GENETICS AND INSURANCE: A QUESTION OF JUSTICE

by

Judy Vivacqua

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This thesis examines whether the results of genetic testing should be used by life, disability, and additional health insurance companies to determine risk. The ethical issues relevant in a Canadian context are dealt with. Insurers argue that they risk significant loss as a result of possible adverse selection by consumers. This thesis argues that genetic testing exacerbates ethical problems already present in risk- and experience-rated systems of insurance. A model of insurance is defended which balances liberal, free-market ideals with communitarian ideals. Types of insurance that can be considered basic goods are distinguished from those which are actually non-necessary goods.

In this thesis a constructive ethic is developed to help deal with this issue. Principles on which to model the insurance industry are proposed. The thesis argues that private insurers should be prohibited from using both traditional medical information and genetic information for underwriting unless that information seems to indicate inevitable future disease. Should the adjusted premium become unaffordable (as with early-onset inevitable disease), a subsidized government program should cover such basic insurance.
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INTRODUCTION

The topic of this thesis is the use of genetic testing results to determine risk by life, disability, and additional health insurance companies. These tests are capable of providing carrier and presymptomatic information including risk of future disease, disability, and future death (Lapman, Kozma, and Weiss 621). In particular, this thesis will explore the claim made by some insurance companies that as genetic testing becomes more common, insurers risk significant financial loss as a result of possible adverse selection by consumers. Does this claim justify sacrificing the confidentiality of genetic test results, so that they can be used by insurers to adjust rates or reject insurance applicants? This thesis will argue that genetic testing does not represent an entirely new problem for the insurance industry, but only exacerbates ethical problems already present in risk- and experience-rated systems of health, disability, and life insurance.

It will be demonstrated that with respect to medical information, such as family history or genetic predispositions, the concept of determining rates depending on the likelihood of making a claim is often morally unsound. It will be necessary to distinguish between tests that can only indicate a increased probability of developing a disease (such as the case of multifactorial disorders such as breast cancer), from genetic disorders that inevitably lead to disease (such as some monogenic diseases such as Huntington’s). This thesis will argue that in the former case it is not appropriate to use such genetic information to increase one’s insurance premium, while in the latter case there is justification to take such information into account when setting premiums. A liberal, free-market model of insurance will be contrasted with a communitarian understanding of
insurance in order to argue for an insurance model that better balances communitarian and free-market ideals.

It will also be necessary to distinguish between types of insurance that could be considered basic goods (those that affect individuals at a more basic level, such as dental and pharmaceutical insurance, or those that are linked to mortgages), and types of insurance that are actually non-necessary goods (such as life insurance contracts worth more than $100,000 that are not linked to mortgages). The type of insurance being dealt with is important because it is more appropriate to base non-necessary insurance on a free-market model, while making sure all have access to basic forms of insurance.

The topic of this thesis has become more important as a result of the knowledge obtained from the Human Genome Project (HGP). The HGP is a fifteen-year, three billion dollar project to identify and map every gene in the human genome (Barrad 1042). The mapping of the human genome will allow a wide range of genetic material to be available for testing and diagnostic labelling (Tancredi 47). Already more than 1,400 genes have been mapped to specific chromosomes. For instance, many single-gene disorders such as Huntington's disease and cystic fibrosis have been identified. But up until now few cures have been developed for the genetic disorders identified (Lemmens and Bahamin 144).

This thesis will review the literature on the issue of insurance and genetics in order to develop a constructive ethic that will help ethicists to deal with this issue. In particular, principles on which to model the insurance industry will be developed. This will require a critical analysis of the varying underlying views of justice that influence the debates over the use of genetic information by the insurance industry. Except for public
health insurance for basic medical services, the current insurance industry is concerned
mainly with commutative justice, functioning on the basis of liberal free-market values
such as freedom and autonomy. Libertarians argue for a ‘minimal state’ which claims a
monopoly on the legitimate use of force in its jurisdiction, but does not have any
redistributive functions (Lebacqz 54). This study will contrast this conception of justice
with a communitarian conception of justice which claims that the good of the individual
is to be found in his or her relationships with others (Badhwar 3). A shared
understanding of the common good is the primary bond between the members of a
society (Badhwar 4). Moral norms are defined with respect to these goods.

The purpose of this thesis is not to determine the value of these theories of justice
for all areas of social life, but to look at how insurance is understood within each of these
two conceptions of justice. It will be important to determine which theory of justice is
dominant in Canada. Most of the literature that discusses insurance and genetic
information tries to find a solution to the problem without questioning the underlying
conceptions of justice on which insurance policies are based. Furthermore, the ways in
which a communitarian ethic is consonant with a Christian ethic will also be discussed.

This study will be unique in several other ways. First, unlike most of the
literature available on this issue, it will deal with the ethical issues relevant in the
Canadian context, where universal public health insurance is provided for basic medical
services through the provinces. Yet private insurance is still necessary to cover the cost
of additional services, such as dental and pharmaceutical services. Life insurance and
disability insurance are also purchased through private insurance companies. Thus, while
in the U.S. basic health insurance is the main concern with respect to genetic testing, in
Canada it is these other types of insurance that could be affected by genetic testing.

Second, much of the literature on this issue tries to demonstrate how the results of genetic testing are somehow different from other medical information already being used by the insurance industry, such as family history. This thesis will argue that not only is it becoming increasingly difficult to differentiate between genetic information and other medical information, but even if clear categories did exist, there are often no morally relevant differences between genetic disorders and non-genetic disorders.

While the thesis will outline how the issue of genetic information and insurance is dealt with in Canadian law, it will not base its main arguments on technical legal issues, since this type of argumentation would fail to uncover some of the fundamental assumptions regarding the conception of justice currently operative in the insurance industry. Similarly, while the problem of confidentiality (for our purposes used interchangeably with 'privacy’) will be dealt with in this thesis, the common strategy of simply trying to prove that genetic information is ‘confidential’ in order to prevent insurance companies from having access to it will be avoided. This so-called solution only begs many of the questions this thesis deals with. Since privacy is actually more of a secondary principle serving utilitarian concerns, we must try to determine what confidentiality laws are meant to achieve and then explore other means of achieving these ends that might be more useful in an age where computer databases make confidentiality difficult to maintain (McGleenan 44). Furthermore, while there will be some discussion that deals with the issue of ‘rights’, for the most part the language of rights will be avoided. Simply recognizing something as a right often fails to determine why people value it as a right, or what should be done when rights are in conflict (Glover 105).
There is evidence that the issue of insurance and genetics is becoming increasingly important in Canada. A recent survey of Canadian geneticists reported fifteen cases of people with asymptomatic predisposition and four cases of people with carrier status being denied life insurance (Lemmens and Bahamin 124). In 1995 several Canadian hospitals indicated that they would provide genetic tests for breast and colon cancer for individuals with a family history of cancer. In response, one insurance representative informed Radio Canada (a multilingual international service established by the government and the CBC) that the insurance industry would request the results of tests from insurance applicants. Moreover, he did not rule out the possibility that genetic testing would be carried out by the insurance industry once such testing became cheaper.

Although there is no evidence that insurers are demanding that applicants undergo genetic tests, progress in the speed, cost, and accuracy of genetic tests could lead to the use of these tests as part of standard procedure (Anderson 1507). Furthermore, this issue is particularly important because the use of the results of genetic testing by insurers may limit the possible benefits of genetic research if people become unwilling to participate in genetic research for fear of insurance discrimination (Hudson et al 391). Similarly, if individuals do not inform their physicians of genetic testing results, their physician cannot advise them with respect to the available preventative measures, and as a result their health care may be compromised.

In their article “Genetics in Life, Disability and Additional Health Insurance in Canada”, Trudo Lemmens and Poupak Bahamin point out that since insurance involves ascribing a monetary value to risk, and genetics has been concerned almost exclusively so far with predicting risk, both seem to be made for each other (Lemmens and Bahamin
124). Yet since at this point in our knowledge of genetics we are in a Rawlsian ‘original position of ignorance’, this is a good time to make decisions regarding the use of genetic information by the insurance industry (Lemmens and Bahamin 179). Since most people are still unaware of their own genetic conditions, it would be easier to reach an agreement on the issue.

This thesis will be divided into three main chapters. The first chapter will describe the nature of the problem. This chapter will begin by outlining the basic scientific information necessary to understand the study of genetics. For example, terms such as ‘genetic marker’ and ‘chromosome’ will be defined. Moreover, the ethically relevant characteristics of genetic information, such as uncertainty, will also be discussed. The first chapter of the thesis will also clarify how the insurance industry currently functions. Terms such as ‘adverse selection’ and ‘underwriting’ will be defined. This chapter will conclude with an outline of how Canadian law currently deals with the use of genetic information by insurance companies.

The second chapter, entitled ‘Revision’, will be a critique of the underlying assumptions currently being made with respect to the issue of genetics and insurance. The question of whether the information generated by genetic testing is different from other medical information will be dealt with in this chapter. A discussion of the usefulness of looking at the issue of genetics and insurance from the perspective of confidentiality will come next. This will be followed by a similar discussion that will consider whether it is helpful to think about insurance and genetics using the language of rights. This chapter will also include some analysis of the understanding of justice that currently dominates the insurance industry. At this point there will be some discussion of
principles such as 'actuarial fairness'. It will also be necessary to present a brief summary of the main concepts in the liberal, free-market understanding of justice. The second chapter will conclude by determining whether it is appropriate for such a free-market understanding of justice to dominate the insurance industry in contemporary Canadian society.

The third chapter of this thesis will deal with the problem of insurance and genetics by rebalancing the communitarian and free-market ideals operative in the insurance industry. First it will be necessary to outline the social purpose of insurance. Next, a liberal, free-market understanding of justice will be compared to a communitarian understanding, which shares many of the same values as Christian ethical traditions. At this point, it will be possible to determine how the liberal, free-market model of justice can be balanced with the communitarian model within the context of insurance. In particular, some criteria, or principles, that would help create a balanced insurance industry will be proposed as an alternative ethic for the use of traditional medical and genetic information by the insurance industry. After this third chapter, the main points of the thesis will be summarized to conclude the thesis.
Chapter One
NATURE OF THE PROBLEM

1. THE SCIENCE OF GENETICS

Although most people today are aware that our genes are responsible for the passing on of hereditary traits, most of us lack detailed knowledge regarding human genetics. Trudo Lemmens and Poupak Bahamin provide a good introduction to human genetics in their article, yet it is necessary to provide some basic information about the science of genetics in this thesis because its main argument requires that the reader develop an understanding of the complexities and uncertainties involved in the study of genetics.

To start at the beginning, then, almost all human cells, except red blood cells, contain genetic information about an individual (Privacy Commissioner 5). Each of these cells carry an identical set of an individual’s estimated 50,000 to 100,000 genes. The egg and sperm cells (germ cells), however, contain only the genes that the parents will contribute to their child. In the cells is the DNA (deoxyribonucleic acid), which is the basic bearer of genetic information in the body, and which is ordered into genes. DNA is a chemical substance which resembles a spiral ladder with two strands (Hartl and Jones 9). It is composed of four chemical constituents (nucleotides): adenine (A), cytosine (C), guanine (G), and thymine (T).

These ‘bases’ are generally paired so that A forms a base pair with T and C with G (the pairing between A-T and G-C is said to be complementary). The two elements which pair with each other are located on different strands (Hartl and Jones 10). The pairing of these bases provides the DNA with its ‘double helix’ structure, so that the bonds between bases can be thought of as rungs on the DNA spiral ladder (Privacy
A gene is actually a series of base pairs found in a specific section of DNA. Hence, it is simply a section of the spiral ladder. Some genes carry relatively few base pairs (rungs)—for instance, only a few thousand—while others carry more than one million base pairs. It is currently estimated that there exist about 3.3 billion base pairs which together make up the human genome.

Genes are organized into larger units called chromosomes, so that every gene is located on a chromosome. The nucleus of each cell contains 46 chromosomes: 23 from the father and 23 from the mother. Two types of chromosomes exist. Autosomal chromosomes ( autosomes) are the 22 pairs of non-sex chromosomes (Hartl and Jones 97). The 23rd chromosome pair, called the sex chromosome, determines the sex of an individual. Women ordinarily have two ‘X’ chromosomes, while men normally have one ‘X’ chromosome and one ‘Y’ chromosome. Since there are two copies of every chromosome (one from each parent), there are also two forms of every gene. These forms are referred to as alleles (Hartl and Jones 40). Individuals who have two different alleles are heterozygous for that gene, while individuals with two identical alleles are homozygous for it. Dominant disorders are those that are expressed when an individual is heterozygous for that gene (only one parent transferred a disordered gene) (Hartl and Jones 803). Recessive disorders are those that are expressed when one is homozygous for that gene (both parents transferred a disordered gene) (Hartl and Jones 818).

The Science Council of Canada maintains that genes are probably implicated in most diseases (Privacy Commissioner 8). In 1991 the Council reported that so far nearly 5,000 genetic disorders and traits with classic inheritance patterns had been identified. Of these, about 3,600 are disorders caused by a single gene (monogenic disorders).
Cystic fibrosis is an example of a monogenic disorder. Yet since genes interact with each other, most diseases cannot be explained by one gene alone (Hartl and Jones 670). Multifactorial disorders are caused both by environmental factors and from the effects of multiple abnormal genes (Hartl and Jones 812). Coronary heart disease, diabetes mellitus, and epilepsy are examples of multifactorial disorders (Privacy Commissioner 9). The Medical Research Council of Canada suggests that at least ten percent of individuals are affected by multifactorial disorders. Lemmens and Bahamin report that “[T]he more scientists begin to understand genetics, the more they are astonished by the complexity of genetic phenomena. New discoveries are already challenging the simplicity of traditional genetics” (Lemmens and Bahamin 129).

Chromosomal disorders occur if the number or structure of an individual’s chromosomes is abnormal (Hartl and Jones 260). Non-inherited disorders are caused by changes in genes that were normal at birth yet experienced a change in DNA that caused disorder. For instance, changes may occur if genes are damaged or if environmental factors such as radiation, chemicals or viruses modify the genetic structure of cells (this is the case with some cancers or AIDS).

A gene probe is a technique for genetic testing that looks for the specific gene which causes a genetic disorder (Privacy Commissioner 10). The sequence of base pairs of the gene that causes the disease must be known in order to develop a gene probe. Such probes are currently used to identify disorders such as cystic fibrosis and Duchenne muscular dystrophy. Another technique for genetic testing involves genetic markers, which help locate genes which cause disorders if there is no known gene probe for the disorder. In other words, genetic markers are used when the particular sequence of base
pairs associated with the disorder is unknown. These markers are genes or stretches of DNA which may not themselves cause a genetic disorder, yet are known to be close to the gene that is responsible for the disorder. An example of a genetic marker that is already known is that for Huntington's disease. Since genetic markers may appear in different forms in different individuals, genetic markers are generally less helpful for indicating the presence of a given genetic trait than gene probes.

2. UNCERTAINTY

One of the problems complicating the prediction of genetic disorders is 'variable expressivity'. This term refers to the fact that genetic disorders show varying degrees of severity, so that a genetic disorder may cause one person to become very sick, yet it leaves another only mildly affected (Hartl and Jones 71). Genetic tests are rarely able to determine the severity of expression. In addition, genetic disorders can also vary with respect to age of onset. Furthermore, incomplete penetrance in some individuals who are homozygous or heterozygous for a trait will result in those individuals never developing that particular disorder. Although it is not clear why this happens, environmental factors, lifestyle, or the intervention of other genes may be involved.

Another problem in predicting genetic disease is that more than one change in DNA can lead to the same genetic disorder (Lemmens and Bahamin 134). In particular, genetic heterogeneity refers to the phenomenon whereby a single disorder is associated with several genes and chromosomal locations. Allelic heterogeneity means that various mutations in the same gene can cause the disease. For instance, although a diagnostic test for cystic fibrosis seemed very promising, it became obvious soon after the gene was
detected in 1990 that cystic fibrosis is caused by many DNA changes and that the frequency of variation differs in different populations. Breast cancer also involves a limited form of heterogeneity (Lemmens and Bahamin 135). Because some individuals are affected by mutations in one chromosomal region, and others by mutations in another area, a test that searches for only one of these mutations might suggest inaccurately that someone is unlikely to develop the disease.

Further uncertainty results from the fact that although some genetic disorders almost always affect individuals, others only imply an increased chance of developing disease. Among these ‘susceptibilities’ are monogenetic disorders and multifactorial diseases with varying risk factors. Some diseases are curable or can be controlled, and others can possibly be avoided with suitable diets or lifestyles. Yet other disorders are incurable and unavoidable. Moreover, the common name for a disease may in fact refer to various different types. For instance, some breast cancers originate from a single gene, while others are multifactorial disorders. Even when a gene has been linked to a particular disorder, it often only accounts for a minority of the cases. Furthermore, the predictive value of available tests varies broadly.

All of these factors illustrate that uncertainty is an important ethically relevant attribute of genetic information. Not only do tests often only indicate statistical risks, but it may be unjust to deny coverage or increase premiums because of the existence of a positive genetic test result when most individuals affected by the disease are not detected by the test. In addition, whether a test is developed for a particular disorder is influenced by factors such as the availability of funding for that disease, the interests of researchers, pressure from social groups, and political motivations. The various factors described
above regarding uncertainty may change in the future as the understanding of human genetics increases. For instance, the predictive value of the available tests may drastically improve. Yet this thesis will argue that the level of uncertainty in genetics is not ultimately the crucial issue, since legislation regarding genetics and insurance must go beyond the science of genetics to consider how insurance involves issues of social justice.

It is important to note the difference between genetic testing and genetic screening. Genetic testing refers to identifying disease or the potential for disease in an individual patient (Burris and Gostin 139). Screening, on the other hand, refers to the systematic application of testing to a defined population. The purpose of screening is to determine the incidence in a population, and, if possible, to make interventions to reduce the overall burden of the disease (such as lung cancer) through behavioural or environmental changes. Now that the basic concepts in the study of genetics have been clarified, we can move on to explain how the insurance industry functions.

3. HOW THE INSURANCE INDUSTRY CURRENTLY FUNCTIONS

The purpose of insurance is to create controlled uncertainty. Insurance involves applicants agreeing to pay premiums (specific amounts of money) at regular intervals to insurers, who in turn promise to pay out particular amounts of compensation in the case of specified events (Lemmens and Bahamin 152). The basic life insurance policy, for instance, involves the payment of a benefit upon the death of the life insured (Lemmens and Bahamin 155). Life insurance contracts often contain a clause providing for income in the case of disablement. Disability insurance includes an agreement to waive the
payment of premiums in case the applicant becomes disabled. Disability might also be covered through ‘accident and sickness insurance’ contracts, whereby the insurer provides for payment in the case of accident or sickness. Payment can be a lump sum, a replacement of salary, or compensation for expenses. Additional private (health) insurance covers the cost of prescription drugs, dental, optometric, chiropractic, and physiotherapeutic services (Lemmens and Bahamin 156). Such insurance is likely to become more important if cuts are made to universal coverage.

Norman Daniels argues that an insurance market exists “[B]ecause prudent people are willing to face modest losses (premiums) on a regular basis rather than encounter catastrophic losses at unpredictable times. The modest losses are perceived as the cost of security” (Daniels, “Insurability” 501). Risk is an important factor, since both parties enter an insurance contract without knowing exactly how much they will contribute or benefit. But insurers use statistics to try to determine how much they will have to pay out to the total group of insurance applicants. Having a pool of insured people guarantees that insurers can pay substantial amounts when risks occur because they receive payments from more than one client (Lemmens and Bahamin 153). Since insurers must make a profit to stay in business, the contributions from clients must be greater than the amount paid in insurance claims.

Creating a pool to spread risk illustrates how insurance involves the idea of mutual support among individuals with common interests. Lemmens and Bahamin argue that “Whether consciously or not, those insured promote the idea that sharing costs and benefits within a larger community decreases the risk and promotes stability” (Lemmens and Bahamin 153). Yet the insurance contract today is not justified on the basis of social
support or compassion. Applicants contribute according to the level of risk they represent, which determines whether they are classified as standard, substandard, or denied (Kass 7). Those deemed substandard are offered a policy that comes with an exclusion waiver, a higher premium, or both. Some argue that if individuals had to pay premiums disproportionate with risk, they would have no interest in insurance. But this has not always been the case. For instance, health insurance in the United States moved from a system based on community rating, where each individual in a given community were charged the same rates, to a risk-or experienced-based system where individuals contribute according to expected claims (Murray, "Genetics" 12).

The first private health insurance plan in the U.S. was established in 1929 to cover hospital expenses for teachers in Texas (Kass 6). By the mid 1940s such Blue Cross hospital plans existed in 43 states. The first plans designed to reimburse for physician services, which came to be known as Blue Shield, were instituted in 1939. Up until 1986, these plans were both non-profit and tax exempt. Initially their premiums were community-rated, but commercial insurance companies emerged in the 1940s that competed for employer contracts by offering premiums based on the new concept of ‘experience rating’. Because those in the work force tend to be healthier than the general population, experience-rated premiums were lower than community-rated premiums. Eventually the non-profit companies were forced to change their own rating practices in order to compete in the insurance industry.

This change in the insurance industry has ethical implications. For example, community rating reflected the idea that a community was responsible for providing health care for its members. In such a system the qualifying principle was community
membership, so that factors such as preexisting risks were not considered morally relevant considerations. Risk- and experience-based systems assume, on the other hand, that predicted need for care is an ethically relevant consideration. The question of a morally relevant difference with respect to insurance will be investigated in depth later in the thesis when different conceptions of justice are explored. At this point it is sufficient to understand that insurers accept a particular concept of fairness: actuarial fairness.

Actuarial fairness refers to the claim that “[P]olicyholders with the same expected risk of loss should be treated equally... 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” (Murray, “Genetics” 14).

Another argument commonly made to justify the use genetic information for insurance is the need to avoid adverse selection. This refers to the claim that applicants who find out through genetic tests that they are at risk for a particular condition will be more likely to buy insurance, or will buy excessive amounts of insurance, to cover the costs of expected disease or death. Insurers would then be forced to increase premiums to cover increased costs, so that low risk individuals would eventually stop buying insurance. Individuals at high risk would continue to buy insurance, and insurers would eventually go bankrupt. Yet it is not clear to what extent adverse selection actually affects insurance premiums. Since it is difficult to investigate a situation that has either been prevented through underwriting or is happening secretly or unconsciously, there is little reliable and current information available on adverse selection (Lemmens and Bahamin 172).
4. CANADIAN INSURANCE LAW

Under current Canadian insurance law, insurers can ask applicants to take genetic tests before signing contracts or ask them to fill out questionnaires (Lemmens and Bahamin 116). Applicants are required to declare in good faith everything that could assist insurers in the assessment of risks. Insurers may also request access to their medical records. Access to confirm this information is almost unlimited in Canada. The information provided by applicants is often verified through the Medical Information Bureau (MIB), which keeps information in coded form. The MIB is a non-profit association of more than 700 insurance companies operating in the United States and Canada (Lemmens and Bahamin 167). It functions as a central bureau for medical-actuarial statistics for morbidity and mortality related studies, and exchanges medical information on behalf of its members.

As individuals apply for health, life, or disability insurance to its member companies, information is entered into the MIB database. The database allows insurers to make decisions regarding the insurability of applicants by determining whether the applicants have already applied to other insurers and, if so, into what risk classification they have been categorized. The MIB does not store entire medical records or insurance files, nor does it specify whether the applicant has been denied insurance by other companies. It registers names, birth dates, places of birth, and occupations, as well as medical information and other factors that could affect insurability in coded form (Lemmens and Bahamin 168). The MIB stores information about various genetic diseases and family diseases, but the genetic diseases are not explicitly identified. For
instance, Huntington’s disease is classified under the general category ‘a disorder of the nervous system’.

The MIB keeps its records for a maximum of seven years. Because it is most likely the case that several standards are used by the member companies in reaching conclusions regarding the health of applicants, the MIB maintains that the information it makes available should only be used as a warning for a member, who would substantiate an adverse underwriting decision using other sources. While it is not obvious that this policy can be enforced, MIB underwriting specialists regularly audit MIB members to ensure that regulations are being adhered to. If rules are not being followed, the member loses its privileges.

Although legislative authority with respect to insurance is divided between the federal and provincial governments, most aspects of insurance fall under provincial jurisdiction over property and civil rights, which are dealt with under section 92(13) of the BNA Act (Lemmens and Bahamin 188). Provincial and territorial governments have jurisdiction over the form and content of insurance policies, agent and broker licensing and conduct, as well as marketing and business practices, even for companies that are extraprovincial in scope. The federal government only has jurisdiction over bankruptcy and the winding-up aspects of insurance. During the 1920’s the common-law provinces collaborated to create uniform provisions for insurance legislation (*Uniform Insurance Act*), so that the laws of these provinces would be consistent (Lemmens and Bahamin 189). Although Quebec did not join the other provinces, the provisions of the *Civil Code of Quebec* (*C.c.Q*) are very similar to those of the *Uniform Insurance Act*. 
It is important to remember, however, that the provinces could introduce different legislation. If the provinces wanted to regulate the use of genetic information by insurance companies, cooperation between the provinces would be necessary to establish consistent requirements. Otherwise, insurance companies would be able to avoid stringent regulations in one province by making the law of another one applicable. For instance, businesses can do this by concluding the contract in another province. Furthermore, if Ontario, for example, permitted the use of genetic test results by insurance companies, but Manitoba did not allow this, insurance companies in Ontario could encourage individuals from Manitoba with favorable genetic testing results to sign contracts in Ontario, where they would be offered lower premiums. Since insurers in Manitoba would be unable to determine who the genetically ‘healthy’ were, they could not offer the same low premiums. Eventually, insurers in Manitoba would be dealing with a disproportionate number of applicants at high risk.

Both the *Uniform Insurance Act* and the *C.c.Q.* require that insurance applicants provide all information that is relevant to risk (Lemmens and Bahamin 190). In particular, with respect to life, accident, and sickness insurance, the *Uniform Insurance Act* states that applicants “[S]hall each disclose to the insurer in the application, on a medical examination, if any, and in any written statements or answers furnished as evidence of insurability, every fact within the person’s knowledge that is material to the insurance and is not so disclosed by the other” (Lemmens and Bahamin 190). Not only must applicants be honest in the positive information they provide, but they are also prohibited from concealing the truth by omitting information which is material to risk (Lemmens and Bahamin 191). The law also recognizes, however, that applicants must
provide information about their genetic make-up only if they themselves are aware of it (Lemmens and Bahamin 192). This provision could discourage individuals from undergoing genetic tests in order to remain uninformed of genetic disorders.

Both the *Uniform Insurance Act* and the *C.c.Q.* specify that either failing to disclose a material fact or misrepresenting one could be grounds to annul the contract even with respect to losses (i.e. death) not related to the risks misrepresented or concealed (Lemmens and Bahamin 195). Yet both the *Uniform Insurance Act* and the *C.c.Q.* stipulate that when a contract for life, accident, or sickness insurance has been in effect for two years, a failure to disclose or a misrepresentation of a material fact does not, except for fraud, render the contract voidable (Lemmens and Bahamin 196).

The *Canadian Charter of Rights and Freedoms*, the *Canadian Human Rights Act*, and the human rights legislation of all Canadian provinces prohibit discrimination in the provision of services customarily offered to the public (Lemmens and Bahamin 197). Yet underwriting in the insurance industry regularly uses personal information such as age, sex, and health status to determine whether to offer coverage and at what rate. This is permitted because most human rights statutes exempt the insurance industry from the application of some or all of their provisions (Lemmens and Bahamin 198). For instance, the *Ontario Human Rights Code* allows for insurers to use genetic information and discriminate against candidates if they can show that their decision is based on a sound and accepted insurance practice that allows insurers to charge premiums that are proportionate to risks (Lemmens and Bahamin 200). The insurer must prove the validity of the statistical and actuarial basis of their practice. Moreover, insurers must prove that they have no practical alternative other than to use genetic information in the
underwriting process. Similarly, while section 15 of the Canadian Charter prohibits "[D]iscrimination based on race, national or ethnic origin, colour, religion, sex age or mental or physical handicap", section 1 of the Charter allows for a Charter right to be overridden if there is an important objective served by doing so (Lemmens and Bahamin 215, 216).

Human rights legislation prohibits discrimination on several grounds, usually including 'handicap', 'disability', and 'physical characteristics', all of which can be connected to genetic disorders (Lemmens and Bahamin 201). It can be argued that insurance underwriting for genetic traits that are characteristic of particular ethnic or racial groups is a form of ethnic or racial discrimination, which is prohibited by human rights codes. An even more obvious link can be made between genetic disorders and 'disabilities' or 'handicaps' (usually used interchangeably in statutes and legal documents). The term disability is generally defined as "any degree of physical or mental disability, infirmity, malformation, or disfigurement that is caused by bodily disability, birth defect, or illness" (Lemmens and Bahamin 202). Examples given in these statutes include epilepsy, diabetes mellitus, and any degree of paralysis.

Courts have also decided that "[a] handicap should be construed to mean something which affects, or is perceived to affect, an individual in carrying out life's important functions" (Lemmens and Bahamin 202). Although this definition requires deciding what criteria we should use to determine whether an activity is an 'important function', it is clear that genetic disorders can hinder an individual in carrying out many of life's necessary functions. Even when this is not the case, genetic disorders can still be perceived to be disabilities in this sense. Even though the only Canadian human rights
legislation that recognizes perceived disability as a prohibited grounds for discrimination is the Ontario Human Rights Act, Canadian human rights tribunals have acknowledged on several occasions that perceived disability should be a prohibited grounds for discrimination (Lemmens and Bahamin 204). On the other hand, it could be seen as discriminatory for insurers to charge standard premiums to applicants with genetic predispositions while demanding higher premiums from applicants with non-genetic disabilities (Lemmens and Bahamin 208). Furthermore, even if a genetic disorder can actually be designated a disability, many legislators allow discrimination on the basis of a handicap if there exists “reasonable and bona fide grounds” to make a distinction (Lemmens and Bahamin 208).

Since it was noted above that various human rights statutes prohibit discrimination in the provision of services ‘customarily offered to the public’, it must also be determined whether insurance falls under this category. In the case of Insurance Corporation of British Columbia v. Heerspink, which dealt with property insurance, the Supreme Court decided that insurance contracts were services ordinarily available to the public (Lemmens and Bahamin 211). Yet two subsequent decisions (Vitcoe v. The Dominion Life Insurance Company, Nova Scotia Human Rights Commission v. Canada Life Assurance Co.) made a distinction between the different types of insurance contracts, arguing that some insurance contracts are not ‘services customarily available to the public’. These two cases dealt with salary replacement insurance and group mortgage life insurance, respectively. In any event, subsequent to the decisions in Heerspink and Vitcoe, the Human Rights Act of British Columbia was amended so that insurance contracts were exempted from the application of the provision for ‘services customarily
available to the public’, as is the case with other human rights statutes and the legislatures of various provinces (Lemmens and Bahamin 214, 215). Yet it is important to mention the two previous decisions since they made distinctions between different types of insurance contracts. In essence, they seemed to be arguing that some types of insurance are more necessary to participation in society than other types of insurance. The solution to the problem of insurance and genetics presented in this thesis will also make that assumption.
Chapter Two
REVISION

1. GENETIC INFORMATION VS. TRADITIONAL MEDICAL INFORMATION

One of the most important areas to be explored for the issue of genetic information and the insurance industry is the question of whether genetic information is different from other types of medical information that the insurance industry already uses. Some of the information already being used for risk classification includes age, sex, health history, physical condition, occupation, alcohol and tobacco consumption, serum cholesterol, and family history (Lemmens and Bahamin 160). Clearly much of the information already being used and the results of genetic testing can both be used to predict an individual’s likely medical future. Similarly, both often provide information regarding one’s parents, siblings, and children. These characteristics are most obvious in the case of family history. We are beginning to see that “[T]he very notion of what constitutes genetic information is influx [sic]” (Murray, “Ethics” 82D).

A good example to demonstrate this is cholesterol level. Although high density lipoprotein (HDL) and low density lipoprotein (LDL) can both be affected by diet, exercise and drugs, one’s cholesterol level is at least in part influenced by one’s genetic inheritance (Murray, “Genetics” 14). Variations in individual metabolism can also strongly influence one’s cholesterol level, so that two individuals with very similar diets and similar levels of physical activity can have very different cholesterol levels. Furthermore, one’s cholesterol level influences, but does not necessarily determine, his or her risk for coronary artery disease and hence, for heart attacks.

The problem of distinguishing genetic information from other medical information is further complicated by the fact that the insurance industry allows for pre-
existing conditions to be excluded from coverage (Lemmens and Bahamin 159). Hence, if a genetic predisposition can be defined in such a way that it is considered a ‘disease’, insurers could deny coverage by arguing that the genetic predisposition is a pre-existing condition (Glazier 46). The term ‘disease’ is defined by the *Dorland’s Illustrated Medical Dictionary* (27th ed.) as: “Any deviation from or interruption of the normal structure or function of any part, organ, or system...of the body that is manifested by a characteristic set of symptoms and signs and whose etiology, pathology, and prognosis may be known or unknown” (Annas, *Some* 103). Since a genetic disorder could easily be understood as a deviation from the normal genetic structure, even the term ‘pre-existing condition’ may come to be understood as including presymptomatic genetic disorders. This is even more clear in the definition of disease accepted by the Iowa Supreme Court which included “Any abnormal condition of the body or its components of such a degree that in its natural progression would be expected to be problematic...” (Annas, *Some* 103).

Perhaps the more important question is whether genetic information differs from personal and family history in a morally relevant way. It is sometimes argued that some elements of personal history, such as whether an individual smokes, are under an individual’s control, but risk classifiers such as genetic information that are not under one’s control should not be used in underwriting. In other words, individual responsibility should be a factor in price setting (Anderson 1514). But since we are not responsible for our genetic inheritance, we should not be held morally accountable for factors we cannot influence (Murray, “Genetics” 14). Yet the situation may become more complicated as geneticists begin to study the role of genetics in areas that were
considered up until now to be under an individual’s control, such as nicotine and alcohol addiction. Furthermore, most illness and disability is neither chosen nor deserved. Thomas Murray argues that this distinguishes disease and disability from, for example, the risks an oil tanker company may take in shipping cargo through the Arabian Gulf during the war between Iraq and Kuwait (Murray, “Genetics” 15). Clearly the owner of a second oil tanker company that ships cargo up the Atlantic to a U.S. port would argue that it was unfair if he or she were charged the same rate for insurance as the first company. In particular, it would be unfair since the first company chase to ship oil in a war zone.

The point was made above that attempting to ban the use of genetic information by insurers by arguing that individuals have no control over their genes is particularly difficult because knowledge on disease is expanding every day, so that illnesses which were once thought to be based on environmental or behavioural factors are now thought to be based on genetic heritage. This is the case, for example, with respect to obesity. Since differentiating genetic from nongenetic information may not be practical or possible, many authors argue that a better approach may be to rethink the entire issue of medical underwriting for certain types of insurance (Rothstein, “Genetics” 170).

Even if we will one day be able to make clear distinctions between genetic and non-genetic disease, it would still be unfair for insurers to issue coverage at the standard rate to an individual with a significant genetic abnormality, while denying coverage or demanding higher premiums from an applicant with a nongenetic disease that carries basically the same risk of mortality or morbidity (Anderson 1520). In an article regarding European policy on genetic information, Per Sandberg argues similarly that
while there are differences between genetic information and other medical information, they are not important enough to justify a separate policy (Lemmens and Bahamin 148). While this thesis will not argue that we should completely eliminate underwriting in the insurance industry, it will argue that we use both traditional medical information and genetic information only when they seem to suggest inevitable disease for an individual.

2. CONFIDENTIALITY

Since liberal individualism tends to be the dominant ideology in Western societies, the literature currently available on the issue of the use of genetic information in insurance often discusses the issue from the perspective of confidentiality (Macklin 157). Some examples include “Accessing Genomic Information or Safeguarding Genetic Privacy” (George P. Smith II), “U.S Privacy Laws May Curb Access to Medical Data” (Meredith Wadman), and Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era (Mark Rothstein, ed.) (full citations can be found in the works cited). In her article “Genetic Privacy: Emerging Concepts and Values”, Anita Allen distinguishes between four different types of privacy (Allen 33). In contemporary bioethics and public policy, privacy refers to one of these four categories: 1) informational privacy concerns regarding access to personal information; 2) physical privacy concerns regarding access to persons and personal spaces; 3) decisional privacy concerns about governmental and other third-party interference with personal choices; and 4) proprietary privacy concerns regarding the appropriation and ownership of interests in human personality.

The problem of the use of genetic information by the insurance industry falls into the category of informational privacy. George Annas was referring to this type of
privacy when he argued that the "Access to the information contained in an individual’s genome gives others potential power over the personal life of the individual by providing a basis not only for counseling, but also for stigmatizing and discrimination" (Allen 33). Alan Westin defined the core concept of privacy to be "The claim of an individual to determine what information about himself or herself should be known by others" (Allen 33). This definition illustrates the link between genetic privacy and self-determination.

On the issue of confidentiality, the Ontario Select Committee on Company Law recommended in 1980 that regulation should ensure that people are: 1) told what type of information is being collected about them, how it will be used, and to whom it will be disclosed; 2) given copies of their records and an opportunity to correct errors; 3) assured that there will be no improper disclosure of their records; and 4) told the reason for any adverse underwriting decision that may be based on personal data (Lemmens and Bahamin 228).

The Canadian Privacy Commissioners recommend in addition that "information gathered by service or benefit providers through genetic testing should be strictly controlled" (Lemmens and Bahamin 228). Yet to date, no privacy legislation dealing with confidentiality of personal information held by private companies has been adopted by any of the Canadian commonlaw provinces. Hence, the collection, retention, use and communication of personal, medical, and genetic information by insurance companies are not regulated in most Canadian provinces.

The assumption of many who write on the issue of genetic privacy seems to be that if we could simply demonstrate somehow that our genetic information is 'confidential' or 'private', and we then passed legislation which reflected this, we would
be able to avoid problems such as the use of genetic information by insurance companies. In particular, the assumption is that when such information is deemed confidential, insurance companies will not have access to it anyway. Yet the American Council of Life insurance (ACLI) and the Health Insurance Association of America (HIAA) Task Force Report guidelines on confidentiality, for instance, only apply after the insurer has obtained an applicant’s genetic information (Anderson 1521).

Thus, the so-called solution that involves labelling genetic information ‘confidential’ or ‘private’ only begs many of the questions this thesis deals with, such as the appropriateness of the use of genetic information as a risk classifier. If we go to the root of the issue of privacy, we are forced to acknowledge that privacy is actually more of a secondary principle serving utilitarian concerns (McGleenan 44). We must determine what privacy laws are designated to achieve. It was noted above that privacy is an important protection against discrimination. In an age where computer databases increase access to information, hence making confidentiality more difficult to maintain, it may be more important to organize social and economic institutions in ways that diminish the consequences of increased access to information.

For instance, Madison Powers argues that “[P]olicy makers must take seriously the possibility that the most feasible alternative for protecting the interests at stake may be the elimination of a risk-based insurance scheme. For only then are the powerful incentives for undermining the privacy of individuals effectively eliminated” (Powers 365). Since “[P]rivacy...simply is a matter of limited or restricted access to information, however that restriction is achieved. Rather than achieving the goal...through a system of legally enforceable rights, the same desired effect may be achieved by making access
to such information economically worthless” (Powers 365). It is important to note that both genetic privacy protection policies and changes to the insurance industry would represent direct state intervention into private market transactions. Since such interventions seem inevitable, changes which are most helpful in rebalancing the insurance industry should be encouraged, even if this demands changes to the insurance industry.

In the U.S., the limits of privacy legislation are clearly reflected in the Genetic Privacy Act of 1995 (Annas, “Genetic Prophecy” 1197). It gives individuals several rights, including the right to:

1) determine who may collect and analyze DNA;
2) determine the purposes for which a DNA sample can be analyzed;
3) order the destruction of DNA samples
4) inspect copies of records containing information obtained from genetic analysis; and
5) refuse to permit the use of the DNA sample for research or commercial uses.

Although the act requires that one who holds genetic information, such as a physician, keeps such information confidential, only disclosing the information when the individual has authorized the disclosure in writing, the act does not actually prohibit the use of genetic information by insurance companies. Similarly, the Privacy Commissioner of Canada recommended that applicants should have the option to refuse to be tested, but this may result in a loss of the service or benefit (Privacy Commissioner 34). The issue of when applicants should be forced to authorize disclosure of information will be dealt with in a later section of this thesis.
Moreover, American attempts at legislating confidentiality for genetic information have other fundamental flaws. Although twenty-six states enacted or considered legislation regulating the use of genetic information, self-insuring employers are largely exempt from state regulation (Davis and Mitrius 71). Federal bills that do apply to self-insured employers sometimes explicitly exclude providers of life insurance from the statutory prohibitions. In Europe, Austria, Belgium, and Norway have all prohibited the use of genetic information for insurance underwriting, yet family histories are not included under this prohibition in Austria, and non-genetic diseases can still be used for underwriting in Belgium (Lemmens and Bahamin 119, 242). Since we saw earlier that it is becoming increasingly difficult to distinguish genetic from other medical information, the prohibitions in these laws may become unenforceable (Lemmens and Bahamin 244). It is obvious that it will be impossible to solve the problem of insurance and genetics by legislating confidentiality without making any fundamental changes in the way the insurance industry functions. Yet these fundamental changes need not involve completely eliminating the use of information related to risk by the insurance industry in all cases. If the purpose of privacy legislation for genetic information is to protect people with genetic abnormalities from becoming uninsurable, a solution to this problem that does not rely simply on privacy legislation is to design an insurance model that is both financially feasible for private insurers, and provides access to basic forms of insurance to everyone, regardless of their genetic inheritance.

3. RIGHTS

The language of ‘rights’ often enters the discussion of genetics and insurance. For instance, some discuss the possibility of a ‘right not to know’ about their own genetic
This right not to know is particularly important now since there are few cures or treatments available for genetic conditions. Hence the knowledge of a genetic condition would often be useless to the individual, and may in fact lead to psychological consequences, such as a lack of hope for the future or meaning in his or her life. Yet again, just as labelling genetic information 'confidential' ignored fundamental questions, identifying a 'right not to know' is not sufficient for solving the problem of the use of genetic information by the insurance industry. For instance, such a right may prohibit insurers from demanding that applicants take genetic tests, but it would not stop insurers from using the results of tests already taken. The right not to know would offer the best chances on being well-insured, but it would be a constraint on autonomy to the extent that it would discourage individuals from taking genetic tests that might be helpful in making medical, life-style, or reproductive decisions.

The limitations of the concept of rights are made clear in "Eugenics and Human Rights", where Jonathan Glover points out that

> There seems so little that is clear and convincing about the criteria by which we recognize something as a right, or how we decide what to do in cases where apparent rights are in conflict... rights are trumps. If your interests and mine conflict, some weighing up of their relative importance is called for... But if what my interest conflicts with is your right, my interest simply has to give way. (Glover 105)

It is obvious that simply labelling something a 'right' is futile without some discussion of why it is a 'right'. People want the 'right not to know' to be recognized primarily because they fear insurance discrimination, and because they do not want to be compelled to discover genetic disorders for which there is no available treatment. But guaranteeing individuals basic types of insurance at an affordable rate would clearly be a better way of dealing with the fear of being left uninsurable because it does not require having to make
any philosophical claims regarding a ‘right not to know’. Furthermore, Solomon Benatar reminds us that human rights is a highly individualistic concept based on the notion of individuals as merely autonomous (Benatar 181). We must go beyond this understanding to a socially responsible concept of human rights which appreciates both our individuality and the mutually beneficial relationships between individuals.

4. THE UNDERSTANDING OF JUSTICE CURRENTLY DOMINANT IN INSURANCE

In order to get to the root of the issue of insurance underwriting and genetics, we must approach it from the perspective of justice. Thomas Murray states rightly that the problem involves distributive justice in that it deals with how benefits and burdens are to be distributed among persons in a society (Murray, “Ethics” 80D). Yet it also involves comparative justice because it requires making comparative judgements among persons. Aristotle defined justice as treating like individuals alike and unlike individuals differently. Although this sounds like a simple notion, it still requires that we determine what is a morally relevant difference for distributing the benefits and burdens in question. For example, height is a morally relevant difference when choosing who will play at the most competitive levels of basketball. We have already seen that actuarial fairness involves the risk represented by each individual policyholder being treated as a morally relevant difference. Norman Daniels points out that the term ‘actuarial fairness’ implies a moral judgement that ‘fair’ underwriting practices must reflect the division of individuals into groups according to the actuarially accurate determination of their risks (Daniels, “Insurability” 500). Yet Daniels argues that actuarial fairness is not always an obvious requirement of justice.
In order to prove this claim, we begin by reminding ourselves that insurance functions as a way to manage the risk of serious loss under conditions of uncertainty (Daniels, “Insurability” 501). An important change takes place when the amount of uncertainty diminishes because new information allows us to disaggregate the risk and thus divide people into stratified risk pools. Insurance applicants may now see themselves as having diverse rather than common interests. If the insurance market is structured so that the only consideration at work is the ability of consumers to pursue economic advantage, then those at lower risk will seek a divided pool with premiums that reflect risks. But the behaviour of applicants working within a given institutional arrangement does not imply that those applicants believe that institutional structure is morally appropriate.

We have also seen that insurers make the claim that they could not survive financially if they were not permitted to use genetic information. But this assumption can easily be shown to be false. In fact, there is opportunity to profit from both community-rated pools and risk-based pools. For example, if all insurers were required by law to community rate for applicants who do not have a pre-existing condition and whose medical or genetic information does not indicate inevitable disease, then insurers who used community rating would not have to compete with others who did not. Furthermore, participation in insurance schemes could be made almost compulsory. For instance, individuals are often required to have life insurance in order to obtain a mortgage or a bank loan. Similar policies should be encouraged, since they serve to eliminate the threat of adverse selection because those who discover through genetic testing that they are a ‘good risk’ would probably be required to buy life insurance
anyway. Moreover, since molecular biologists believe that each person carries between five to seven lethal recessive genes, the threat of adverse selection may actually diminish as people learn more about their genetic inheritance, since few would be 'genetically perfect' (Anderson 1504).

Daniels uses these arguments in order to show that the concept of actuarial fairness should be assigned a descriptive, rather than a normative function in the insurance market (Daniels, "Insurability" 502). In fact, since the term 'actuarially fair' creates confusion by implying moral fairness, the term 'actuarially accurate' should be used in its place (Daniels, "Genome" 114). Yet insurers strategically make the strong claim that actuarial fairness demands that underwriting practices are *morally required* for a just insurance industry, as opposed to making the weak claim that such practices are *morally acceptable* (Daniels, "Insurability" 504). The weak claim is less useful, since it could not adequately be used to defend underwriting if it could be shown that underwriting created consequences that were incompatible with what our society saw to be the purpose of insurance. The strong claim has the advantage of allowing insurers to avoid having to defend the effects of the current institutional structure of insurance by meeting the accusation of unfairness not only with a denial, but also with a countercharge. The assumption being made by the strong claim is that individuals have a right to benefit from any of their individual differences, in this case in their different risks for disease and disability, regardless of how small those differences are.

This assumption is characteristic of a liberal, free-market understanding of justice. The liberal understanding makes the concept of right prior to that of the good (Kuczewski 46). Liberal John Rawls does this, for example, in his argument against utilitarianism,
when he argues that individual rights cannot be sacrificed for the general good. This understanding of rights depends on the idea that principles of justice do not derive from any notion of the good life or the natural ends of man (telos). Individuals choose ends within the confines of an understanding of justice. Also important to liberal philosophy is the view of the individual as an ‘unencumbered self’, or the voluntaristic theory of the person (Kuczewski 25). Individuals are understood to be rational agents who transcend any particular choices or commitments (Furgusson 140). This unencumbered self is defined only by its ability to choose certain general principles of justice (Kuczewski 48). As in the Kantian understanding, the individual is defined by volition (choice) rather than by cognition (knowledge) of the good.

Although the unencumbered self does not know the particular goods that will be useful in the vision of the good life, the individual does have an interest in the distribution of basic instrumental goods, such as opportunities, wealth, rights, and liberties, since these goods will be necessary for realizing any vision of the good life that an individual may choose. The Rawlsian understanding requires that the subject determine rationally the principles of justice that will govern society’s basic institutions. In order to determine the appropriate principles, Rawls introduces two notions crucial to his system, which are commonly referred to as the ‘original position’ and the ‘veil of ignorance’. Rawls argues that the principles of a fair and just society must be agreed to by individuals who are denied knowledge about their place in society (Mulhall and Swift 3). In Liberals and Communitarians, Stephen Mulhall and Adam Swift describe Rawl’s system as one where

Principles of justice...should be understood as what would emerge as a hypothetical contract or agreement that would be arrived at by people ignorant of
particular aspects of their own beliefs and circumstances...if people don't know who they are going to be, then it will make sense for them to choose fair or just principles to regulate their society. (Mulhall and Swift 3)

In particular, in the original position one is denied knowledge regarding whether he or she will be at the top or the bottom of the social ladder, or what his or her particular talents or natural endowments will be (Mulhall and Swift 4). If individuals had this information, then the agreement reached would reflect the unequal bargaining power of the people involved. But without this information, each person seeks out of self-interest to secure as favorable an arrangement as possible for himself or herself. The veil of ignorance would force people, out of self-interest, to ensure that the worst position in society is as good as it can be (Mulhall and Swift 8). It is important to note that the concept of original position tries to capture the idea that since people are not responsible for what family they were born into or their natural endowments, a theory of justice should in most cases understand these attributes as morally arbitrary.

In Rawls' view, people in the original position would agree to two principles of justice. The first principle requires that "Each person is to have an equal right to the most extensive total system of equal liberties compatible with a similar system of liberty for all" (Mulhall and Swift 7). The other essential principle is the 'difference principle', which demands that "Social and economic inequalities are to be arranged so that they are both a) to the greatest benefit of the least advantaged, and b) attached to offices and positions open to all under conditions of fair equality of opportunity" (Mulhall and Swift 7). The second principle attempts to correct for the arbitrariness of fortune by only allowing for those social and economic inequalities that will work in favour of the least advantaged members of society (Kuczewski 49). It is also argued that those in the
original position would agree that the first principle has lexical priority over the second, and that within the second principle, part b) has priority over part a).

One form of liberalism is Robert Nozick’s ‘entitlement’ view of justice. Although Rawls’ arguments are often used to justify a ‘welfare’ state, Nozick argues for a minimal state that is not redistributive (Lebacqz 51). For example, Nozick’s liberalism views taxation as unfairly “seizing” one’s labour (Lebacqz 58). Nozick has a purely procedural understanding of justice, so that with respect to the pattern of distribution of goods “[W]hatever arises from a just situation by just steps is just” (Lebacqz 55). In other words, people should begin with a set of holdings that seems just, and then be permitted to make choices about exchanging those goods and giving to each other from their portion. Nozick’s understanding of justice does not consider need or merit in distributing goods (Lebacqz 56). Although Nozick supports the underlying assumptions of market exchange regarding acquiring and transferring property, he still maintains that it would not be just for one to acquire, transfer, or purchase something so limited that such an exchange worsens the situation of others (Lebacqz 57). Yet it is obvious that this principle is largely ignored in Nozicks’s system, which puts limits neither on the conditions for the poor, nor the disparities between rich and poor (Lebacqz 59). Nozick’s libertarianism is important to the issue of insurance and genetics because it allows individuals the liberty to exchange any of their marketable abilities or traits for personal advantage, even if this requires that social goals are overridden (Daniels, “Insurability” 505).

Much has been written in critique of liberalism, but this thesis will only deal with the issues relevant to topic at hand. For instance, David Furgusson points out in
Community, Liberalism and Christian Ethics that although the purpose of liberalism was to provide a moral justification for the democratic state and the market economy, in fact no single theory exists, so that the term ‘liberalism’ actually represents competing interests (Furgusson 48). Even among liberals there exist different understandings of what liberalism entails. Some liberal philosophers argue that social policies are the result of a bargain made by rational individuals for the purpose of dividing the benefits of mutual cooperation (Daniels, “Insurability” 505). Within this understanding, “[B]argainers who have initial advantages in assets would only accept social arrangements that retain their relative advantages” (Daniels, “Insurability 505). In the case of insurance, such a view of justice would maintain the advantages of those at low risk of disease through insurance markets that use underwriting in order to promote actuarial fairness.

Yet if bargaining can yield agreement only when unjustified initial advantages are maintained, then bargaining does not satisfy the demands of justice. Rawls’s notion of a ‘veil of ignorance’ is an improvement on the ‘bargaining’ understanding because just what individual differences should be allowed to yield individual advantage becomes an issue for debate within the theory of justice, not a starting point for it (Daniels, “Insurability” 506). Daniels gives several examples to illustrate that the strong assumption which claims that individual differences should be allowed to yield advantage or disadvantage is too strong. For example, both American and Canadian legislation do not allow characteristics such as race or gender to influence distribution of rights, liberties, opportunities, or economic gain. In fact, this rejection of the view that all
individual differences can be a moral basis for advantage or disadvantage is what makes affirmative action policies so controversial.

Similarly, although we permit talents and skills to influence the generation of inequalities, we tax those with the most highly rewarded talents and skills in order to help those who lack them (Daniels, “Insurability” 507). Furthermore, only the strictest libertarians believe that there is no social obligation to correct for the relative advantages and disadvantages caused by disease or disability. The Canadian health care system is clearly designed in such a way that rejects the view that individuals should have the opportunity to gain economic advantage from any difference in their health risks. These observations regarding the role of individual differences are important because they demonstrate that actuarial fairness rests on a philosophical assumption that does not always correspond to common moral beliefs.

Daniels draws attention to another important issue regarding the role of actuarial fairness in the insurance industry. He makes the point that since insurers are highly selective about which information they will use to determine risk, actuarial fairness involves an element of moral arbitrariness (Daniels, “Insurability” 508). First, actuarial fairness might actually demand that we seek out all relevant information regarding the risks people face. This understanding implies that justice would demand that, for example, insurers commit resources to mapping the human genome and to developing tests relevant to underwriting practices. Moreover, the question of who determines which information is relevant must be dealt with. Justice may demand that criteria developed by a non-biased party be used to determine which information should be used to decide whether applicants are offered insurance at standard rates. Second, actuarial fairness
might demand that insurers *use all relevant and available information regarding risk.* Such a policy "[L]oosens the connection slightly between individual differences and the distribution of advantages, for people are entitled to derive benefit only from those differences in risks about which information happens to be available" (Daniels, "Insurability" 508).

Yet even those who support actuarial fairness, such as Karen Clifford and Russell Luculano, do not seem to accept the first interpretation, which makes research obligatory (Daniels, "Insurability" 509). Similarly, standard insurance practice does not support the second interpretation either (requiring that all available information regarding risk be used). Instead, insurers often seem to understand actuarial fairness as using information about risks whenever it is their economic interest to do so. In other words, the strong assumption regarding individual differences is used arbitrarily by insurers so that people are entitled to gain advantage from those differences that insurance markets happen to reward. Daniels is arguing, quite rightly I believe, that the point here "[I]s not to prove that the market is unfair because such arbitrary factors as information costs play a role in what distinctions it makes. Rather, it is that we need to be shown that the market is at least as good as any alternative procedure for making distinctions among individual differences that society thinks should be rewarded" (Daniels, "Insurability" 509). For this reason, criteria for a balanced insurance industry is the key to determining when free-market ideals are appropriate for achieving the goals of insurance. Such criteria will be presented later in the thesis.

Any analysis of the role of actuarial fairness in the insurance industry must consider the fact that insurance market regulations often allow other considerations to
override the principle of actuarial fairness. For instance, race can often influence the likelihood of disease or death. Deborah Stone points out that the fact that blacks have higher rates of heart disease and kidney disease and lower life expectancy than do whites implies that insurers could argue that it is actuarially fair to use race to determine risk (Stone, “AIDS” 66). Moreover, being a Vietnam veteran and marital status are also correlated with health. Yet insurers do not require higher premiums from blacks, Vietnam veterans, or divorced women (Lemmens and Bahamin 181). The use of criteria such as race is prohibited under Canadian human rights codes. Criteria such as military status are not used for political reasons (Stone, “AIDS” 66). Stone argues that these facts are important because they demonstrate that:

The classifications used by the industry are dictated by neither medical science nor financial principles. They are a policy choice. The industry cannot use race because it is legally forbidden to do so as a result of a political choice made outside the industry. It does not use veteran status because it does not dare to penalize political heroes. But it does use medical criteria. (Stone, “AIDS” 66)

Both Stone and Daniels are important thinkers on this issue because they are able to prove that actuarial fairness is not always an obvious requirement of justice. In the third section of the thesis, which proposes a possible strategy in dealing with the problem of the use of genetic information by the insurance industry, an alternative ethic will develop criteria to determine when it is appropriate to use actuarial information.

Other authors raise also raise important issues with respect to justice in the insurance industry. For instance, it is also clear that with respect to insurance, consumer choice for the middle and upper classes is often obtained at the expense of denying choice to the poor and uninsured (Fleck 214). This issue is raised by Leonard Fleck in his article “Is National Health Insurance Congruent With Liberalism?”, where he
comments on the American health care situation. Regarding the poor and uninsured, Fleck points out that health benefits for the American middle class are currently subsidized heavily by the government, yet the working poor cannot afford health insurance. This is particularly disturbing since their taxes help support the health care system and the cost containment mechanisms that exclude them from actually benefitting from that same system. Furthermore, contrary to the rhetoric of market efficiency, the reality is that American health care is very inefficient, so that, for instance, while Canadians spend about 6% of their health care dollars for purely administrative costs, Americans spend about 16% of their health dollars for such administrative costs (Fleck 214). This means that in 1990, $66 billion was spent in excess administration costs that did not provide any health benefit for anyone. Since “It is impossible to imagine a rational reconstruction of this state of affairs that would yield the conclusion that these individuals have consented to the policies and institutions that have kept them in this state of subjugation”, this is clearly an “[I]liberal outcome” (Fleck 213, 214).

While it can be argued that the American situation with respect to basic health insurance is irrelevant in Canada, this example illustrates well that with some types of insurance, the savings that are supposed to be achieved by using an insurance model based almost exclusively on free-market values are often illusory (Daniels, “Insurability” 514). In Canada, any savings for low-risk consumers that would result from denying basic forms of insurance to all individuals with genetic predispositions, or increasing the premiums of such individuals so that insurance becomes unaffordable, may only lead to an increase in taxes to cover the increased burden on public welfare programs. In other words, allowing basic forms of insurance to be structured on a free-market model may
only lead to cost-shifting, not to savings in costs. Yet this does not apply for non-necessary forms of insurance, since the government would not have an obligation to ensure access to non-necessary goods.

Similarly, if basic forms of insurance are denied to people with genetic abnormalities, regardless of whether this genetic condition seems to lead inevitably to disease or only represents an increased probability of disease, then many will avoid genetic testing. This will eventually result in greater medical costs, since individuals will not be able to take advantage of early or preventive care (Anderson 1525). Moreover, without insurance, people will also lack coverage for illness or death that is unrelated to the genetic condition, and this will lead to an increased burden on government welfare programs, which are supported by taxes (Anderson 1526). For instance, if a parent (particularly the family breadwinner) does not have access even to a basic amount of life insurance because of a genetic disorder, then his or her dependents may have to be supported by welfare in the case of the death of that parent. While it can be argued that this should not be the primary concern of an insurance company, we can at least expect that a business should consider the good of the least advantaged in society to the extent that it is able to do so without sacrificing its profitability. This is important because we saw in a previous section that some changes in the way the insurance industry currently functions would make it possible to profit from a pool that is mainly community-rated.

5. THE CANADIAN SITUATION

Lemmens and Bahamin rightly point out that the libertarian understanding of justice that allows for all individual differences to be used for financial advantage is not
universal in Canada. They state that "The notion of distributive justice and the need for everyone to participate in society—which is made possible through risk-spreading—are deeply embedded in Canada" (Lemmens and Bahamin 117). For instance, while there is some discussion in Canada regarding whether the current tax rates are too high, Canada still has a considerable social safety net in place. This commitment to distributive justice through risk-spreading is made most obvious by the fact that Canada has universal public health insurance for basic medical services through the provinces. In other words, Canadian policy-makers have decided that access to basic medical services should be guaranteed to all Canadians. Hence, if some forms and amounts of insurance were deemed to be as necessary to participation in society as basic medical services, then it would be appropriate for Canadian policy-makers to devise a model of insurance in Canada that allowed for private insurers, while guaranteeing that all Canadians had access to necessary forms of insurance.

This is not to suggest, however, that it will be easy to determine what types and amounts of insurance are necessary goods. The Canadian experience of publicly financed health care has demonstrated how difficult it is to determine which services are necessary goods, and which are non-necessary goods. The discussions regarding in vitro fertilization and circumcision are good examples of the types of debates that can arise when we are forced to separate luxuries from basic goods. Yet to engage in such a debate is a more honest way of handling the question of insurance than attempting to argue that additional health insurance, disability insurance, and life insurance always represent non-necessary goods. Finding a way to give Canadians a voice in such discussions may be time-consuming and expensive, but such discussions are necessary if some forms of
insurance are essential to participation in Canadian society. The next section will deal with this question as it deals with the social purpose of insurance in Canadian society.
Chapter Three

PROPOSED ALTERNATIVE

1. THE SOCIAL PURPOSE OF INSURANCE IN CANADA

In order to determine the appropriate place for libertarian/free market values in the insurance industry, we must first identify the social purpose of insurance. Insurance is generally viewed as a way for individuals and communities to obtain security. In the case of life or disability insurance, it functions to protect either the insurees or their dependents from economic devastation. While these forms of insurance are often viewed as luxurious 'extras', in reality they are linked to other necessary goods, since their purpose is often only to maintain a fixed level of existence and normal functioning for the insuree and his or her dependents (de Wachter and van Luijk 168). Canadian health care offers basic medical services, yet additional health insurance is necessary to cover the cost of medical products and services, such as medications and therapy, that are often essential to a patient's treatment (Lemmens and Bahamin 183).

At the beginning of this thesis it was noted that it is important to make the distinction between insurance for medications or treatments prescribed by a physician which have been proven effective for a particular medical condition and are necessary to protect normal functioning for the patient, and other medications or treatments which do not meet this criteria. The former case represents a basic good, while the latter case represents a non-necessary good. For instance, dental and pharmaceutical insurance is often a basic good, while insurance to cover reproductive technologies such as in vitro fertilization is a non-necessary good. The recent concern regarding the needless prescription of antibiotics is a good example of a medication that may be a necessary good in some cases, but not in others. Similarly, it is possible to differentiate between
different life insurance policies, so that a life insurance policy worth $100,000 or less represents a basic good, while a life insurance policy worth more than $100,000 is a non-necessary good. On the other hand, a life insurance policy worth more that $100,000 may not be non-necessary if it is linked to a mortgage. The $100,000 amount is only used arbitrarily as an example throughout this thesis. Further research may lead Canadian policy-makers to decide that another amount is more appropriate.

Although Canada currently has a welfare system that would support those who depend on others in the case of the death or injury of the breadwinner, it was noted earlier that life or disability insurance may become more important if budget cuts are made to government programs. Strong family ties in the past allowed individuals to rely on family for support, but a more individualistic contemporary Western society has meant that people can no longer rely on family for assistance (Lemmens and Bahamin 184). Furthermore, access to some forms of insurance have become crucial to equality of opportunity. For instance, life insurance contracts are often required to acquire mortgages, buy cars, or start businesses (Lemmens and Bahamin 154). Moreover, employers may not want to hire someone who will not qualify for the company insurance plan, which generally provides for benefits such as dental and pharmaceutical insurance. This is important because even a liberal understanding of justice requires that social policies allow for equality of opportunity (Kuczewski 48). Since any type of insurance that protects functioning that is normal for an individual in our society is a basic good that ensures equality of opportunity, such insurance must be made available to as many people as possible.
Deborah Stone argues that the insurance industry currently functions in a way that often undermines the purpose of insurance. She states that “With enough predictive tests of sufficient accuracy, insurers could virtually eliminate risk-sharing and redistribution. We would each pay strictly for ourselves. The insurance industry... assumes a vision of insurance as a personal savings plan operated by insurance companies instead of banks” (Stone, “AIDS” 65). In other words, if actuarial scientists had enough traditional medical information and genetic information about an applicant so that they could perfectly predict that applicant’s future claims, applicants would essentially be paying for their future health care costs. Stone’s comment is important because it is suggesting, quite rightly I believe, that the current insurance industry is based too heavily on a liberal, free-market model of justice. Risk-spreading is largely ignored, while accurately determining each applicant’s risk-level is over-emphasized. As stated previously, the purpose of this thesis is to suggest a way in which the policies of the insurance industry can better balance liberal, free-market principles of justice with communitarian principles of justice.

2. COMMUNITARIANISM

The origins of the communitarian movement date back to the early 1980s, when some philosophers began to take seriously the themes of community and responsibility (Kuczewski 24). In his book Fragmentation and Consensus, Mark Kuczewski identifies the most important works of the early period to be Alasdair MacIntyre’s After Virtue (1981), and Michael Sandel’s Liberalism and the Limits of Justice (1982). The exact definition of communitarianism is disputed, but it generally involves several main ideas. Perhaps most important is the communitarian criticism of the conceptual resources of
liberal theory. In particular, they ask what understanding of life is advanced by contemporary liberal political theory.

For example, communitarians seek to construct a fuller notion of the self than the one usually defended by deontological ethics. Communitarians are especially critical of the 'neutrality thesis' that characterizes liberal theory. This thesis involves the understanding of the person as 'unencumbered'. In particular, Michael Sandel claims that the liberal priority of the right over the good reflects a view of the individual as the 'unencumbered self' (Kuczewski 46). In the section of this thesis that discussed liberal theory, the unencumbered self was defined to be a view of the individual as a rational agent who transcends any particular choices or commitments (Furgusson 140). Yet Michael Sandel points out that individuals cannot be unencumbered because the self is always shaped by its social attachments and circumstances prior to any choices it makes. The identity and fulfilment of an individual is inextricably bound up with relations and communities (Furgusson 143). Even if it were possible for people to be unencumbered, communitarians argue that such a view of the person cannot justify even the level of cooperative activity that liberalism requires.

We saw above that liberals argue that the unencumbered self would agree to the principle of equal liberty and the difference principle. Yet Sandel points out that the liberal system cannot actually support the difference principle, which requires that social and economic inequalities are to be arranged so that they are to the greatest benefit to the least advantaged. This principle is partly based on Rawls's assumption that one's assets and abilities are common assets which the community may govern or redistribute through institutions. Yet the difference principle is inconsistent with the concept of the
unencumbered self. This concept involves a lack of a substantive understanding of the
good and does not demand that the good is defined as being intertwined with the good of
others in the community (Kuczewski 51).

Central to communitarian thought is the need to rebalance libertarian values such
as freedom or autonomy with a shared vision of the good life and a shared hierarchy of
goods (Kuczewski 24). Communitarians argue that this lack of a conception of the
‘common good’ is a result of the failure of post-Enlightenment ethics to develop a new
foundation for morality (Kuczewski 25). This situation has come about both as a
consequence of liberalism’s emphasis on the individual and its rights, and as a
consequence of the modern acceptance of pluralism. Moreover, the fragmentation of our
moral thought originates from the loss of the conceptual traditions that underpinned
moral terms in ages past. This loss is felt in our inability to come to agreement on ethical
issues such as abortion. Communitarians argue that “Without these frameworks, the
terms have no rational employment and contemporary discourse decays into
meaninglessness” (Kuczewski 25). This situation results from the liberal belief that value
expressions have only relational meanings, not factual meanings. In fact, the loss of an
Aristotelian conception of a telos (goal, final cause) to guide human activity causes moral
discourse to lapse into ‘emotivism’ (Kuczewski 27).

Mark Kuczewski describes how even though our current moral language comes
from a time when moral statements had objective reference, contemporary moral
discourse involves a subjectivist understanding of the good:

[P]rior cultures embodied shared understandings of the human good and it was in
light of these common goals that particular ethical prescriptions were judged to be
true or false. When ethics is cut off from any concept of the final cause, it is
effectively decapitated and values can only be judged from a completely
subjective perspective. Judging something to be good becomes equated with one's particular purposes, wishes, and emotional responses without any intersubjective reference. (Kuczewski 27)

MacIntyre uses the Aristotelian ethical tradition as an example of a tradition that perceived morality to be rational (Kuczewski 28). Such a system involved using a set of rules that were helpful in the fulfillment of the telos. These rules of morality functioned as clear standards that could be used to judge any professed rule true or false. The loss of a telos creates the fact/value distinction. Understanding what humans are involves knowing our highest goals and allows us to interpret the actions and social roles that will aid in asserting our nature.

MacIntyre blames the Reformation for denying the possibility of rationally comprehending perfected human nature (Kuczewski 29). Describing normative rules becomes difficult if reason can only determine appearances. Reality, or 'facts', become severed from what ought to be, or 'values'. This difficulty generally gets overlooked because practical consensus regarding everyday moral practice hides the conceptual inability to seriously address moral questions. On this issue the Kantian system is particularly important since it acknowledges that the lack of a descriptive and normative understanding of human nature renders justifying morality problematic. In the words of David Fergusson, liberalism attempts to “provide a moral basis for societies in the absence of any shared conception of the good” (Fergusson 138). Society requires a substantive conception of human nature and those goods which are to be sought. These goods or goals are generally referred to as the 'common good'.

A common criticism of communitarianism is that pluralistic societies make it impossible to agree to a shared vision of the good life or a hierarchy of goods (Fergusson
146). Although this is not the place to determine the validity of this argument, it must be noted that in one sense it is not relevant to the issue of genetics and insurance, since virtually all cultures value health and security. Yet the current discussion with respect to natural medicines demonstrates that people do disagree on the issue of which medicines and treatments actually improve health. Similarly, other debates indicate that Canadians are divided on the issue of how much responsibility governments should have in providing security for their citizens through the social safety net. Rebalancing the insurance industry would still require dealing with these issues.

Another common charge is that communitarianism is opposed to the concept of individual rights (Furgusson 150). Yet communitarians argue that they are not against the concept of rights, but simply wish to emphasize the fact that rights create corresponding duties on some person or institution. Similarly, the communitarian perspective is not against individuals, but simply requires that more attention is given to the social side of human nature. In other words, communitarians are simply trying to rebalance the current liberal emphasis on rights and individualism with communitarian ideals. Furthermore, communitarianism can also avoid the hierarchies of the past by restoring community life in a democratic manner that recognizes the equality and dignity of every person (Jardine 37). Finally, many charge that communitarianism ignores the needs of minority groups while responding to the needs of the majority. To this allegation communitarians respond that in fact the community must be responsive to everyone by developing moral values that are applied equally to all members.

Michael Walzer argues rightly that market exchange is appropriate as a basis for justice within certain spheres, but not in all areas of life (Lebacqz 61). The purpose of
this thesis is to make some recommendations regarding how insurance policies can better balances communitarian principles with liberal, free-market values. In his book *Community and Communitarianism*, Haig Khatchadourian argues that a moral community enables individuals to satisfy their basic needs and realise their potential (Khatchadourian 3). Since virtually everybody considers health and security to be a good, particularly because it allows for equality of opportunity to aquire other goods and to exercise liberty, necessary forms of insurance can be viewed as common goods.

In his book *Some Choice*, George Annas points out that the market model is inappropriate to distribute goods whose supply and demand are unrelated to price (Annas, *Some* 46). In health care, for instance, a particular pharmaceutical product may be crucial to one’s recovery, so that a patient will purchase it regardless of price. Without this medication, the disease will inevitably progress, leaving the patient unable to function normally, and in some cases the patient may eventually die. Similarly, basic disability insurance is necessary to provide income in the case of disability. Security is also provided by life insurance, but certain amounts may be excessive in that such amounts are not necessary in order to provide basic financial assistance to one’s dependents.

3. THE CHRISTIAN RESPONSE TO COMMUNITARIANISM

There are many parallels between the communitarian understanding of justice and Christian ethical principles. This thesis will concentrate mainly on Roman Catholic teachings. In *Community, Liberalism, and Christian Ethics*, David Furgusson draws attention to the importance of community in the moral world of the New Testament and the early church. For instance, in the weekly Eucharistic meal, the memorial of the Last
Supper in 1 Corinthians 11 is a reminder of the equality that arises from belonging to the body of Christ (Furgusson 11). This went against the traditional understanding in which a meal reinforced social stratification. Paul argued that treating guests differently according to their social status was not acceptable. Furgusson also points out that Christian ethics had a stronger social dimension than the traditions of Plato and Aristotle (Furgusson 14). For example, the writings of John Chrysostom in the late fourth century emphasize the idea of a common humanity which imposes obligations upon slave-owners and the rich. Chrysostom argued that not only that the best way to utilise wealth was to distribute it to those in need, but also that it was impossible to enter the kingdom of God without giving alms.

The term ‘common good’ appears frequently in recent Roman Catholic documents, including Pope John Paul II’s *Veritatis Splendor* (1993), but the use of this concept can be traced back to much older Christian documents. In “The Individual, the State, and the Common Good”, John Haldane discusses the history of the term in Catholic social teaching. He traces this history back to the writings of Jacques Maritain and Yves Simon, which are based on the moral theology of Thomas Aquinas (Haldane 70). The *Prima Secundae* of the *Summa Theologiae* discusses the common good in question 90, article 2 where Aquinas writes:

[S]ince every part is ordered to the whole as the imperfect to the perfect and one man is part of the perfect society, it is necessary that the law properly regard the order to the happiness of the society... Hence, since law is most of all ordered to the Common Good, it is necessary that any other precept concerning a particular matter must needs lack the nature of law except insofar as it is ordered to the Common Good. And therefore every law is ordered to the Common Good. (Haldane 70).
The issue Aquinas is dealing with in this passage is particularly important because it can be argued that the two most fundamental disagreements between liberal theory and Catholicism involve the place of morality in politics, and the status of the community and the common good (Haldane 79).

In *Six Theories of Justice*, Karen Lebacqz describes Catholic social teaching as being rooted in three basic principles which are generally accepted within the wider Christian community: 1) the inviolable dignity of the human person; 2) the essentially social nature of human beings; and 3) the belief that the abundance of nature and of social living belongs to all people (Lebacqz 67). The transcendental worth of the person is the foundation on which social structures must be built. Several ideas arise from these principles that are relevant to the topic of genetics and insurance. For instance, these principles demand that institutions exist for the sake of people. Moreover, Catholic social teaching eventually came to define limits to the place of free-market values in society (Lebacqz 68). In *Quadragesimo Anno* (1931), Pius XI argues that “the proper ordering of economic affairs cannot be left to free competition alone” (part II, section 5). In *Populorum Progressio* (1967), Paul VI defends this view by arguing that if the positions of the contracting parties are too unequal, their contract may not be just even if it has the consent of both parties. While the tradition affirms a right to private property based on the dignity of the person, it has also argued for limits based on the common good. In fact Pius XI and the succeeding tradition maintain that justice demands that the wealthy must share their goods (Lebacqz 69).

Also important to the issue of this thesis is the concern of Catholic social teaching for the plight of the poor (Lebacqz 70). The modern development of this tradition can be
found in the writings of Leo XIII and Pius XI, who argued that the fact that poverty exists indicates the presence of injustice. This concern culminated in what is currently referred to as the 'option for the poor', which is the belief that the relationships of justice require preferential respect due to the poor. Since the poor are often most affected by economic decisions, such decisions must be judged by how they affect the poor (Lebacqz 72). In *The Bishops' Letter on the U.S. Economy* (1986), the U.S. bishops argue that fulfilling the basic needs of the poor is of the highest priority (Lebacqz 73). They also defend the importance of increasing participation for the marginalized, and supporting investment policies that will benefit those who are poor or economically insecure.

By now the differences between the liberal understanding of justice and the Catholic understanding of justice should be obvious. Both Nozick and Catholic tradition support certain individual 'rights' that cannot be abrogated by the state, yet Nozick's rights are primarily negative rights against interference, while Catholic tradition supports positive rights to welfare (Lebacqz 75). This crucial difference results in the rejection in Catholic social teaching of the unfettered market exchange system that Nozick argues for. Similarly, while the plight of the poor is important both to Catholic social teaching and to Rawls' liberal understanding of justice, the bishops recognize more explicitly than does Rawls that economic differences result in political and social inequalities. Furthermore, for Rawls the concern for the least advantaged is based on a self-interested calculation under conditions of ignorance, while for the bishops, it is based on the acknowledgement of the presence and will of a loving God.

With respect to issues involving genetics, the parallels between communitarianism and Catholic social teaching are made clear by Roman Catholic
theologian Richard McCormick, who identifies several themes as essential to bioethical reasoning. One of these themes is the idea that our well-being is pursued only interdependently (Shannon 161). Here McCormick is emphasizing that the fact that we are social beings is an essential part of both our being and our becoming. With respect to genetic engineering, one of the values McCormick points to is social responsibility, arguing that we should look beyond the narrow calculation of individual risks and benefits (Shannon 163).

Similarly, Charles Curran argues that in the area of genetics, one must recognize "the existence of other responsibilities which limit one's options and freedom" (Curran 117). Furthermore, Curran maintains that it is important to avoid an excessive individualism: "My contention is that the complexity and interrelatedness of human existence, plus the tremendous power that science may put into human hands, are going to call for a more communitarian and social approach to the moral problems facing our society" (Curran 119). At the same time, theologians such as Bishop William Friend add that technologies must be used for the good of the person (Friend 522). Hence, this principle would reject using the results of genetic tests if such use would leave people uninsurable or unable to afford insurance.

In "Genetics, Ethics, and Theology: The Roman Catholic Discussion", Thomas Shannon draws similar conclusions. He points out that the study of genetics has caused the understanding of the individual to undergo tremendous change, and yet there are currently few communal resources available to help address the question of identity (Shannon 168). It is only clear that the model of radical individualism contains many inherent weaknesses that stem from its lack of a robust notion of the common good. In
order to address important issues "We must look beyond ourselves to the society in which we live and recognize its profound effects on us" (Shannon 168).

4. AN ALTERNATIVE MODEL FOR INSURANCE

The alternative ethic suggested with respect to insurance will seek to balance liberal, free-market principles of justice with communitarian principles of justice. In particular, this ethic will be based on the idea that insurance is intended to create controlled uncertainty. The claim made in this thesis is that communitarian principles are appropriate when traditional medical information and genetic information still allow for uncertainty with respect to one's future health. In particular, in such cases, all provincial insurance legislation should require that insurers offer a community-rated insurance policy if the type of policy in question is determined to be a necessary good. In the section of this thesis that dealt with the science of genetics, a distinction was made between single-gene disorders and single-gene susceptibilities. While some single-gene disorders almost inevitably lead to disease, such as Huntington's disease, single-gene susceptibilities are less 'determinant' than single-gene disorders, since they only indicate an increase in the risk of developing disease (Lemmens and Bahamin 131). The level of uncertainty increases in the case of multifactorial disorders, which are caused by the interaction between several genes and environmental factors. The majority of genetic disorders fall into this category.

The two breast cancer genes that have been identified are a good example of susceptibilities, because although they indicate an 87% chance of developing the disease before the age of 80, those statistics clearly allow for much uncertainty (Lemmens and
Bahamin 136). For example, some of the women only develop the disease very late in life, and 13% of those who carry one of the two genes never develop the disease. Since genetic susceptibilities indicate a high degree of uncertainty, they should not be used for underwriting by insurers provided that there is no clinical evidence of disease. On the other hand, justice would require that traditional medical information or genetic information that seems to indicate inevitable disease, such as in the case of Huntington’s disease, be used for underwriting by the insurance industry. The argument being made is that risk-spreading is appropriate in the case of uncertainty, but not in cases where there is almost certainty regarding future disease. This is not to suggest that those who are most likely to become ill should be left without basic forms of insurance. A proposal regarding how such cases could be handled will be offered later in this thesis.

Another important factor to consider is whether the genetic defect being dealt with involves an early-onset disease or a late-onset disease. This becomes relevant in the case of insurance, because insurers’ concern with respect to high-risk applicants is that they will become sick and collect from the insurer before they have contributed enough to cover their costs to the insurer. In the case of a late-onset disorder, an applicant under the age of thirty-five probably has another thirty years before he or she becomes affected by the disease. During this time, that individual will be paying premiums to the insurer. On the other hand, those carrying a copy of the Huntington’s gene develop the disease between the ages of thirty and fifty, so it would be inappropriate, for example, for a thirty-five year old insurance applicant who carries the Huntington’s gene to be offered disability insurance at the standard rate.
Yet persons who have the genetic disorders that seem to indicate certain disease should not be rendered uninsurable. It may be acceptable, however, to demand higher premiums from such applicants. Any solution to the problem of the use of genetic information by insurers must demand that as many people as possible have access to insurance. Yet for life insurance, for instance, Lemmens and Bahamin argue quite rightly that "acknowledging...the survival of the insurance industry is an essential element of any solution. The durability of insurance should not be threatened by allowing unlimited insurance coverage for people who know that they are at high risk" (Lemmens and Bahamin 185). For example, Mark Rothstein points out that it would clearly be unethical for an applicant identified with presymptomatic Huntington's disease to obtain a $5 million life insurance policy at the standard rate (Rothstein, “Genetics” 168).

Both liberal theory and the communitarian understanding of justice emphasize the importance of equality of opportunity. This thesis has suggested that equality of opportunity requires that individuals have access to a minimum amount of life insurance regardless of medical or genetic factors, perhaps at rates slightly higher than the standard rate if medical or genetic factors seem to indicate that disease is inevitable. For example, the Canadian Privacy Commission has suggested that insurers do not underwrite for life insurance policies under $100,000 (Rothstein, “Genetics” 170). Such a policy already exists in the U.K., where genetic tests which are to the detriment of applicants for life insurance up to $250,000 will be ignored when the insurance is connected to a new mortgage for a home (Pokorski 836).

In the case of almost inevitable disease, however, insurers may be forced to set premiums so high (to cover their predicted costs) that insurance will no longer be
affordable for such individuals. These cases will be quite rare, since we have seen that most genetic information involves much uncertainty. But when such cases do arise, a subsidized government program should be available for these extremely high-risk individuals. Such a program is necessary because it was demonstrated above that access to some forms of insurance is essential to equality of opportunity for participation in Canadian society. Some may be disappointed that this solution involves using tax money to subsidize this government insurance program, since these high-risk individuals will not be contributing enough in insurance premiums to cover their costs to the program. Yet leaving individuals uninsured for basic needs may cost taxpayers indirectly through other government programs. In fact it may cost taxpayers more, since a government insurance program will be covering at least a portion of their costs through the premiums contributed by the high-risk individuals.

It has also been made clear that underwriting for all susceptibilities may not be in the best interests of the insurer. First, it would be impractical, since it is estimated that each person carries between five and seven lethal recessive genes (Anderson 1504). In other words, it is not useful to underwrite for susceptibilities if all applicants are generally in the same position with respect to susceptibilities. It would make more sense to underwrite in the rare cases where future disease is certain. Second, since the purpose of underwriting is to prevent adverse selection, it would be unnecessary to underwrite for susceptibilities because they create little threat of adverse selection compared to genetic disorders that indicate inevitable disease. This is particularly true if each person carries several susceptibilities. The irony is that as geneticists are able to test for more genetic conditions, adverse selection will become less of a problem, since very few individuals
will be in a position to avoid purchasing insurance because they have found out that their genetic constitution presents no risk of disease. Furthermore, in the second section of the thesis it was shown that there is opportunity for insurers to make a profit even when most of their policies are community rated, as long as all insurance companies are required by provincial insurance legislation to community rate under certain conditions. Insurers would be able to use any medical or genetic information, regardless of whether it implied inevitable disease, or merely susceptibility to disease, in cases where the type of insurance being purchased was deemed to be a non-necessary good (such as $1 million life insurance policies). This would require, of course, that there was actuarial justification for using the information in question.

Any reform of the insurance industry should also include legislation that prevents insurers from demanding applicants take genetic tests as a condition of eligibility. Although this thesis has not particularly defended a ‘right not to know’, such a right can be assumed at this stage in our knowledge of genetics, since few treatments are available for the genetic disorders that we can diagnose. Individuals who are forced to discover that they carry genetic disorders could be harmed psychologically by finding out about future disease that they are unable to prevent or cure. Preventing insurance companies from demanding genetic testing will not encourage individuals to avoid genetic testing for fear of being left uninsurable, since the insurance model recommended here would guarantee Canadians basic insurance regardless of genetic testing results.

The solution proposed in this thesis does not offer any easy answers, since it requires that we make specific choices with respect to which genetic mutations seem to indicate inevitable disease, what rates are fair to those who have been identified as
carriers of genes that will almost certainly lead to disease, and who should qualify for the subsidized government insurance program. Most of these issues will have to be dealt with before any changes are made to the insurance industry, but some of the policies will change in the future as more information regarding the human genome is discovered. Yet the advantage of this solution is that it allows Canadians to undergo genetic testing without fear of being left uninsurable. The achievements of scientists in the field of genetics would be in vain if medicine was unable to benefit from genetic information simply because individuals were avoiding genetic testing. Another obvious benefit to this solution is that it deals with genetic information in the same way it deals with traditional medical information. This is important to any constructive ethic regarding the use of genetic information by insurers, since we saw in the second section of the thesis that not only is it often difficult to distinguish between genetic information and traditional medical information, but it is also difficult to demonstrate that genetic information is different from other medical information in a morally relevant way.

The recommendations made in this thesis can be summarized in 8 principles:

1) All Canadians, regardless of their medical history or genetic constitution, should have access to necessary (basic) forms of insurance (a balanced committee consisting of insurance representatives, consumer advocacy groups, economists, ethicists, and government representatives should determine which forms of insurance fall under this category).

2) Private insurance companies should be reformed only in such a way that they are able to remain profitable.
3) Provincial insurance law should prohibit private insurers from using traditional medical information and genetic information for the purpose of underwriting unless that information seems to indicate inevitable future disease. In all other cases, policies should be community-rated.

4) In the case that an applicant's genetic or medical information seems to indicate inevitable disease, private insurers should consider whether the predicted future disease is an early-onset disease or a late-onset disease when adjusting premiums.

5) In the case that the adjusted premium becomes unaffordable (such as the case of early-onset inevitable disease), a subsidized government program should cover such applicants for basic insurance.

6) Private insurers should not be permitted to ask applicants to undergo genetic testing as a condition of eligibility, although they should be able to use the results of genetic tests already taken which seem to indicate inevitable disease.

7) In order to prevent adverse selection by low-risk individuals, policy-makers should structure policies in such a way that as many people as possible purchase insurance. For instance, a minimum amount of life insurance should be required to acquire mortgages or to start a business. The non-biased committee mentioned above could also ensure that such policies do not ignore particular segments of society (such as low-income families who do not own their own home and do not have their own business).

8) Applicants should only be forced to authorize disclosure with respect to the results of genetic tests already taken that involve genetic disorders which seem to imply
inevitable disease. If applicants refuse to authorize disclosure, they can be denied insurance in any form.
CONCLUSION

These recommendations are meant to balance the benefits of liberal, free-market principles with the advantages of communitarian principles. Both communitarian theory and liberal theory emphasize the importance of access to basic instrumental goods for preserving equality of opportunity. Rawls' 'veil of ignorance' also demands that individuals protect their self-interest by making sure all have access to basic forms of insurance. The proposal presented also involves an insurance model that maintains the principal role for private insurers. It allows for Canadians to be given room for choice when purchasing insurance, since non-necessary forms of insurance will also be available for purchase. Most importantly, the recommendations made here promote the societal goals of insurance, such as risk-spreading, while protecting the financial interests of private insurers.
Works Cited


McGleenan, Tony. "Rights to Know and Rights not to Know: Is There a Need for a Genetic Privacy Law?" In Chadwick, Ruth, Levitt, Mairi, and Darren Shickle, eds. Right to Know and Right not to Know.


Murray, Thomas H. "Ethics, Genetic Prediction, and Heart Disease." American Journal of Cardiology 72 (Sept. 30, 1993): 80D-84D.


