have an unlimited privilege to underwrite on the basis of genetic test results and should enjoy *full disclosure* to genetic information. (ACLI-HIAA 1991) First, they argue that it is unfair to other policyholders to not treat those with significant genetic risks differently, since these persons are much more likely to require expensive medical treatments, the cost of which are passed along to all other policyholders. The healthier policyholders, it is claimed, are unfairly taxed by the policyholders with less favorable genetic prospects.

Second, insurance companies argue that there should be full disclosure of genetic test results since individuals who possess detailed knowledge of their genetic inheritance could use this information to engage in "adverse selection" to exploit insurance companies. Smith et. al (1999, 58) outline the following four conditions which must exist for adverse selection to occur: (1) there must be heterogeneity of risk among consumers, (2) insurers must not be able to detect (and therefore cannot appropriately price) this risk, (3) consumers must have access to information that allows them to predict their personal risk better than insurers, and (4) consumers must seek and obtain additional insurance coverage based on this information. Adverse selection occurs, then, when a person who possesses a high risk for genetic disease purchases extra health insurance in light of this guarded information, and when those who have low risks for serious genetic disease minimize their coverage on this basis. The claim is that if the consumer acts on information not available to insurance companies, this is unfair since it would have a devastating effect on insurance markets.

Philosopher Thomas Murray (1992) believes that the insurers' argument is fundamentally

mistaken, and argues that insurance companies should have no access to genetic information. He defends what I will call the *no disclosure* position. He supports his position by arguing that the model of actuarial fairness upon which insurance is based is not just when applied in this context. Certainly, insurance companies have always indirectly obtained genetic information from other data gathered in the application process (such as family history). Murray argues, however, that when insurance companies use more pointed genetic information to deny coverage or offer coverage at increased insurance premiums, this results in an unjust form of "double-jeopardy." For instance, LDL cholesterol levels are used as a determinant for risk of heart disease, yet one's LDL cholesterol is partly determined by genetics. Two persons who are equally careful with respect to diet and exercise can have significantly different chances for heart disease. Utilizing test results for genetic disorders that are out of one's control will add to the existing unfairness already experienced by those who have come up short in the genetic lottery.

Murray (1992, 218-19) clarifies his attack on the concept of actuarial fairness as it functions in the insurance industry in the following example. Suppose we had two oil tankers similar in all other respects, (age, upkeep, experience of the captain, etc.) except one was shipping oil in the Atlantic Ocean, and the other in the Persian Gulf during wartime. Is it morally acceptable to charge more to insure the latter vessel? Murray quite correctly thinks this is defensible. The second vessel is undergoing different risks which are voluntarily undertaken, and these risks are knowingly assumed for the purposes of making a profit. It is not fair to apply this actuarial model to health insurance, however, since a significant amount of the risk associated with illness stemming from genetic factors is not voluntarily assumed. Further, in the case of health insurance, making a profit via risky behavior is not the goal--securing satisfactory health and the sort of life one can lead with adequate insurance protection is. These are eminently

reasonable goals with favorable social consequences, and health insurance has become an essential means to reach these ends.³

Murray's conclusion is that the model of actuarial fairness is not fair when used in the insurance industry, but is fair with respect to voluntarily assumed, risky behavior. I think that the guiding ideas in Murray's discussion are enlightening, yet he does not provide a solid philosophical foundation for these ideas. In addition, I do not believe these guiding ideas imply that it is always impermissible to disclose genetic information to insurance companies. I will first criticize both the health insurers' and the no disclosure position, and will then develop and ground the guiding ideas just suggested.

IV. Criticisms of the Health Insurer's Position and the No Disclosure Position

The insurers' position is burdened with a number of serious problems. Their claim to unlimited rights to underwrite on the basis of genetic test results could be interpreted in several ways. This could simply include *full disclosure of genetic test results on tests ordered by the person*, or could suggest *mandatory testing requirements* for insurance eligibility (at least for eligibility at affordable rates). If insurance companies wish to support mandatory genetic testing, the fact that the average person carries six to eight genes that could lead to disease would seem to suggest that all persons are bad risks. (Munson 1996, ch. 7) At the very least, insurance rates would likely increase, making insurance unaffordable for more persons.

In addition, exacting economic costs on the basis of genetic risk is analogous to punishing persons before they commit a crime. Even if we could accurately predict who was more likely to have criminal tendencies, this would not justify incarcerating them or otherwise punishing them before they had broken the law. Similarly, genetic risks are just that: *risks*. Only if one believes in a strict form of genetic determinism would the imposition of such economic penalties by insurance companies obviously be justified. However, given the importance of

environmental influences, belief in such genetic determinism is unfounded. (Holm 1999; Gould 1999; Kitcher 1996) Certainly, genetics contributes something to the determination of the upper limits of our capacities, but genes do not ultimately determine our destiny. This is obvious enough: a predisposition to heart disease does not ultimately control how one's life will go, or how it will end, since a person with this predisposition could escape the disease by making intelligent choices with regard to exercise and diet, or could simply die in an auto accident. The central point is that since possessing genetic risk is not the same as being stricken by illness, it is morally questionable to economically penalize persons on the basis of genetic risk alone since these individuals may not in fact require additional costly medical care.⁴ This point is especially forceful if these economic penalties put the fundamental protection afforded by health insurance out of reach for such persons.

If insurance companies instead lay claim to results from genetic tests ordered by the person, it is unclear why they are necessarily entitled to *full disclosure* of such test results. Insurers attempt to justify this belief by appealing to the possibility of adverse selection in the health insurance market. However, a simple example illustrates that the possibility of adverse selection does not necessarily support a claim to full disclosure. A person with a family history of Huntington's disease may order a genetic test for herself, or for her fetus via amniocentesis, only out of an interest in this disease. Even if we suppose that the mother's test is negative, genetic tests may uncover other unfortunate aspects of her genetic inheritance (e.g. predisposition for hypertension). If the test is administered to the fetus and is negative, other genetic risk factors for the fetus could be discovered. If full disclosure includes revealing these other unfortunate aspects to insurers, then full disclosure may lead to increased premiums when the insurance company learns of these other genetic risk factors. However, if only the negative

test results regarding the gene for Huntington's are disclosed to the individual by the genetic counselor, it is unjust to increase this person's insurance premiums on the basis of other factors which are discovered, since she has no knowledge of these additional genetic risk factors. Only those troubling aspects of one's genetic inheritance which one knows can be used to engage in adverse selection.

Murray's arguments in support of the no disclosure position have difficulties of their own. The general principle behind Murray's criticism of the model of actuarial fairness is that if one's genetic risk factors and medical condition are not in that person's control, then it is not fair to economically penalize that person for those risk factors or medical condition (should the condition result). Call this the *Control Principle*. I find this principle compelling. The main problem with Murray's application of this principle, though, is that it does not properly acknowledge the phenomena of adverse selection. While insurance companies make too much of adverse selection, Murray's position does not take the possibility of adverse selection seriously enough. If genetic information is never disclosed to insurance companies, then if consumers gain knowledge of certain genetic risk factors and act on the basis of this asymmetric information, this unfairly puts insurance companies in peril. These considerations suggest that the results of genetic testing can be disclosed to insurers if this specific genetic information is known by the insured individual.

Further, Murray does not provide positive support for the Control Principle, only negative support. While he has successfully argued against applying the model of actuarial fairness to insurance, we are given no compelling argument for the Control Principle itself. What is the precise reason why we should adopt this principle? In what follows, I will examine the philosophical foundations that support the Control Principle, as well as draw out its scope and

implications.

V. A Rawlsian Approach to the Use of Genetic Information

On a Rawlsian social/political theory, the vision of a just society is one which is governed by principles that persons choose from an impartial standpoint. Impartiality is represented through the hypothetical device of the original position, where representatives are put behind a veil of ignorance which deprives them of many crucial facts about themselves. The goal in the original position is for the representatives to come to agreement on the principles of justice. In his discussion of the original position, Rawls introduces the notion of 'primary goods,' those goods which every rational person is presumed to want whatever else he or she wants. To decide which conception of justice is most to their advantage, the representatives assume that they prefer more rather than less primary goods, since these are useful in advancing all rational plans of life.

Primary goods fall into two basic types: social primary goods and natural primary goods. (1971, 62) Examples of social primary goods include basic rights and liberties, powers and opportunities, and income and wealth. Also included here are the social bases of self-respect. . Other primary goods such as health, vigor, intelligence, and imagination are considered to be natural primary goods. The main difference between the two types of primary goods is that social primary goods are distributed by the basic structure of society, as governed by the principles of justice arrived at in the original position. The possession of natural primary goods, by contrast, is influenced by the basic structure of society, but is not directly under its control.

An initial question needs to be confronted before a Rawlsian approach to genetic information and health insurance can be outlined: how would the insurance industry be conceived on a Rawlsian view? Would insurance companies be considered public or private entities?

Rawls does not address this question, but the answer depends on whether or not insurance companies are considered part of the basic structure of society. For Rawls, principles of justice apply only to "...the main public principles and policies that regulate social and economic inequalities," (1996, 282) and it is the basic structure of society, "...a society's main political, social, and economic institutions," (1996, 11) which enacts these public policies. In essence, it is by reference to the basic structure that social and economic inequalities are determined, and this is done by regulating the distribution of primary goods. It may appear that health insurance companies are to be part of the basic structure of society, since they are an economic institution which affects the distribution of inequalities with regard to the primary good of health. However, all companies affect the distribution of primary goods, at least with reference to the primary goods of income and wealth. On this broad conception, all business institutions would be considered part of the basic structure, a result that does not fit well with the idea that in a Rawlsian society, private businesses and other elements of a market economy will exist.⁵

While it is unclear whether insurance companies would be considered part of the basic structure of society, offering a definite answer to this question is not essential for the purposes of this paper. While I will argue along Rawlsian lines that it is unjust to use genetic information to determine insurance eligibility and premiums, I wish to remain neutral regarding the question of responsibility for accepting the economic consequences of such a policy. It may seem that this policy unjustly shifts significant additional economic burdens onto insurers, but if insurance companies are considered part of the basic structure of society, it is the state that ultimately bears the burdens. If insurers are considered a private entity, then the state could establish a public fund or other mechanism (such as tax advantages) to ameliorate the consequences of these burdens for insurance companies. The purpose of this section is not to spell out all the details of

how to oversee a health insurance system, but is instead to philosophically ground the unfairness of using genetic information in health insurance decision-making.

Earlier, a reply to the 'adverse selection' argument was offered. The appeal to a Rawlsian conception of justice will address the other argument offered by insurance advocates, namely, that policyholders with less favorable genetic prospects unjustly "tax" more genetically fortunate policyholders. There are four main points which need to be examined to develop a Rawlsian approach for the use of genetic information in relation to health insurance:

1. The social purpose of health insurance is intimately tied to the fact that health is a natural primary good.

Adequate health is necessary for fulfilling every person's conception of the good. It is undeniable that one's genetic makeup affects one's health in some ways, even if we avoid (as we should) belief in genetic determinism. Health is a particularly interesting natural primary good, since while it cannot itself be literally distributed by the basic structure of society, the necessary conditions of good health can (such as competent medical care, pharmaceuticals, etc.). Two persons with very similar genetic prospects can have vastly different health prospects if one has sound medical care and the other is victim to a number of disabling yet preventable illnesses. The possession of this natural good is tied much more closely to the level of social primary goods enjoyed than the other natural primary goods. (e.g. vigor, intelligence, and imagination)

If the distribution of natural primary goods cannot be controlled as directly as the distribution of social primary goods, what does justice require if one person is naturally more healthy than another? This is precisely the question which faces us in this discussion, since some object on grounds of justice to (in essence) paying higher insurance premiums because of other less genetically fortunate policyholders. Rawls addresses this general question in *Political Liberalism* by arguing that a just society secures to everyone the same index of primary goods to

cover their needs as citizens. Several thinkers (such as Kenneth Arrow and Amartya Sen) object that given the wide differences between persons' moral, intellectual and physical capacities, it simply is not fair to secure to everyone the same index of primary goods.

Rawls begins his response to this objection by admitting the obvious point that we do not find factual equality in terms of moral, intellectual, and physical capacities. However, his theory does assume that citizens have the essential minimum degree of such capacities to enable them to be fully cooperating members of society over a complete life. (1996, 183) This is all that is needed for his theory, since Rawls views the central concern in political justice to be the determination of fair terms of cooperation between free and equal citizens as fully cooperating and normal members of society over a complete life. (1996, 181)

The thrust of Rawls' response is similar to arguments contained in *A Theory of Justice*, when he points out that all persons gain greatly by being part of the "scheme of cooperation" in society, even if at times persons choose to ignore this truth. (1971, 15) The point is that if a person has the capacities to be part of this scheme of cooperation over a complete life, they are owed duties of justice, since all of our lives are enriched by others' contributions to society. On a Rawlsian theory, citizens are to be given the all-purpose means necessary to actually utilize their liberties in order to pursue what they value in life. Since adequate health is necessary for realizing all conceptions of the good, health insurance coverage should be offered to all persons without reference to their genetic prospects.

2. In the Original position, representatives would not vote for a principle which disadvantages those with unfavorable genetic prospects.

To begin to see why a Rawlsian theory would not support a principle that allows genetic information to be used by health insurers to economically penalize some persons, we must understand its principles of justice. There are two principles which Rawls believes the parties

in the Original position will ratify, and these are as follows:

(1) Each person is to have an equal right to the most extensive total system⁶ of equal basic liberties compatible with a similar system of liberties for all, and (2) social and economic inequalities are to be arranged so that they are both: (a) to the greatest benefit of the least advantaged, consistent with the just savings principle⁷, and (b) are attached to offices and positions open to all under conditions of fair equality of opportunity. (1971, 302)

Principle (1) is given priority over (2), and part (b) of the second principle is prior to part (a), which is called the *difference principle*.

Rawls reasons that the parties in the Original position will be very conservative in their decisions, given the constraints on information imposed on them. This suggests they will not support institutional policies regarding health insurance which economically favor persons with better genetic prospects, just as they will not support policies which favor men over women, or Caucasians over African-Americans. The reason is simple: each representative is assumed to be self-interested, and by supporting such a policy one may be hurting oneself, since he or she may be a member of the disfavored class.

Rawls notes that behind the veil of ignorance, the representatives do not know the following things: social position, class position, natural assets and abilities, intelligence, strength, particular conception of the good, or special psychological propensities. (1971, 12; 1996, 79) A Rawlsian theory should explicitly exclude knowledge of one's genetic makeup as well, since such information undermines the assumption that the representatives in the Original position will choose from an impartial perspective in which persons are represented as equals. As Rawls (1996, 23) says of the original position with its veil of ignorance, it "...provides conditions for a fair agreement on the principles of political justice between free and equal persons," and it does this by "...eliminat[ing] the bargaining advantages that inevitably arise within the background institutions of any society from cumulative social, historical, and natural tendencies." Genetic

advantage and disadvantage affects relative bargaining position, and therefore should not be known by the parties to ensure that the decision in the Original position is fair.

It is important to point out that 'genetic disadvantage' is a complex notion which is in part determined by the amount of primary goods one has to trade off to cover outlays for increased medical and insurance costs. Imagine a case where two persons have unfortunate genetic prospects, yet one is rich and the other lives just above the poverty line. The former may simply redirect income and wealth to cover increased costs for health insurance, while this possibility is not available to the latter person. In this case, the former person may experience no real change in quality of life, while the latter may have to significantly revise her life goals in light of these greater costs. Since 'genetic prospects' or 'genetic risk' are probabilistic concepts, the extent of one's disadvantage is also a function of whether or not the person actually contracts the disease associated with the genetic risk factor. While this is true, one can be genetically disadvantaged even if one does not in fact suffer from genetic illness, if he or she is charged higher insurance premiums simply as a result of possessing unfavorable genetic prospects.⁸

3. Adopting a principle which economically penalizes those with unfavorable genetic prospects undermines the primary good of self-respect, and hence does not recognize persons as free and equal citizens.

In his discussion of primary goods, Rawls points out that self-respect is perhaps the most important primary good. (1971, 440) This is the case since for Rawls, a person is happy if she is in the process of successfully executing a rational plan of life under favorable conditions, and possessing self-respect is necessary for having such a life plan. Without it one will not feel that her plans are worthwhile and will lack the confidence to believe that these plans are attainable. Since having a rational plan of life is crucial for happiness and self-respect makes viable rational plans possible, self-respect is an all-important primary good.

Some (Kass 1973, Kevles 1993) argue that using genetic information to make distinctions

between persons constitutes an attack on human dignity and will create a genetic underclass. The worry of a genetic underclass does not simply refer to the worry that a new group of persons will be economically disenfranchised by losing health insurance. This possibility also raises the concern that a whole class of persons will internalize these judgments, will see themselves as incapable of fulfilling their rational plans of life because of their genetic makeup.

There is a very close relation between a person's self-respect and her rational plans of life; substantial failure in realizing the latter will inevitably have negative effects on the former. Since health plays an important role in conceiving and implementing one's rational plans of life, some form of health insurance has become a necessary means for safeguarding one's rational plans. Due to the economic and psychological instability that is caused by uncertainty about meeting present or future health needs and the corresponding effect on one's life plans, the use of genetic information in insurance decision-making is a direct attack on the social bases of self-respect and thereby precludes the affected persons from being full and cooperating members of society over a complete lifetime.

Rawls hints at the relationship between self-respect and the acknowledgment of persons as free and equal citizens in the following passage:

A second reason political society is a good for citizens is that it secures for them the good of justice and the social bases of their mutual self-respect. Thus, in securing the equal basic rights and liberties, fair equality of opportunity, and the like, political society guarantees the essentials of persons' public recognition as free and equal citizens. In securing these things political society secures their fundamental needs. (1996, 203)

Persons who have self-respect will rationally wish to live only in a society in which they are treated as free and equal citizens. Supporting a policy which allows insurance companies to use genetic information to determine health insurance eligibility and premiums sacrifices fair equality of opportunity, contradicts the public recognition of persons as equal citizens, and

undermines self-respect, and thereby is not allowable in a just society.

4. The Rawlsian "Control Principle" does not support using genetic information to determine health insurance premiums and eligibility.

The Rawlsian Control Principle states that in a just society, principles determining or affecting the distribution of primary goods should not be based upon factors that are not within citizens' control. This principle is implicit in Rawls' theory, and it must be qualified. Rawls' clearest discussion bearing on the Control Principle occurs when he discusses how differential natural assets are handled on his theory of justice as fairness. Rawls echoes the theme discussed earlier that as long as a person has the minimum degree of abilities necessary to be a full and cooperating member of society, then she or he receives political equality. He directly criticizes conceptions of equality on which "...the strength of men's claims is directly influenced by the distribution of natural abilities, and therefore by contingencies that are arbitrary from the moral point of view." (1971, 510-511) Rawls also draws out another implication of the Control Principle in the following passage concerning natural assets:

A greater capacity for a sense of justice, as shown say in a greater skill and facility in applying the principles of justice and in marshaling arguments in particular cases, is a natural asset like any other ability. The special advantages a person receives for its exercise are to be governed by the Difference principle. (1971, 506-507)

Rawls clearly disdains views of political equality on which persons may reap the full benefits of their natural abilities without any questions of fairness arising. These persons have not done anything to allow them the full benefits which result from the exercise of these capacities. A corollary to this principle suggests that for Rawls, questions of fairness would arise if persons who were disadvantaged with regard to natural abilities were economically penalized. The reason for this is that the factors which are used to determine the economic disadvantages are not in their control; they have done nothing to deserve these penalties. I suggest that one's genetic makeup is a plausible example of a natural asset in the sense in which Rawls uses this

term. It is the ultimate inherent or natural talent of the body, and on a Rawlsian theory of justice, the benefits which accrue to individuals with fortunate genetic prospects would be distributed through the basic structure of society in accordance with the difference principle. Redistributing these benefits would allow individuals with less fortunate genetic prospects to avoid the economic penalties arising from higher insurance premiums.

Exactly what would a Rawlsian policy on genetic information and health insurance look like? It would be a moderate position, somewhere between the extremes of requiring full disclosure and no disclosure of information from genetic testing to health insurers. The task of locating the Rawlsian position will complete the positive project of this paper.

One moderate position worth examining is proposed by Philip Kitcher. (1996, 138-39) He is aware of the potential problems caused by adverse selection, and to avoid unfairness to insurance companies while also protecting consumers, he advocates a "two-tiered" approach to health insurance. At the first tier, genetic information is considered irrelevant for determining eligibility or rates for health insurance. At this tier, only the basic level of health coverage that is needed by all persons to pursue their life projects is offered. At the second tier, supplemental coverage is available, but Kitcher thinks it is reasonable to permit the use of genetic information for eligibility and rate determinations at this level. Such supplemental coverage may, for instance, cover experimental or expensive medical procedures. Precisely where the levels will be set for "first tier" and "second tier" coverage are dependent upon medical technology and the society's resources.

Kitcher's position is plausible, and it clearly avoids the problems associated with adverse selection. While Rawlsians also adopt a moderate position, such a two-tiered approach is likely unacceptable from this perspective. Kitcher's two-tiered position fares better than either of the

extremes, but it falters since only allowing those who are genetically fortunate to afford treatment "above" the minimum is a violation of the difference principle. As I interpret the difference principle, the least well-off members of society must be put in the best possible position, relative to all other possible distributions. The least well-off group is an indexical concept; in every distribution, there must be some group that is least well-off (even if that group is not doing badly in absolute terms). The difference principle clearly allows for differences to exist in the amount of primary goods (such as income and wealth) possessed by different groups, but it is doubtful whether it would endorse a two-tiered approach to health insurance.

Let us assume that at the first tier, insurance eligibility and premiums are unaffected by one's genetic makeup. At the second tier, then, those who are genetically unfortunate will have to pay higher premiums, or will not be able to afford the higher level of coverage at all. Yet, those who are less likely to suffer from serious genetic diseases (diseases which would require the more expensive procedures covered under the second tier health insurance) have already benefited from their favorable natural inheritance. To charge those with worse genetic prospects more for second-tier insurance is an instance of double-jeopardy, and is unfair in a society founded upon a political conception of justice as fairness. In a just society, the desire for low insurance premiums does not trump the principles which determine or affect a fair distribution of primary goods. This is especially true when the distribution of the primary good is affected by accidents of natural endowment, and hence is out of persons' control, as is the case with one's genetic makeup. These points, which stem directly from the Rawlsian position I have been developing, suggest that the objection that less fortunate policyholders unjustly "tax" policyholders with more favorable genetic prospects fails.

The difference principle implies that the economic benefits which accrue to those with

better genetic prospects on a two-tiered approach should be redirected to those with less favorable genetic prospects. This then becomes a one-tier model, and on this system, it may be true that those who are least well-off should pay less for health insurance than those who are healthier. To say this, however, is not to say that access to health care should be distributed so as to make those who are worse off in terms of health as well off as they could be with respect to health, since Rawls' difference principle is applied to an *index* of primary goods, and health is only one primary good among others.⁹

While the Rawlsian position would not be a two-tiered approach, it addresses the possibility of adverse selection by allowing genetic information to be disclosed to insurers only when an individual has knowledge of a significant genetic risk factor, say, by being given this information from a counselor after having a genetic test performed. While my approach allows the disclosure of genetic information in these circumstances, I have not yet discussed what may properly be done with this information by insurers. At the present time, I do not believe that the possibility of adverse selection justifies either increased insurance premiums or denial of coverage based upon genetic test results. Currently, since the predictive power of genetic testing is very small, the possibility of individuals using this information to successfully engage in adverse selection is also very small. Given the limited predictive power of such testing, in almost all cases individuals simply do not know if they will actually contract disease. Since this is the case, by adjusting their insurance buying behavior, individuals cannot be certain that they will avoid greater economic costs. In our current state of relative ignorance regarding the relationship between possession of genes and actually contracting disease, the amount of harm that consumers who attempt to engage in adverse selection can do to insurers is severely limited. The Rawlsian approach employed in this paper takes this contingency into account, but also

recognizes that as the predictive power of genetic testing increases, so will the possibility of successful adverse selection.

In present circumstances, genetic tests showing existence of a "suspect" gene could justify at most a cap on the amount of health insurance coverage for which an individual is eligible. This would be justified currently only for diseases such as Huntington's chorea or ALS, since the gene-disease connection has been positively identified--if one has the relevant mutated gene, one will get the disease (assuming one lives long enough). Even in these cases, I do not accept that in present circumstances such genetic tests can be used to deny coverage or increase premiums, since genetic tests with such predictive power are available only for a handful of diseases and it is unfair to single out those persons who happen to be affected by one of the few diseases for which we can conduct such a test. It is possible to stop short of embracing this conclusion since imposing a cap on the amount of health insurance coverage for which one is eligible in such rare cases effectively addresses the possibility of adverse selection.¹⁰

In addition to acknowledging reasons stemming from the current limited predictive power of genetic testing, it is unclear in general why the possibility of adverse selection should compel us to conclude that denying coverage or increasing premiums based on genetic testing is justified. The reason for this is that if adverse selection does occur, it would set in motion a cycle that hurts consumers worse than insurance companies. While it is the case that adverse selection may cause a short-run drain on profits, insurance companies will raise rates to cover the greater expenses that result from those persons who buy more insurance on the basis of their unfortunate genetic prospects. With the higher prices, those who remain ignorant of their genetic makeup or those who know that they possess more fortunate genetic prospects will decrease their level of insurance coverage, and the percentage of those buying insurance on the basis of unfortunate

genetic prospects will increase. Prices will have to increase further and so forth until nobody who is rational will buy insurance except those who know they are likely to actually become ill. At the end of the process insurance companies will indeed be hurt, but the really serious consequences will be for all those consumers who become uninsured as part of this cycle.

My approach allows limited disclosure of genetic information to insurers since if this information is revealed to an individual and kept private, there is no way to ensure that it is not exploited when and if the possibility of successful adverse selection becomes a reality. This knowledge itself puts policyholders at an unfair bargaining advantage, even if the information is not in fact ever used to influence insurance purchasing behavior. For this reason, it is acceptable in a just society to disclose this genetic information to health insurers only in these circumstances.¹¹

Looking past the current situation into the future, the argument of this paper points towards a universal or socialized system of health care. The restrictions on using genetic information for which I have argued are justified because Rawlsianism can powerfully express the notion that health insurance is a public good. As we learn more and more about the complex relationship between genetics and disease, the ignorance upon which an insurance-based system of health care rests will continually decrease. This will eliminate insurance pools as we know them, even given that there will always be accidents and environmental factors which lead to a need for unanticipated medical care. We will then face a dilemma. If we attempt to prevent insurers from utilizing this predictive genetic information in any way, individuals will still have access to such information, and by adjusting their insurance purchasing behavior they will drive many insurers out of business. This will initiate a movement away from a private insurance-based system. Or, if we allow a free exchange of genetic information which possesses significant

predictive power, there will be little risk to spread among persons. On this alternative, the private sector will become too expensive for many persons, spurring the government to step in and create a public health care system. As the predictive power of genetic information increases, a movement towards a socialized system seems inevitable.

VI. Objections and Replies

One could object that given the argument in this paper, it also follows that health insurers cannot use family history to determine eligibility and premiums, and this is an absurd implication. There are two things to consider in response to this objection. First, does this implication follow? Second, if so, is this implication absurd?

To address the first question, we must get clear on the similarities and differences between using the results of genetic testing on DNA and RNA (i.e. genetic information) and family history. Both are probabilistic devices for risk assessment, and both refer to factors that are for the most part out of the insured person's control. Both of these similarities are compelling, and both are important for the sake of my argument. Therefore, I am willing to grant that my argument implies that the use of family history is prohibited in a fair process of insurance decision-making.

Is this implication absurd? It may seem absurd since it is now common practice to use family history in the underwriting process. However, in this paper we are engaged in a normative enterprise which can question familiar practices; for instance, as discussed above, the common use of LDL cholesterol levels in insurance decisions is not necessarily above moral scrutiny. Assuming that the argument concerning genetic information based upon the Control Principle is compelling, the implication regarding the use of family history is easy to accept. Family history is a factor out of the range of control of the individual, just as one's own genetic prospects are. In fact, the usage of family history is even more unfair than incorporating the results of genetic

testing on the insured person, since using family history is like utilizing a secondhand report on one's genes. It is analogous to using circumstantial evidence, while genetic testing is analogous to using an eyewitness report. While genetic testing of individuals is a more accurate predictor than family history, as I have argued, utilizing the results of genetic testing is not acceptable in a just society. Given the fact that many genetic risk factors for disease are transmitted from parent to child via recessive genes, family history is an even more unreliable indicator of the risk of actual illness, and utilizing it results in unfair decisions regarding health insurance eligibility and premiums.

I stated above that I wish to remain neutral on the question of assigning the economic consequences of the policy proposed in this paper, due to the general difficulty of applying a Rawlsian theory of justice to a non-Rawlsian society (and the more specific question of whether insurance would be a private or public enterprise in a Rawlsian society). However, the position defended in this paper, especially given the remarks immediately above prohibiting the use of family history, could still inspire the objection that it puts unjust restrictions on insurance companies which would damage and perhaps even destroy them. If family history and genetic testing cannot be used, then what *can* be used to determine eligibility and premiums? If insurance companies must charge everyone the same premiums, without being able to use actuarial methods to properly price risk, one could object that this is unfair to insurance companies.

On my view, it need not be the case that insurance companies charge every person the same premiums in a just society. According to the argument contained in this paper, they could modify premiums on the basis of factors that are within a person's control. These factors include engaging in risky behaviors, such as (e.g.) knowingly undergoing exposure to hazardous

chemicals in the workplace. Further, as discussed above, in very limited instances insurers can put a cap on the amount of health insurance for which one is eligible based on the results of certain genetic tests, if these results are known to individuals. These points rebut the objection that my position establishes unfair restrictions which will destroy insurance markets.

One may object that my approach is unacceptable since allowing (at most) a cap on the amount of health insurance for which one is eligible still emanates from factors that are out of one's control, and will discourage persons from undertaking genetic testing. It is important to see that this proposal only applies to genetic tests which positively identify a gene-disease connection (such as those for ALS), tests which possess more predictive power than the overwhelming majority of current genetic tests. In response to this objection, I will make two points. First, on my approach, the proximate cause of this outcome does not arise from factors outside of insured persons' control. While it is true that the inherited genetic factors are out of persons' control, my approach respects the Control Principle by instead making such outcomes depend upon one's choice to undergo genetic testing. The choice to gain knowledge of one's genetic makeup is a choice within one's control. This implies that individuals possess a "right not to know" their genetic inheritance; even though some find this controversial, a plausible case can be made in defense of this right. (*c.f.* Tukala 1999) The scope of this right should be properly limited. If one would cause serious, avoidable harm to another person by exercising this right, then this decision can be morally wrong. Second, the choice to get genetic testing can be rational on my approach, and therefore it is unclear that this will unduly discourage genetic testing. If a person does possess a gene associated with an increased risk of contracting a serious illness, by being genetically tested the person gains knowledge which could help him or her get earlier treatment than those who remain untested and wait for symptoms to appear. As I see it, the

choice to gain such knowledge inevitably involves tradeoffs and has costs, and if one exercises one's "right to know," with the exercise of this right comes responsibilities. Striking this balance is essential if my approach truly aims to protect the interests of all parties involved.

VII. Conclusion

The project in this paper has been to philosophically ground the unfairness of utilizing genetic information in health insurance decision-making. As I have discussed, a Rawlsian theory seems to imply that a universal, socialized system of health care is necessary as a matter of justice. However, my undertaking has been to philosophically analyze our current private system, since the move towards a socialized system is not likely for the foreseeable future in the present political climate in the United States. This project is not trivial since perhaps adopting the thesis of this paper will pave the way for more significant, step-by-step changes in the future; attempts at radical change in the health care system have failed in the recent past. The conclusions of this paper may appear relatively modest, yet this fits with the goal of establishing a firm footing with respect to issues of justice and genetics. This paper stresses that restricting the usage of genetic information by health insurers does not necessarily imply that such insurers will be disproportionately burdened. If the case for grounding the unfairness of utilizing genetic information is successful, then we can address how to institute a public policy in a manner that is fair to all parties involved. The task undertaken in this paper is crucial since philosophically establishing the unfairness of using genetic information is a necessary first step for any public policy concerning genetics, health insurance and the health care system.

This paper also makes a contribution in terms of its methodology by emphasizing that *how* a policy is instituted is an important consideration apart from a prediction of the likely harms stemming from the policy. I have utilized Rawls' theory since it appeals to deeply seated

intuitions regarding fairness. Justice as fairness is a forceful philosophical theory, and therefore the position I have developed regarding genetic information and health insurance gains additional plausibility from its theoretical foundations. I have argued for a moderate position on the disclosure of genetic information to health insurers. Disclosure may occur only in cases in which a person has specific knowledge of a genetic condition as a result of genetic testing that he or she could exploit to his or her own advantage. Presently, it is unjust for insurers to use genetic information to deny coverage or to increase premiums on the basis of genetic testing. This conclusion is plausible given a proper understanding of adequate health as a natural primary good, health insurance as a necessary means for safeguarding self-respect and the implementation of persons' rational plans of life, and the lack of control that persons have over their genetic prospects.¹²

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Notes

¹ The 1995 revision to the Americans with Disabilities Act clarifies that genetic discrimination in employment is also prohibited under this act. (Smith, et. al. 1999, 69) However, this clarification does not specifically address the use of genetic information for decision-making regarding health insurance.

² For a helpful and probing discussion of this topic, see Sober (2000).

³ I focus solely on health insurance in this paper, since life and disability insurance can be seen as optional as compared to health insurance. The arguments of this paper apply only to health insurance, and would have to be modified *mutatis mutandis* for other forms of insurance.

⁴ I will return to develop this point below by adding that since genetic risks are not in one's control, it is in fact unfair to economically penalize persons for such risks. This additional point distinguishes this case from the (justifiable) case of modifying automobile insurance premiums on the basis of one's past driving record.

⁵ Part of the difficulty of answering this question may stem from the troublesome nature of drawing a distinction between the public and the private within Rawls' theory. For one interpretation of how this distinction itself may lead to difficulties within Rawlsianism, see my Card 2001

⁶ Rawls replaces this phrase with 'a fully adequate system' in later work. See his discussion of the reason for this change in Rawls 1996, 331-334.

⁷ For explanation of the just savings principle, see Rawls 1971, 284-293.

⁸ Certainly, there are other means whereby those who are affluent could circumvent the system and secure better health care for themselves (say, by getting additional expert medical opinions in cases of serious illness). This is probably unavoidable in any social political theory which allows differences in resources to exist among citizens, yet as long as these practices are not part of the institutional structure itself, they do not threaten the political conception of justice.

⁹ While I have argued that the two-tier model would not likely be acceptable on a

Rawlsian theory, this depends upon answers to difficult empirical questions. For instance, would the spill-overs from permitting inequalities in the upper-tier health provision result in better health care for those who are worse off than the alternatives available in other possible distributions? If so, then the two-tier system could be acceptable. However, this system would then hardly differ in its effects on the least well-off, if all spill-overs from the upper-tier were redirected downward.

¹⁰ One could object that putting (at most) a cap on the amount of eligible health insurance coverage is not different from the "two-tier" approach I rejected above. However, this is not true. Utilizing the cap does not economically penalize affected persons in the way that the two-tier approach does. The cap is meant simply to be a stopgap measure to be used in current circumstances only in rare cases such those involving Huntington's disease. By contrast, Kitcher (1996) does not limit his proposal to only to those few diseases for which we have positively identified the gene-disease connection. The two-tier approach would economically penalize persons if they simply possess a greater than average probability of getting a genetic disease. I allow the use of caps in such rare instances since this is the least invasive means necessary for safeguarding the interests of both consumers and insurers.

¹¹ What about cases in which persons have favorable genetic test results; should they receive lower insurance premiums? Given the very limited predictive power of current genetic tests, this implies only that the person does not possess a greater than average chance of contracting the disease in question. In my view, this is not a sufficient reason to claim that this person deserves reduced insurance premiums, since these results are out of this person's control. What if this person has a family history of genetic disease X for which current genetic testing can positively identify the gene-disease connection, and through testing is found to have not inherited the relevant gene? Does he or she then deserve lower insurance premiums? I would argue that premiums should not be adjusted on this basis regardless of the outcome of the genetic test and would question the fairness of the presumption that family history can be used to determine insurance premiums. (See section VI.)

¹² A version of this paper was presented at the World Congress of Philosophy of Medicine, Jagellonian University, Krakow, Poland, and the Midsouth Philosophy Conference, University of Memphis, Memphis, TN. I wish to thank audiences at these sessions for helpful questions and remarks.