
Selective Justice, Genetic Discrimination, and Insurance: Should We Single Out Genes in Our Laws?

Trudo Lemmens*

This article discusses the desirability of legislation focusing on genetic discrimination, in particular in the context of insurance. Many American states and some European countries as well as the Council of Europe have introduced protective measures against discrimination on the basis of genetic susceptibility. The author questions their effectiveness and queries whether they may be inequitable, because they fail to address more fundamental underlying issues related to the nature of insurance, access to health care, and unequal distribution of wealth. There is also a problem of definition in these statutes. They fail to capture what constitutes genetic information. Nonetheless, the author argues it is important to consider the social consequences of genetic testing.

Michael Walzer's theory of justice is used to examine the role of insurance and health care. Using this approach, the author finds the American system of distribution for health care to be problematic. This is then used to inform the author's discussion of the future of health care in Canada.

Anti-discrimination provisions could be used in a way that is consistent with Walzer's theory of justice. They would encompass both genetic and non-genetic health factors. These can be modelled on current anti-discrimination statutes in Canada. The author then proposes administrative committee structures to regulate the use of genetic data in Canada.

Cet article met en cause le bien-fondé de l'adoption de lois portant sur la discrimination génétique, en particulier dans le domaine de l'assurance. Plusieurs états américains, ainsi que certains pays européens et le Conseil de l'Europe, ont adopté des mesures visant à protéger les individus contre la discrimination basée sur la susceptibilité génétique. L'auteur remet en question l'efficacité de ces mesures et leur équité, étant donné qu'elles ne s'attaquent pas à nombre de problèmes plus fondamentaux reliés à la nature même de l'assurance, à l'accessibilité aux soins de santé et à l'inégalité dans la distribution des richesses. Leur peu de réussite à identifier correctement, dans leurs définitions, ce qui constitue de l'information génétique les affaiblit davantage.

Néanmoins, l'auteur soutient qu'il est important de tenir compte des conséquences sociales des tests génétiques. La théorie de la justice avancée par Michael Walzer, lorsque utilisée afin d'étudier le rôle de l'assurance et des soins de santé, révèle que le système américain de distribution des soins de santé soulève plusieurs problèmes. Ces constatations servent alors de guide à la discussion de l'auteur sur l'avenir du régime de soins de santé au Canada.

Les dispositions anti-discrimination pourraient être utilisées de manière compatible avec la théorie de la justice de Walzer. Elles incluraient alors des facteurs de santé autant génétiques que non-génétiques, et suivraient le modèle fourni par les lois anti-discrimination existantes au Canada. L'auteur propose finalement l'institution de comités administratifs pour régler l'utilisation de données génétiques au Canada.

* Assistant Professor, Faculty of Law and Department of Medical Genetics and Microbiology, University of Toronto. Earlier and reduced versions of this paper were presented at "Human Rights into the Twenty-first Century: A Conference in Celebration of the 10th Anniversary of the International Human Rights Programme", Faculty of Law, University of Toronto, 3 October 1998; at the annual Atlantic Research Centre Symposium, Dalhousie University; and at the University of Toronto Joint Centre for Bioethics Seminar Series. I want to thank Laura Purdy and Leigh Turner for helpful comments on this earlier version. I am very much indebted to Laura Wiebe for research assistance and to Paul Miller for editorial comments. Research for this paper was supported by a Research Grant of the Canadian Breast Cancer Research Initiative (National Cancer Institute). Parts of this article are further developments of earlier work. See T. Lemmens, *infra* note 4; T. Lemmens & P. Bahamin, *infra* note 18.

Introduction

- I. Gene Fright**
- II. Is There Genetic Discrimination in Canada?**
- III. Regulatory Responses to Genetic Discrimination**
- IV. Prohibitory Approaches in Reaction to the Threat of Genetic Discrimination**
- V. International Reactions**
- VI. Genetic Discrimination Legislation in the United States**
- VII. Genetic Privacy Acts**
- VIII. Why Legislative Initiatives Focusing on Genetics?**
- IX. The Efficacy of Statutes Focusing on Genetics**
- X. What is "Genetic Data"?**
- XI. The Claim of Genetic Exceptionalism**
- XII. How Genetics Highlights Existing Problems**
- XIII. Degrees of Unfairness**
- XIV. Insurance Underwriting, Adverse Selection, and Fairness**
- XV. Health Care and Insurance in a Just Society**
- XVI. Fairness in Access to Health Care in the United States**
- XVII. Fairness and Genetic Discrimination Statutes in Europe**
- XVIII. Lessons for the Canadian Health Care and Insurance Systems**
- XIX. Regulatory Framework in Canada**
- XX. Human Rights Exceptions for Insurance Discrimination**
- XXI. Curbing Potential Negative Consequences of Genetics in Canadian Health Care and Insurance**
- XXII. Proposals for Specialized Commissions Responsive to Societal Concerns**

Conclusion

Introduction

When the Belgian Parliament discussed what was to become the world's first insurance law to have a sweeping prohibition on the use of genetic data for underwriting purposes,¹ a senator argued that the provisions focusing on genetic information were unfair, insofar as they discriminated against people affected by other health conditions.² He pointed out, as an example, that high cholesterol levels are already used to determine one's risk in insurance terms and that there is no reason to protect carriers of a genetic susceptibility more than those having high cholesterol levels. Both are statistically predicative of increased risk to health but do not offer certainty on an individual level. His example is perhaps not the most appropriate one—research indicates that high cholesterol levels may very well be associated with specific genetic mutations³—but it touches upon one of the most fundamental problems of the current wave of genetic anti-discrimination provisions.

In this paper, I will argue that statutes singling out genetic susceptibility as a category, and offering it much wider protection than other similar health conditions, although intended to promote equity in access to social goods, may themselves be ineffective and to some extent even inequitable. I will discuss the way in which many policy analysts in the United States have embraced anti-discrimination and privacy legislation focusing on genetics as an imperfect way of protecting an already insufficient degree of access to health care. I will suggest that this may lead to the ignoring of more fundamental issues related to the nature of insurance, access to health care and unequal distribution of wealth. Moreover, I will argue that many of the genetic anti-discrimination and genetic privacy statutes are flawed, because they fail to capture what constitutes genetic information.

However, I will not argue that it is unreasonable to pay particular attention to the social consequences of genetic testing. While genetic testing does not necessarily raise entirely new issues, it does highlight existing problems in, for example, access to health care and financial security. Referring to Michael Walzer's theory of justice, I will analyse the role of insurance and suggest that such analysis reminds us that health care ought to be offered on the basis of need.⁴ Walzer's theory is useful when thinking

¹ *Wet 25 juni 1992 op de landsverzekeringsovereenkomst*, B.S. 20 August 1992.

² H. Cousy & G. Schoorens, *De nieuwe wet op de landverzekeringsovereenkomst. Parlementaire voorbereiding van de Wet van 25 juni 1992 en van de wijzigende Wet van 16 maart 1994* (Antwerp: Kluwer, 1994) at 306.

³ See e.g. I. Oren *et al.*, "The D Allele of the Angiotensin-converting Enzyme Gene Contributes Towards Blood LDL-cholesterol Levels and the Presence of Hypertension" (1999) 145 *Atheroscler.* 267 and D.J. Waxman, "P450 Gene Induction by Structurally Diverse Xenochemicals: Central Role of Nuclear Receptors CAR, PXR, and PPAR" (1999) 369 *Arch. Biochem. Biophys.* 11.

⁴ I presented a first analysis of the relevance of Walzer's theory at the International Conference on Genetic Information: Acquisition, Access and Control, Preston (U.K.), 5-6 December 1997. See T. Lemmens, "Private Parties, Public Duties? The Shifting Role of Insurance in the Genetics Era" in A. Thompson & R. Chadwick, eds., *Genetic Information: Acquisition, Access, and Control* (New York:

about the lessons we can learn from the U.S. debate on genetic discrimination and from the European initiatives in this area. I will argue that genetic anti-discrimination statutes, and the justification given for their introduction, highlight fundamental problems in the U.S. with respect to fair distribution of health care as a social good. The saga of these statutes, and the patchwork approach they represent, has to be revealed when discussing the future of the health care system in Canada and the need for specific anti-discrimination statutes. The European initiatives in the context of genetic discrimination are of particular interest to us, because they have arisen in countries with some form of universal access to health care.

Finally, I will suggest how we can use anti-discrimination provisions in the context of insurance in a way that would be congruent with Walzer's theory of justice, based on a fair distribution of goods. This solution should encompass both genetic and non-genetic health factors and should respect our communal understanding of what constitutes a fair distribution of or fair access to goods, taking into consideration the meaning of these goods in our society. Some current anti-discrimination statutes in Canada and the regulatory framework developed by these statutes could be used as models for a flexible system to address the potential negative consequences of discrimination resulting from indicators of future health, including genetic testing. This model will be helpful not only to address questions with respect to the reasonableness of insurance discrimination, but also to analyze discrimination in the context of, for example, employment. Considering the pace of development of genetic technologies, it is crucial to think of an administrative structure which can respond adequately and swiftly when protection of human rights is needed, without falling back on patchwork regulations that are inconsistent with global social policies. A committee structure could be developed, in which the necessary expertise, representation and scientific support is ensured to enable committee members to engage in socially responsible debate over the appropriate use of this technology and, if necessary, in regulatory action.

I. Gene Fright

Although genetics has become medicine's most powerful modern tool to understand and control health and disease, many observers have raised concerns about the dangers of discriminatory practices resulting from genetic testing. Alarmist predictions of the early 1990s, suggesting that we are on the verge of the creation of a new social class, a genetic proletariat, a class of people who are excluded from many aspects of ordinary social life solely because of their genetic make-up,⁵ have not yet come true. Early reports indicate that insurers have an interest in using genetic infor-

Plenum Press, 1999) 31. I am indebted to Benjamin Freedman and Charles Weijer for discovering the importance of Michael Walzer for analyzing issues of justice in health care. See Walzer, *infra* note 152.

⁵ R.C. Dreyfuss & D. Nelkin, "The Jurisprudence of Genetics" (1992) 45 Vand. L. Rev. 313; P.R. Billings *et al.*, "Discrimination as a Consequence of Genetic Testing" (1992) 50 Am. J. Hum. Genet. 476.

mation and that they often are ill informed about the significance of genetic data.⁶ However, systematic testing does not seem to take place at this time. Some of the authors who first drew attention to cases of discrimination based on genetic susceptibility are now also suggesting that "the use of genetic information by insurance companies and other institutions is quite limited."⁷ So far, insurers have not been particularly interested in using genetic testing as an underwriting tool for several reasons. Fear of negative public reactions is certainly among them. Other reasons include the prohibitive cost of genetic testing⁸ and the complexity of the information gained from genetic testing.

The fear of genetic discrimination continues, however, to be exacerbated by developments in genetic research. Research into the development of DNA chip and microarray technology, which makes it possible to "scan" entire genes for the detection of different mutations, will bring to the market diagnostic tools that are faster, more efficient, and cheaper.⁹ Prominent genetic researchers such as Francis Collins predict that it will be possible in the future to undergo a battery of genetic tests and to have information about a variety of susceptibility genes and potential prevention strategies.¹⁰ The interest in conducting and undergoing such tests as part of medical research and treatment will also increase with the development of pharmacogenomics.¹¹ Pharmacogenomics is the area of genetic research that analyses how drug therapies may impact differently depending on individual people's specific genetic code. It is expected that the identification of genetic variations will make it possible to provide treatment that is tailored to an individual person's genetic structure. This may create a situation in which predictions can be made about an individual's expected health care expenditures.

The capacity to conduct such tests quickly and, more importantly, cheaply will boost demand, commercial production and distribution of the tests, making it potentially cost-effective to introduce genetic screening in a variety of non medical settings,

⁶ See *ibid.*; M.R. Natowicz, J.K. Alper & J.S. Alper, "Genetic Discrimination and the Law" (1992) 50 *Am. J. Hum. Genet.* 465; and L.N. Geller *et al.*, "Individual, Family and Societal Dimensions of Genetic Discrimination: A Case Study Analysis" (1996) 2 *Sci. Eng. Ethics* 71.

⁷ J. Beckwith & J.S. Alper, "Reconsidering Genetic Antidiscrimination Legislation" (1998) 26 *J. L., Med. & Ethics* 205 at 206 [hereinafter "Genetic Antidiscrimination"].

⁸ R.E. Braun, "Keeping Life Insurance Affordable in the Era of Genetic Medicine" (September 1999) *J. Finan. Serv. Prof.* 46 at 47.

⁹ For a recent overview of new genetic technology and its impact on medicine, see K.M. Kurian, C.J. Watson & A.H. Wyllie, "DNA Chip Technology" Editorial Comment (1999) 187 *J. Pathol.* 267; see also S.J. Watson & H. Akil, "Gene Chips and Arrays Revealed: A Primer on Their Power and Their Uscs" (1999) 45 *Biol. Psychi.* 533; for a view on the ethical implications of this technology, see W. Henn, "Genetic Screening with the DNA Chip: A New Pandora's Box?" (1999) 25 *J. Med. Ethics* 200.

¹⁰ F.S. Collins, "Shattuck Lecture—Medical and Societal Consequences of the Human Genome Project" (1999) 341 *New Engl. J. Med.* 28 at 33-34.

¹¹ See R.P. Erickson, "From 'Magic Bullet' to 'Specially Engineered Shotgun Loads': The New Genetics and the Need for Individualized Pharmacotherapy" (1998) 20 *Bioessays* 683.

including insurance, employment, and immigration. A further hurdle to the use of genetics as a testing tool in insurance, employment, and other areas is also gradually disappearing. The "wait-and-see approach" towards genetic testing,¹² for example, is partly due to the fact that many of the associations between genetic mutations and increased risk for disease remain within the confines of research. As Lowden argues, "Research results, on their own merit, should have little interest for insurers, employers, and others, because without associated data on the consequences of mutations in individuals who were asymptomatic at the time of testing, the results will lack predictive value."¹³

Since insurance underwriting is based on detailed actuarial predictions of risk, most genetic findings so far have not been integrated into underwriting procedures because of the lack of clear data. However, large population studies are underway to establish risk predictions more precisely, for example in the context of hereditary breast cancer.¹⁴ In the future, more and more reliable risk information will become available on a variety of diseases. Increased accuracy of genetic risk calculations combined with cheaper and faster genetic detection of a variety of mutations will constitute a significant incentive to conduct genetic testing outside the medical context. The commercial interests in this booming technology are huge. Notwithstanding ethical concerns about the premature introduction of new tests, these interests will inevitably create pressures for faster integration of genetic testing into daily clinical practice.¹⁵ It can be expected that the predictive value of genetic tests will be used in the determination of insurance premiums, and will lead to increasing individualization of underwriting.

II. Is There Genetic Discrimination in Canada?

In Canada, there are no reports of systematic genetic testing undertaken by an insurance company as part of the underwriting process.¹⁶ However, family traits are taken into consideration for the determination of individual life and disability insurance premiums and people may have difficulty obtaining insurance when they partici-

¹² J.A. Lowden, "Genetic Discrimination and Insurance Underwriting" Letter to the Editor (1992) 51 Am. J. Hum. Genet. 901-02.

¹³ J.A. Lowden, "Certificates of Confidentiality" Letter to the Editor (1996) 58 Am. J. Hum. Genet. 436 [hereinafter "Certificates of Confidentiality"].

¹⁴ D. Shattuck-Eidens *et al.*, "BRCA1 Sequence Analysis in Women at High Risk for Susceptibility Mutations" (1997) 278 J. Am. Med. Assoc. 1242; B.L. Weber, "Update on Breast Cancer Susceptibility Genes" (1998) 152 Recent Results Cancer Res. 49.

¹⁵ T. Caulfield, "Genetic Testing in the Biotech Century: Are Physicians Ready?" (1999) 161 C. Med. Assoc. J. 1122. For discussions of several aspects of the commercialization of genetics, see T.A. Caulfield & B. William-Jones, eds., *The Commercialization of Genetic Research: Ethical, Legal, and Policy Issues* (New York: Kluwer Academic, 1999).

¹⁶ Underwriting is the actuarial process by which insurance companies determine an insurance applicant's risk status and the commensurate premium to be charged to that applicant. See below for a more detailed discussion of the role genetics could play in this process.

pate in research that reveals that they are carrying a specific genetic mutation. A clear example of this would be a positive test result for Huntington's disease, a late-onset dominant genetic disorder. Those who carry one copy of the Huntington's mutation know with near certainty that they will develop the fatal condition, likely before the age of 50.¹⁷ Testing positive almost inevitably affects insurability. People will be excluded, either from any form of coverage or from coverage for death or disability as a result of Huntington's. There are also reports of people with a family history of Huntington's disease who had not yet undergone genetic testing but were refused coverage and told that they could undergo testing to qualify for insurance.¹⁸ According to one of these anecdotal reports, an insurer informed an applicant to reapply "should his health improve". The insurer thereby either tried to put pressure on the applicant to undergo testing, or else demonstrated a clear lack of understanding of the nature of this genetic disorder. This anecdote shows why Huntington's is also an interesting example of how genetic testing may improve insurability of people who have problems obtaining insurance because of a family history. While positive test results for a genetic condition may hinder someone's insurance application, a negative test result may often make it possible for people who were previously uninsured to obtain insurance.

Huntington's is not the only disease of which the test results may be used in the insurance context. In interviews undertaken as part of an ongoing study on breast cancer and insurance, participants who tested positive for one of the breast cancer genes expressed concerns about keeping insurance coverage and about shielding access to that information. Two participants could not obtain insurance coverage, but not directly as a result of genetic testing. One woman was denied coverage on the basis of family history of breast cancer, another tested positive for one of the breast cancer genes, but had insurance problems because she was also diagnosed as having breast cancer.¹⁹

A 1990 Quebec case involving myotonic dystrophy gives us an indication of the type of issues that are likely to become the subject of court procedures as a result of genetic developments. In *Audet v. Industrielle-Alliance*, the Superior Court annulled

¹⁷ However, recent studies raise doubt about the assessment that a positive test indicates a certainty of developing the disease. See "Genetic Antidiscrimination", *supra* note 7 at 208 and reference there.

¹⁸ T. Lemmens & P. Bahamin, "Genetics in Life, Disability and Additional Health Insurance in Canada: A Comparative Legal and Ethical Analysis" in B.M. Knoppers, ed., *Socio-Ethical Issues in Human Genetics* (Cowansville, Qc.: Yvon Blais, 1998) 107 at 122-23, nn. 10, 15.

¹⁹ Information reported by Angela Shik, who is conducting interviews as part of a research project funded by the National Cancer Institute of Canada to study the medical, ethical, and legal implications of breast cancer genetics on insurance. (Co-Principal Investigators on the grant are Dr. Donna Stewart, Trudo Lemmens & Dr. Angela Cheung.) Interviews and surveys for this research project are still being conducted.

the life-insurance contract of Mr. Tremblay, a man who had died in a car-accident.²⁰ Mr. Tremblay carried the genetic mutation for myotonic dystrophy of Steinert and had been informed about this. He also knew that his father and brother had the disease. Myotonic dystrophy is a degenerative disease, which can be extremely disabling in some, while affecting others only mildly. When applying for insurance, the insurer had asked Tremblay whether he had any physical or mental anomaly. He answered no to that question. The court decided that this amounted to a false declaration, even if the disease was expressed only very mildly in him and even though his widow suggested he was "super normal" from any point of view.²¹ As a result, the court annulled the contract *ab initio*.

Increasingly, the results of genetic tests will be integrated into medical files and will become part of the array of common diagnostic tests. Insurance applicants will have to be aware of their obligation to divulge the results of tests that indicate a higher than average risk for disease or premature death. The *Audet* case highlights possible consequences of non-disclosure, while also indicating that efforts have to be made to help people understand the nature of the risk information.

III. Regulatory Responses to Genetic Discrimination

There is, in other words, reason for concerned reflection on the potential implications of genetic testing for insurance. So far, two different strategies have dominated the debate. One approach has been to require limitations on the contractual liberty of parties to an insurance contract. Many authors urged for such a prohibitory approach based on either anti-discrimination law or specific prohibitions integrated within insurance statutes. Several countries and American states have responded to this call, while insurance organizations in other countries replied by implementing moratoria on the use of genetic testing. A second approach has been to urge for more sophisticated privacy legislation to protect genetic data from being distributed without the consent of those involved. This comes down to granting individuals more power over genetic information without necessarily restricting its use. Some statutes, particularly in the United States, combine elements of both: they provide protection against discrimination and contain protection of privacy clauses.

I will first briefly describe how these two approaches have been implemented in some European countries and in the United States. I will then discuss the rationale for these particular initiatives, and assess whether there is reason to single out genetic information. I will then deal with the question whether these approaches are effective and equitable.

²⁰ [1990] R.R.A. 500 (Sup. Ct.) [hereinafter *Audet*]. See the discussion in Lemmens & Bahamin, *supra* note 18 at 139, 165-66; H. Guay, B.M. Knoppers & I. Panisset, "La génétique dans les domaines de l'assurance et de l'emploi" (1992) 52 R. du B. 185 at 209-10.

²¹ *Audet*, *ibid.* at 502.

IV. Prohibitory Approaches in Reaction to the Threat of Genetic Discrimination

Among the measures to curb the negative social consequences of genetics, the cry for a prohibitory approach has been most prominent. In particular, since the early 1990s, the fear of exclusionary practices based on genetic susceptibility has resulted in calls for legislative intervention. With these calls, a new concept emerged: genetic discrimination. This concept, now firmly established in the legal and bioethics literature and translated into different statutes, has been defined in various ways.²² The varying definitions found in the literature already indicate its problematic nature. Some describe it in general terms as any form of differentiation based on genetic information. Mark Rothstein uses the term to describe "differential treatment based on genetic status."²³ According to Larry Gostin, genetic discrimination is "the denial of rights, privileges or opportunities on the basis of information obtained from genetically-based diagnostic and prognostic tests."²⁴ In contrast, in one of the first studies analyzing occurrences of genetic discrimination, Paul Billings *et al.* define genetic discrimination as "discrimination against an individual or against members of that individual's family solely because of real or perceived differences from the 'normal' genome of that individual."²⁵ They thereby distinguish it from "discrimination based on disabilities caused by altered genes."²⁶ In this view, the criterion for genetic discrimination is whether the disease has actually occurred or not. If the disease has not yet occurred, the discrimination is termed genetic. If the disease is expressed, it becomes another type of discrimination, most likely discrimination based on someone's health condition. Michael Yesley also mentions that "[t]he quintessential feature of genetic discrimination is the use of genetic information about an asymptomatic person."²⁷

²² See e.g. J.S. Alper *et al.*, "Genetic Discrimination and Screening for Hemochromatosis" (1994) 15 J. Pub. Health Pol'y 345; Geller *et al.*, *supra* note 6; L. Gostin, "Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers" (1991) 17 Am. J. L. & Med. 109 [hereinafter "Genetic Discrimination"]; C. Lee, "Creating a Genetic Underclass: the Potential for Genetic Discrimination by the Health Insurance Industry" (1993) 13 Pace L. Rev. 189; and Natowicz, Alper & Alper, *supra* note 6.

²³ M.A. Rothstein, "Genetic Discrimination in Employment: Ethics, Policy and Comparative Law" in Swiss Institute of Comparative Law, ed., *Human Genetic Analysis and the Protection of Personality and Privacy* (Zürich: Schulthess Polygraphischer Verlag, 1994) 129 at 129.

²⁴ *Supra* note 22 at 110.

²⁵ Billings *et al.*, *supra* note 5. A similar definition is given in Natowicz, Alper & Alper, *supra* note 6. See also two other publications of the same research group: Alper *et al.*, *supra* note 22 at 345, where they describe genetic discrimination as "discrimination against an asymptomatic individual who is found to have an abnormal genotype and, as a result, considered to be affected according to the redefinition of the disease"; and Geller *et al.*, *supra* note 6 at 72, where they define it in a more succinct way as "differential treatment of individuals or their relatives based on actual or presumed genetic differences as opposed to discrimination based on phenotype."

²⁶ Billings *et al.*, *ibid.*

²⁷ M.S. Yesley, "Protecting Genetic Difference" (1999) 13 Berkeley Tech. L.J. 653 at 662.

The distinctions made by these authors may be untenable. What if a genetic condition is only mildly expressed, but an individual is excluded solely on the basis of a genetic test? For the purpose of this paper, genetic discrimination ought not to be defined in such a narrow manner. It suffices to say that genetic discrimination is a term used in a variety of settings in which people are considered to be disadvantaged or at risk for being so, on the basis of factors related to genetics.

V. International Reactions

The authors who conducted studies on genetic discrimination are not alone in their concerns. Reports and statements by a variety of national and international organizations express a similar desire for regulatory interventions. On an international level, the World Medical Association issued in 1992 a *Declaration on the Human Genome Project*, in which it suggests that “[i]t may be desirable, regarding genetic factors, to adopt the same tacit consensus which prohibits the use of race discrimination in employment or insurance.”²⁸ More recently, in November 1997, UNESCO approved a long-debated *Universal Declaration on the Human Genome and Human Rights*.²⁹ The *Universal Declaration* provides in its section 6 that “[n]o one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity.” The *Universal Declaration* further stresses the importance of confidentiality of genetic data,³⁰ the need for informed consent and the right of individuals to decide whether they want to be informed of a genetic condition.³¹

The World Health Organization is in the process of adopting general bioethics guidelines. While highlighting the incredible potential of the new genetics, the *Draft World Health Organization (WHO) Guidelines on Bioethics* state that “[t]he new biotechnology also has potential to cause major harm if misapplied or misused”³² and that “[g]enetic information should not be used as the basis for refusing employment or insurance.”³³

In many countries, national task forces were set up as early as 1987 to discuss the social risks of the new genetics, but real initiatives did not take place until the 1990s. A German parliamentary committee recommended in 1987 that the use of genetic testing for insurance purposes should be prohibited, although it made an exception for

²⁸ World Medical Association, 44th Assem., *World Medical Association Declaration on the Human Genome Project*, Doc. 17 S/1 (1992).

²⁹ *Universal Declaration on the Human Genome and Human Rights*, UNESCO, 29th Sess., 29 C/Resolution 19 (1997) [hereinafter *Universal Declaration*].

³⁰ S. 7.

³¹ Ss. 5, 9.

³² *Draft World Health Organization (WHO) Guidelines on Bioethics* (1999), online: Nature: International Weekly Journal of Science <<http://helix.nature.com/wcs/b23a.html>> (date accessed: 8 January 2000) [hereinafter *Draft Guidelines*].

³³ *Ibid.*

genetic conditions with a certain and determined prognosis.³⁴ In 1989, a Committee of the Health Council of the Netherlands and the Danish Board of Technology both recommended that legislation be implemented to deal with the issue. The Dutch report suggests that limitations to insurers' right to use genetic data are appropriate, without excluding the use entirely,³⁵ while the Danish Board states that gene analysis should never be the basis of insurance underwriting.³⁶ The latter opinion is expressed in a 1989 resolution of the European Parliament.³⁷

In the 1990s in Europe, these calls and formal recommendations resulted in two approaches: either stringent legislation or the voluntary imposition of a moratorium by the insurance industry.³⁸ The member states of the Council of Europe³⁹ have recently come under a much stronger obligation to deal with genetic discrimination by prohibitory legislative measures. On 19 November 1996, the Committee of Ministers adopted the *Convention on Human Rights and Biomedicine*,⁴⁰ which focuses on the protection of human dignity, identity, and integrity in medicine. The *Convention* includes a specific chapter on the human genome project. Article 11 states: "Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited."⁴¹ Furthermore, article 12 of the *Convention* explicitly prescribes that genetic testing may be performed for health care purposes or for scientific research only. It

³⁴ W-M. Catenhusen & H. Neumeister, eds., *Enquete-Kommission des Deutschen Bundestages, Chancen und Risiken der Gentechnologie, Dokumentation des Berichts an den Deutschen Bundestag* (Frankfurt: Campus Verlag, 1987), in particular at xxxiv, 173-75.

³⁵ *Heredity, Science und Society: On the Possibilities and Limits of Genetic Testing and Gene Therapy: Report Submitted by a Committee of the Health Council of the Netherlands* (The Hague, 1989) at 133.

³⁶ Danish Board of Technology, *Final Report of the Consensus Conference on the Application of Knowledge Gained from Mapping the Human Genome* (1989).

³⁷ EC, *Resolution on the ethical and legal problems of genetic Engineering* [1989] O.J. C. 96 at 165.

³⁸ For a more detailed discussion of the international initiatives, see Lemmens & Bahamin, *supra* note 18; see also E. Masood, "Gene Tests: Who Benefits from Risk?" (1996) 379 *Nature* 389.

³⁹ The Council of Europe was established in 1949 and has 38 member states. The first major convention adopted by the Council was the 1950 *Convention for the Protection of Human Rights and Fundamental Freedoms*. The work of the European Commission on Human Rights and the European Court of Human Rights, now integrated in one Court of Human Rights has had a major impact in the development of human rights law in Europe.

⁴⁰ Council of Europe, *Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine*, E.T.S. No. 164 (1997) [hereinafter *Convention*]. As of December 1, 1999, 28 states have signed the convention, 6 of which also ratified it. The *Convention* entered into force on December 1, 1999 (for updated information, see the Website of the Council of Europe, <<http://www.coe.fr/eng/legal/txt/164t.htm>> (date accessed: 27 April 2000)). For a comparison between U.S. statutes and the provisions in the European *Convention* dealing with genetics and for an interesting discussion of the potential impact of the *Convention* on insurance issues, see A. Lawton, "Regulating Genetic Destiny: A Comparative Study of Legal Constraints in Europe and the United States" (1997) 11 *Emory Int. Law Rev.* 365.

⁴¹ *Convention, ibid.*, art. 11.

also specifies that appropriate genetic counselling should be provided.⁴² The strict character of the prohibition against discrimination on genetic grounds is highlighted by the fact that signatories to the *Convention* cannot restrict the exercise of the rights protected by articles 11 and 12. According to article 26(1), states can restrict rights and protective provisions of the *Convention* by law and when necessary "in a democratic society in the interest of public safety, for the prevention of crime, for the protection of public health or for the protection of the rights and freedoms of others." These restrictions cannot be imposed, however, on the prohibition to discriminate on the basis of one's genetic heritage.

The discussion of article 12 in the *Explanatory Report* highlights further how the *Convention* aims at limiting the use of genetic testing for health care purposes only. According to the *Explanatory Report*, article 12 prohibits the carrying out of predictive tests for reasons other than health or health-related research, even with the assent of the person concerned.⁴³ It further states that

[i]nsofar as predictive genetic testing, in the case of employment or private insurance contracts, does not have a health purpose, it entails a disproportionate interference in the rights of the individual to privacy. An insurance company will not be entitled to subject the conclusion or modification of an insurance policy to the holding of a predictive genetic test. Nor will it be able to refuse the conclusion or modification of such a policy on the ground that the applicant has not submitted to a test, as the conclusion of a policy cannot reasonably be made conditional on the performance of an illegal act.⁴⁴

In other words, genetic testing without a health care purpose is considered to be unlawful *per se*.

This *Convention* could have significant consequences. Implementation of the latter rule in national legislation would mean that insurers could not impose genetic testing for underwriting purposes, while the former could render it impossible to make distinctions based on genetic susceptibility.⁴⁵ Taken to an extreme, the common practice of asking insurance applicants about their family history of disease would become unlawful.

This must make the insurance industry nervous, as it could lead to a major overhaul of current insurance practices. At a 1999 conference on breast cancer genetics,⁴⁶ a

⁴² *Ibid.*, art. 12.

⁴³ Council of Europe, *Explanatory Report to the Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine* (1997) at para. 85 [hereinafter *Explanatory Report*].

⁴⁴ *Ibid.* at para. 86 [emphasis added].

⁴⁵ The Draft Explanatory Report to the Draft Convention contained a reference to the need for national law to specify solutions to the risk of adverse selection. The article to which this explanation referred has not been retained in the final version. For a discussion of this development, see Lawton, *supra* note 40 at 395-99.

⁴⁶ Personal Conversation at Crossroads '99, The Scientific Symposium: Heritable Breast, Ovarian and Colon Cancer (29 October 1999).

representative of the Association of British Insurers pointed out that the *Explanatory Report* to the *Convention* refers to "unfair discrimination", thereby suggesting that this leaves the door open for actuarially correct insurance underwriting. The *Explanatory Report* to the *Convention* indeed specifies that discrimination must be understood as unfair discrimination.⁴⁷ However, contrary to what the insurance representative suggested, the qualifier "unfair" in the *Explanatory Report* does not necessarily reflect support for the notion of actuarial fairness as seen by many insurance experts. The *Explanatory Report* does not clearly open the door for insurance underwriting practices but rather seems to aim at allowing positive discrimination or affirmative action benefiting those affected by genetic conditions. The *Explanatory Report* specifies that, "[i]n particular, it [the article] cannot prohibit positive measures which may be implemented with the aim of re-establishing a certain balance in favour of those at a disadvantage because of their genetic inheritance."⁴⁸ While there is no reference to the insurance context, "a positive measure" could, for example, cover the use of a negative genetic test result (indicating the absence of a genetic mutation) to obtain insurance by those who have trouble obtaining coverage because of family history of disease. This interpretation presupposes that the use of family history is lawful and is thus not covered under the prohibition against discrimination on grounds of genetic heritage. While this is not consistent with a strict reading of the text (genetic heritage does include family history of disease), it is in line with current insurance practices in all countries. Considering the fact that the exclusion of any distinction on the basis of family history would conflict so profoundly with current legislation in most countries, it is reasonable to argue that the notion of "unfair" discrimination in the explanatory report introduces some form of proportionality assessment. The explicit proportionality assessment from which article 11 is excluded thus enters the back door, through the notion of 'unfair' discrimination. Unfairness itself is contextual in nature. In insurance, as I will argue, the fairness of the distribution of private insurance goods will depend on the role they play and on the presence of other distributive mechanisms in society, such as appropriate welfare provisions and universal health care.

States signing the *Convention* may make reservations in respect of particular provisions if their existing laws are incompatible with certain sections of the *Convention*.⁴⁹ It is to be expected that several states will use this clause to create an exception for insurance purposes. To date, 28 states have signed the convention and 6 have ratified it. These 6 countries are thus under an obligation to introduce legislation prohibiting the use of genetic results for non-medical purposes.

To my knowledge, at least three European countries have already implemented explicit legislation prohibiting the use of genetic testing for insurance purposes: Aus-

⁴⁷ *Explanatory Report*, *supra* note 43 at para. 77.

⁴⁸ *Ibid.*

⁴⁹ *Convention*, *supra* note 40, art. 36.

tria, Belgium and Norway.⁵⁰ These countries introduced their statutes before the adoption of the *Convention*. In these countries, insurers can neither request genetic testing, nor use the test results of applicants that are already available in medical records. The three statutes also contain provisions prohibiting voluntary submission of genetic test results, thereby making it impossible for applicants to obtain a better premium by showing a negative test result. The logic of the latter provision is clear, if insurers are allowed to offer a lower premium or another financial incentive to those who indicate by voluntarily submitting genetic test results that they are at lower risk for premature death or disease, the prohibition can be circumvented. Norwegian law further prohibits insurers from even asking whether a genetic test has been carried out.⁵¹ In Denmark, the government submitted a similar bill to Parliament, where it was rejected. A new bill dealing with genetics and insurance is being prepared.⁵²

In the Netherlands, a 1997 statute on medical examinations may pose a barrier to the use of genetic testing for insurance purposes, without fully excluding it.⁵³ Article 3 provides that a medical examination cannot involve inordinate intrusion into the privacy of the individual being tested.⁵⁴ It further provides that a medical examination cannot be undertaken if the risks of the examination, including the risk of receiving information on an incurable illness, outweigh the expected benefit⁵⁵ or, more generally, if the examination would place a disproportionate burden on the individual.⁵⁶ The law thus embraces a proportionality test for the determination of the acceptability of genetic tests.

This law follows an interesting initiative by the Dutch insurance industry. The insurance industry introduced a moratorium in 1990, which was extended in December 1994 for another five years. Under the moratorium, insurers are not allowed to request access to genetic information unless the contracts exceed a specific limit of around CDN \$140,000. For contracts above this limit, access to genetic information already available in medical files can be requested, but applicants cannot be required to submit to genetic tests.

⁵⁰ Austria: Federal Law of 1994 (BGB1. No. 510/1994) *regulating work with genetically modified organisms, the release and marketing of genetically modified organisms, and the use of genetic testing and gene therapy in humans* (the Gene Technology Law) and amending the Product Liability Law (1995) 46 Int'l Dig. Health Legis. 42 at art. 67; Belgium: *supra* note 1, art. 95; Norway: Law No. 56 of 5 August 1994 on the medical use of biotechnology (1995) 46 Int'l Dig. Health Legis. 51, s. 6-7.

⁵¹ Norway, *ibid.*

⁵² Danish Minister of Labour: *Bill to prohibit the use of genetic tests in appointments and in underwriting pensions and insurance*; reprinted in Danish Council of Ethics, *Ethics and Mapping of the Human Genome* (Copenhagen: Danish Council of Ethics, 1993) at 85-86.

⁵³ The Netherlands: *Wet van 5 juli 1997, houdende regels tot versterking van de rechtspositie van hen die een medische keuring ondergaan* (Staatsblad 1997: 365).

⁵⁴ *Ibid.*, art. 3(1): "Bij een keuring worden geen vragen gesteld en geen medische onderzoeken verricht die een onevenredige inbreuk betekenen op de persoonlijke levenssfeer van de keuring."

⁵⁵ *Ibid.*, art. 3(2)(a).

⁵⁶ *Ibid.*, art. 3(2)(b): "een onevenredig zware belasting."

In France, the National Ethics Committee (*comité national d'éthique*) recommended in October 1995 that insurers be forbidden from using any genetic information, even if applicants submit it voluntarily.⁵⁷ A year earlier, a law *On respect for the human body* introduced new provisions on genetic testing and DNA identification into the French Civil Code.⁵⁸ According to article 16-10, the genetic study of the characteristics of a person may be undertaken only for medical purposes or for scientific research. While this seems to prohibit insurers from using genetic tests for underwriting purposes, it does not prevent insurers from obtaining genetic-test information from medical files. Under public pressure, however, in 1994 the French Federation of Insurers imposed a moratorium on its members. The Federation decided that for the coming five years, genetic testing could not be required from insurance applicants and that genetic information in medical records could not be the sole basis upon which to refuse coverage.

More recently, with the publication of a Code of Practice the Association of British Insurers implemented a two-year moratorium.⁵⁹ This moratorium was announced after a critical report of the House of Commons Select Committee on Science and Technology.⁶⁰ In its 1995 report, the House Committee ordered the insurance industry to come up with a satisfactory proposal on genetic testing within one year or else face legislative restrictions. The industry responded by developing, in 1997, the new Code of Practice, which contains detailed guidelines with respect to genetics. According to the industry's new Code of Practice, insurers cannot ask people to undergo genetic tests when they apply for insurance. It further provides that insurers will not ask for the results of genetic tests for life insurance contracts that are directly linked to a mortgage for a private house of up to £100,000.⁶¹ For other contracts it can use genetic information available to insurance applicants to determine premiums. In this report, the Association appointed a special independent advisor on genetics whose opinion would be sought, for example, in the determination of the scientific validity and predictive power of new genetic tests.

⁵⁷ Comité consultatif national d'éthique pour les sciences de la vie et de la santé, "Avis et recommandations sur *Généétique et Médecine: de la prédiction à la prévention*" (30 October 1995), online: Comité consultatif national d'éthique pour les sciences de la vie et de la santé <<http://www.ccnethique.org/home.htm>> (date accessed: 19 January 2000). Recommendation 4 begins in this way: "L'utilisation des résultats d'un examen des caractéristiques génétiques, à des fins autres que médicales ou de recherche, par exemple dans le cadre d'un contrat d'assurance ou de l'emploi, est interdite, même si elle est le fait des sujets testés eux-mêmes ou qu'elle se fait avec leur accord."

⁵⁸ *Law No. 94-653 of 29 July 1994 on respect for the human body* (*Journal officiel de la République française, Lois et Décrets*, 30 July 1994, No. 175, pp. 11056-11059).

⁵⁹ Association of British Insurers, *Genetic Testing: ABI Code of Practice* (1997).

⁶⁰ U.K., H.C., Science and Technology Committee, "Human Genetics: The Science and Its Consequences", 3d report, vol. 1 (1995).

⁶¹ This provision is of particular importance because in the U.K. life insurance is a precondition to obtaining a mortgage for a house. Being excluded from life insurance thus also excludes people from access to ownership. See below for a discussion of this clause.

VI. Genetic Discrimination Legislation in the United States

In the United States, as of January 15, 1999, at least 44 states enacted specific legislation regulating the use of genetic data by insurers, either in the form of genetic discrimination statutes, genetic privacy statutes or a combination of both.⁶² Most of the state statutes deal exclusively with health insurance contracts to the exclusion of life and disability insurance. They generally prohibit insurers from excluding or raising insurance premiums for those who have a genetic mutation that puts them at increased risk for disease. They further provide that insurers should not require insurance applicants to submit to genetic testing. Some of the older statutes on genetic discrimination aim at protecting people affected by particular genetic conditions, such as sickle-cell trait. On the federal level, calls for protection against genetic discrimination have motivated several representatives and senators to propose comprehensive federal legislation in this area.⁶³ The American Congress has enacted the *Health Insurance Portability and Accountability Act of 1996*, which provides some protection against genetic discrimination in the context of health care.⁶⁴

VII. Genetic Privacy Acts

A second approach to controlling access to genetic information has been to stress the need for privacy legislation. The need for privacy and for protection against unwanted breaches of confidentiality of health information is increasingly recognized as a major concern. Many countries, states and provinces have introduced general privacy legislation or are in the process of doing so. In 1993, Quebec became the first Canadian province to enact comprehensive privacy legislation, both for the private and public sectors.⁶⁵ In Europe, both the European Community and the Council of

⁶² See W.F. Mulholland & A.S. Jaeger, "Genetic Privacy and Discrimination: A Survey of State Legislation" (1999) 39 *Jurimetrics* 317; this article contains a comparative list of the state legislation. See also Yesley, *supra* note 27; M.A. Jagutis, "Insurer's Access to Genetic Information: The Call for Comprehensive Federal Legislation" (1999) 82 *Marquette L. Rev.* 429; L.E. Egan, "Genetic Discrimination in Health Insurance" (1998) 24 *J. Legis.* 237. A comparative list is also published and updated by the National Cancer Institute, online: National Cancer Institute <<http://www.sclnd-nci.net>> (date accessed: 8 January 2000). To have an idea of the changes in the last three years, compare with H.R. Davis & J.V. Mitrius, "Note: Recent Legislation on Genetics and Insurance" (1996) 37 *Jurimetrics* 69.

⁶³ See Jagutis, *ibid.* at 441-45; Egan, *ibid.* at 244-46; K.H. Rothenberg, "Breast Cancer, the Genetic 'Quick Fix,' and the Jewish Community" (1997) 7 *Health Matrix* 97 at 110-13; B.P. Fuller *et al.*, "Privacy in Genetics Research" (1999) 285 *Science* 1359.

⁶⁴ *Health Insurance Portability and Accountability Act of 1996*, Pub. L. No. 104-191, 110 Stat. 1936.

⁶⁵ *An Act respecting access to documents held by public bodies and the protection of personal information*, R.S.Q. c. A-2.1; *An Act respecting the protection of personal information in the private sector*, R.S.Q. c. P-39.1. For a discussion of this legislation on the private sector in the context of genetics, see P. Bahamin, "La génétique et la protection de la vie privée: confrontation de la législation québécoise au concept du droit à la vie privée" (1995) 55 *R. du B.* 203; Lemmens & Bahamin, *supra* note 18 at 231-39.

Europe adopted regulatory measures on privacy. Within the European Community, states are bound by the *Directive on the Protection of Individuals with Regard to the Processing of Personal Data and on the Other Free Movement of Such Data*.⁶⁶ This imposes a duty on member states of the European Community to implement appropriate privacy legislation, in line with the rules set out in the Directive. Signatories to the Council of Europe's *Convention for the Protection of Individuals with regard to Automatic Processing of Data* are also bound to establish legislation that is consistent with the Convention's principles.⁶⁷ Several countries have specific laws dealing with privacy of medical data in general.

Many authors have recognized that new discoveries in genetics, combined with ongoing developments in computer technology and communication, render it more necessary than ever to implement strict data safety measures. Policy advisors, legal experts, and the insurance industry all seem to recognize the importance of privacy protection in the context of genetics even though their views on how to obtain the best protection may differ.⁶⁸ Indeed, it is not only the Canadian Privacy Commissioner who recommends that adequate protection of genetic information is urgently needed.⁶⁹ Representatives of the industry agree. The American Council of Life Insurance cautioned the insurance industry as early as 1991—clearly from a utilitarian perspective—that “[it] would be well advised to think ahead in terms of confidentiality expectations of its insurance-buying public and the increased concerns that thus far have been raised by the media, consumer groups and others.”⁷⁰ Sandy Lowden, a genetics expert and former medical director of a leading insurance company, also argues that there is a need for better privacy protection, even though he opposes restrictions on the use of genetics for insurance underwriting. According to him, medical files often end up in the files of insurance brokers, who shop around for insurance contracts and who are not bound by the confidentiality procedures of the major insurance companies. Moreover, many companies do not have documented confidentiality procedures.

⁶⁶ For a discussion of European legislation, see P.M. Schwartz, “European Data Protection Law and Medical Privacy” in M.A. Rothstein, ed., *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* (New Haven: Yale University Press, 1997) 392 [hereinafter *Genetic Secrets*].

⁶⁷ Council of Europe, *Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data*, E.T.S. No. 108 (1981).

⁶⁸ President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research, *Screening and Counseling for Genetic Conditions: A Report on the Ethical, Social, and Legal Implications of Genetic Screening, Counseling, and Education Programs* (Washington: U.S. Government Printing Office, 1983) (e.g. at 42); Privacy Commissioner of Canada, *Genetic Testing and Privacy* (1992); NIH-DOE Working Group on Ethical, Legal, and Social Implications of Human Genome Research, *Genetic Information and Health Insurance: Report of the Task Force on Genetic Information and Insurance* (1993); American Council of Life Insurance, *Genetic Test Information and Insurance: Confidentiality Concerns and Recommendations: Report of the ACLI Subcommittee on Privacy Legislation to the Task Force on Genetic Testing* (1991); L.O. Gostin, “Genetic Privacy” (1995) 23 J. L., Med. & Ethics 320.

⁶⁹ Privacy Commissioner of Canada, *ibid.*

⁷⁰ American Council of Life Insurance, *supra* note 68 at 2.

This situation, he claims, clearly requires particular attention by privacy regulators.⁷¹ Notwithstanding this degree of agreement among members of the insurance industry, privacy legislation focusing on genetics has not been developed in Europe or Canada.

In contrast, as I mentioned earlier, some of the American states that introduced legislation with respect to genetic testing also included provisions to protect the privacy of genetic data. Others focus on the protection of privacy, rather than preventing genetic discrimination. In an effort to further push for privacy protection legislation, George Annas, Leonard Glantz, and Patricia Roche drafted a model *Genetic Privacy Act*,⁷² which has inspired several of the federal legislative initiatives in this area.⁷³

VIII. Why Legislative Initiatives Focusing on Genetics?

More than just ethical concerns about one's right to control highly personal information and the right to self-determination underlie the attention to confidentiality of genetic data. There is a very practical explanation for the interest of the research community in this matter: people have been reluctant to participate in research for fear of discrimination if test results were to indicate an increased risk. Several studies, for example, have indicated that women at risk for breast cancer because of family history often refuse to undergo testing out of fear of the impact of testing on insurability.⁷⁴ With genetic testing becoming a veritable diagnostic tool, clinicians are also becoming concerned that the health care of patients could be adversely affected if they were not to be reassured as to the confidentiality of genetic testing.⁷⁵ National action groups have lobbied hard to improve the protection of people who could be affected by genetic discrimination, and their lobbies have often met with success. Francis Collins, for example, points out that the Clinton administration largely followed recommendations made by the National Action Plan on Breast Cancer⁷⁶ when it pushed for congressional action. The lobby resulted in the *Health Insurance Portabil-*

⁷¹ J.A. Lowden, "Genetic Testing and Screening in Insurance Underwriting" in *Genetics and the Law Symposium* 21 (October 1995) (Toronto: Osgoode Hall, 1995).

⁷² G.J. Annas, L.H. Glantz & P.A. Roche, *The Genetic Privacy Act and Commentary* (Boston: Boston University School of Public Health, 1995) [hereinafter *Genetic Privacy Act & Commentary*]. See also G.J. Annas, L.H. Glantz & P.A. Roche, "Drafting the Genetic Privacy Act: Science, Policy and Practical Considerations" (1995) 23 *J. L., Med. & Ethics* 360 [hereinafter "Drafting the Genetic Privacy Act"].

⁷³ Senator Peter V. Domenici, for example, introduced in 1996 a bill entitled "Genetic Privacy and Nondiscrimination Act of 1996" (S. 1898, 104 Cong. (1996)), which was inspired by this model *Genetic Privacy Act*.

⁷⁴ See P.B. Jacobsen *et al.*, "Decision-Making About Genetic Testing Among Women at Familial Risk for Breast Cancer" (1997) 59 *Psychosom. Med.* 459 at 460 and references there.

⁷⁵ "Certificates of Confidentiality", *supra* note 13 at 436-37; "Genetic Discrimination", *supra* note 22; C. Lerman *et al.*, "BRCA1 Testing in Families With Hereditary Breast-Ovarian Cancer: A Prospective Study of Patient Decision Making and Outcomes" (1996) 275 *J. Am. Med. Assoc.* 1885.

⁷⁶ The National Action Plan on Breast Cancer is a public-private partnership set up to promote research, policy and services in the area of breast cancer.

ity and Accountability Act of 1996.⁷⁷ Meredith A. Jagutis, who does not disguise her discomfort with the panoply of genetic privacy statutes, remarks that "five organizations typically support the bills, including the American Cancer Society, the National Breast Cancer Coalition, the Council for Responsible Genetics, the National Action Plan on Breast Cancer, and the National Advisory Council for Human Genome Research."⁷⁸

In light of this, one wonders whether it is a matter of pure happenstance that the proliferation of legislative initiatives on genetic privacy and discrimination coincide with concerns raised by the medical establishment that fear of discrimination and privacy could hamper genetics research. In an effort to explain what he perceives to be disproportionate attention to laws focusing on insurance in the context of genetics, Mark Hall speculates "that leading scientific researchers view insurance discrimination as a barrier to recruiting research subjects."⁷⁹ Michael S. Yesley states in the same vein that "[t]he laws barring genetic discrimination in health insurance do not respond to a substantial problem but to a perceived threat of loss of insurance that might hinder genetic researchers' search for human subjects."⁸⁰ A recent article in *Science* by members of a subcommittee of the National Action Plan on Breast Cancer confirms this. Throughout the article, which contains detailed recommendations to protect privacy in genetic research, the authors urge for stringent privacy legislation because of "[t]he social value of research, the altruistic nature of research participation, and the reliance of the research enterprise on volunteers."⁸¹

There might be yet another reason for the legislative vogue. Genetic discrimination is more likely to affect those who currently have insurance and, in the United States, have appropriate access to health care. These are the people who are most likely to have access to the new genetic tools that their physicians will want to use for diagnostic or predictive purposes. Genetic testing, and the possibility of being excluded from insurance on the basis of test results, will have a much greater impact on their lives than on the lives of those people excluded from health care altogether. Compare the plight of the insured with, say, that of a street person who is struggling to survive. Exclusion from insurance as a result of genetic testing is clearly more of a concern for the "better off". These are the same people who are more likely to have influence on the regulatory process. Can one have a more powerful alliance than the

⁷⁷ *Supra* note 64.

⁷⁸ *Supra* note 62 at 442.

⁷⁹ M.A. Hall, "Insurers' Use of Genetic Information" (1996) 37 *Jurimetrics* 13 at 14. He also wonders whether "biotechnology firms support insurance legislation because they realize that peoples' fear of losing insurance could squelch the booming commercial opportunities in testing technology." (*Ibid.*) However, the latter seems not so likely. On the contrary, the biotechnology industry would have a major financial interest in promoting genetic testing outside the medical context. Insurance companies could be among the best clients of this industry.

⁸⁰ Yesley, *supra* note 27 at 663.

⁸¹ Fuller *et al.*, *supra* note 63 [emphasis added].

medical and social establishment, and perhaps even the biotechnology industry, joining forces?

A detailed discussion of these initiatives is beyond the scope of this paper.⁶² I would like here to comment briefly on both genetic privacy legislation and genetic discrimination provisions. Two questions are of primary importance in judging this approach: first, is this type of legislation effective and, second, is it fair to have legislation that focuses on one particular type of medical information and gives it better protection? These questions are related, in turn, to the issue of whether one can single out genetic data from other forms of health information, on a practical basis as well as on ethical grounds.

IX. The Efficacy of Statutes Focusing on Genetics

Although the previous discussion suggests that privacy legislation is urgently needed, it does not mean that this need came about with the advent of genetic data. In fact, privacy issues are of concern regardless of the precise nature of the medical information. While many medical data are either trivial or obvious (like physical characteristics of a person and visible disabilities), there are a great number of other data that should be protected from public distribution and that people want to keep confidential. People who are or have been suffering from a socially stigmatizing disease, for example, generally do not want information related to their condition to be freely distributed among insurance brokers. Few would be happy to learn that information on one's HIV-positive status, one's history of depression, or information on past sexual abuse is easily accessible. In this context, genetic information is not very different from other medical information. It belongs among existing concerns. As such, it would seem to be most appropriate to deal with the most basic concern for the protection of all sensitive medical data, rather than deal with genetic information and leave other sensitive data less protected.

Moreover, many genetic privacy acts make vague references to the risk of genetic discrimination or express a concern for discrimination as one of the motivating factors for having genetic privacy legislation, without providing protection against it. Annas, Glantz, and Roche, for example, mention in the preamble of their widely cited *Draft Genetic Privacy Act* that employers and insurers could be interested in this type of information.⁶³ They also mention, as one of the main reasons for regulating genetic information, the history of discrimination against the genetically unfit. Since this concern is expressed in the preamble of a legislative proposal, one would expect that the proposed legislation would offer appropriate protection against discrimination. It does not. While many of the privacy statutes or legislative proposals contain rules restrict-

⁶² For detailed discussions of these initiatives, see *supra* note 62.

⁶³ Annas, Glantz, and Roche simply mention that employers and insurers could be interested in this type of information. See the discussion of their *Draft Act* in "Drafting the Genetic Privacy Act", *supra* note 72.

ing unauthorized distribution, they generally do not protect against the biggest threat for discrimination, the authorized distribution of information. This is an even greater concern in the context of a system such as insurance, which is based on contractual liberty and largely ignores the unequal bargaining position of insurer and insurance applicant. Privacy acts are based on the right to self-determination and introduce a system whereby individuals remain in control over information pertaining to them. As Mark A. Hall points out, "The premise of privacy is individual control of the information. Control means the right both to conceal and reveal the information."⁸⁴ In the insurance context, however, applicants are not in a position to bargain about access to information. If insurance companies ask applicants to sign a waiver of confidentiality as a condition for insurance, there is little in the way of choice: ultimately applicants will sign.

The same is true for requests to undergo genetic testing. The right to refuse genetic testing provides little protection. Yesley points out that "[m]erely requiring informed consent for genetic testing will not prevent an employer or insurer from insisting on testing as a condition of employment or insurance."⁸⁵ Privacy laws provide no protection against authorized, freely accepted discrimination.⁸⁶ In other words, people are generally not excluded from insurance coverage on the basis of quasi-secret searches for medical data and violations of privacy. Exclusions are based on information gained from legally sanctioned access to medical files or freely undertaken medical tests that indicate a higher than average risk for disease.

X. What is "Genetic Data"?

The determination of what exactly constitutes genetic data is also a concern that is insufficiently addressed in the context of both privacy laws and anti-discrimination provisions. What indeed is the focus of these statutes or proposals for legislation? The *Draft Genetic Privacy Act* of Annas, Glantz, and Roche, for example, only protects private genetic information, which it defines as

any information about an identifiable individual that is derived from the presence, absence, alteration, or mutation of a gene or genes, or the presence or absence of a specific DNA marker or markers, and which has been obtained: (1) from an analysis of the individual's DNA; or (2) from an analysis of the DNA of a person to whom the individual is related.⁸⁷

⁸⁴ Hall, *supra* note 79 at 19-20 [footnote omitted].

⁸⁵ Yesley, *supra* note 27 at 658.

⁸⁶ It should not come as a surprise that insurance experts tend to argue in favour of the right of individuals to access genetic data that are obtained in the course of research empowering individuals in this context also makes it possible for insurance companies to obtain access to these data.

⁸⁷ S. 3. Definitions, see *Genetic Privacy Act & Commentary*, *supra* note 72 at 45.

The drafters explain that not all genetic information needs protection. More importantly, they also declare that by including protein tests⁸⁸ and family history-based risk information in the definition of private genetic information, virtually all medical records would be subject to the provisions of the act.⁸⁹ This, they suggest, is clearly not feasible. In an article on their drafting process, they even admit⁹⁰ (ruefully, as Murray remarks with some irony) that including these data in the definition would make the distinction between genetic information and medical information generally more difficult to justify.⁹¹ Although they defend their decision in stating that they had a clear mandate to draft privacy rules focusing on genetic information derived within the Human Genome Project, the lack of a coherent rationale remains nonetheless questionable.

As several authors have pointed out, many statutes dealing with genetic information suffer from similar problems of definition.⁹² They are often seriously narrow or overly general and unworkable. Some of the older anti-discrimination statutes prohibit discrimination only when it relates to specific genetic conditions. Others limit the scope of the anti-discrimination provisions to the results of genetic tests, which are defined as DNA analyses. They do not cover, for example, family history of disease.⁹³ As mentioned earlier, the Austrian, Belgian, and Norwegian statutes also fail to prohibit the use of family history in the context of insurance.⁹⁴ This basically means that insurers can exclude people on the basis of vague family information indicating the presence of a genetic condition in the family, whereas they could not rely on similar more detailed information resulting from DNA analysis. Moreover, the Norwegian statute specifies that while the use of data from predictive genetic testing in underwriting is not permissible, information obtained through genetic tests used as diagnostic tools for existing diseases can be taken into consideration.

In criticizing a bill which proposed similar rules, the Danish Council of Ethics pointed out that it has long been possible to obtain information on the likelihood of future disease, susceptibility to external factors, or possession of certain genes.⁹⁵ In other words, by further allowing these practices and by focusing exclusively on newer

⁸⁸ Proteins are gene products. They tell us something about the functioning of particular genes. Irregular protein production can be a clear indication of ill-functioning genes.

⁸⁹ *Genetic Privacy Act & Commentary*, *supra* note 72 at 48.

⁹⁰ T.H. Murray, "Genetic Exceptionalism and 'Future Diaries': Is Genetic Information Different from Other Medical Information?" in *Genetic Secrets*, *supra* note 66 at 68.

⁹¹ "Drafting the Genetic Privacy Act", *supra* note 72.

⁹² See Yesley, *supra* note 27 at 659-62; "Genetic Antidiscrimination", *supra* note 7 at 207-08; Jagutis, *supra* note 62 at 436-38.

⁹³ See M.A. Rothstein, B.D. Gelb & S.G. Craig, "Protecting Genetic Privacy by Permitting Employer Access only to Job-related Employee Medical Information: Analysis of a Unique Minnesota Law" (1998) 24 *Am. J. L. & Med.* 399 at 402-03. Rothstein mentions a new New Jersey statute dealing with genetic discrimination which does include in its definition "inherited characteristics derived from an individual or family member" (*ibid.* at n. 43).

⁹⁴ *Supra* note 50.

⁹⁵ Danish Council of Ethics, *supra* note 52 at 80.

forms of genetic testing, discrimination is not adequately prevented. Other critics of the Danish bill also argued that the regulation of genetic testing in the bill is inadequate, since similar methods can produce the same results.⁹⁶

Genetic information will be an increasingly important component of medical files. The results of genetic tests will be intermingled with other data. Often, results of clear-cut DNA tests will be accompanied by protein tests and family histories in medical files. These tests might indirectly tell insurers all they could know directly from a genetic test: that a specific gene function is affected, and that the reason for this deviant protein production is a condition running in the family. Jon Beckwith and Joseph S. Alper point out that "some would argue that most medical tests are ordered in an effort to detect conditions or potential conditions that have an underlying genetic contribution."⁹⁷ In another article, Alper and Beckwith clearly indicate, with different examples, how difficult it is to maintain a distinction between genetic and non-genetic tests.⁹⁸ They conclude that "in concentrating on the genetic nature of the information rather than on the consequences of the dissemination of all types of medical information, the [genetic anti-discrimination] legislation relies on a distinction between genetic and nongenetic information that is essentially artificial."⁹⁹

Indeed, would it make sense to provide particular privacy or anti-discrimination protection to some test results while other results, giving similar information on future risk, are freely accessible? This certainly cannot be considered an effective way of protecting privacy or preventing discrimination.

XI. The Claim of Genetic Exceptionalism

The anti-discrimination and privacy laws focusing on genetics have one thing in common; they reflect the idea that specific legislation focusing on genetics is essential and appropriate. One cannot avoid asking: why is this so? What is the motive behind laws and regulations focusing exclusively on genetic information? It is granted that these anti-discrimination and privacy provisions provide some, albeit limited and partial, protection against discrimination. But what is the justification for partial protection? Is there a coherent reason to single out genetics? This question deals with what Thomas Murray calls "genetic exceptionalism"—the claim that there is something so unique about genetics that it merits special legislation.¹⁰⁰

⁹⁶ L. Nielsen & S. Nespør, *Genetic Test, Screening and Use of Genetic Data by Public Authorities in Criminal Justice, Social Security and Alien and Foreigners Acts* (Copenhagen: University of Copenhagen, 1993) at 23.

⁹⁷ "Genetic Antidiscrimination", *supra* note 7 at 207.

⁹⁸ J.S. Alper & J. Beckwith, "Distinguishing Genetic From Nongenetic Medical Tests: Some Implications for Antidiscrimination Legislation" (1998) 4 *Sci. Eng. Ethics* 141 at 145 [hereinafter "Distinguishing Genetic From Nongenetic"].

⁹⁹ *Ibid.* at 148.

¹⁰⁰ Murray, *supra* note 90.

Murray identifies four different elements of genetics exceptionalism: genetic prophecy, concern for kin, concern about discrimination, and generalizability of data to families, communities, racial, and ethnic populations. A fifth characteristic, which is not discussed as a separate issue by Murray, but which is often invoked in the context of genetics' claim to uniqueness, is the lack of control over one's genome.¹⁰¹

Murray refers to the claim that genetics is unique because it reveals sensitive and detailed information about someone's future health risks as "the concern for genetic prophecy." Genetic information indicates a factor of risk. It enables us to give an estimate of the future possibility of disease and is not limited to an analysis of current health. It allows third parties to obtain detailed information on the likelihood that individuals will be affected by a particular condition. Since someone's health condition has financial implications, employers, insurers, and even immigration authorities could be particularly inclined to use this type of health predictor. However, as Murray and others indicate, genetic testing is not the only tool with which to evaluate people's future health prospects.¹⁰² Information gathered from questionnaires about family diseases or habits, or medical tests indicating high cholesterol levels, are examples of other tests or methods that give similar information. Murray mentions other potential sources of probabilistic information. Some people engage in risky activities such as skydiving or parasailing, while others suffer from hepatitis B or HIV infection. The comparison between a positive HIV test result and genetic test results is particularly interesting. In the past, HIV testing was often seen as somehow fundamentally different from genetic testing. Finding out one's HIV-positive status was considered to be very much like a diagnosis of actual or at least imminent and unavoidable disease. A positive test result brought to fact the prospect of a certain and swift death. As Per Sandberg points out, the distinction between genetic predisposition and HIV infection no longer holds.¹⁰³ Many people who are infected with HIV now survive for more than ten years. It is still unclear how long life can be prolonged for those who are currently infected and have access to experimental drugs. Research further suggests that some HIV-infected people might not even develop the disease. An HIV-positive test might become less predictive of early death than a test for, say, Huntington's disease.

It also seems inappropriate to invoke in general terms the probabilistic nature of genetics to distinguish it from other medical information. There is no such thing as *the*

¹⁰¹ Hall, *supra* note 79 at 19-20 mentions as a special characteristic the fact that genetic information is "uniquely private." It is unclear what he understands under this argument, since he discusses the concern for privacy in this context. However, this is clearly not specific to genetics. Many other forms of health information are considered to be of particular private concern. Genetic information is, on the contrary, particular because it is shared. It reveals information on other family members and perhaps even one's ethnic group. He may be referring here to the fact that genetic information tells us so much, in so much detail, about an individual, in particular one's risk for premature death or disability. For this, see below.

¹⁰² Murray, *supra* note 90; see e.g. "Distinguishing Genetic From Nongenetic", *supra* note 98.

¹⁰³ P. Sandberg, "Genetic Information and Life Insurance: A Proposal for an Ethical European Policy" (1995) 40 Soc. Sci. Med. 1549 at 1550-51.

genetic test result. There are several kinds of genetic disorders, with fundamental differences between them. Some genetic disorders come to affect people with near-certainty. The paradigm case for such a disorder is Huntington's disease, a late-onset dominant and single-gene disorder. Having the genetic mutation generally implies that one will develop the disease.¹⁰⁴ Others indicate only an increased chance of developing a disease and are either related to a single genetic mutation or to complex polymorphisms. The risk factors associated with these disorders and the statistical reliability of the tests vary significantly from disorder to disorder. Some diseases are curable or controllable; others can perhaps be avoided by changes in diet or lifestyles. Still other diseases are incurable, leading inevitably to physical decline and death. The common name for a disease might cover several different types of that disease. Some breast cancers are associated with a single gene, while others are complex traits for which no tests are currently available. The genetic determinants of a disease are also often overstated to the detriment of other factors. As Alper and Beckwith indicate, "the environment, gene-environment covariance, and gene-environment interactions can be as important as genes and gene-gene interactions in determining the expression of these conditions."¹⁰⁵

The predictive value of genetic tests varies widely. Moreover, the prophetic character of genetic testing is often overstated in the early phases of research, further inflating its uniqueness in comparison with other health predictors. For example, early estimates of the predictive value of genetic tests for two breast cancer related genes, BRCA1 and BRCA2, were significantly higher than now. Women who carry BRCA1 were first estimated to have an 85% lifetime chance of developing breast cancer and a 40% risk of ovarian cancer.¹⁰⁶ A more recent estimate based on a more population-based (as opposed to family-based) study suggests that there may be a 60% risk that people with the mutation will develop breast cancer by the age of 70.¹⁰⁷

The concern for kin arises because of genetic links between family members. Genetic information traverses the bounds of personal autonomy,¹⁰⁸ insofar as genetic tests necessarily reveal information about the family of those who undergo testing.¹⁰⁹ This characteristic of genetics and genetic testing has important ramifications with respect to issues of confidentiality, the ethical duty to collaborate in family studies, the duty to

¹⁰⁴ But see "Genetic Antidiscrimination", *supra* note 7 at 208. They refer to some studies which indicate that some people with the Huntington gene do not develop the disease: see their n. 25. See also below.

¹⁰⁵ "Distinguishing Genetic From Nongenetic", *supra* note 98 at 146.

¹⁰⁶ J.P. Struewing *et al.*, "The Carrier Frequency of the BRCA1 185delAG Mutation is Approximately 1 Percent in Ashkenazi Jewish Individuals (1995) 11 *Nature Genetics* 198 at 198.

¹⁰⁷ See Weber, *supra* note 14.

¹⁰⁸ A.M. Capron, "Which Ills to Bear? Reevaluating the 'Threat' of Modern Genetics" (1990) 39 *Emory L.J.* 665 at 694.

¹⁰⁹ For a discussion of the ramifications of the family relevance of information in the context of research, see K.C. Glass *et al.*, "Structuring the Review of Human Genetics Protocols: Gene Localization and Identification Studies" (1996) 18 *IRB: A Review of Human Subjects Research* 1 at 5-6.

inform or disclose to family members information of genetic risks, informed consent with respect to accidental discoveries of non-paternity or non-maternity, and so on.¹¹⁰ Discussion of these important legal and ethical issues is beyond the scope of this article.

While there are certainly important familial issues surrounding genetic testing, Murray is right in arguing that many other types of information raise similar issues. The fact that a person is suffering from tuberculosis tells us something about the risk for infection of people living in the same household. When someone has a gambling problem, the family's financial security may be in jeopardy. What if the "breadwinner" in the family has a serious heart disease? Murray suggests that surely other family members have an interest in knowing about it. And when a person is suffering from a sexually transmitted disease, sexual partners are at risk. A recent case before the British Columbia Human Rights Commission is interesting in respect to the latter example. The case was that of a man whose application for life insurance was rejected because his wife was infected with HIV/AIDS. The Commission declared, among other things, that this was a case of discrimination based on "the propensity for becoming disabled" and as such constituted a violation of the *Human Rights Act* of British Columbia.¹¹¹

These examples clearly raise issues with respect to the duty to inform others, the duty to reveal troublesome information and the duty to collaborate in treatment programs. Moreover, in the context of insurance, it is worth stressing again that insurers have traditionally been keen to investigate the existence of diseases running in the family. Even on the basis of information gathered through traditional channels—by its nature, is more uncertain than information gathered from genetic tests—family members are denied coverage or charged higher premiums. In other words, genetic information with implications for family members has already been gathered long before the existence of modern genetic tests. It seems difficult, therefore, to argue that genetic tests raise entirely new and unique ethical and legal questions in this respect.

A third characteristic often invoked to emphasize genetic exceptionalism is its relevance for populations: ethnic, racial, or local groups. Genetic information links members, not only of families, but also of larger communities. Genetic diseases are

¹¹⁰ See e.g. E.W. Clayton, "What Should the Law Say About Disclosure of Genetic Information to Relatives?" (1998) 1 *J. Health Care Law Pol'y* 373; C. Lerman *et al.*, "Family Disclosure in Genetic Testing for Cancer Susceptibility: Determinants and Consequences" (1998) *J. Health Care Law Pol'y* 353; M.M. Burgess, C.M. Laberge & B.M. Knoppers, "Bioethics for Clinicians: 14. Ethics and Genetics in Medicine" (1998) 158 *C. Med. Assoc. J.* 1309; W.F. Flanagan, "Genetic Data and Medical Confidentiality" (1995) 3 *Health L.J.* 269; J. Miller, "Physician-Patient Confidentiality and Familial Access to Genetic Information" (1994) 2 *Health L.J.* 141; B.M. Knoppers, "Human Genetics: Parental, Professional and Political Responsibility" (1993) 1 *Health L.J.* 13; S.M. Suter, "Whose Genes Are These Anyway? Familial Conflicts over Access to Genetic Information" (1993) 91 *Mich. L. Rev.* 1854; D.C. Wertz & J.C. Fletcher, "Privacy and Disclosure in Medical Genetics Examined in an Ethics of Care" (1991) 5:3 *Bioethics* 212.

¹¹¹ R.S.B.C. 1996, c. 210 [hereinafter *BCHRA*].

sometimes over-represented in some ethnic groups, or in specific local communities. Tay-Sachs disease, for example, is common among Ashkenazi Jews and some French Canadians.¹¹² Among the former, 1 in 30 carries a gene for this very severe recessive disorder that affects 1 in 3,600 of their infants. Many Ashkenazi Jews are also carriers of Gaucher's disease. Recent research has highlighted three specific mutations that are particularly prevalent in Ashkenazi Jewish women. Women in this community who have a family history of breast cancer are at higher risk of developing cancer than women of other ethnic groups.¹¹³ The sickle-cell trait has a very high incidence among Africans and people of African origin. In the U.S., from 8% to 10% of African-Americans are carriers of the sickle-cell trait, and 1 in 400 to 600 has sickle-cell anaemia.¹¹⁴ Several genetic disorders are said to be prevalent in the Saguenay-Lac-Saint-Jean region of Quebec.¹¹⁵

The prevalence of genetic disorders within communities can result in further stigmatization of groups already affected by racial or ethnic discrimination.¹¹⁶ Screening programs and government interventions are sometimes interpreted as evidence of racism, especially when they lead to the denial of employment or insurance. Substantial controversy has already arisen over sickle-cell screening: in the 1970s in the United States, massive sickle-cell screening, which was introduced as a health care program, led to discrimination against African-Americans. Many African-Americans identified as carrying the sickle-cell trait were excluded from a variety of occupational settings as a result of protective measures that were based on what later appeared to be erroneous scientific grounds—the theory that carriers of the genetic trait are at risk for losing consciousness as a result of exposure to low oxygen levels.¹¹⁷ Other types of

¹¹² Science Council of Canada, *Genetics in Canadian Health Care* (Ottawa: Minister of Supply and Services, 1991) at 42.

¹¹³ See S.V. Hodgson *et al.*, "Risk Factors for Detecting Germline BRCA1 and BRCA2 Founder Mutations in Ashkenazi Jewish Women with Breast or Ovarian Cancer" (1999) 36 *J. Med. Genet.* 369; see also Struewing *et al.*, *supra* note 106.

¹¹⁴ According to the Science Council of Canada, one in every 625 African-Canadian newborns has sickle-cell anaemia: *supra* note 112 at 20.

¹¹⁵ M.J. Mélançon & D. Larouche, "Une réflexion régionale et transrégionale sur l'éthique en génétique humaine" in M.J. Mélançon, ed., *Bioéthique et génétique: Une réflexion collective* (Chicoutimi, Qc.: Éditions JCL, 1994) 17; M. Perron, "Les maladies héréditaires au Saguenay-Lac-Saint-Jean: Responsabilité individuelle ou collective?" in *ibid.* 43; M. De Braekelcer, "The Ethics of Cystic Fibrosis Carrier Screening: Where Do We Stand?" Letter to the Editor (1990) 47:3 *Am. J. Hum. Gen.* 581-582.

¹¹⁶ See H.T. Greely, "Health Insurance, Employment Discrimination, and the Genetics Revolution" in D.J. Kevics & L. Hood, eds., *The Code of Codes: Scientific and Social Issues in the Human Genome Project* (Cambridge, Mass.: Harvard University Press, 1992) 264 at 274-280; Natowicz, Alper & Alper, *supra* note 6. For a discussion of American law in relation to discrimination and workplace screening, see "Genetic Discrimination", *supra* note 22 at 120-34.

¹¹⁷ For a discussion on the controversy surrounding sickle-cell screening, see D.J. Kevics, *In the Name of Eugenics: Genetics and the Uses of Human Heredity* (New York: Alfred A. Knopf, 1985) 255-56, 278; L.B. Andrews *et al.*, eds., *Assessing Genetic Risks: Implications for Health and Social Policy* (Washington, D.C.: National Academy Press, 1994) at 40-42, 258.

discrimination, too, could be provoked by the use of genetic testing. Some behavioral genetics' research has already raised substantial controversy because of the links made between ethnicity and, for example, intelligence and criminality.¹¹⁸ In light of the often vague diagnostic criteria for assessing mental illness, there is also concern that ethnic and racial bias may influence research questions and the interpretation of data and that the results of such studies may contribute to further stigmatization.

Fear of stigmatization and discrimination could affect the willingness of these groups to co-operate with research or with preventive screening programs. Willingness to co-operate with extremely revealing research could actually aggravate the stigma of belonging to a particularly diseased group. Genetic traits can be more easily identified in isolated regions with a "genetically isolated" population than elsewhere. Intense scientific research could exaggerate the prevalence of particular diseases in these communities, compared to other groups. Specific groups could become victims of their scientific importance. This has been perceived as unfair, especially insofar as these groups often serve in scientific studies that are of great value for the entire population.

Mark Rothstein invokes the history of eugenics in this context. "[G]iven the history of eugenics," Rothstein argues, "there is a justifiable reticence to embrace any program of systematic application of genetic criteria."¹¹⁹ This history places upon researchers and health care promoters the burden of demonstrating the necessity of genetic testing and providing protective safeguards for privacy and confidentiality. History indeed gives rise to legitimate fears surrounding the systematic use of inborn criteria in social policy and forces us to be cautious.

While these are very serious concerns, they are again not unique to genetics. Statistics indicate differences in the incidence of cancers among local communities,¹²⁰ the lower incidence of high cholesterol levels among certain ethnic groups, and the fact that HIV/AIDS is more prevalent among gays and intravenous drug users and specific ethnic communities. Postal codes, for instance, can be a statistical indicator for having a higher chance of being infected by HIV/AIDS or for bad housing and living conditions which may affect one's life expectancy. In general, rates of poverty in America are much higher among certain ethnic groups. Poverty rates are one of the most important factors in explaining differences in life expectancy and overall health. In Canada, some Inuit communities have very high rates of youth suicide and lower average

¹¹⁸ See e.g. J. Horgan, "Trends in Behavioral Genetics: Eugenics Revisited" *Scientific American* 268:6 (June 1993) 122 at 130. A more controversial analysis of the link between intelligence and ethnicity can be found in R.J. Herrnstein & C. Murray, *The Bell Curve: Intelligence and Class Structure in American Life* (New York: Free Press, 1994).

¹¹⁹ M.A. Rothstein, "Genetics, Insurance and the Ethics of Genetic Counseling" (1993) 3 *Mol. Genet. Med.* 159 at 170 [hereinafter "Genetic Counseling"].

¹²⁰ M.A. Lappé, "Justice and the Limitations of Genetic Knowledge" in T.F. Murphy & M.A. Lappé, eds., *Justice and the Human Genome Project* (Berkeley: University of California Press, 1994) 153 at 156.

life expectancy than elsewhere in the country. Prohibiting genetic discrimination will not protect people from discrimination based on these other factors.

The prohibition of third-party use of genetic information has also been defended on the grounds that genetics are beyond individual control, and that people should not be negatively affected by conditions for which they are not responsible.¹²¹ However, many other health conditions are beyond individual control.¹²² When is becoming diseased really one's own fault? What does it mean to "have control" over one's health?¹²³ Is one morally justified in making a distinction between those who have contributed to their disease and those who have not? And if so, how do we decide on what constitutes a morally relevant contribution? The relationship between biological, social and environmental determinants of health is extremely complex. The assignment of responsibility for one's own health is thus far from a simple matter. The debate over the exclusion of battered women from insurance in the United States highlights the problematic nature of insurance distinctions based on the question of who should be held accountable for contributing to their own risk status.¹²⁴ To hold people accountable for "lifestyle-related" increased health risks without taking into consideration the social, cultural and environmental context is, in many cases, to further discriminate against those already vulnerable to the negative affects of discrimination. Such assignment of responsibility may itself be understood as an expression of existing prejudice. The claim that HIV/AIDS is somehow a "self-inflicted" condition, for example, resulting from one's choice of sexual behaviour or injection drug use, is in many ways a moralistic expression of bigotry and ignorance.

Genetics may create some interesting surprises for those who buy into the idea that biological predisposition to disease is beyond individual control and should therefore not be the basis of discrimination, whereas risky behaviour is within one's control and can therefore be socially sanctioned. Research into behavioural genetics now suggests that genetic factors may account, at least partially, for many behavioural

¹²¹ See e.g. "Genetic Counseling", *supra* note 119 at 169; R.S. Brown, "The Impact of Advances in Genetics on Insurance Policy" in R.S. Brown & K. Marshall, eds., *Advances in Genetic Information: A Guide for State Policy Makers*, 2d ed. (Lexington, Ky.: The Council of State Governments, 1993) 43.

¹²² N. Park & B. Dickens, "Legal and Ethical Issues in Genetic Prediction and Genetic Counselling for Breast, Ovarian and Colon Cancer Susceptibility" in K.M. Taylor & D. De Petrillo, eds., *Critical Choices: Ethical, Legal and Sociobehavioural Implications of Heritable Breast, Ovarian and Colon Cancer: Background Paper for the International Research and Policy Symposium* (Toronto, 28-30 April 1995) 61 at 77-78; Murray, *supra* note 90 at 65-66.

¹²³ For a discussion of the issues of risk behavior and access to health care, see R. Bayer, "Voluntary Health Risks and Public Policy" (1981) 11:5 *Hast. Cent. Rpt.* 26; G. Dworkin, "Taking Risk, Assessing Responsibility" (1981) 11:5 *Hast. Cent. Rpt.* 26; and, more recently, A. Darby, "The Individual, Health Hazardous Lifestyles, Disease and Liability" (1999) 4 *DePaul J. Health Care L.* 787 at 798-807; and E.M. Holmes, "Solving the Insurance/Genetic Fair/Unfair Discrimination Dilemma in Light of the Human Genome Project" (1997) 85 *Kentucky L.J.* 503.

¹²⁴ See D. Hellman, "Is Actuarially Fair Insurance Pricing Actually Fair? A Case Study in Insuring Battered Women" (1997) 32 *Harv. C.R.-C.L. L. Rev.* 355.

traits and psychiatric disorders.¹²⁵ If one accepts that genetic factors contribute to conditions such as alcoholism¹²⁶ and nicotine addiction, as some preliminary studies claim, are individuals no longer responsible for the health consequences of these conditions? This possibility is particularly ironic in light of the fact that smoking and alcohol consumption are two of the most common factors justifying higher insurance premiums. They are frequently cited as examples of lifestyle choices which clearly merit financial penalty or exclusion from health care. Some argue that, since people clearly have control over smoking and alcohol consumption, they should not claim the right to socially supported medical care for conditions caused by these habits.¹²⁷ Although the genetic associations I mentioned are controversial and raise many questions, they illustrate problems in presuming the existence of simple relationships between genetic and other determinants of health. Current studies in genetics pose important challenges to well-established beliefs regarding causal mechanisms of, and control over, disease.

The last example also reveals difficulties that could be raised by prohibitions against using any genetic factor in insurance underwriting. If research would demonstrate a clear relationship between nicotine addiction, alcoholism, and genetic mutations or polymorphisms, could insurers no longer increase premiums for those addicted to nicotine or alcohol? In life and disability insurance, mental health problems are a serious concern for insurers, since they are a major cause of suicide and are generally associated with a high morbidity rate. What if research were to provide us with a genetic test to detect increased risk for common mental health disorders such as bipolar depression or schizophrenia? Would those at risk for a mental health condition be protected under the prohibitory approaches because it constitutes a "genetic condition"? Surely, this would profoundly alter insurance practices. But it would also seem unfair that those whose condition has received a genetic *imprimatur* receive substantially better protection against discrimination than those who suffer from a condition which has not or not yet received the genetic label. To refer once more to the example of alcoholism; those who are able to invoke a genetic predisposition for addiction could use genetic discrimination rules as a shield against higher insurance premiums. Drinkers without such a mutation would be held accountable for their behaviour and would be at a disadvantage. Would such a disadvantage be fair?

¹²⁵ See National Institute of Mental Health, *Report of the National Institute of Mental Health's Genetics Workgroup* (Bethesda, Md.: National Institutes of Health, 1997).

¹²⁶ D. Carmelli, A.C. Heath & D. Robinette, "Genetic Analysis of Drinking Behavior in World War II Veteran Twins" (1993) 10 *Genet. Epidemiol.* 201; for a critical analysis of the genetic studies on alcoholism, see G.E. Vaillant, *The Natural History of Alcoholism Revisited* (Cambridge, Mass.: Harvard University Press, 1995).

¹²⁷ See e.g. A.H. Moss & M. Siegler, "Should Alcoholics Compete Equally for Liver Transplantation?" (1991) 265 *J. Am. Med. Assoc.* 1295. In an eminently cynical discussion of the legal regulation of genetic discrimination, one famous legal scholar refers to one of their arguments—that a reason to deny coverage to alcoholics is that their behaviour renders them less deserving—as "an eminently sensible position." See R.A. Epstein, "The Legal Regulation of Genetic Discrimination: Old Responses to New Technologies" (1994) 74 *Boston U. L. Rev.* 1 at 5 and then n. 265.

XII. How Genetics Highlights Existing Problems

I have thus far argued that it is difficult to convincingly demarcate genetic information from other health-related information. So, have ethical questions surrounding genetics all been much ado about nothing? Surely not. There are sound reasons for expressing concern. More systematic use of genetics deserves special attention because it could exacerbate existing problems. More than ever before, significant ethical and social problems could be created by the use of medical data for commercial purposes. Regulating the use of genetic data, as a separate category, could be impractical, but it is important to attend to the problems that genetics highlights. Questions raised in the context of genetics might convince people of the need for stricter regulation of the use of medical information in general.

It could be argued that a combination of the following factors justifies current attention to problems surrounding genetics: the volume of data likely to become available;¹²⁸ the fact that so much information can be gathered from one sample, which itself can be kept for an indeterminate length of time; the relatively high predictive value of many of the tests combined with remaining uncertainty and difficulty of interpretation; the often fatal or incurable nature of the predicted disease; and the way others (such as family members and ethnic groups) could be affected by genetic data gathered from individuals. While other medical information may have an impact on and relevance for family members, genetic data may sometimes be particularly sensitive. For example, it may indicate a high risk of fatal or serious illnesses among family members, thus raising questions with respect to moral responsibilities towards relatives and the legal duty to warn of the person undergoing testing and of the physician or researcher who is informed of the results. For some conditions, the development of a genetic test is only possible with the collaboration of family members. Genetic screening can reveal more than the test result aimed at. Cases of non-paternity are often revealed in the course of testing. This can be disruptive for people undergoing testing, as well as for their families.¹²⁹

Furthermore, as Murray maintains, the increasing number of genetic tests "broadens the pool of possible factors that might be used to discriminate against an individual, and it likewise expands the pool of individuals who might become the subjects of discrimination."¹³⁰ In the context of insurance, this could have particular consequences. Group risk classification could be replaced by individual genetic risk profiling. The prospect of cheap testing makes such profiling a realistic possibility. A form of economically imposed solidarity between those included in large risk groups might disappear with the advent of individualized underwriting. More people could face serious financial consequences as a result of their individual risk status.

¹²⁸ Danish Council of Ethics, *supra* note 52 at 63.

¹²⁹ For a discussion of the ethical implications, see Wertz & Fletcher, *supra* note 110.

¹³⁰ Murray, *supra* note 90 at 66.

Solidarity and empathy arise more easily when people feel connected to the problems and suffering of others and realize that they, too, could be affected by discrimination. Genetics might stimulate society's overall concern for the way some people, already negatively affected by serious illness, are denied full participation in society.

It is still too early to predict what could happen. According to some, so many predispositions and susceptibilities could be discovered that the number of people unaffected by any genetic risk factor may be reduced. This development, it is argued, would necessarily reduce the incidence of genetic discrimination, since almost all people would be susceptible to it.¹³¹ A cautious approach is still necessary, however. The means of gathering genetic information, and the information that is gathered, will renew debate on pre-existing social issues. It might well be, as Rothstein argues, that "the status quo of virtually unregulated medical underwriting in life insurance will become increasingly untenable as genetic technologies improve and proliferate."¹³²

In the meantime, the amazing pace at which genetic research develops and the unavoidable uncertainty that exists in this time of discovery and testing of hypotheses warrants special consideration. Ineliminable uncertainty and constant changes to our understanding of disease resulting from genetic research should be taken into consideration when discussing its potential use outside the research or medical context. First, it takes time for genetic tests to establish a reasonable and fairly reliable degree of predictive value. Meanwhile, private parties may be tempted to use this information, and as such, they may misunderstand the findings and make erroneous health predictions. Insurance companies may want to play it safe in refusing to offer coverage on the basis of the uncertainty created by a new test. The recent case of *J. v. London Life Insurance*¹³³ highlights the possibility of such attitudes by insurers. As mentioned earlier, this case involved a refusal by an insurance company to offer insurance to the partner of an HIV/AIDS infected person, based on the potential risk of transmission of the disease. The company based its refusal on the apparent lack of statistical evidence with respect to the risk for infection. It thus preferred to play it safe, and to exclude the person from coverage, rather than trying to accommodate that person.

Our understanding of medical conditions, including conditions for which there was previously thought to be a clear genetic explanation, is often in flux, making it problematic to count on an appropriate use of genetic test results by third parties. Cystic fibrosis is a very interesting example in this context.¹³⁴ The identification in 1989 of the gene responsible for this condition, originally characterized as "early onset and fatal," was one of the first great success stories of modern genetics. However,

¹³¹ Dreyfuss & Nelkin, *supra* note 5 at 334.

¹³² "Genetic Counselling", *supra* note 119 at 170.

¹³³ [1999] B.C.H.R.T.D. No. 35, online: QL (BCHR) [hereinafter *J. v. London Life*].

¹³⁴ "Genetic Antidiscrimination", *supra* note 7. Beckwith & Alper rightly add a caveat when they mention that only in the single-gene diseases is there a clear link between a gene and a particular disease.

further genetic research on cystic fibrosis has lead specialists to draw a more complex picture of the disease. Many more different genetic mutations are now linked to cystic fibrosis than were previously thought to be, resulting in different expressions of the disease. More than 550 genetic mutations have been identified.¹³⁵ The age of onset, the severity of the expression, and the pace of development differ significantly depending on the type of mutations involved.¹³⁶ Recent research involving infertile men, for example, indicates that some men develop the condition only at a much later age and may have only a very mild variation of the disease.¹³⁷ They would previously have been diagnosed as having, not cystic fibrosis, but rather other respiratory problems. Whereas it was originally seen as the paradigm of a single-gene early onset fatal condition, cystic fibrosis is now known to be a more complex disease, varying in expression. It is perhaps more appropriately considered a cluster of conditions rather than a monolithic condition. Interestingly, some of the rarer mutations associated with late onset mild cystic fibrosis are detectable only in the most sophisticated genetic laboratories. This means that accuracy in diagnosis may depend in part upon where people undergo testing. Often, milder forms of cystic fibrosis are detected only after couples having reproductive problems visit an infertility clinic, clinicians may find that the infertility is caused by the fact that the man has no *vas deferens*.¹³⁸ Absence of the *vas deferens* is typical for males suffering from cystic fibrosis. Many of these infertile men do not have any of the other typical clinical manifestations of the disease, are already past the common age for onset of the disease, but have two copies of one of the rare cystic fibrosis mutations. This raises the following question: if experts are still struggling with the meaning and predictive power of tests for one of the most classic genetic conditions, and if diagnosis may depend on the sophistication of particular laboratories, how can we rely on third parties with commercial interests to use this information in a reasonable way?

Genetic anti-discrimination laws, and the national and international declarations calling for such protection, reflect a public perception that there is something unique about genetics that warrants special attention. While I have argued that many of the distinctions invoked are either not fundamental or else not tenable, the combination of factors and the total volume of data likely becoming available justifies attention. Such attention reflects an awareness of the fact that possible uses of genetic information in the social context highlight existing problems. Genetics forces us to reconsider certain basic problems and issues. One of these issues is the potential for increased individualization within our society in private, contractual contexts.

¹³⁵ V. Mak & K.A. Jarvi, "The Genetics of Male Infertility" (1996) *J. Urol.* 1245 at 1249 and reference there.

¹³⁶ See e.g. M.-C. Romey *et al.*, "Complex Allele [-102T>A+S549R(T>G)] is Associated with Milder Forms of Cystic Fibrosis than Allele S549R(T>G) Alone" (1999) 105 *Hum. Genet.* 145.

¹³⁷ K. Jarvi *et al.*, "Heterogeneity of Reproductive Tract Abnormalities in Men with Absence of the Vas Deferens: Role of Cystic Fibrosis Transmembrane Conductance Regulator Gene Mutations" (1998) 70 *Fertil. Steril.* 724.

¹³⁸ The *vas deferens* is the duct by which semen is transmitted in the male reproductive system.

The basic question which remains is whether the singling out of genetic conditions the right response? Does this process of "singling-out" genetics, through legislation and debate, not hide fundamental injustices in other domains. Ought we not also ask ourselves what can be done with respect to poverty, housing problems, environmental risks to health, and other factors that may affect health and life expectancy? Narrow prohibitions against genetic testing ought not to distract us from paying heed to other instances of injustice, which affect our collective health and well being, such as inappropriate governmental support for health and welfare.

XIII. Degrees of unfairness

So far, I have discussed insurance as a global concept and have analyzed why, on the one hand, genetic exceptionalism is untenable, while, on the other hand, genetic developments aggravate existing issues. So far, I have purposefully ignored the fundamental differences between various forms of insurance, as well as the gulfs between health care in the United States, Canada, and Europe. The aim was to first give a more general, global response to existing legal and regulatory initiatives focusing on genetic data and to discuss the coherence of these initiatives. And yet, when we discuss the fairness of these approaches, we need to look more closely at the context in which these regulations play out, and at the role of insurance contracts in particular societies.

Both the American statutes, prohibiting the use of genetic data for health insurance, and the European legislation, focusing on life insurance, suffer from inadequacy and are potentially even inequitable for the same reason. However, there are salient differences in degrees of injustice. In the United States, state legislation now often protects carriers of genetic traits against exclusionary practices, while continuing to allow insurers to exclude people from health insurance on the basis of other health predictors. Without rational grounds, some people now obtain access to the social good that is health insurance, while others in similar situations—for example, people who are at a comparable risk for early death or disease because of a non-genetic condition—are excluded from it or else are financially penalized. In a system where health care is controlled by the underwriting practices of private insurance contracts, the injustice is most basic, having to do with the inequality in access to health care. Inequality in access to health care is clearly a more serious issue than, for example, exclusion from a life insurance contract. The latter offers some financial stability to surviving partners and family members but does not seem as essential. But this does not take away from the fact that even in the latter case, statutes based on genetic exceptionalism treat people who are similarly situated differently.

The inequity is made worse by the prospect that, in the near future, those who are most likely to be protected by genetic discrimination statutes are those who currently have access to some form of health insurance. People who will seek information on their genetic susceptibility will be those who have the financial means to undergo testing or those who have a good insurance plan (and thus already benefit from better health care). They will be more comfortable adding genetic screening to the array of available diagnostic tests, while others already excluded from appropriate care will also be deprived of this new medical tool. The commercialization of genetic services

recommended by some will only widen differences in accessibility to genetic testing. The selective protection of persons having such access may further accentuate the existing rift in access to health care in the United States.

Two examples may clarify the inequity in singling out genetic data for protection. Under some of the selective genetics laws, a woman who carries the BRCA1 gene and who is thereby at higher risk for developing breast cancer, cannot be charged a higher premium. However, another woman who has undergone a mastectomy because of breast cancer, who does not have one of the identified mutations and who has been successfully treated, could be excluded or forced to pay higher premiums. If a predictive genetic test for schizophrenia were to be developed (which is unlikely at this time) a person identified as being at high risk for the disease could not be excluded from life insurance. Other people who have been treated for depression may encounter difficulty in obtaining a similar contract if their condition were to not be linked to specific genetic mutations.

That said, the *proliferation* of protective laws in the area of genetics should raise awareness about more fundamental issues that need to be addressed. There are reasons for the recent appearance in the United States of statutes focusing on genetic discrimination. The perception that the increasingly widespread use of genetic testing is more likely to affect all of us adds to the pressure to deal with more general issues of access to health care and the need for financial security.

Considering the impact genetic developments are likely to have on underwriting practices, it should not come as a surprise that more and more health care specialists in the United States have called for the introduction of a universal health care system, as exists in most European countries and in Canada.¹³⁹ In pointing out the flaws in many genetic anti-discrimination laws, Beckwith and Alper posit that:

the optimal solution to this dilemma is a single-payer universal health care system. In such a system, distinctions between genetic and nongenetic diseases and tests become totally unnecessary. Because everyone would already be insured, problems such as adverse selection in health insurance would not exist.¹⁴⁰

In an influential report on genetic testing, the Committee on Assessing Genetic Risks also recommends that "risk-based health insurance should be eliminated"¹⁴¹ and that

¹³⁹ See e.g. "Universal Access to Health Care" Note (1995) 108 Harv. L. Rev. 1323; M.A. Rothstein, "Genetic Secrets: A Policy Framework" in *Genetic Secrets*, *supra* note 66 at 451 [hereinafter "A Policy Framework"]; Department of Health and Human Services, *Health Insurance in the Age of Genetics* (1997), online: National Human Genome Research Institute <<http://www.nhgri.nih.gov/NEWS/Insurance/>> (date accessed: 8 January 2000); "Genetic Antidiscrimination", *supra* note 7; "Distinguishing Genetic From Nongenetic", *supra* note 98; for a succinct discussion and references on the recent U.S. debate on universal health care, see R.A. Bornstein, "Genetic Discrimination, Insurability and Legislation: A Closing of the Legal Loopholes" (1996) 4 J.L. & Pol'y 551 at 576, in particular n. 98.

¹⁴⁰ *Supra* note 7 at 208.

¹⁴¹ Andrews, *supra* note 117 at 281.

Americans should have access to health care "without regard to the individual's present health status or condition, *including genetic make-up*."¹⁴² The Committee thus recognized the need for a more global approach that encompasses health insurance in general.

These developments are yet further confirmation of a widespread conviction that, in the United States, access to health care is already a serious problem, particularly for the un- or under-employed. For those who do have access to government-funded medicare programs, the quality of care received is often significantly lower than that provided to those who subscribe to private health care plans. Karen Rothenberg, relying on information from a 1994 population survey of the Employee Benefit Research Institute, declares: "[W]e live in a society where over forty million people have no health insurance and limited or no access to our health care system."¹⁴³

While these views on issues of access are widely shared among many health care analysts in the United States, they stand in sharp contrast to the lack of political support for serious health care reform. "There can be little dispute," Rothstein points out, "... that the likelihood of a drastic change occurring soon in the United States is exceedingly small."¹⁴⁴ In this context, it becomes more understandable why most states opted to deal with this threat through prohibitory approaches focusing on genetics. Acknowledgement of the fact that universal health care is not on the foreseeable horizon creates a dilemma when considering the flaws of current genetic discrimination laws. Rothstein, for example, seems to support genetic anti-discrimination laws inasmuch as they provide at least some protection. Beckwith and Alper argue, in the same vein, that "laws controlling genetic discrimination represent an effort in the direction of comprehensive reform of the health care system."¹⁴⁵

According to this line of argument, genetic discrimination laws are 'better than nothing' and are a first step in the right direction. Others argue, on the other hand, that protections against genetic discrimination take away incentives for further reform. It is argued that in reassuring the public that genetic data will not negatively impact on their access to health care, public support for significant change will disappear. Those who are already deprived of health care will again be left in the cold. The self-interested solidarity that they might have benefited from will be eliminated. For Yesley,

¹⁴² *Ibid.* [emphasis added].

¹⁴³ *Supra* note 63 at 103 [footnote omitted]. Amy Darby estimates that there are thirty-seven million Americans without health care and adds that neo-natal mortality in the U.S. compares to third world countries (*supra* note 123 at 788). She also refers in a footnote to the 1994 State of the Union Address, in which President Bill Clinton evokes that there are 58 million Americans without coverage for some time each year (*ibid.*).

¹⁴⁴ "A Policy Framework", *supra* note 139 at 456. Beckwith & Alper also admit that "in the present political climate, the prospect of a universal health care system seems unlikely" (*supra* note 7 at 208).

¹⁴⁵ *Ibid.* at 209.

Removing the basis for this fear of insurance loss may seem a reasonable step, but the possible cost of laws barring genetic discrimination in health insurance should also be weighed. Although the piecemeal approach of barring genetic discrimination may help a few people, it also removes a compelling argument for the ultimate goal of universal health coverage, which would benefit far more people.¹⁴⁶

In observing the health care system in the United States, and the attempts to reform it, it is easier to criticize from the outside the lack of coherence of the genetic anti-discrimination and privacy statutes than to judge the comparative value of these claims. On the one hand, fear of genetic discrimination could indeed create the necessary conditions for general health care reform in the United States. Regulating genetic discrimination could take away the support for such reform. On the other hand, it is difficult to justify the suffering of those who could be affected by genetic discrimination on the basis of public good or future benefit for all. If one cannot achieve global health care reform, is it so wrong to avoid at least one category of discrimination, as a first step towards a more comprehensive form of access to health care?

This is the approach taken by Alper and Beckwith:

[I]n the short term, legislation covering genetic discrimination may unintentionally serve to forestall more far-reaching reform of the health insurance system. In view of this potential narrowing of focus, we believe that it is increasingly important for advocates of legislation covering genetic discrimination and privacy to work together with advocates of more far-reaching reforms. The success of the campaign for the strictly genetic legislation should serve as a first step towards comprehensive antidiscrimination and privacy legislation.¹⁴⁷

XIV. Insurance Underwriting, Adverse Selection, and Fairness

Arguments in favour of prohibitions against genetic discrimination often invoke the concept of fairness. I used this same concept to criticize that approach, arguing that singling out genetic information for protection may add to already existing inequities. The crucial question is: to what extent is it unfair to make access to insurance dependent on a health condition, be it a genetic one or not? To what extent, if any, should people be able to obtain coverage irrespective of particular health predictors?

Insurers traditionally argue that there are two main reasons why they have to obtain access to health information of insurance applicants: one economic and the other moral. The economic reason is related to the phenomenon of *adverse selection*. Adverse selection (or anti-selection) refers to the hypothesis that if insurance applicants are allowed to hide health factors, insurers will soon be confronted with a disproportionate number of people at risk applying for extended coverage. Insurance applicants who know that they are at risk and know that they can hide this have an incentive to obtain insurance. As a result, insurers will have to pay out more claims. Extra costs

¹⁴⁶ Yesley, *supra* note 27 at 663.

¹⁴⁷ "Distinguishing Genetic from Nongenetic", *supra* note 98 at 148.

will result in higher insurance premiums and people who are at low risk will gradually lose interest in obtaining insurance. The proportion of high-risk individuals will thus systematically increase. Insurance will enter a spiral of price increases and, according to the insurance experts, in the end the industry will collapse.¹⁴⁸ While the extent of adverse selection is the subject of controversy, it is fair to say that some exchange of information and some assessment of risk remain the basis for private insurance. It can be expected that many people would take out insurance coverage if they knew that they or their beneficiaries would be able to benefit from it in the near future.

The other argument invoked by insurers is the ethical concept of equity or fairness; the same concept invoked by people who claim that use of genetic information by insurers should be limited. According to insurers, they have to distinguish people on the basis of individual risk for reasons of fairness to policyholders. According to Pokorski, for example, "The fundamental goal of the underwriting process is equity: policyholders with the same or similar expected risk of loss are charged the same."¹⁴⁹ He goes on to say that "[a]n insurer may—and must—discriminate to achieve equity, insofar as the discrimination remains fair."¹⁵⁰ This statement begs the question, since the criterion for deciding whether equity is achieved is whether the means to achieve it are fair. What Pokorski argues is that, in insurance terms, an insurance scheme is equitable if it respects actuarial rules. It presupposes that the use of actuarial rules itself is neutral and not questionable from the standpoint of equity.

Equity in this sense is rooted in the notion of contractual liberty. People who sign an insurance contract know what they are getting into, and understand that the rule of the game is underwriting, which involves assessment of individual risk. As Norman Daniels indicates, however, equity in this context is more accurately described as actuarial equity. It is fairness according to existing insurance practices, based on "actuarially accurate determination of ... risk."¹⁵¹

This is to say nothing of the fairness of the premise that access to insurance should always be based on presumptions of contractual liberty. This is a much more fundamental question, and it is one that goes to the heart of the debate over the limits of contractual liberty and issues of distributive justice in health care and social security. The equity invoked by insurers is valid for those who accept the premise on

¹⁴⁸ For a more detailed discussion of adverse selection and references, see Lemmens & Bahamin, *supra* note 18 at 171-75 and references there.

¹⁴⁹ R.J. Pokorski, "Use of Genetic Information by Private Insurers" in Murphy & Lappé, *supra* note 120, 91 at 92 [hereinafter "Use of Genetic Information"]; see also R.J. Pokorski, "Genetic Information and Life Insurance" (1995) 376 *Nature* 13; K.A. Clifford & R.P. Iuculano, "AIDS and Insurance: The Rationale for AIDS-related Testing" (1987) 100 *Harv. L. Rev.* 1806. But see M.C. Anderson, "Genetic Testing in Insurance Underwriting: A Blessing or a Curse? An Examination of the Tension Between Economics and Equity in Using Genetic Testing in Risk Classification" (1992) 25 *Creighton L. Rev.* 1499.

¹⁵⁰ "Use of Genetic Information", *ibid.* at 93.

¹⁵¹ N. Daniels, "Insurability and the HIV Epidemic: Ethical Issues in Underwriting" (1990) 68 *Milbank Q.* 497 at 500.

which the insurance game is based. The more important issue as to how insurance fits within our vision of a just society calls into question the premise upon which claims of fairness are made.

It is important to note that a discussion of the role of insurance in society cannot and should not be avoided when discussing the fairness of genetic discrimination in insurance. Although the insurance laws providing exclusive protection against genetic discrimination seem inappropriate in many ways, they make clear the need for a more global approach towards the issues of access to health care and financial security.

Following Michael Walzer, I will argue that the way insurance as a good ought to be distributed depends very much on its meaning. And since the meaning of goods can only be determined by examining patterns of exchange of goods in particular societal and cultural contexts, we can only judge the equity of a particular insurance scheme by looking at its role in the context of a particular society. On the basis of this argument, one can understand and explain the temporary focus of American statutes on genetic discrimination, while at the same time making a case against the development of similar laws in Canada. The latter, as I will point out, is conditional on a strengthening of the public health care system and the development of appropriate democratic structures to determine what constitutes reasonable underwriting practices in private insurance.

XV. Health Care and Insurance in a Just Society

In *Spheres of Justice*, Walzer argues forcefully that a just society is one in which different goods are distributed according to autonomous distributive principles, depending on their particular role.¹⁵² Equity, Walzer claims, is not attained by giving people equal access to all goods, which is an idealistic and untenable ideal, simply because people value goods differently. Human nature being what it is, many goods would be distributed unequally shortly after they would have been distributed in an egalitarian way. They may be traded, exchanged, divided, abandoned, or become subject to speculation. Equal distribution of goods would be a continuous and never-ending process. A just society, according to Walzer, is therefore not a society in which everyone possesses the same. It is, rather, a society in which relationships of dominance are avoided. Such dominance occurs when the possession of one particular type of good gives the owners privileged access to other types of goods. An example of such dominance is when money gives its possessors power over all other goods that are exchanged in society, including political office and representation, medical care, and education. A just society, in other words, does not allow the concentration of power over different types of goods. This explains the public outrage in our democratic societies, for example, when the public perceives that someone has privileged access to ministerial cabinets because of her money or when people protest against the

¹⁵² M. Walzer, *Spheres of Justice: A Defense of Pluralism and Equality* (New York: Basic Books, 1983).

granting of an honorary degree for what they perceive to be fundraising purposes. Money ought not to determine political attention, and honorary titles ought to be deserved.

Walzer's arguments are based on a theory of goods in which goods are understood as essentially social in nature. Goods, as such, derive their particular meaning from human interaction and sharing. Human interaction itself is determined by, and closely connected to, the exchange of goods. To a great extent, people define themselves through goods. They identify themselves, and are identified by others, through interchange with others—much of which involves the exchange of goods. If the meaning of goods differs fundamentally, Walzer claims, then their distribution must be distinct, and dependent on their meaning. He outlines three different criteria according to which goods can be distributed: free exchange, desert, and need. What counts as an equitable distributive criterion in one sphere is not necessarily appropriate as a criterion in another. Justice is attained when the distinctions between different spheres are respected and when the appropriate distributive criterion is applied within each particular sphere.

Walzer discusses several examples of how goods are distributed within different spheres of justice, regulated by appropriate procedures and according to distinct criteria. Two of the spheres he discusses are particularly interesting in the context of insurance: the sphere of Money and Commodities and the sphere of Security and Welfare.

The goods in the sphere of Money and Commodities, Walzer argues, ought to be distributed according to the distributive criteria of the marketplace. People spend money differently, depending on personal preferences, on character traits (for example, whether they are risk takers or conservatives) and on their particular vision of what they need to have a good life. Walzer recognizes the importance of respecting free exchange as an appropriate criterion within this sphere. Money and commodities ought not necessarily be available to all in the same way. Remember that people have a tendency to spend things differently and value these goods in a different way. There are, however, limits to the use of the principle of free exchange, even when dealing with goods that can be qualified as falling in the category of Money and Commodities. Access to some of the goods in this sphere is essential, since “[c]ommodities are symbols of belonging; standing and identity are distributed through the market, sold for cash on the line ...”¹⁵³ Since participation in the exchange of goods is so essential, there have to be corrective forces (*i.e.* redistribution within the market) in order to avoid over-concentration of money and commodities.

The market itself is based on contractual liberty, on an exchange between approximate equals. Such liberty makes sense only if people are in a position of choice. Walzer therefore strongly argues that desperate exchanges should be banned. Minimum wage laws and health and safety regulations are examples of corrective forces. They make sure that people who are in a vulnerable position are not forced to accept

¹⁵³ *Ibid.* at 106.

any contractual condition merely to have access to specific goods of the market. Redistribution takes place through limitations of market power, through the tax system, and through the regulation of property rights.

It should be clear how this could be relevant in the context of, for example, life insurance contracts that aim at offering some financial security and stability. Walzer recognizes that some degree of access to money and commodities is crucial for full membership in society. This form of minimal access to goods is normally obtained through means other than insurance. However, there may be circumstances in which insurance contracts could play a role in safeguarding some elementary form of financial independence or they could be a pre-condition for access to other goods. Furthermore, when concluding contracts people should not be powerless, even if the aim is to obtain goods in the category of Money and Commodities. They should have some flexibility in either accepting or rejecting these contracts. The state, in other words, might be justified in intervening in such a way as to limit contractual liberty.

Another distinct sphere of justice that Walzer discusses in much detail is the Sphere of Security and Welfare. If anything at all is fundamental within a community, it must be the existence of some form of mutual provision. Mutual provision is the result of living in a community, but it is also the precondition for constituting a community. Goods that belong in this sphere are goods to which all in a given society should have access. In this sphere, goods ought to be distributed according to the criterion of need. These mutually shared goods have a double function, according to Walzer. People receive them because society perceives them as essential, but they are also given as recognition of membership. The goods of this sphere carry much moral weight and express core values of a community. Communal agreement of what ought to be distributed to all is an expression of the kind of social contract through which members of a community share a moral bond.¹⁵⁴ The precise content of the goods of this sphere differs according to time and place, but there are always some goods the value of which seems to be universal.

In discussing issues related to insurance, other authors explicitly note that choices regarding insurance systems impact on the way a community defines itself. Deborah Hellman, writing about insurance discrimination against battered women, recognizes that “[a] way of understanding the disagreement over the justifiability of insurance rating is as a discussion about what kind of a community we want to be.”¹⁵⁵ Referring to Deborah Stone, she argues that “the debate about whether the actuarial fairness principle ought to govern health insurance pricing is a debate about whether ours is a community that is committed to the provision of aid to those who are sick or disabled.”¹⁵⁶ This recognition of access to health care as a defining feature of society is very much in line with Walzer’s theory. He highlights the importance of health care in

¹⁵⁴ *Ibid.* at 82.

¹⁵⁵ Hellman, *supra* note 124.

¹⁵⁶ *Ibid.*

our contemporary society in the following way: medical care has become a socially recognized need so that

deprivation [of medical care] is a double loss—to one's health and to one's social standing. Doctors and hospitals have become such massively important features of contemporary life that to be cut off from the help they provide is not only dangerous but also degrading.¹⁵⁷

In other words, people's dignity is at stake when they do not have access to decent health care. The degree of current public debate over health care is unprecedented. Health and physical well being are the foci of an inordinate part of public discourse. Issues related to health care are the subject of major talk shows, and are at the centre of an extraordinary number of television series in the United States.¹⁵⁸ Difficult medico-ethical dilemmas or spectacular performances in health care make heroes of physicians, researchers, bioethicists, and health care workers. More fundamentally, health care is a recurrent theme in the political arena.

XVI. Fairness in Access to Health Care in the United States

Since Walzer recognizes that the content of Security and Welfare is subject to communal understanding and decision making, he therefore has to accept that societies may offer differing levels of medical care. What constitutes a social good is determined on a communal level. Different communities make different choices reflecting different priorities. Walzer acknowledges that the absence of a universal health care system in the United States could mean that the community has set a low standard of what belongs to this sphere. This could be a political decision and it would, according to Walzer's theory, be difficult to argue against such a social perception of the common good. However, certain facts pose a challenge to this interpretation. As Walzer observes, "So long as communal funds are spent, as they currently are, to finance research, build hospitals, and pay the fees of doctors in private practice, the services that these expenditures underwrite must be equally available to all citizens."¹⁵⁹ In other words, although large portions of communal provisions are spent on the development of health care, health care resources are distributed unequally, and many have no access to appropriate care. Medical care is clearly recognized as a part of the sphere of Security and Welfare, and as such, is an essential good in society, but its distribution is unequal. Distribution takes place very much according to the rules of the marketplace. In other words, possession of money allows people to buy access to goods that should be distributed according to a different distributive criterion. Money allows people to transgress the boundaries and buy access to goods that should be distributed according to need.

¹⁵⁷ Walzer, *supra* note 152 at 89.

¹⁵⁸ For an entertaining analysis of this phenomenon, see C. Elliott & J. Kahn, "Docs on the Box: Or, How We Learned to Stop Worrying and Love The Tube" (1994) 24:6 *Hast. Cent. Rpt.* 22.

¹⁵⁹ *Supra* note 152 at 90.

As pointed out, Walzer's theory of justice is relevant for our discussion of the role of insurance and the equity of regulations focusing on genetics. State and federal statutes in the United States dealing with genetic discrimination and privacy are precisely a confirmation of Walzer's argument that medical care is a primary social good, even if health insurance is submitted to private market mechanisms, and even if many have no access to decent health care. Writing about American statutes, Hall notes:

Our instincts about the social versus private market dimensions of insurance are much different for life versus health insurance because health care is much more of a social necessity than are burial expenses or cash support for dependants. Accordingly, most statutes only restrict use of genetic information in health insurance.¹⁶⁰

The tendency to ban genetic testing for insurance purposes, despite its flaws, illustrates at least a couple of fundamental points: access to health care on the basis of need remains a precious good, and there is an attempt to preserve some form of it in the United States.

If health care is so important in society that it should be offered on the basis of the criterion of need, serious reforms are needed in the United States to offer basic access, regardless of one's health predictors. Health care should in fact be provided in proportion to need. Many of the people who are in greatest need risk falling between the cracks if they can be excluded from insurance coverage on the basis of genetic or other risks to health. As discussed earlier, however, by guaranteeing access to health care only to those who could become excluded because of a genetic condition, others whose health is at risk for different reasons are treated unfairly. The distributive criterion for health care is overall need, not exclusively need that is related to being at genetic risk. Further, narrow protections against genetic discrimination could also unfairly benefit those who are already in a more favourable position with respect to access to health care. Genetic tests are not freely available, even though some populations may have access to genetic screening as part of research projects. These tests will likely be available on a commercial basis for those who can afford them or perhaps for those who already have insurance and are reimbursed for testing. As I mentioned earlier, those who currently do not have access to health care are unlikely to go for genetic testing. Their position will not improve as a result of genetic exceptionalism. On the contrary, these laws may very well reinforce existing injustices in the health care system.

XVII. Fairness and Genetic Discrimination Statutes in Europe

While the desire to preserve some access to private health insurance may explain the wave of genetics legislation in the United States, the same cannot be true for Europe. Most European countries have some form of universal access to health care. Countries that have established the most stringent legislation do have universal health

¹⁶⁰ *Supra* note 79 at 18.

care. Many of these countries also have stringent privacy legislation. According to Paul Schwartz, the latter clearly shows that confidentiality and privacy of medical information is an important value in and of itself, irrespective of the issue of access to health care and genetic discrimination.¹⁶¹ While this rings true, concern for privacy is clearly not the only reason for these legislative initiatives, since some laws explicitly prohibit the use of genetics by insurers. The existence of a universal health care system does not seem to be sufficient to dissolve people's concern about genetic discrimination. Something other than the desire to keep genetic information under personal control and within the sphere of privacy is at stake.

The fact that the first laws dealing with the prohibition to discriminate on the basis of genetic information were proposed or adopted in countries with a universal health care system may simply confirm the existence of a different moral bond. It may reflect a different interpretation of what members need to become full participants in society. The support in many European countries for limitations on insurers' underwriting power in the context of life and additional health insurance is an indication that these insurance contracts are considered to be more than mere commodities or, at least, that they should be traded on the market with serious restrictions.

Societies that embrace universal health care and other social policies are also tempted to impose solidarity in other domains. Walzer's observation that "[t]he closer and more inclusive [the social contract] is, the wider the recognition of needs, the greater the number of social goods that are drawn into the sphere of security and welfare,"¹⁶² is very poignant in this regard. In general, there are more redistributive measures in Europe than in the United States. The role of labour unions in many European countries, the provision of social housing, public education (including access to universities), the redistribution of wealth through proportionally higher taxation, and so on, are all indicators of a more inclusive sphere of Security and Welfare. The tendency to limit insurers' power to discriminate in life and additional health insurance may suggest that access to some form of financial security for family members and relatives, and to additional health care coverage are highly-valued social goods.

As mentioned, an interesting attempt was made to combine the rules of the insurance market with the provision of some basic access to life insurance in the Netherlands. There, the insurance industry provided on its own a guaranteed access to life insurance for contracts under about \$140,000. In a way, this provision can be seen as a recognition of the importance of some minimal form of financial security provided by the market.

It is important to point out that in some countries, life insurance contracts also play a particular role insofar as they are a prerequisite for other important contracts. In the United Kingdom, for example, mortgages to buy a house have to be supported by life insurance. Under such a system, people need insurance to obtain what is for many

¹⁶¹ Schwartz, *supra* note 66 at 397.

¹⁶² *Supra* note 152 at 83.

a fundamental good. This is the reason why the British insurers agreed to provide basic life insurance up to £100,000 without asking access to genetic testing.¹⁶³ Such practices that aim at safeguarding some form of universal access to these goods are just another expression of the social value placed on these goods.

These examples highlight Walzer's analysis of the crucial role goods may play within society, even when they are distributed according to the rules of the market. Insurance coverage may be seen as important for one's full membership in society, even when universal health care and social security provide health care and minimal financial security. Even if the insurance contract itself is not seen as crucial, it may still be a necessary condition for obtaining access to a more important, central good. Ownership of a house clearly is an important good in many states in which socially supported housing projects work towards the creation of access to home ownership. Ownership is part of the creation of one's private space. At least insofar as insurance is a pre-condition for ownership, it should be made available as much as possible across society, through rules which limit the insurance market.

What lessons can be learned from the genetic discrimination debate in the United States and Europe? Have we reached the point where we can comfortably conclude that specific measures ought to be taken in Canada to curb the potential negative impact of the use of genetic information by third parties? If so, what are these measures? It is to these issues that I turn next.

XVIII. Lessons for the Canadian Health Care and Insurance Systems

I have argued that the debate over the need for genetic discrimination laws in the United States highlights the problematic and contradictory nature of the American health care system. Health care is clearly recognized as a social good, but distribution is provided on the basis of market criteria. Genetic discrimination laws in the United States are an imperfect response to a pre-existing crisis in health care distribution—a crisis that could be aggravated with the advent of genetic testing. Genetic testing would only increase social stratification and exclude an even larger section of the community from needed health care services.

What can we learn from this for the Canadian context? First, the strong arguments made by American health care experts for health care reform, and the need for a system of universal health care should serve as a wake up call for those in Canada who call for privatization of important components of the health care system. One should consider very carefully whether privatization of specific health care services, including genetic services, would not bring with it a pressure for individualized risk assessment in the context of insurance. This could undermine equitable access to health care, not only of those who are genetically at risk, but also those at risk for other

¹⁶³ *Supra* note 59 at 5.

health factors. It is far from clear that governmental intervention, limiting the rules of the insurance market in order to improve access to private insurance goods, can curb the tendency of the market to exclude those who need health care the most. Again, the saga of the genetic discrimination statutes in the United States illustrates how difficult it is to develop an equitable system when underwriting and premium setting on the basis of risk status is used in the distribution of a good that belongs within the sphere of security and welfare.

Second, it should be understood that the implementation of genetic discrimination legislation in the United States is a particular response within a particular community, which has opted for a particular distributive system of health care. The legislation has specific, American-based rationale. At this point, the claim cannot be made for a similar urgent need for protective legislation in Canada, since at least basic health care is universally distributed according to the criterion of need. Could that change? Or alternatively, does that mean that we can sit back and contemplate, without worry, the vices of the health care worlds "out there"?

We should not lend such self-congratulatory praise to Canadian health care as part of our distinct national identity without first examining threats to the system and its increasing deficiencies. The recent debate surrounding the proposals by Alberta premier Ralph Klein to increase the role of privately funded health care services has highlighted the pressure on Canada's health care system and the precariousness of the perceived social consensus around the system.¹⁶⁴ As Colleen Flood indicates, the significant drop in the cash contributions by the federal government, even though partially compensated by the transfer of tax points to the provinces, has undermined the ability of the federal government to enforce the standards of the *Canada Health Act*.¹⁶⁵ Unless the federal government satisfies some of the financial requests of the provincial governments, some provinces may be tempted to solve budgetary constraints in health care by partial privatization of services currently covered by public funding. In other words, there is increasing pressure to allow private actors into the health care arena, not only to offer services in areas where the public sector has traditionally not been very active, but also to offer faster or more sophisticated care for those who are willing to pay for it.

The importance of additional health and disability insurance is increasing steadily. People with *private* health insurance plans already have access to many health care services (including dental care, prescription drugs, home care, and vision care) that others may not be able to afford.¹⁶⁶ It must be said that most people subscribe to addi-

¹⁶⁴ For a defence of Premier Klein's proposals, see R. Klein, "Dr. Klein's Prescription" *The Globe and Mail* (3 December 1999). See also J. Travers, "Medicare Needs Cash Transfusion" *The Toronto Star* (2 December 1999).

¹⁶⁵ C. Flood, "The Structure and Dynamics of Canada's Health Care System" in J. Downie & T. Caulfield, eds., *Canadian Health Law and Policy* (Toronto: Butterworths, 1999) 5, in particular at 24-27.

¹⁶⁶ See *ibid.* at 9 for a discussion of health care services that are not publicly funded in Canada.

tional health and disability insurance plans through their place of employment. For these group insurance plans, there currently is no detailed underwriting process and people are not excluded from insurance coverage on the basis of individual risk assessment. However, those without employment do not have access to these plans. Moreover, it is not inconceivable that even access to group insurance plans may change as a result of increasing health care costs and increasing possibilities for individualized assessment (through, for instance, genetic testing). Insurance companies and employers negotiate and come to an agreement on the different types of health care expenditures that will be covered by the insurer. Could companies increase their bargaining power to obtain lower insurance premiums if they offered insurers a low-risk employee population? Employers would have a strong interest in excluding people who are at a high genetic risk for developing costly diseases. Further developments in genetic testing may affect insurability for additional health and disability insurance, thus impacting on access to health care for people at genetic risk. Again, it is important to stress here that the increasing importance of additional health and disability insurance would affect not only people at genetic risk. There are already serious problems of equitable access to health care. People who are unemployed, for example, often do not have the same level of health care as do those who are employed. If additional private insurance increases in importance, this inequity will only become more serious.

In the context of genetics, differences in access to drugs may also proportionally increase in importance. Genetic research may lead to the development of more individually tailored drugs and preventive therapies.¹⁶⁷ Pharmacogenetics might thus exacerbate differences in access to health care between those with and those without a decent drug insurance plan. This should be taken into consideration when thinking about the future of universal health care and the need for comprehensive pharmacare plans. The serious challenges to the American health care system, and the significant efforts needed to adapt the American system in light of the development of genetic testing, should make it clear that simply privatizing health care in Canada is not an equitable solution to the problems in Canadian health care.

European attempts to introduce genetic discrimination laws add an interesting alternative perspective. Although local differences remain, it is fair to say that access to health care in Europe and Canada are similar. Still, we have seen that genetic discrimination laws have been developed in Europe. Although these laws suffer from problems similar to the American statutes, they are worthy of our attention insofar as they highlight the fact that even life and additional health insurance may be very important goods. While such insurance may not be as important as basic health care, particular societies may value it in such a way as to command some form of equitable distribution.

¹⁶⁷ See *supra* at 123.

There are two ways in which to explain this special attention to insurance issues in light of Walzer's theory of justice. First, it might fit Walzer's analysis of the distribution of goods within the sphere of Money and Commodities. Walzer argues that when goods are distributed within the sphere of Money and Commodities according to the criterion of free exchange, there may still be a need for limits to contractual freedom and to the rules of the liberal market. Walzer mentions that governments can intervene to establish a better equilibrium between contractual parties. Other public policy concerns may also require governments to intervene in insurance markets. We generally already accept that insurers may not be allowed to make distinctions according to certain criteria that make sense in actuarial terms but not in terms of justice, because of the particular meaning attached to these distinctions. It would be hard to morally justify, for example, charging women who are victims of abusive relationships a higher life insurance premium.¹⁶⁸ The same is true for distinctions based on ethnic background. An insurance company would not likely feel comfortable defending a policy of charging higher life-insurance premiums on the basis of ethnicity, even if it *were* to make sense from an actuarial perspective.¹⁶⁹ Historical and contemporary social considerations, such as the tales of racial and sexual discrimination, have moral significance.

These examples illustrate the fact that, while certain practices may be defended in economic terms, they may be prohibited on ethical grounds. A legal system that would endorse these practices would reinforce social stigma and contribute to injustice. This raises the question: do the European initiatives reflect a view of genetics as having particular characteristics, which result in it falling under the rubric of morally objectionable discrimination? Are these statutes and the European *Convention on Human Rights and Biomedicine*¹⁷⁰ a reflection of the fact that people affected by a genetic predisposition merit particular protection by virtue of being "genetically disabled"?

I have discussed the ways in which genetic data is not fundamentally different from other types of health information, although a combination of factors make it very reasonable to pay attention to its social impact. I also indicated that it may not be feasible to single out genetics as a separate category, insofar as genetic exceptionalism might only add to existing injustices.

The European provisions remain interesting, however, as a reminder of important issues surrounding the potential social implications of genetic testing, even within societies that have universal health care systems. This brings us to consider a second way in which one could situate the special protective legislation on insurance and genetics within the framework of Walzer's theory. The regulatory initiatives surveyed may be based on a confusion of the place of insurance within contemporary European society, a confusion that speaks further to the need for improving access to health care

¹⁶⁸ See the discussion in Hellman, *supra* note 124.

¹⁶⁹ See D. Stone, "AIDS and the Moral Economy of Insurance" (1990) *American Prospect* 62.

¹⁷⁰ *Convention*, *supra* note 40.

altogether. The regulatory initiatives may indicate a shift in the role of private insurance in countries with a universal health care system. Concerns raised by this are highlighted by developments in genetic testing. The idea seems to be that insurance may be a social good—a good to which all people should have access irrespective of their particular genetic predisposition. The insurance statutes of Austria, Belgium, and Norway clearly reflect this idea, and so does the *Convention on Human Rights and Biomedicine*. The *Convention* is grounded in the need to protect human dignity and the valuing of the interests and welfare of individuals over the interests of society,¹⁷¹ but it also makes explicit reference to the notion of “equitable access to health care”. The *Convention* reinforces the right of equitable access to health care that is expressed in other conventions, such as the *European Social Charter*.¹⁷² Article 3 obliges states to “take appropriate measures with a view to providing, within their jurisdiction, equitable access to health care of appropriate quality.”¹⁷³ The *Explanatory Report* states that the aim of this provision is “to ensure equitable access to health care in accordance with the person’s medical needs” and that “equitable access implies effectively obtaining a satisfactory degree of care.”¹⁷⁴ The articles dealing with the prohibition against discrimination on the basis of genetics also reflect concern for the negative effects of genetic technology, which should aim at providing better medical care to in-

¹⁷¹ Articles 1 & 2.

¹⁷² Council of Europe, *European Social Charter*, E.T.S. No. 35 (1961) [hereinafter *Social Charter*]. Part I of the *Social Charter* contains among others the principles that the signatories

accept as the aim of their policy, to be pursued by all appropriate means, both national and international in character, the attainment of conditions in which the following rights and principles may be effectively realised:

11. Everyone has the right to benefit from any measures enabling him to enjoy the highest possible standard of health attainable.
13. Anyone without adequate resources has the right to social and medical assistance.
14. Everyone has the right to benefit from social welfare services.

Principle 16 may also be of interest in the context of genetics, to the extent that genetic discrimination may impact on families affected by a genetic disorder. It states that “[t]he family as a fundamental unit of society has the right to appropriate social, legal and economic protection to ensure its full development.”

Article 11 of the *Social Charter*, entitled “The right to protection of health”, states:

With a view to ensuring the effective exercise of the right to protection of health, the Contracting Parties undertake, either directly or in co-operation with public or private organisations, to take appropriate measures designed *inter alia*:

1. to remove as far as possible the causes of ill-health;
2. to provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health;
3. to prevent as far as possible epidemic, endemic and other diseases.

¹⁷³ *Ibid.*

¹⁷⁴ *Explanatory Report*, *supra* note 43 at paras. 24, 25 [footnote omitted].

dividuals. One could argue that the articles dealing with genetic discrimination in the *Convention* also touch upon the importance of access to health care.

At the risk of making some sweeping generalizations, one can say that European countries do have some form of universal health care and do have generous public support for access to health care, compared to the United States. In other words, in Europe, there would not seem to be the same obvious need for protective legislation. People affected by a genetic predisposition in Europe do not risk being immediately excluded from access to health care. And yet, many European countries have still introduced stringent legislation (or are under an obligation to do so by signing the *Convention*), limiting the right to use genetics in the context of private life, disability, and additional health insurance plans. This confirms earlier discussions with respect to the lessons to be learned from the American context. Pressures on universal health care systems may increase the need for additional private insurance. Additional health insurance has become more essential than ever and it is becoming a crucial pre-requisite for obtaining quality care. Dental care is generally not covered by the health care system. Private drug insurance plans are also important in ensuring access to medication. In short, private contracts are becoming increasingly important for access to appropriate care, and private partners are increasingly involved in the provision of access to social goods.

The European *Convention* and the national statutes dealing with genetics and insurance may be indication of this development and an expression of an increasing need for public regulation of private insurance. As Thompson notes in discussing developments in the United Kingdom, where private actors are becoming increasingly involved in the provision of care:¹⁷⁵

[I]n light of the political shift in favour of increased partnership between the public and private sectors for the provision of health care in the UK, it would seem prudent to act now to establish an environment that is conducive to private-enterprise participation, but at the same time firmly reiterates the social rights which are central to public policy.¹⁷⁶

It remains to be seen whether the dynamics of the market can be reconciled with the inherently social character of the need for health care. Can private insurers still flourish if requested to play a part in a system aimed at distributing social goods on the basis of the criterion of need? To what extent can limitations be placed on the rules of the market? Or rather, what can be expected in terms of collaboration between public

¹⁷⁵ For a thorough analysis of the health care reforms in the United Kingdom, United States and Canada, see C.J. Tuohy, *Accidental Logics: The Dynamics of Change in the Health Care Arena in the United States, Britain, and Canada* (New York: Oxford University Press, 1999); see also C.M. Flood, *International Health Care Reform: A Legal, Economic and Political Analysis* (London: Routledge, 1999), comparing health care reforms in the U.S., the Netherlands, New Zealand, and the United Kingdom, and discussing the implications for the Canadian system.

¹⁷⁶ B. Thompson, "Viewpoint: Time for Reassessment of Use of All Medical Information by UK Insurers" (1998) 352 *Lancet* 1216 at 1217.

and private sectors? These are the challenges with which health policy analysts, consumer groups, insurance companies, health economists and governments will have to struggle.

The preceding arguments concentrated on the role that private, additional health insurance schemes could play in providing access to health care. Similar arguments can be made about the potential shift in the role of life and disability insurance in our society. Reductions in welfare budgets and an increasingly unequal distribution of wealth may make it more important to have some form of private insurance, providing some form of financial security for less fortunate times. Offering financial security to dependants through life insurance or other private investment plans may become increasingly important. In countries with an imperfect system of universal health care and social security, one could argue that access to additional health insurance and life insurance becomes more of a necessity.¹⁷⁷

Prohibitions against genetic discrimination reflect the social importance of this type of safeguard against uncertainty. Some of the initiatives discussed earlier express a view of this type of insurance as a social, or at least quasi-social, good. Minimum insurance contracts, as offered by insurance industries in the Netherlands and United Kingdom, have been supported as an inventive way of providing access to basic goods.¹⁷⁸ The American Task Force on Genetic Information and Insurance, while focusing on health insurance issues, also points out that it is worth discussing whether there should be universal access to basic insurance for all. The report concludes a short discussion of life and disability-income insurance with the question: "What level of coverage would meet the test of social justice?"¹⁷⁹

As I mentioned, it is easier to qualify for the minimal insurance offered in the United Kingdom as a social good, because of the important role of this type of insurance for access to property ownership. Since life insurance in the United Kingdom is a pre-condition for obtaining a mortgage, being excluded from life insurance would mean exclusion from access to home ownership. If basic life insurance *per se* is not a social good, access to ownership may very well be.

Attempts to combine elements of universal access with market-oriented distribution systems are not necessarily in conflict with Walzer's theory of justice. The crux of the matter is whether there is some basic distribution of goods belonging to the sphere of Security and Welfare according to the criterion of need. This does not mean that such goods can never enter the market. If basic segments are provided to those in need, Walzer argues, the market can play a role in distributing according to the criterion of free exchange. "Needed goods are not commodities," Walzer argues, "[T]hey can be bought and sold only insofar as they are available above and beyond whatever

¹⁷⁷ See *e.g.* the discussion in Sandberg, *supra* note 103.

¹⁷⁸ *Ibid.*

¹⁷⁹ NIH-DOE Working Group, *supra* note 68 at 29.

level of provision is fixed by democratic decision making ..."¹⁸⁰ This seems to suggest, though, that at least some form of welfare and health care should be offered within the public sphere, outside of the commercial context. But would need-based limitations on the free exchange of the market be irreconcilable with Walzer's theory? If the community decides that some form of basic insurance—be it health insurance in the United States or life, disability and additional health insurance in Europe or Canada—is essential, it should be provided on the basis of need. It might not matter whether this is established by limiting the rules of the private market or by providing it through public distribution. Economic rules may impose limits on what the market could do. What one has to keep in mind is that needed goods should be distributed through the mechanisms of the market only if this does not unduly affect the universal distribution of basic (*i.e.* minimal) goods. Genetic discrimination statutes may be an effort in this direction. Unfortunately, as I indicated, the exclusive focus on genetics constitutes a problem, both in terms of feasibility and the moral terms of justice.

It is worth mentioning again that even if some of these insurance contracts cannot be qualified as social goods, access to them can still be of major importance. Some insurance contracts clearly seem to be part of a set of core market items, thereby belong to the sphere of Money and Commodities. A life insurance contract under which an insurer accepts to pay out three million dollars to one's spouse, for example, cannot be qualified as a social good to which all should have access. Such a contract seems to be an extravagant personal choice and as such does not merit public protection. But what about a life insurance contract for CDN \$100,000? If this contract is not needed for access to ownership, and if appropriate welfare provisions are in place to limit the vulnerability of the surviving family, could one still argue that all should have access to it? Being able to buy this good may very well be a major symbol of full membership in society.

Walzer recognizes that it is not feasible and morally unnecessary to distribute money and commodities in the same way as social goods, but that does not mean that they play no significant role in society, a role which may justify at least some minimal intervention for the purposes of redistribution. Invoking the sociologist Lee Rainwater, he argues that "in America today and in every society where the market is triumphant, commodities mediate membership. Unless we own a certain number of socially required things, we cannot be socially recognized and effective persons."¹⁸¹ Since "[c]ommodities are symbols of belonging,"¹⁸² it is appropriate to ensure that all people have access to some core set of these goods. It would be difficult to argue that any form of insurance-as-commodity would have to be accessible to all in every circumstance, since that would give it the character of a social good. At the same time, it would be appropriate to argue for protection and regulatory intervention if the development of genetic testing were to have the incidental result that people who were af-

¹⁸⁰ *Supra* note 152 at 90.

¹⁸¹ *Ibid.* at 106.

¹⁸² *Ibid.*

ected by a given health condition were systematically excluded from access to a wide variety of commodities. In that case, the integration of these people as full members of society, and the promotion of access to goods in the market place should be a priority.

XIX. Regulatory Framework in Canada

In order to determine how these lessons can be implemented effectively in the Canadian context, it is important to highlight briefly the regulatory regimes that are affected by my discussion. An outline of the regulatory regime of our universal health care system and of private insurance law is the focus of this section. I will argue that a new regulatory structure is needed, one that does not necessarily focus on genetic discrimination, but one that is able to take into consideration the impact of technological revolutions on our health care system and on human rights issues in the context of private insurance.

As I highlighted earlier, the discussion on genetic discrimination and the role of insurance is influenced by and impacts on the system of health care in a given society. Access to universal health care services in Canada is provided for by the *Canada Health Act*.¹⁵³ The *Canada Health Act* aims to ensure universal access to all "medically required" and necessary hospital and physician services. Problems occur when interpreting what this means, since there is no definition of these terms and no criteria are given for interpreting them. For the purposes of this discussion, it suffices to say that in the *Canada Health Act* there is a clear recognition of health care as a social good, and of the need to give access to this good irrespective of one's ability to pay. Advances in genetics should provide further fuel for debate over what counts as a "medically required" service. These debates will be marked by questions concerning what types of genetic services should be covered by provincial health insurance schemes, when genetic testing is sufficiently informative to be used in the clinical context, who should have access to these tests. A recent Ontario decision, compelling the Ontario Health Insurance Plan to cover BRCA1 and BRCA2 testing highlights the importance of these issues.¹⁵⁴ As mentioned earlier, the increased need for drug insurance, further spurred by developments in pharmacogenetics, highlights the importance of a public debate on the need for a comprehensive, universal pharmacare plan. A recent survey reported in *The Globe and Mail* reveals that the use of prescription drugs has increased dramatically over the last few years, while twenty-seven percent of Canadians have no private or public drug coverage at all.¹⁵⁵ Another study, undertaken by the Canadian Institute of Health Information, indicates that for the first time, Canadians are spending more money on drugs than on doctors' fees.¹⁵⁶ Since there is a

¹⁵³ R.S.C. 1985, c. C-6.

¹⁵⁴ See Caulfield, *supra* note 15 at 1122.

¹⁵⁵ A. Picard, "Prescription Spending Soaring" *The Globe and Mail* (20 December 1999).

¹⁵⁶ A. Picard, "Drugs Now Cost Canadians More Than Doctors' Fees" *The Globe and Mail* (17 December 1999).

clear recognition of health care as a social good, we have to give serious consideration to the impact of privatization of health care services combined with a further development of genetic testing. Lessons from the United States have to be taken seriously and are a serious warning that comprehensive health care should not only continue to be provided on the basis of need, but also that such a system could be hampered and undermined by unfettered privatization. There has to be more discussion on how the system can be strengthened.¹⁸⁷ Developments in genetics make it urgent to do more to assure appropriate coverage on the basis of need.

There is currently no Canadian legislation that addresses the issue of genetic discrimination in the context of private insurance contracts. Whether or not people can be excluded from insurance on the basis of genetic traits is thus determined according to the general legislative regime governing insurance.¹⁸⁸ It has been clearly established that the regulation of insurance falls under provincial jurisdiction, under the property and civil rights power, even if many aspects of insurance are interprovincial in scope.¹⁸⁹ The interprovincial nature of insurance led the common-law provinces and territories in the 1920s to develop quasi-uniform regulations, commonly referred to as the *Uniform Insurance Act*. These regulations are very similar to the insurance rules in the *Civil Code of Québec* ("C.C.Q."), the only province that did not join the effort. While a detailed discussion of these rules is beyond the scope of this paper, it would be worthwhile to consider the general regulatory structure within which genetics may become an issue, including the human rights framework as it relates to distinctions made in insurance underwriting.

As in other jurisdictions, insurance contracts are contracts of utmost good faith (*uberrima fides*), in which truthful exchange of information is essential. Insurance applicants have a duty to reveal every fact within a person's knowledge that is material to the insurance. There are two elements to this obligation: applicants have to declare facts that are first, "within their knowledge", and second, material to the risk.¹⁹⁰ The availability of genetic information may cause problems of interpretation with respect to both components.

Discussion of the first aspect will involve the consideration of complex philosophical questions with a very practical component: what constitutes knowledge and when can people really be expected to possess it? What allowances are made for the

¹⁸⁷ For an interesting discussion of how legal challenges of funding decisions by provincial government under the *Canada Health Act* could be used as a political tool to strengthen the Canadian health care system, see S. Choudhry, "The Enforcement of the *Canada Health Act*" (1996) 41 McGill L.J. 461.

¹⁸⁸ For a more detailed discussion of insurance legislation in Canada, see D. Norwood & J.P. Weir, *Norwood on Life Insurance Law in Canada*, 2d ed. (Toronto: Carswell, 1993); D. Lluellas, *Précis des assurances terrestres*, 3d ed. (Montreal: Thémis, 1999).

¹⁸⁹ *Constitution Act, 1867* (U.K.), 30 & 31 Vict., c. 3, s. 92(13), reprinted in R.S.C. 1985, App. II, No. 5; *Citizens Insurance Co. v. Parsons* (1881), 7 A.C. 96 (P.C.); *Canadian Indemnity Co. v. British Columbia (A.G.)*, [1977] 2 S.C.R. 504, 73 D.L.R. (3d) 111, 11 N.R. 466.

¹⁹⁰ See Norwood & Weir, *supra* note 188 at 299-304.

possibility of misunderstanding or forgetfulness?¹⁹¹ It is easy to presume that applicants are aware of information available in their medical files. We should be wary of the presumption that ideally open and comprehensive communication exists between patients and health care providers. Further, knowledge of facts is not equal to an understanding of their relevance. This point is of particular importance in the context of genetics. Many physicians are likely to encounter problems with respect to fulfilling their duty to inform patients of the meaning of complex genetic information.¹⁹² Even in the more familiar domain of cancer genetics, Eric Kodish stresses that “[c]linicians should . . . recognize their own limitations in this rapidly changing field” and “must educate themselves.”¹⁹³ Given limited understanding and lack of education on the part of physicians, it surely is reasonable to expect limited understanding on the part of those undergoing testing.

*Audet*¹⁹⁴ demonstrates how people may interpret genetic risk information very differently than insurers. Even choices regarding the terminology used to describe the meaning of a particular genetic disorder or genetic mutation may depend very much upon a person’s perspective. What is a “physical anomaly” to an insurer may sometimes seem more or less irrelevant to a person who has learned to cope with this invisible threat.

The materiality of information is equally contentious, and even more so in the context of genetics. The information insurance applicants have to declare is to be relevant to the risk against which they are insured. Insurers must demonstrate, through the use of actuarial tables, reasonable grounds for using this type of information in the calculation of a particular premium. Information resulting from genetic testing is often premature and subject to varying interpretation.¹⁹⁵ Insurers would likely experience difficulty in coming up with actuarial tables when a new genetic study first suggests a link between a genetic mutation and a susceptibility to disease. As we mentioned earlier, statistical data in genetics is still very much in flux. Association rates between mutations and particular diseases often change after larger population studies are undertaken. Insurers try to cope with this by constantly updating their actuarial tables, but frequent fluctuations in findings may still complicate matters for both applicants

¹⁹¹ It should be mentioned that the sanction for non-disclosure is significantly softened by the “incontestability period”. The common law provinces and Quebec prescribe that failure to disclose a material fact no longer renders a contract voidable after two years if the insured acted in good faith: *Insurance Act*, R.S.A. 1980, c. I-5, s. 254; *Insurance Act*, R.S.B.C. 1996, c. 226, s. 42; *Insurance Act*, R.S.M. 1987, c. 140, s. 162; *Insurance Act*, R.S.N.B. 1973, c. I-12, s. 146; *Accident and Sickness Insurance Act*, R.S.N. 1990, c. A-2, s. 21; *Insurance Act*, R.S.N.S. 1989, c. 231, s. 83; *Insurance Act*, R.S.O. 1990, c. I.8, s. 184; *Insurance Act*, R.S.P.E.I. 1988, c. I-4, s. 133; art. 2424 C.C.Q.; *Saskatchewan Insurance Act*, R.S.S. 1978, c. S-26, s. 147; *Insurance Act*, R.S.O. 1990, c. 18, s. 184.

¹⁹² Caulfield, *supra* note 15 at 1123.

¹⁹³ E. Kodish *et al.*, “Genetic Testing for Cancer Risk: How to Reconcile the Conflicts” (1998) 279 *J. Am. Med. Assoc.* 179 at 180.

¹⁹⁴ *Supra* note 20.

¹⁹⁵ Glass *et al.*, *supra* note 109 at 6-8.

who have to declare information and for insurers who have to use reasonable distinctions. Determining the sufficiency of statistical evidence is difficult, and insurers may be tempted to use premature data in order to play it safe or may simply refuse coverage because of a lack of statistical data, as was highlighted by the recent case of *J. v. London Life*.¹⁹⁶

The duty to disclose relevant information is to be judged according to the perspective of the average, reasonable insurer. The rule of thumb is: what would a reasonable insurer want to know in assessing an applicant's insurability and in calculating a premium that is commensurate to the person's risk status? Genetic information, which often reveals more detailed information about people's risk for disease than information gained from other types of medical tests, is likely to be of interest to a reasonable insurer who is attempting to establish a detailed risk profile.

How do insurers obtain this information? In individual underwriting, insurers will conduct an interview, ask applicants to fill out a questionnaire, submit them to specific tests and ask that they sign a waiver of confidentiality. This waiver of confidentiality entitles insurers to access the medical files of the applicants. Insurers can do so at the time of underwriting, or, as is often the case, when they receive a request for payment. In the latter case, they have a clear interest in verifying whether or not the insured withheld or tried to hide any information at the time of application, or whether the cause of death or disability was not one that is excluded from coverage. In *Frenette v. Metropolitan Life Insurance*,¹⁹⁷ the Supreme Court confirmed that confidentiality of medical records can be waived without restriction as to time or scope of access. This means that if no time limit is specified and if there is no restrictive clause in the waiver, insurers have a right to access the entire medical record of the insured for an indefinite period of time.¹⁹⁸ The Supreme Court rejected the argument of the Court of Appeal, that to give insurers unlimited access amounts to letting them undertake "fishing expeditions" that violate the right to privacy.

The waiver of confidentiality usually also contains a clause permitting insurers to transmit information about an applicant's risk status to the Medical Information Bureau in order to verify any information about the applicant held by the Bureau. The Medical Information Bureau is a non-profit association of more than 700 American and Canadian insurance companies. It functions as a central register for medical-actuarial statistics, and it exchanges medical information on insurance applicants. Information on individual applicants for health, life, and disability insurance is entered

¹⁹⁶ *Supra* note 133.

¹⁹⁷ [1992] 1 S.C.R. 647, 89 D.L.R. (4th) 653, 134 N.R. 169.

¹⁹⁸ In *obiter*, L'Heureux-Dubé J. also suggested that courts could always order access to medical files "where the state of the health of the holder of the privilege is the central issue of the case and where there are no other means for a party to prove his case" (*ibid.* at 685-686). This means that even in the absence of a waiver of confidentiality, insurers could easily argue that they need access to medical files if they base their refusal on an issue of interpretation of health data. See Lemmens & Bahamin, *supra* note 18 at 164-66 for a discussion of this case in light of genetic testing.

in coded form in the Medical Information Bureau's database, and insurers can verify whether applicants have already applied to other companies and in what risk category they were classified. The fact that an insurance applicant suffers from a genetic disease will be reported in coded form, without specification as to the precise condition. People carrying the Huntington's gene, for instance, will receive the three digit-code for "a disorder of the nervous system" after their name.¹⁹⁹

As mentioned, insurers already require individual applicants to submit to medical tests. For many insurance contracts, companies require HIV/AIDS tests, in particular for life, disability, and additional health insurance contracts above a certain amount. Other tests commonly required include a cotinine test to detect smoking and a test to detect the applicant's risk for prostate cancer. There is nothing that prohibits insurers from using genetic testing to determine risk status, and no legislation that defines specific standards to be respected when introducing new testing methods. Insurers would not have to provide, for example, appropriate genetic counselling for their insurance applicants. Nor is there any obligation to use qualified testing facilities, which follow strictly determined standard procedures.²⁰⁰ It is worth noting that the standards for regulating genetic testing are also lacking outside the domain of insurance, even though, as Timothy Caulfield points out, "[t]here is concern that pressure from the growing biotechnology industry, coupled with understandable public excitement, will induce premature implementation and inappropriate use of some testing services."²⁰¹

Recall, however, that genetic information is not gathered exclusively from test results. For some time, it has been standard practice to use family histories, obtained by questioning applicants and analyzing medical files. Increasingly, genetic information is being included in medical files, which can be accessed by insurers. The Medical Information Bureau also has limited information on disease categories, which may hint at the existence of a particular genetic disorder.

On the basis of the information provided by applicants through questionnaires, through tests and through further investigations, insurers attempt to establish the degree of risk associated with the application. Depending on the type of insurance, the risk corresponds to the likelihood that insurers will have to pay out on a policy because of death, disability or health care costs. People are categorized into different risk groups, usually framed as "standard, substandard, and uninsurable." On the basis of available information and the resulting categorization, insurers decide what premiums to charge applicants, according to a set of premium tables. This entire sequence of gaining information, categorizing risk status and setting premiums is the underwriting process. As I will discuss further, insurers have a great deal of discretion in

¹⁹⁹ See Lemmens & Bahamin, *ibid.* at 167-69.

²⁰⁰ Professional genetic counselling is generally considered to be a pre-condition for undertaking genetic testing. For a general discussion of the ethical issues and the needed safeguards for genetic screening, see Andrews, *supra* note 117; Burgess, Laberge & Knoppers, *supra* note 110.

²⁰¹ Caulfield, *supra* note 15 at 1122 [footnotes omitted].

deciding what constitutes an acceptable underwriting practice. The insurance industry more or less sets its own standards for actuarial practices.

XX. Human Rights Exceptions for Insurance Discrimination

In the underwriting process, insurers weigh various personal characteristics that fall under the category of prohibited grounds for discrimination as specified in the provincial human rights codes,²⁰² the *Canadian Human Rights Act*²⁰³ and the *Canadian Charter of Rights and Freedoms*.²⁰⁴ Insurers clearly discriminate—*i.e.* treat people dif-

²⁰² *Human Rights Act*, R.S.A. 1970, c. 178; *BCHRA*, *supra* note 111; *Human Rights Act*, R.S.M. 1987, c. H175 [hereinafter *MHRA*]; *Human Rights Code*, R.S.N.B. 1973, c. H-11 [hereinafter *NBHR*]; *Human Rights Code*, R.S.N. 1990, c. H-14 [hereinafter *NHRC*]; *Human Rights Act*, R.S.N.S. 1989, c. 214 [hereinafter *NSHRA*]; *Human Rights Code*, R.S.O. 1990, c. H.19 [hereinafter *OHRC*]; *Human Rights Act*, R.S.P.E.I. 1988, c. H-12 [hereinafter *PEIHRA*]; *Charter of Human Rights and Freedoms*, R.S.Q. c. C-12 [hereinafter *Quebec Charter*]; *Saskatchewan Human Rights Code*, S.S. 1979, c. S-24.1 [hereinafter *SHRC*].

²⁰³ R.S.C. 1985, c. H-6.

²⁰⁴ *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c. 11 [hereinafter *Charter*]. The *Charter* does not apply directly to private insurance practice, which is governed by provincial law, but the federal and the provincial governments and legislators must respect *Charter* rights. Provincial insurance acts and the provisions in the provincial human rights acts with respect to insurance could be submitted to a s. 15 analysis. S. 15 of the *Charter* prohibits discrimination based on race, national or ethnic origin, colour, religion, sex, age, or mental and physical handicap. However, s. 1 introduces a proportionality principle and allows for limitations on individual rights if these are reasonable and demonstrably justified in a free and democratic society. The approach of the human rights acts to allow discrimination for insurance purposes if the distinctions made are "reasonable and *bona fide*" or "genuine" allow for the type of proportionality assessment involved in a s. 1 analysis. The *Charter* could also be invoked to challenge the legitimacy of governmental decisions with respect to funding of health care programs, including genetic testing services. For an interesting discussion of this possibility, see R. Mykitiuk & S. Penney, "Screening for 'Deficits': The Legal and Ethical Implication of Genetic Screening and Testing to Reduce Health Care Budgets" (1995) 3 *Health L.J.* 235. In the wake of the Supreme Court's decision in *Eldridge v. British Columbia (A.G.)*, [1997] 3 S.C.R. 624, 151 D.L.R. (4th) 577, 218 N.R. 161, a careful scrutiny can be expected of how health care funding decisions that impact on a particular group's access to health care services may constitute adverse effect discrimination. It would also be interesting to consider whether specific provincial genetic discrimination statutes, protecting individuals with genetic mutations against exclusion from insurance while allowing discrimination against people suffering from a non-genetic predictive health factor, would pass *Charter* scrutiny. Arguments invoked in this paper suggest that there is here reason for concern. Such analysis will be the focus of further research. In *Battlefords and District Co-operative v. Gibbs*, [1996] 3 S.C.R. 566, 140 D.L.R. (4th) 1, 203 N.R. 131, the Supreme Court had already dealt with a group employment benefits plan that made a distinction between different types of disability, in this case mental and physical disability. According to the plan, designed to insure employees against the income-related consequences of becoming disabled, people suffering from physical disability could obtain life-long support, whereas people with mental disabilities could only receive support for a maximum of two years. The Court stated that this plan violated s. 16 of the *SHRC*, *supra* note 202, which prohibits discrimination with respect to employment or any term or condition of employment. However, s. 16 does

ferently—because of age, sex, health, disability and sometimes marital and family status. Differentiating between people according to risk status, and charging them different premiums accordingly, is an essential feature of the underwriting process. It is of the nature of private insurance that people pay premiums commensurate with risk status. Most human rights statutes explicitly recognize the validity of this practice by providing an exception to the prohibition against discrimination for insurance purposes. The exceptions provided for under the provincial human rights statutes are described with different terminology in each statute. For example, depending on the provincial statute, distinctions must be “reasonable and *bona fide* in the circumstances,”²⁰⁵ “based on a genuine qualification,”²⁰⁶ “warranted” and based on “actuarial data,”²⁰⁷ or such “that the insurance or annuity can be provided only if the distinction is permitted.”²⁰⁸

For the purposes of this paper, it is worthwhile to discuss briefly under what circumstances insurance discrimination has been held to be “reasonable and *bona fide*.” The Supreme Court clarified this issue in *Zurich Insurance v. Ontario (Human Rights Commission)*.²⁰⁹ This case dealt with discrimination against young, single, male drivers in the calculation of automobile insurance premiums by the Zurich Insurance Co. The insurance company argued that this distinction was defensible “on reasonable and *bona fide* grounds” and thus fell under the scope of the exception provided for by section 21 of the *OHRC*. Section 21 allows insurance companies to make distinctions “on reasonable and *bona fide* grounds because of age, sex, marital status, family status or handicap.”²¹⁰

In discussing the case, Justice Sopinka, speaking for the majority of five, recognizes the tension between insurance practices and human rights law:

The determination of insurance rates and benefits does not fit easily within traditional human rights concepts. The underlying philosophy of human rights legislation is that an individual has a right to be dealt with on his or her own merits and not on the basis of group characteristics. Conversely, insurance rates are set based on statistics relating to the degree of risk associated with class or group of persons.²¹¹

He then goes on to specify the criteria that one should use in determining whether discriminatory insurance clauses are acceptable. While the decision focuses on the

not contain an insurance-related exception and the Supreme Court explicitly recognized that it therefore could not consider whether there could be special insurance-related reasons to justify such discrimination.

²⁰⁵ *OHRC*, *supra* note 202, s. 11(2).

²⁰⁶ *PEIHRA*, *supra* note 202, s. 14(1)(d).

²⁰⁷ *Quebec Charter*, *supra* note 202, s. 20.1.

²⁰⁸ *MHRA*, *supra* note 202, s. 7(2)(b).

²⁰⁹ [1992] 2 S.C.R. 321, 93 D.L.R. (4th) 346, 138 N.R. 1 [hereinafter *Zurich Insurance* cited to S.C.R.].

²¹⁰ *Supra* note 202, s. 21.

²¹¹ *Supra* note 209 at 338-39.

“reasonable and *bona fide*” justification of the *OHRC*, the Court’s analysis can be used to interpret the proportionality of the insurance discrimination as allowed under other human rights statutes.

The Court found that a discriminatory practice is reasonable, if, first, it is based on a sound and accepted insurance practice and, second, there is no practical alternative.²¹² The first condition allows practices that are desirable “for the purpose of achieving the legitimate business objective of charging premiums that are commensurate with risk.”²¹³ With the second condition, the Supreme Court rejects the argument put forward by the Human Rights Commission, which suggested that an insurance company must demonstrate that the very essence of its business would be undermined if it could no longer rely on discriminatory group characteristics to determine premiums. The Supreme Court sets a less stringent standard, namely that it is sufficient to show that an alternative approach would be “impractical.”²¹⁴ The Court considered it sufficient that the insurance company had credible actuarial evidence to support its claim.

If we are to follow this line of reasoning, insurers may use genetic information and discriminate against people with genetic susceptibilities in underwriting if they can demonstrate that such discrimination is based on a sound and accepted insurance practice that aims at achieving the business objective of charging premiums that are commensurate with risk. If they are able to support their practice with statistical and actuarial tables and can show that there is no practical alternative, insurers will be able to use genetic information in the underwriting process. Since most genetic tests aim at indicating a specific risk factor, based on statistical calculations, it would not be difficult for insurance companies to justify the use of genetic information and of genetic testing. Insurers could argue that they have no practical alternative but to obtain the same level of accurate information as may be obtained through genetic testing. As mentioned earlier, insurance is based on a full disclosure of risk. Insurers would argue that they must be able to use genetic testing to obtain information that insurance applicants may otherwise try to hide. Insurers would have no possibility of verifying whether applicants are at high risk for death or disability and are aware of their high-risk status.

XXI. Curbing Potential Negative Consequences of Genetics in Canadian Health Care and Insurance

I have argued thus far that, while genetics may not necessarily raise a bevy of entirely new ethical and legal issues, it does add to existing concerns and problems. One example is the impact it might have upon access to health care and private insurance. Developments in genetics might thus be said to contribute to existing problems by

²¹² *Ibid.* at 342.

²¹³ *Ibid.* at 342-43.

²¹⁴ *Ibid.* at 350.

raising issues regarding the personal, familial, and ethnic relevance of information, through the high predictive character of many test results in combination with remaining uncertainty, and by the fact that so much information can be gathered from one sample. This cluster of issues, and the commercial interests involved, provide clear grounds for caution. Advances in genetics will likely have a significant impact on social structures, health care systems, and individual, familial and societal well-being. There are legitimate fears surrounding the risk-to-benefit ratio if developments in genetics were to be applied in an inequitable social context.

I have argued that discrimination statutes focusing on genetics may not be the best solution for Canada, but this should not be taken to imply that there should be no regulatory or policy initiatives. Such initiatives would be most appropriate, and they are—I would argue—urgently required. By comparison to the panoply of international and national initiatives in Europe and the United States, the regulatory silence in Canada is remarkable. More than eight years ago, Bartha Maria Knoppers already argued in a paper commissioned by the Law Reform Commission of Canada that

the three areas of genetic testing (workplace, insurance and reproductive testing) pose risks of adverse genetic discrimination while at the same time providing information on cause and prevention. It is not too early to begin a societal debate on these issues with the aim of developing a coherent policy respectful of human rights and dignity.²¹⁵

Since then, the Royal Commission on New Reproductive Technologies issued its report,²¹⁶ which was followed by the legislative initiative of Bill C-45, the *Human Reproductive and Genetic Technologies Act*.²¹⁷ No substantial debate on the use of genetics in the context of insurance and employment has taken place. The following recommendations provide a framework for engaging in the societal debate recommended by Knoppers and more recently by international guidelines.

XXII. Proposals For Specialized Commissions Responsive to Societal Concerns

Is it possible to envisage a system lending itself to fostering continuing public debate over the shifting role and meaning of insurance in society? Shifts in roles of such social institutions may be the result of internal institutional changes, political choices or new economic realities, but they may also, as emphasized in this present paper, be the result of technological revolutions.

²¹⁵ B.M. Knoppers, *Human Dignity and Genetic Heritage: A Study Paper Prepared for the Law Reform Commission of Canada* (1991) at 58 [archived with author].

²¹⁶ Canada, Royal Commission on New Reproductive Technologies, *Proceed with Care: Final Report of the Royal Commission on New Reproductive Technologies* (Ottawa: Minister of Government Services Canada, 1993).

²¹⁷ Bill C-47, *An Act respecting Human Reproductive Technologies and Commercial Transactions Relating to Human Reproduction*, 2d Sess., 35th Parl., 1996 (2d reading 5 November 1996).

In light of the variety of factors involved, a regulatory system ought to be as responsive as possible to continuing changes in scientific knowledge in this area, and respect the level of expertise required for understanding the mechanisms of change and their relevance to members of society. Specialized commissions or agencies should be formed for the purpose of advising both federal and provincial governments with respect to the impact of genetic testing on social policy, health care and insurance. These commissions or agencies should also receive regulatory powers with respect to issues that fall within their jurisdiction.

These commissions should have an expansive focus, considering genetic information, but also more fundamental questions of what is appropriate health care, what is the role of private actors in this context, and how can we limit the negative social consequences of new technology such as genetic testing?

I propose a double structure to review the impact genetics and other technological advances may have in various social fields. On the one hand, continuing debate over the future of health care is crucial. Such debate should aim at understanding how genetic technologies may impact health care services, costs and accessibility. At the federal level, a specialized commission should be set up or integrated into existing structures, if this can be done without undermining its necessary independence. The commission should have the appropriate links to provincial governments. The role of this agency or commission should be twofold: first, it could serve as a federal "think-tank" in which the impact of technological changes on the health care system can be discussed. Second, it could be used to recommend and implement regulation and control over, for example, genetic testing facilities, if federal legislation is to be enacted in this area.

The management regime of the proposed legislation on new reproductive technologies could be used as a model for a commission with regulatory powers.²¹⁸ The proposal for a specialized Advisory Committee on Genetic Testing by the Task Force on Genetic Testing of the National Institutes of Health in the United States is also an interesting model for such a commission.²¹⁹ According to the Task Force, the members of this Advisory Committee should represent professional interests (medicine, genetics, pathology, genetic counselling), the biotechnology industry, consumers, insurers, and other interested parties. For its more reflective work, the commission could be inspired by the work and activities of the National Bioethics Advisory Commission²²⁰ in the United States. The recently established Canadian Biotechnology Advisory Com-

²¹⁸ Canada, Minister of Health, *New Reproductive and Genetic Technologies: Setting Boundaries, Enhancing Health* (Ottawa: Minister of Supply and Services, 1996).

²¹⁹ N.A. Holtzman & M.S. Watson, eds., *Promoting Safe and Effective Genetic Testing in the United States: Final Report of the Task Force on Genetic Testing* (Baltimore: Johns Hopkins University Press, 1998) [hereinafter *Final Report of the Task Force on Genetic Testing*].

²²⁰ See online: National Bioethics Advisory Commission <<http://bioethics.gov/nbac.html>> (date accessed: 19 January 2000).

mittee may also prove to be a useful model for the type of reflective and advisory work that needs to be done in the context of new technologies.²¹

While various other committees already exist, including the latter, which could be involved in discussing some of the aspects of new genetic technologies, it is crucial to adapt membership and provide an appropriate mandate to such agency. Other committees may be focusing on particular aspects of the health care system, reside within the structure of funding agencies or may be dominated by professional or economic interest groups. The proposed commission should include representatives from government, consumer and patient groups, health-care specialists and policy experts, medical specialists, insurance representatives, and others representing those who could be affected by developments in genetic testing. Depending on the issues under discussion, additional or alternate members may be required to represent those who could be affected by developments in genetic testing. For example, this agency could also be used to have an open discussion of genetic or other testing in the workplace.

Wide representation would help to ensure the democratic character of the commission and would facilitate social support for its recommendations. This federal health care commission should develop recommendations with respect to services to be covered and should analyze other global impacts of genetics on our health care system. The commission should focus its attention on maintaining the integrity of the goals of our health care system, based on our particular recognition of health care as a social good which all should have on the basis of need, irrespective of one's ability to pay. With respect to genetic testing, it should assess the feasibility of developing federal regulations and make recommendations on federal and provincial interventions.

Some of the important questions it will have to struggle with are: how essential is it that the government controls the distribution of health care? To what extent can private actors play a role in the distribution of some of these goods? If there were a role for private partners, what type of control by governmental agencies would be required? The commission should develop or recommend educational programs and distribute new information to various stakeholders. At the provincial government level, there is also a need for debate on how health care is allocated and distributed and how new technologies, including genetics, impact health care expenditures. A similar advisory body could be established to advise provincial ministers of health.

In light of the increasingly important role of private insurance and the particular problems that may be created by developments in genetics, it is important to develop a system capable of dealing with discrimination in insurance. Although some protection

²¹ The Canadian Biotechnology Advisory Committee is "an expert, arm's-length committee created under the renewed Canadian Biotechnology Strategy (CBS) to advise [federal] Ministers, raise public awareness and engage Canadians in an open and transparent dialogue on biotechnology matters" (Canadian Biotechnology Secretariat, News Release, "20 Members Appointed to Canadian Biotechnology Advisory Committee" (27 September 1999)). It has the mandate to advise the government on broad policy issues associated with the ethical, social, regulatory, economic, scientific, environmental and health aspects of new biotechnology.

is currently provided through provincial human rights codes, the Supreme Court's interpretation of "reasonable and *bona fide*" distinctions has given the industry too great a degree of discretion. Moreover, the system may provide some *post facto* relief, but it does not prevent discriminatory practices. Some protection, however, is provided through provincial human rights codes.

The committee structure needed is one that would have regulatory authority. Some provincial human rights codes give substantial power to human rights commissions in determining what constitutes acceptable discrimination for insurance purposes.²²³ This is a useful model, but the committee structure should be adapted so that it is representative of the different stakeholders and so that it has the necessary scientific, legal, and ethical expertise. The presumption should be against the introduction and use of new technologies to determine insurability, and the commissions should be able to react and issue specific authorization if new tests seem appropriate in particular circumstances. The commissions should also investigate the possibility of regulating the access to medical files by third parties, such as insurers.

As mentioned in the discussion of the federal advisory commission, this committee structure could prove useful in discussing and regulating other areas, such as the use of testing technology in the context of employment.²²³ Why not have specialized subcommittees attached to existing human rights tribunals, set up to issue specific regulations and guidelines with respect to, for example, the introduction of new genetic tests in the context of insurance and employment?

Even if there are good reasons for considering insurance contracts as commodities, there may be overriding concerns that ought to be taken into account when analysing the appropriateness of complete reliance on the rules of the market. Such overriding concerns can be of an essential symbolic nature, such as the prohibition of discrimination on the basis of race, ethnic origin, sexual orientation, or the status of "battered women". Discrimination on some of these grounds is currently prohibited even for insurance purposes. It would seem difficult to argue that it is inappropriate to allow a weighing of other interests by a specialized, representative commission in determining the reasonableness of discriminatory practices in insurance. Vaughan Black argues similarly in a case comment on the Ontario Court of Appeal's decision in the *Zurich* case. According to Black,

It would be odd indeed for the Code to rely on the "symbolic" argument for banning entirely insurance classifications on the basis of race, yet make such considerations irrelevant to the evaluation of permitted classifications such as sex.²²⁴

²²³ See e.g. *NBHRC*, *supra* note 202, s. 5(2); *NHRC*, *supra* note 202, s. 6(2); *NSHRA*, *supra* note 202, s. 15(2); *PEIHRA*, *supra* note 202, s. 33(2)(b).

²²³ See T. Lemmens, "What About Your Genes? Ethical, Legal, and Policy Dimensions of Genetic Testing in the Workplace" (1997) *Polit. Life Sci.* 57.

²²⁴ "Case Comment: *Zurich Insurance Co. v. Ontario (Human Rights Commission)*" (1990) 45 *C.C.L.I.* 304 at 308.

There can be circumstances in which genetic information has such a symbolic, stigmatizing character, that allowing it to be used for insurance purposes would be considered inappropriate *per se*.

Currently, insurers set their own standards for classification schemes and the types of statistical information that support them. They defend their policies with reference to the rules of a game they establish and control. Within the rules of the game, they can claim the fairness of unequal distributions. At the same time, they profit from the increased importance of their products and enter a sphere in which the social meaning and importance of the goods they distribute is less clearly defined. In light of these considerations, it seems appropriate to promote a system wherein insurers are to be made more accountable for their practices. Under such a system, the profit-based rationale of insurance rules would have to be balanced against the basic (*i.e.* minimal) needs of members of the community. Further attention needs to be paid to the issue of reconciling the economic realities of the insurance industry with social needs.

Continuing assessment by a specialized and interdisciplinary commission offers a number of advantages: it would enable discussion between various stakeholders and promote public support for both the public and private providers of health care and insurance; this may very well include public support for the use of some genetic information in insurance. The commission would prevent the premature use of preliminary genetic test results and would protect individuals participating in research. It would prevent insurance companies from being pressured into adopting practices simply because competitors have done so before them. The commissions could also set standards for genetic testing, including quality standards for testing facilities and provisions for genetic counselling. Dialogue between stakeholders, and the obligation of responsible members to be informed of new developments and to educate the organizations and communities to which they belong, could also promote public education. The commissions could be involved in educational efforts of both insurers and the public. The commissions could impose restrictions on new tests and oblige insurers to submit regular reports once a new test is allowed, for example, to verify changes in actuarial evidence. Ongoing analysis and discussion could be an essential function in maintaining the standards set by such commissions. They could also discuss the relationship between private insurance and the health care system, and make recommendations to the appropriate authorities when they find that particular goods are not being appropriately distributed through the private market for example, because the economic reality of insurance does not allow certain restrictions.

Various international initiatives and recommendations support this approach. As mentioned earlier, the Task Force on Genetic Testing recommends the establishment of a specialized committee, as well as the need for safety standards, quality control of testing facilities, and education of stakeholders.²²⁵ By appointing an independent geneticist as consultant, the Association of British Insurers also recognized how impor-

²²⁵ *Final Report of the Task Force on Genetic Testing*, *supra* note 219.

tant external and scientifically sound assessment of genetic technology is, both for the insurers and for the public.²²⁶ Insurers have to keep abreast of new genetic information, while the public wants to be reassured that insurance decisions will be based upon an independent expert assessment of the value of the risk-information.²²⁷ The *Draft Guidelines*, prepared for the World Health Organization by Abdullah Daar and Jean-François Mattei, warn that “hurried and premature legislation in the rapidly evolving field of human genetics can be counterproductive,” but it also urges for national regulations for genetic testing and for mechanisms to monitor further developments.²²⁸

This call for more social debate on the reasonableness of distinctions in private insurance is in line with the dissenting opinion of Justice L’Heureux-Dubé in *Zurich Insurance*. L’Heureux-Dubé J. lambasted the insurance company for not making any effort to find new ways of obtaining useful statistical information: “No human rights legislation could ever attain its objectives if discrimination could be justified by the self-serving claim that a practice ‘has always been done this way.’” Furthermore, “[i]f this were so, complacency and a history of discrimination would be rewarded at the cost of progress and the recognition of higher societal norms of behaviour.”²²⁹ The development of genetic testing should focus attention on how some of these “higher societal norms of behavior” could be affected if means for public discussion of these new technologies are not found.

Creation of fora for public debate would be a valuable democratic tool—it would help us to determine the bounds of justice, and the social meaning of different goods. Walzer states it succinctly:

A given society is just if its substantial life is lived in a certain way—that is, in a way faithful to the shared understandings of the members. (When people disagree about the meaning of social goods, when understandings are controversial, then justice requires that the society be faithful to the disagreements, providing institutional channels for their expression, adjudicative mechanisms, and alternative distributions.)²³⁰

²²⁶ *Supra* note 59.

²²⁷ *Ibid.*

²²⁸ *Supra* note 32.

²²⁹ *Zurich Insurance*, *supra* note 209 at 378.

²³⁰ Walzer, *supra* note 152 at 313.