

REVISITING GENETIC DISCRIMINATION ISSUES

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1. Science Fiction of Yesterday is Science of Today and possibly Science Nightmares of tomorrow

Law, ethics and public policy have lagged far behind in the rapid advances in technology and science. The Internet and modern communications technology has forced legislatures, ethicists and public policy to hastily deal with a host of challenges and opportunities posed by these advances. Challenges include grave threats to privacy from appropriation of confidential information on the web, data mining, and challenges to hate propaganda and pornography laws of sovereign states that are undermined by the difficulty of policing the Internet.

Genetics and genetic discrimination will pose an even bigger challenge because, unlike the Internet, the predictive value of genetic testing has large areas of uncertainty that can either be of benefit to humanity or be a cause of great concern and potential for discrimination against large numbers of Canadians. Indeed, the challenges from data mining of genetic information across borders will create overlapping challenges arising from the rapid advances in both information technologies and genetic science.

What is of particular concern, however, to genetic science is both the great promise but also the great uncertainty of advances in the field. While the so called “low hanging fruit” of genetic science involving some 10,000 monogenic diseases arising out of a single gene provides for greater, but not absolute predictive ability arising out of genetic science, there are thousands more which are multifactoral polygenic disorders. Genetic testing does not provide sufficient predictive value with these disorders given the multitude of environmental and other external causes, including variations such as diets, that in variations of combinations with the abnormal genes can produce a variety of diseases.

In addition, genetic markers can be conflated with the abnormal genes even though such markers only disclose the probability of the abnormal genes being present and therefore the probability of the future disease. But perhaps the fact that gene probes and further advances in gene mapping can result, at some time in the future, in the possibility of everyone being born with a complete genetic profile that will predict all the diseases that the individual will encounter, produces the ultimate moral, ethical and legal challenges, if not the ultimate nightmares. Will those born in this future be categorized into social and economic streaming that will determine their entire future lives? We are on the threshold of what may seem like science fiction, but if we do not start thinking seriously about the potential for genetic testing to result in future social engineering, then the science of today may turn into the nightmares of tomorrow.

2. Genetic Testing and Discrimination

Today, genetic testing becomes a major challenge to law, ethics and policy when used for predicative purposes in a range of human activities from employment, insurance, health care, etc. when such testing only carries the illusion of precision. Even with tests for genes that are alleged to have predictive value for diseases such as Huntington's disease or Cystic Fibrosis or Alzheimer's disease, negative results do not provide precision. Given the uncertainty about genetic tests can they be any form of reliable risk assessment standards for areas such as employment and insurance etc.? ¹

Increased risks of different forms of genetic discrimination will arise from the rapidly expanding direct-to-consumer marketing of a variety of genetic testing. The greatest risks of both the illusion of precision and the dangers of breach of privacy come from such direct-to-consumer private testing. ²

¹ See "Genetic markers to predict polygenic disease: a new problem for social genetics D.J. Galton and G.A.A. Ferns' Q J Med 1999; **92**: 223-232 : <http://qjmed.oxfordjournals.org/cgi/content/full/92/4/223>
See also 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.

² Genetic tests give consumers hints about disease risk; critics have misgivings" Chris Berdik, Washington Post, January 26th, 2010: <http://www.geneticsandsociety.org/article.php?id=5052>

Given the above dangers, policy options should include:

* In addition to PIPEDA and other provincial privacy laws being rigorously applied, consider regulations on how commercial testing is marketed, including claims on precision and matters relating to privacy of the results of testing. In addition, given the present ability of highly sophisticated data mining technologies that can transmit genetic information not only within a country, but across borders, there is a need for federal and provincial privacy commissioners to examine and study the dangers in this potential grave breach of reasonable expectation of privacy and suggest regulatory or other forms of preventative strategies. Given the international scope of such data mining, there may well be a need for international cooperation and coordination in this area.

* Given that the results of direct-to-consumer genetic testing could and most probably will be transferred to medical records of patients and used for not only assessing future health care strategies, but must also be disclosed for insurance purposes, consideration should be given to a regulatory framework that determines what types of results of genetic testing should be regarded as mandatory for insurance applicants to disclose.

3. The Law And Genetic Discrimination

There is no express mention of genetic discrimination in either the *Canadian Human Rights Act* (CHRA) or the *Ontario Human Rights Code* (Sec. 10) But both have disability as a prohibited ground and genetic discrimination could come within it. The crucial wording in the Ontario Code is found in S. 10 (3) that states:

Past and presumed disabilities

[\(3\)](#) The right to equal treatment without discrimination because of disability includes the right to equal treatment without discrimination because a person has or has had a disability or is believed to have or to have had a disability. 2001, c. 32, s. 27 (4).

If genetic testing results in a person being treated as if the person has or is believed to have a disability than a *prima facie* case of discrimination could be made out. The

Canadian Supreme Court in *Boisbriand*, in interpreting the *Quebec Charter of Human Rights and Freedoms*, has advocated a broad interpretation of the prohibition against discrimination on the grounds of disability in ruling that “given both the rapid advances in biomedical technology and more specifically in genetics, an overly narrow definition would not necessarily serve the purpose of the *Charter* in this regard.” The Court went on to state that “...Further the Supreme Court also ruled that the *Quebec Charter* also prohibits discrimination based on the actual or perceived possibility that an individual *may develop a handicap in the future.*”³

Given that genetic testing can lead to identifying whole groups as susceptible to certain genetic diseases if members of that group are predominantly the carriers of the gene, then women and minority groups and intersectional members of such groups could be subject to both intentional and adverse effects discrimination on the basis of sex and/or racial or ethnic groups.⁴ For example there is no doubt that known genetic predisposition of First Nations peoples and South Asians to diabetes and heart disease may be already impacting on the ability to have equal access to certain types of life and long term disability insurance, despite the fact that life style and diet may postpone or prevent such predisposition. For millions of Canadians, their genes should not be regarded as their inescapable destiny.

4. Workplace Discrimination and the Law

While evidence about genetic discrimination in employment in Canada is limited, there are areas where it may become more prevalent, especially where employers under collective agreements have to cover the cost of long term disability insurance and drug coverage of employees. We cannot be complacent given the U.S. experience. In a U.S.

³ *Quebec (Commission des droits de la personne et des droits de la jeunesse - CDPDJ) v. Montréal ; Quebec (CDPDJ) v. Boisbriand [2001] 1. S.C.R. 665 at 698-700.)*

⁴ See the Report of the Ontario Law Reform Commission studying the adverse impacts of such testing in Ontario Law Reform Commission, Report on Genetic Testing (Toronto: Ontario Publishing, 1996).

study, 30% of large and mid-sized employers required genetic testing while 7% used the information for hiring and promotion purposes.⁵

Sec. 5 of the *Ontario Human Rights Code* mandates equal treatment with respect to employment without discrimination because of the listed enumerated grounds that include not only handicaps that may be relevant to genetic discrimination, but also race, ancestry, ethnic origin and sex, all prohibited grounds which could also be relevant. After the Supreme Court's ruling in the *Meiorin*⁶ and *Grismer*⁷ decisions, it is suggested that it would be very difficult for an employer to argue that the results of genetic testing are a *bona fide occupation requirement* (BFOR) given the predictive value of such genetic testing and the exclusion of cost as a legitimate BFOR unless it alters the substantial nature of the business or threatens its viability. The good faith requirement may also be lacking if the motivation is disguised sex or racial discrimination.

Possible human rights options:

- Support NDP private member's bill adding "genetic characteristics" to the CHRA.
- Make more specific provisions regarding genetic discrimination in existing human rights commissions' interpretive guidelines and regulations such as the Ontario Human Rights Commission's Policy and Guidelines on Disability and the Duty to Accommodate (Nov. 23, 200, rev. Dec. 2009). This could include provisions on when mandatory testing is permissible and what constitutes undue hardship.

However, given this author's own experience over a decade as a human rights tribunal member, the human rights process is not, by itself, sufficient to deal with all

⁵ D. Martindale, "Pink Slip in Your Genes" (2001) 284 Scientific American 19 at 20.

⁶ BC (PSERC) v. BCGSEU [1999] 3. S.C.R. 3, 176 which laid down a three part test for a BFOR namely 1) A rational connection between the general purpose of the standard and the job or profession 2) The particular standard must have been adopted in good faith and 3) The employer must establish that the standard is reasonably necessary to the accomplishment of the legitimate work related purpose in step one. Reasonably necessary means that the accommodation up to the point of undue hardship was impossible.

⁷ BC (Sup. Of Motor Vehicles) v. BC (Council of Human Rights) [1999] 3. S.C.R. 868.

the potential challenges from genetic discrimination. The human rights process is very long and in many provincial and federal complaints processes, the backlog of complaints do not effectively deal with the urgent situations of complainants who may be facing the worst examples of genetic discrimination. While there are very few existing human rights complaints based on genetic discrimination, there is no doubt substantial numbers of those who have suffered such discrimination may be afraid to start the process in fear that it may endanger future prospects for employment or access to needed forms of insurance. There are indications that support organizations for certain diseases such as Huntington's have received reports that their members have suffered genetic discrimination, but have not triggered the human rights process in the jurisdiction in which they live. For these reasons, in addition to the human rights proposals above, a regulatory framework to deal with genetic testing will ultimately be needed.

4. The Challenges of Insurance and Genetic Testing

The Ontario Law Commission has asserted that the current human rights legislation already provides protection. I am not convinced. Section 22 of the *Ontario Human Rights Code* states:

Restrictions for insurance contracts, etc.

22. The right under sections 1 and 3 to equal treatment with respect to services and to contract on equal terms, without discrimination because of age, sex, marital status, family status or disability, is not infringed where a contract of automobile, life, accident or sickness or disability insurance or a contract of group insurance between an insurer and an association or person other than an employer, or a life annuity, differentiates or makes a distinction, exclusion or preference on reasonable and *bona fide* grounds because of age, sex, marital status, family status or disability. R.S.O. 1990, c. H.19, s. 22; 1999, c. 6, s. 28 (10); 2001, c. 32, s. 27 (5); 2005, c. 5, s. 32 (13).

The Supreme Court in *Zurich Insurance Co. v. Ontario (HRC)*⁸ in a majority decision written by Sopinka J that the reasonable and *bona fide* grounds as (a) it is based on a sound and accepted insurance practice (b) there is no practical alternative. Further the

⁸ [1992] 2. S.C.R. 321

majority accepted that a practice is sound if it is part of the legitimate business objective of charging “premiums commensurate with risk” and that the availability of a practical alternative is a question of fact.

While the Zurich Insurance Co decision of the Supreme Court is an insurance friendly interpretation of section 22 of the *Human Rights Code* and would allow access to existing genetic information, the test of section 22 as regards genetic discrimination is whether it will allow mandatory genetic testing. Can insurance companies use the *Zurich Insurance Co.* decision to claim that mandatory testing is necessary to “charge premiums that are commensurate with risk”. Those that are concerned about the expansion of existing genetic discrimination would prefer the opinion of dissenting Justice L’Heureux-Dubé who argued for a “causal connection” to be the required threshold to calculate risk, not the “correlation” requirement asserted by the majority decision of Justice Sopinka. In addition, the majority decision also stated that the practical alternative should not be narrowly defined. For example in the Zurich Insurance Co facts, the young, single, male driver was classified on his age, sex and marital status. The stereotyping of large groups was what led Justice L’Heureux-Dubé to dissent against the discriminatory classification used by Zurich under Section 22 of the Code. Likewise the lack of precision of genetic testing could lead to stereotyping of large groups of people if mandatory testing is allowed as discussed above.

For this reason, I am not convinced that existing provisions in the *Ontario Human Rights Code* and similar provincial legislation will protect Canadians from genetic discrimination in the insurance context. If the science advances and leads to actual precision in terms of susceptibility of individuals to genetic diseases, the insurance industry will face further legal, ethical and policy challenges which may well revolutionize the entire industry and also present its greatest challenges. This may well require a more comprehensive regulatory framework.

Possible Policy Options

Several European countries such as Austria, Belgium and Norway have mandated that insurance companies cannot ask for predictive testing or ask for results already in existing medical files. The sector associations for the various forms of insurance have asserted that there is no existing policy by their members that require predictive testing. However, as mentioned there are reports from support organizations of certain genetic diseases, that despite such policies being in existence, individual applicants are still asked to perform such predictive testing. If such reports are indeed accurate, then a regulatory framework will ultimately be needed.

A comprehensive framework of stand- alone legislation as in the European models could include a comprehensive review of genetic testing and the establishment of a specialized regulatory body along the lines of the U.K. Human Genetics Commission. There is no doubt that pre-emptive regulation is far better than dealing with a huge backlog of individual complaints before human rights tribunals or privacy commissioners.

Due to critical relationship between employment and health insurance, in the U.S., even before the recent Obama health reform at least 45 states have regulated the use of genetic data and 35 states prohibit genetic discrimination in employment while at the federal level the Genetic Information Non-Discrimination Act (GINA) was passed in 2008. It should be kept in mind that while Canada has a publicly administered health care system, the percentage of privately insured medical services is growing while the rising costs of health costs could lead to more delisting of health services, there may well be the need for a GINA-type legislation at the provincial level for the increasing percentage of health care services that are outside the publicly administered sector.

Canada should consider following suit in areas of federal jurisdiction or support the NDP private member's bill that proposes amending the *Canadian Human Rights Act* to include "genetic characteristics" as a prohibited ground of discrimination.

POSSIBLE VOLUNTARY MEASURES BY THE INDUSTRY ITSELF

Some have suggested that the industry itself could offer two levels of insurance coverage based on access to existing genetic information. First, basic insurance for which no genetic information or access to medical information is required, which will offer lower levels of payouts and appropriate premiums, and advanced insurance for which higher payouts is possible and applicants are asked questions about genetic risks but would not be allowed to request genetic testing from the applicants while allowing use of existing medical information.⁹ This approach has been adopted in England and the Ontario Law Commission has endorsed this approach.

From a human rights perspective there are problems with this suggestion. For example, the scale of the higher premiums for the basic service could be a disguised form of refusal of coverage. Second, the advanced level could also be a disguised form of requested genetic testing given the reports that existing individual insurance company policies against requesting such tests are being violated. My preference is that there should be outright prohibition of genetic tests information in insurance coverage as in several European countries.

Self-imposed moratoriums on the use of genetic testing as in Canada may well be a function of the availability and predictive value of existing testing. As the testing becomes more accurate and more widespread, as stated, the incentives to keep the moratorium will decrease which makes them less sustainable as a policy option.

Sector and employer specific options that should already be in existence, especially in the insurance sector, are comprehensive codes of conduct and employer antidiscrimination policies. Corporate monitoring and accompanying implementation systems should be effective against the prohibited form of genetic discrimination and ensure that genetic testing is not required in violation of the stated corporate policies.

⁹ See this suggestion in B.M. Knoppers, (ed.) *Socio-Ethical Issues in Human Genetics* (Les Editions Yvon Blais, 1998).

Conclusion

The great danger is that the imperfect predictive value of genetic testing could result in some individuals' dignity and human rights being less equal than others. As the Supreme Court has stated time and time again, the core of any form of prohibited discrimination is causing unjustifiable disadvantage based on prejudice and stereotyping. As the science of genetics becomes more able to tell the wellness and illness future of all of us and indeed that of our children, it will trigger even greater moral, ethical and legal dilemmas. If, as has been predicted one day, on birth all humans will have a genetic profile which will predict their entire life's health history, that will pose the ultimate test of society's commitment to the ultimate test of human dignity: to be fully human, is not to be fully genetically perfect.