Ethical and Policy Issues of Genetic Testing in the Workplace

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Abstract

Developments in genetic research and the decreasing cost of genetic testing are likely to stimulate the interest of employers. In this thesis, the ethical, legal and societal consequences of genetic testing in the workplace are analysed and guidelines are proposed that could serve as a basis for regulatory intervention.

This thesis is divided in two parts. The first part contains a scientific introduction on genetics and an overview of ethical, social and legal problems raised by the particularity of genetic information. The second part focuses on genetic screening and monitoring in the workplace and on the ethical and social issues involved. It is suggested that the concept of a bona fide occupational requirement, as developed in anti-discrimination laws, can be useful in assessing the rationality and proportionality of genetic testing.

Abstrait (traduction)

Les développements en recherche sur la génétique et le coût décroissant des tests génétiques stimuleront vraisemblablement l'intérêt des employeurs. Ce mémoire analyse les conséquences éthiques, juridiques et sociales du dépistage génétiques en milieu de travail et propose des lignes directrices qui pourraient servir de point de départ à une intervention législative.

La première partie contient une introduction scientifique et une analyse des problèmes ethiques, sociaux, et juridiques évoqués par les aspects particuliers de la génétique. La deuxième partie discute ensuite du dépistage génétique dans le milieu de travail et les aspects éthiques et sociaux d'un tel dépistage. Il est démontré comment les exigences profesionnelles établies de bonne foi, tel que développé dans les lois anti-discrimination, peuvent être utiles afin d'évaluer la rationalité et la proportionnalité du dépistage.

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Introduction

The human genome project, an international effort to draw a map of our genetic structure, holds out the promise of unimaginable medical progress. It is now believed that hitherto fatal diseases will soon be understood, prevented and perhaps even healed. It just seems to be a question of time and money, of industrious, scientific efforts. The international scientific venture has been compared to Vesalius' trail-blazing anatomic analysis of the human body, or to Columbus discovery of the new continent. It has been suggested that the genome project will "drive the research enterprise for at least the next 100 years."[1] This relatively new approach "is beginning to reveal an extraordinary picture of what we are, what we were and what we become."[2]

The genome project is also particular for the fact that ethical, social and legal analysis has accompanied every step of the project. Traditionally, scientists have been rather reluctant to accept the fact that people in general, and ethicists in particular, are looking over their shoulder –that is, trying to determine the direction that science should take. For science to be effective, according to David Baltimore, scientists must have complete freedom. He argues that "the traditional pact between society and its scientists in which the scientist is given the responsibility for determining the direction of his work is a necessary relationship if basic science is to be an effective endeavor."[3] It is often suggested that scientific progress should not be hindered by the public's "limited" interests, political ideologies or value judgments. But science is not a neutral enterprise. It can have a profound influence on the way we see ourselves in this world. Science has an important impact. Many have argued

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1 Francis S. Collins, cited by D.J. Kevles & L. Hood, "Reflections" in D.J. Kevles & L. Hood, eds, *The Code of Codes, Scientific and Social Issues in the Human Genome Project* (Cambridge: Harvard University Press, 1992) 300 at 309.

2 S. Jones, *The Language of the Genes: Biology, History and the Evolutionary Future* (London: Harper Collins, 1993) at 13.

3 D. Baltimore, "Limiting Science: A Biologist's Perspective" in G. Holton & R.S. Morison, eds, *Limits of Scientific Inquiry* (New York: Norton & Company, 1979) 37 at 37.

that scientists have a moral responsibility toward society, therefore, and that scientific freedom should sometimes be limited.[4]

The human genome project has recognized this societal interest in genetics from the beginning. In several states, part of the budget for research on this genome project has been allocated to the analysis of ethical, societal and legal aspects of the new genetics. In the United States, an Ethical Legal and Social Issues (ELSI) programme was funded by the National Institute of Health to study its consequences.[5] A similar committee for the study of the Medical, Ethical, Legal and Social Issues (MELSI) was established in Canada.

Whatever the underlying reason,[6] the result has been debate. Perhaps for the first time in the history of science, ethical and societal critiques sometimes run ahead of scientific developments. This is the case, at any rate, for genetic testing in the workplace. It could be argued that genetic testing is not yet an urgent problem. Few genetic tests are actually undertaken and few reliable workplace tests are even available. Genetic testing might not even occur in Canada. Several articles have been published on the legal and ethical aspects of genetic testing in general, nevertheless, and of workplace testing in particular. Many reports express concern over the future use of genetic tests and their potentially harmful consequences. Specific workplace tests are likely to become available. But even existing genetic information can be used in the employment context.

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4 For a critical discussion of the social responsibility of scientists, see D. Callahan, "Ethical Issues in the Control of Science" in G. Milunsky & G. Annas, eds, *Genetics and the Law II* (New York: Plenum Press, 1980) 19-24; S. Bok, "Freedom and Risk" in Holton & Morison, eds, *supra*, note 3, 115; R.L. Sinheimer, "The Presumptions of Science" in Holton & Morison, eds, *supra*, note 3, 23.

5 For the history of the ELSI committee, see R. Cook-Deegan, *The Gene Wars: Science, Politics and the Human Genome* (New York: Norton, 1994) at 231-255.

6 The tainted history of genetics might be one of the major reasons why efforts are made to debate the ethical issues. Before and during World War II, genetics was an important tool of the eugenics movement, especially in Nazi Germany. By spending money on ethical and societal issues, those involved in the genome project indicate their willingness to ask questions and avoid historical abuses.

I intend to discuss the reasons for concern. Although genetic testing is only one form of medical or pseudo-medical testing in the workplace, it is worth noting. Existing problems related to workplace testing are highlighted by genetic testing and other distinctive problems are created. The "orgy of available data"[7] yielded by the genome project, apart from anything else, should indicate the possibly harmful consequences for individuals, families and society. The fact that comparable workplace tests are already undertaken, though, is not a good enough reason for brushing aside the critique on genetic ones. Indeed, thinking about the latter could inspire new ways of thinking about the former. I have not made a detailed study of this comparison here, though, because genetic testing is a distinct topic in its own right.

Genetic testing already used outside the workplace, for medical purposes, could eventually be used by employers. In the course of my discussion of genetic testing in the employment context, it should be kept in mind that regulating the accessibility of genetic information in medical files could be essential. Although I do not enter into the details of how to protect the confidentiality of these files, their accessibility is certainly a reasonable cause for concern.

In this study, my focus is on three things: (1) how genetic testing can be used in the workplace; (2) whose interests can be served; and (3) what ethical or legal problems can be created. After analyzing the latter, I recommend a framework in which genetic testing should take place. Clearly, further research is needed. I have provided a general overview of the issues, not a detailed discussion of their legal implications. I have not yet worked out legal mechanisms to counteract the harmful use of genetic testing in the workplace and protecting employees from discrimination. Anti-discrimination provisions are, however, discussed briefly under policy recommendations. There, I argue that regulation should be inspired by provisions and case law dealing with what constitutes a Bona Fide Occupational Requirement.

This study consists of two major parts. In the first, I discuss scientific aspects of genetics in general and mention what is so particular about genetic information. I do so to

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[7] See Kevles & Hood, "Reflections" *supra*, note 1 at 301.

make clear that some novel problems are involved. This introduction to genetics is necessary, for example, to show that specific types of "genetic diseases" have specific characteristics. It would be inappropriate to make statements and recommendations about genetic testing in the workplace, therefore, without pointing out some important distinctions. The relation between genes and disease can vary. Understanding the differences between single-gene disorders and complex traits, for example, or between susceptibilities and "determinant" diseases is essential for assessing the usefulness of each test. In this first part, I also discuss other aspects of genetics, such as the family relevance of genetic information and the uncertainty associated with genetic testing. The second part I begin with discussing the various forms of workplace testing and their scientific validity. The latter will elucidate the ethical and legal aspects of genetic testing for specific purposes, in specific circumstances and for specific genetic disorders. I then turn my attention to the various interests involved in genetic testing in the workplace. I begin with the arguments of authors who believe that attitudes toward genetic testing in the workplace are shaped by the economic positions of employers and employees. I then give an overview of the different interests of employers, employees and third parties.

In the second part, I also consider the problem from an ethical perspective. Four basic ethical principles, as they have been developed in the area of bioethics, can be invoked: (1) autonomy; (2) beneficence; (3) non-maleficence; and (4) justice. These principles, especially that of autonomy, are challenged by genetics. I criticize the theory that individual consent takes absolute primacy. Contrary to the law and economics theory of Richard Posner, I suggest that consent is not a good enough reason for submitting employees to genetic testing. In addition, consent does not oblige us to allow employees to chose a harmful environment. These principles should be seen against a background of existing values and interpreted accordingly. The important role that our society attributes to employment (in connection with individual self-determination) is one of the key elements to be considered.

Finally, I propose that legal regulation should take these values into consideration. This means that some minimum requirements be met before introducing genetic testing to the workplace. Two specific reasons could justify it: (1) protecting the health of employees; and

(2) avoiding risk to others. In judging the acceptability of specific genetic tests, I point out how one could invoke the Bona Fide Occupational Requirements, as they have been developed in human rights legislation and case law dealing with discrimination in the workplace.

PART 1: Human genetics and its social consequences[8]

I. DNA and genes

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[8] The following books and articles provided background for the scientific introduction: A.J.F. Griffiths *et al.*, *An Introduction to Genetic Analysis*, 5th ed. (New York: W.H. Freeman, 1993); S. Jones, *supra*, note 2; R. Hubbard & E. Wald, *Exploding the Gene Myth: How Genetic Information Is Produced and Manipulated by Scientists, Physicians, Employers, Insurance Companies, Educators, and Law Enforcers* (Boston: Beacon Press, 1993); V.A. McKusick, "The Human Genome Project: Plans, Status, and Applications in Biology and Medicine" in G.J. Annas & S. Elias, eds, *Gene Mapping: Using Law and Ethics as Guides* (New York: Oxford University Press, 1992) 18; H.F. Judson, "A History of the Science and Technology behind Gene Mapping and Sequencing" in Kevles & Hood, eds, *supra*, note 1, 37; G.W. Slater & G. Drouin, "En quête d'innovations technologiques" in M. Mélançon & R.D. Lambert, eds, *Le génome humain: une responsabilité scientifique et sociale* (Sainte-Foy: Les Presses de l'Université de Laval, 1992) 17; DOE Human Genome Program, *Primer on Molecular Genetics* (Washington: U.S. Department of Energy, 1992); B. Knoppers, *Human Dignity and Genetic Heritage; A Study Paper Prepared for the Law Reform Commission of Canada*, Protection of Life Series (Ottawa: Law Reform Commission, 1991); Science Council of Canada, *Genetics in Canadian Health Care* (Ottawa: Minister of Supply and Services, 1991); R. Shapiro, *The Human Blueprint: The Race to Unlock the Secrets of Our Genetic Script* (New York: St. Martin's Press, 1991); E.A. Carlson, "Defining the Gene: An Evolving Concept" (1991) 49 Am. J. Hum. Genet. 475; R.M. Cook-Deegan, "Mapping the Human Genome" (1991) 65:1 S.Cal.L.Rev. 565; U.S. Congress, Office of Technology Assessment, *Genetic Monitoring and Screening in the Workplace* (Washington: U.S. Government Printing Office, 1990) [hereinafter OTA, *Genetic Monitoring*]; D. Suzuki & P. Knudtson, *Genethics: The Clash between the New Genetics and Human Values*, 2d ed. (Cambridge Mass.: Harvard University Press, 1990) at 7-122; U.S. Congress, Office of Technology Assessment, *Mapping our Genes- The Genome Project: How Big, How Fast?* (Washington: U.S. Government Printing Office, 1988) [hereinafter OTA, *Mapping the Genome*].

It is common knowledge that genes are an essential part of our biological constitution and that they are linked, somehow, to the transfer of hereditary traits. But what exactly are genes? How do they interfere with health of people and their offspring? Why does genetics receive so much attention nowadays? To understand the ethical and legal dimensions of this new science and related technologies, a basic review of genetics is necessary.

Human organisms can be described from various perspectives: that of the nervous system, the circulatory system, the respiratory system, the digestive system and so on. The body is a complex structure in which various organs interact, allowing people to live and move around. Lungs absorb oxygen and transport it into the blood; the stomach is a part of the digestive system and extracts proteins out of food; the liver filters the blood; the brain transfers information and gives instructions through the nervous system. Each of these organs has a specific function and depends on the healthy functioning of other organs. All consist of cells that are specific to them. Liver cells are different from brain cells, for example, and lung cells from muscle cells. On a more detailed level, though, these organs have essential things in common: most cells contain an identical assortment of the human chromosomes. The nucleus of each, enclosing the genetic material, contains 46 chromosomes –that is, two sets of 23 chromosomes.

Chromosomes consist of DNA (*deoxyribonucleic acid*) and proteins. It is the former that carries genetic information. DNA is a chemical substance composed of four building units, or nucleotides: *adenine* (A), *cytosine* (C), *guanine*(G) and *thymine* (T). These nucleotides pair with each other in a predetermined way. A forms a base pair with T; and C forms one with G. The two elements of nucleotides that pair with each other are located on two different strands, which can be represented as two ribbons spinning around an imaginary axis. If a DNA sequence of one strand (piece of the ribbon) is of the order [-A-A-C-T-T-G-G-], the corresponding part on the other strand will be of the order [-T-T-G-A-A-C-C-]. The double-helix structure of DNA is formed by the way the base pairs are linked to each other.

A gene is the "fundamental physical and functional unit of heredity" and can be defined as "an ordered sequence of nucleotides located in a particular position on a particular

chromosome."[9] Every gene has its specific functions, frequently in interaction with others. There are two different types of gene. Some genes are formed by DNA sequences that transmit, through the messenger molecule RNA (*ribonucleic acid*), information necessary for the production of proteins. Other genes are operational, determining when and how proteins are synthesized. Genes vary in size. Some have only 1,000 base pairs, whereas others consist of more than 100,000. According to the latest estimates, there are probably between 60,000 and 70,000 genes.[10] There are probably around 3.3 billion base pairs. The total sum of these base pairs is the human genome.

Proteins are critical elements of all living organisms and are present in all cells. There are different kinds of protein, each having its specific function. Enzymes, for example, are proteins that activate metabolic processes in cells. The hair and nails are produced by keratin, another protein. Muscle contraction is caused by movement of proteins in the muscle cells. Antibodies of the immune system, too, consist of proteins. Protein synthesis is the whole process by which a gene transcribes its coded information to messenger RNA, which translates it further into a protein.

Not all DNA is involved in the production of proteins. In fact, perhaps only 5% to 10% of DNA is accounted for by genes that code for proteins. DNA not implicated in the production of proteins is called "non-coding DNA." Some of this non-coding DNA is known to regulate the functioning of genes. Other DNA is described as "non-functional DNA," because its role is not clearly understood. The flow of information origination from the DNA and the instructions given on the basis of this information are essential for all living organisms. DNA is "the basis for all of the processes and structures of life.[11] It is the interaction between genes and proteins that allows human organisms to function and partly determines how they act.

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9 DOE Human Genome Program, *supra*, note 8 at 33.

10 C. Fields *et al.*, "How Many Genes in the Human Genome?" (1994) 7 Nat.Genet. 346.

11 Griffiths *et al.*, *supra*, note 8 at 6.

Every organ has its own distinctive cells, as I have noted, but all consist of an identical assortment of chromosomes. All cells also have an identical set of genes. The differences between types of cell (and the organs consisting of them) are due to the fact that only specific genes are activated in each type. Although some genes are active in cells of the liver, say, the same genes are inactive in other organs. Genes are triggered on specific occasions and in specific places. The "manual" for the whole organism is available in every cell, but not all the information is used at the same time and the same place.

Ruth Hubbard and Elijah Wald compare DNA to a cookbook, thereby stressing the fact that DNA provides basic information for the "cooking," but that the "recipe" must still be realized in an original way by the "cook." It must still be used in a specific environment, interacting with other factors. Ingredients and a book of recipes alone do not make a dish. The image of the cookbook also makes clear that one does not constantly need the whole book. Every occasion requires a particular dish; every physiological transformation is activated by a particular genetic interaction.[12]

Others, paying tribute to artistic endeavours, describe DNA as the "alphabet" that is used to form "words" held together by "grammatical rules" in order to create "literature."[13] The base pairs are the letters of an alphabet that have to be structured in a specific way to form recognizable words. This general background should be enough to explain how genetic diseases can be inherited and how they occur. When genes do not act as they should, the production of proteins can be affected. Disordered genes can thereby affect the functioning of organs and disturb the entire organism. This can be due to a mutated gene inherited from either parent or from both parents. It can be due also to a gene that has mutated during or after fertilization. But how does hereditary transfer work?

Nearly every cell has an identical set of the 46 chromosomes – that is 44 autosomes and 2 sex chromosomes. Chromosomes are paired, 23 coming from the mother and 23 from the father. During fertilization, when sperm meets egg and cell division occurs, both sperm

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12 *supra*, note 8 at 11-12.

13 See Jones, *supra*, note 2 at ix-xi.

and egg provide one copy of every chromosome to the newly formed cell. Thus, they both transfer only 23 chromosomes to the new cell. Which copy of each chromosome sperm and egg will transmit is undetermined. Because "genetic traits" are often linked to only one copy of the parental chromosomes, they might not be inherited at all.

An example can make this clear: suppose that a father carries a genetic trait in one copy of chromosome 10 (**A**), but not in the other (**a**) and suppose that the mother is not affected by the trait (her copies are **B** and **b**). The father's sperm can either transmit copy **A** or copy **a** to the new cell. In this case, a child will only inherit the trait if the sperm transfers copy **A** to the offspring. The child thus has 2 chances out of four to inherit the trait. The possible combinations of inheritance are: **AB**, **Ab**, **aB** and **ab**

The 23rd pair of chromosomes is different from the others. It determines the sex. Males have one X chromosome and one Y chromosome; females have two X chromosomes. The inheritance of genetic disorders linked with sex chromosomes is different, therefore, from that of other chromosomes. As I indicated, there are four possible combinations with other chromosomes. With the sex chromosomes, the possible combinations are more limited. The male always inherits a Y chromosome from his father; the female can inherit only an X chromosome from her father.

Because there are two copies of every chromosome, there are always two copies of every gene: one from each parent. Every copy that exists at a specific location on the chromosome is called an *allele*. People who have two identical alleles are *homozygous* for that gene; people who have two different alleles are *heterozygous* for it. Some diseases occur only when someone is homozygous (this is when both father and mother transfer a disordered gene). These diseases are called "recessive" ones. Other diseases occur only when someone is heterozygous (when only one parent transfers a disordered gene). These are called "dominant" diseases.

For the topic under discussion here, it is enough to keep in mind that a gene is "the unit of heredity associated with a specific trait"[14]. Reality, of course, is more complex. Even

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[14] Carlson, *supra*, note 8 at 475.

scientists disagree on what constitutes a gene and call it a "notoriously slippery concept."[15] Until recently, for instance, genes were thought to be side by side on the DNA, each having a determined set of base pairs. This view of a gene as a static element has now been rejected. It is now believed that genes can shift and that they often overlap each other.[16] But this is not the place to discuss the matter.

II. The Genome Project

A. Historical background[17]

The idea that personal traits and certain diseases are transmitted from one generation to another is not new. Even 3,000 years ago, Jewish regulations for circumcision displayed an understanding of the hereditary character of haemophilia.[18] If two sons die from haemorrhage, according to the Talmud, the third need not be circumcised. For decades, physicians, employers and insurance companies have taken into consideration the family histories of specific diseases. With these in mind, they have made diagnoses, established preventive diets, decided whether people would make suitable workers and calculated the premium to be paid for life or health insurance. But no clear explanation was given for the fact that diseases run in families. The hereditary origins of several diseases, moreover, were simply ignored.

Genetics as a systematic scientific approach started in the nineteenth century with the discovery, by Gregor Mendel of visible patterns of inheritance in peas. Mendel was

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15 Fields *et al.*, *supra*, note 10 at 346.

16 Carlson, *supra*, note 8.

17 For a short description of the historical development of genetics, see McKusick, *supra*, note 8 at 20-26 and Shapiro, *supra*, note 8 at 1-102.

18 Jones, *supra*, note 2 at 58; Carlson, *supra*, note 8 at 480.

interested mainly in the *phenotypical* rules of inheritance, the outward characteristics of plants. He observed what kinds of change occurred in breeding of plants and tried to explain how these changes could be predicted. He did not refer to the existence of genes and did not explain hereditary processes. But his mathematical rules of inheritance, referred to as "Mendel's laws," are still regarded as the basic rules of inheritance and the cornerstone of genetics.[19]

Mendel's theory was rediscovered in the early twentieth century. At that time, the notion of "genes" was introduced to describe particles of chromosomes that carry hereditary information. Thomas Morgan performed important linkage studies on fruit flies, indicating that genes are located on different chromosomes. The first pedigree study of an inherited disorder, shortened hands and fingers in a Norwegian village, was also published in that period.[20]

The eugenics movement developed at the same time, especially in America, England and Germany. Racial improvement (particularly of the white and Northern European race) through the use of genetics was its main goal. Advocates believed that heredity determined not only physical characteristics, but temperament, behaviour and intelligence as well. Genetics, they believed, should be applied in everyday life. It was an essential tool in promoting the development of society. Poverty, criminality, deviant behaviour and low intelligence, they claimed, were all determined by heredity and should be controlled. A popular theme was how to counter the negative influence of the poor and "feeble-minded" on the nation's heredity. The obligatory sterilization of psychiatric patients was introduced in several states. Birth control was another strategy. One eugenics supporter stated it as follows: "More children from the fit, less from the unfit - that is the chief issue of birth control."[21]

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19 For a basic description of Mendel's laws, see Hubbard & Wald, *supra*, note 8 at 40-42; his experiments are also discussed by Jones, *supra*, note 2 at 31-34.

20 *Ibid.*, note 2 at 34.

21 Margaret Sanger, cited by D.J. Kevles, *In the Name of Eugenics: Genetics and the Uses of Human Heredity* (Berkeley: University of California Press, 1985) at 90.

It was also in this period that the issue of hereditary susceptibility to workplace hazards was first raised. The geneticist J. B. S. Haldane studied potters suffering from bronchitis and came to the conclusion that some of them had a congenital predisposition to the disease. He believed that it would become possible to select workers by their predisposition to occupational hazards.[22]

The popularity of eugenics and the further developments in the comprehension of genes and hereditary processes were jeopardized by the "scientific" eugenic programmes and genetic experiments of the Nazis.[23] Nowadays, geneticists are often reluctant to talk about the abuse of genetics in the past and do everything to distinguish the current genome project from the eugenics of an earlier period. Concern has been expressed over the fact that many prominent geneticists who participated in the Nazi programmes, remained in position after World War II and quietly continued their research.[24] Of immediate relevance to the discussion of workplace testing is that many geneticists, in discussing the current applications of genetics, are reluctant to openly acknowledge past misapplication. Many others, though,

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22 International Labour Office, "Workers' Privacy, Part III: Testing in the Workplace" in *Conditions of Work Digest*, vol.12:2 (Geneva: International Labour Office, 1993) at 57.

23 For a short description of eugenics on the international scene, see Hubbard & Wald, *supra*, note 8 at 13-22. For a comparison between the genome project and eugenics, see R.N. Proctor, "Genomics and Eugenics: How Fair Is the Comparison?" in Annas and Elias, eds, *supra*, note 8, 57. For accounts of eugenics under the Nazi regime, see R.J. Lifton, *The Nazi Doctors* (New York: Basic Books, 1986); R.N. Proctor, *Racial Hygiene: Medicine under the Nazis* (Cambridge Mass.: Harvard University Press, 1988); A.L. Caplan, ed, *When Medicine Went Mad: Bioethics and the Holocaust* (Totowa: Humana Press, 1992). These accounts make it clear that the Nazi regime was not alone. Compulsory sterilization of the feeble minded existed in "civilized" countries such as the United States and Canada. In Alberta and British Columbia, for example, sexual sterilization acts were repealed only in 1972. For an overview of eugenic laws in Canada, see Science Council of Canada, *supra*, note 8 at 76-78.

24 See also P.S. Harper, "Huntington's Disease and the Abuse of Genetics" (1992) 50 Am.J.Hum.Genet. 460.

argue that lessons should be learned from the past.[25] Geneticist Peter Harper, for example, warns against the development of genetic registers of Huntington's patients, similar to those of the Nazi regime. Access to these registers might have less extreme, but still troubling, consequences for those affected and their families.[26]

As a result of the Nazi horrors, most public applications of genetics (such as sterilizing the feeble minded) were terminated after the world war. Nevertheless, important scientific discoveries were made. In 1953, for example, James Watson and Frances Crick published a model of the famous double-helix structure of DNA. A real breakthrough occurred in the seventies. At that time, molecular biologists discovered two kinds of enzyme: *polymerases* copy the building stone of DNA, nucleic acid, and *restriction enzymes* cut the DNA into manageable pieces. These discoveries made it possible to study DNA structures intensively in labs. The better understanding of the role of DNA and the development of techniques enabling scientists to actually register its constituents have led to what is now known as "the genome project."

B. The human genome map

Four techniques in particular have contributed to genetic discoveries: *electrophoresis*, *cloning*, *polymerase chain reaction* and the use of *restriction enzymes*. With the first technique, molecules on the DNA are separated by placing them between positive and negative electrical charges on a field of polymer gel. Small molecules move faster than large ones toward the positive or negative terminals and are filtered on the polymer gel. In that way, pieces of DNA are separated and can be measured according to their length.[27] *Cloning*

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25 See Proctor, *supra*, note 23 at 84; Harper, *supra*, note 24 at 464 and D.J. Kevles, "Vital Essences and Human Wholeness: The Social Readings of Biological Information" (1991) 65:1 S. Cal. L.R. 255 at 259-264.

26 Harper, *supra*, note 24 at 463; for further discussion of this issue, see infra.

27 For more details, see Slater & Drouin, *supra*, note 8 at 17-35.

involves inserting pieces of DNA into bacteria or yeast cells, which are subsequently replicated. Replication through cell division provides copies not only of the host cell but also of its "visiting" DNA. This technique makes it possible to produce multiple copies of the desired strand of DNA. Polymerase chain reaction is a more recent technique. Described as a "biological photocopier,"[28] it can produce over a million replicas of any DNA sequence. Restriction enzymes play a central role in the use of these techniques. They can be conceived as "submicroscopic wire cutters [used] to snip DNA between specific sequences of bases."[29] They clip DNA each time a specific sequence of nucleotides is recognized. But the first enzymes developed did so too frequently; analyses of the fragments would have taken much too long. Enzymes have now been developed that cut at an average of once every 65,000 bases. By splitting up the DNA strand, it has become possible to study and compare smaller, more manageable sequences.

Two strategies have been developed on the basis of these techniques: genetic linkage mapping and physical mapping of the genome.[30] In genetic linkage mapping, *markers* are used to label large chromosome regions. These are identified DNA sequences. The idea of using markers is based on the observation that specific genetic traits are inherited together with a specified DNA region. Family members who have a specific genetic trait frequently have a similar DNA sequence (the marker), unlike non-affected members. The *locus* (the place on the DNA strand) of a gene is determined by establishing how often markers and traits are inherited together. Here is the hypothesis: the more often a marker and a trait are inherited together, the closer together on a chromosome are the marker and the unidentified gene for that trait.[31] If traits are closely associated with markers, then testing for these trait

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28 The term is from Jones, *supra*, note 2 at 46.

29 Judson, *supra*, note 8 at 63.

30 For a detailed description of gene mapping, see OTA, *Mapping our Genes*, *supra*, note 8; a short history of gene mapping is given by W. Gilbert, "A Vision of the Grail" in Kevles & Hood, eds, *supra*, note 1, 83.

31 Science Council of Canada, *supra*, note 8 at 29.

is made possible even though the genes have not yet been identified. This technique was used in 1983 to document the linkage between a marker on the short arm of chromosome 4 and Huntington's disease.[32] Since then, "[t]he approximate chromosomal position of nearly all of the common inherited diseases under simple control has . . . been mapped."[33]

Because genetic-linkage maps do not give precise information, however, they are only a first step in the genetic analysis of a disease. The discovery of a marker does not necessarily mean that one is very close to understanding the disease. After the discovery of a marker for Huntington's, it took 13 years to identify the specific gene.[34] A genetic map indicates only the DNA region in which to search for a disease-causing gene; a physical map can be used later to identify its precise position.

Drawing the physical map of a genome involves cutting the DNA strand with restriction enzymes and determining the order of obtained fragments on the chromosomes. It is often said that the most detailed physical map of a genome is one that specifies the order of all the 3.3 billion base pairs of the human genome.[35] As Horace Freeland Judson remarks, however, "this is a considerable semantic mistake."[36] A visual representation of every detail in a territory, after all, is no longer a map. The representation is always an interpretation of reality. It is always the result of a scientific approach to nature.[37] On an even more basic

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32 See J. Brandt *et al.*, "Presymptomatic Diagnosis of Delayed-Onset Disease With Linked DNA Markers: The Experience in Huntingdon's Disease," (1989) 261:21 J.A.M.A. 3108; see also Jones, *supra*, note 2 at 55. For a description of the "Huntington's gene hunt," see N. Wexler, "Clairvoyance and Caution: Repercussions from the Human Genome Project," in Kevles & Hood, eds, *supra*, note 1, 211 at 212.

33 Jones, *supra*, note 2 at 48.

34 S.M. Suter, "Whose Genes Are These Anyway? Familial Conflicts over Access to Genetic Information" (1993) 91 Mich. L. Rev. at 1855.

35 OTA, *Mapping the Genome*, *supra*, note 8 at 30.

36 *supra*, note 8 at 78.

37 A.M. Capron, "Which Ills to Bear? Reevaluating the 'Threat' of Modern Genetics" (1990) 39 Emory L.J. 665 at 684.

level, a map of the genome is a real "construction of reality." The human genome is an abstraction.[38] It shows in general what the structure of each individual's genome looks like, but is always different. Indeed, every individual's genome is unique. The map of the human genome can be only an "averaged" picture, illustrating what is a "normal", human being.[39]

Sketching the entire genome is the final aim of the genome project, but this will require some many years of industrious sequencing.[40] The completion of a "rough sketch" is now predicted for 1998.[41] This will consist of 30,000 sites. Problems in completing the map include the fact that scientists around the world have various mapping methods and that universal measures for mapping are lacking.[42] A less detailed but, in the immediate future, more useful picture can be given by simply defining the exact location of larger parts of DNA on the genome, without determining the exact location of all of its base pairs.

Creating the "final map" would be like copying every detail of Canada on one long sheet of paper. The aim would be a map useful for every Canada-like country. With a lot of patience, one could discover the location of streets such as Saint Denis and Saint Laurent, how long each is and how many houses are on each. But it might be more useful for a first analysis of the country to know where the big cities are, whether roads link the industrial centres, where mountain chains are located and so on. Moreover, a detailed copy of Canada

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38 Compare B. Knoppers, "Le génome humain: un patrimoine universel, personnel et communautaire" in Mélançon & Lambert, eds, *supra*, note 8, 101 at 102: "Le `génome humain' comme telle n'existe pas dans la réalité: ce génome est un `mythe,' une construction opérationelle de l'esprit scientifique. Il est un consensus anonyme de séquence d'ADN. . . . Il s'applique comme référence à l'espèce humaine dans sa totalité."

39 Moreover, a readable printout of all sequences would be larger than the genome itself. One should think instead of an enlarged, printed replica.

40 For an approximation of the time and energy spent on genome mapping, see Gilbert, *supra*, note 30 at 88-90 and Slater & Drouin, *supra*, note 8 at 20-21.

41 D.R. Cox *et al.*, "Assessing Mapping Progress in the Human Genome Project," (1994) 265 Science 2031.

42 *Ibid.*

would contain parts that are of no interest in understanding the country's larger structure. It might be less important to see every stone of the prairies than to see major features of the cities. The same is true of the genome: some parts might be of less immediate interest or even no interest at all. To use Steve Jones' image of literature, it might be interesting to have a look at the table of contents before reading the whole book.

The successive use of genetic linkage maps and physical maps has proved very useful. In 1968, only 68 genes had been located, all on the X chromosome. By 1994, a special issue of *Science*, included a human genetic map consisting of 5,840 loci.[43] Of these, 427 are genes.[44]

The registration of gene sequences and the possibility of comparing them have enabled scientists to determine the genetic components of many diseases, such as Huntington's disease, phenylketonuria, cystic fibrosis and hereditary breast cancer.[45] It should be made clear, however, that these discoveries mean neither that scientists understand all expressions of specific diseases nor that genes are solely responsible for them. Talking about genes *causing* diseases, while sometimes difficult to avoid, is not without ambiguity. It should be clear by now that genes and diseases are often merely associated with each other. This association leads to the formulation of a hypothesis that must still be either confirmed or falsified. It is too easy to see in the presence of a disordered gene the *prima causa* that explains everything; there are too many ways in which genes are linked to particular diseases. Because the genetic code is like a "cookbook" or "literature,"[46] it is not very meaningful to study genes in isolation. Genes interact with each other. According to Walter Gilbert, "[t]here is now about a 50 percent probability that when we isolate a new gene we will see

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43 K.H. Buetow *et al.*, "Human Genetic Map: Genome Maps V" [wall chart] (1994) 265 Science 2055.

44 For a description of the map, see J.C. Murray *et al.*, "A Comprehensive Human Linkage Map with Centimorgan Density," (1994) 265 Science 2049.

45 For some examples, see Science Council of Canada, *supra*, note 8 at 24.

46 See *supra* at 8.

that it is related to something that has been previously identified."[47] The presence of mutant genes, for instance, might be mitigated by the presence of normal ones. Mutant genes might produce diseases only in connection with other mutant genes. As Judson puts it, "genes act only in concert."[48] New techniques are being developed for tracking disorders caused by multiple genes.[49]

The interaction of genes is often surprising. French scientists recently discovered what was quickly called "a longevity gene."[50] The association of two genes with long life was based on analysis of DNA from 338 French centenarians. The scientists discovered that few of them shared variety E4 of the APOE gene, a variety that has been associated with heart disease and Alzheimer's disease. More surprisingly, it was also found that a significantly higher number of them than expected carried a variety of the APOE gene and a variety of the ACE gene that are associated with susceptibility to heart disease and predisposition to heart attack. So, these genes are now associated with both early death and long life. In fact, the more scientists begin to understand genetics, the more they are astonished by the complexity of genetic phenomena. New discoveries are already challenging the simplicity of traditional genetics.[51]

Moreover, it is hard to separate nature from nurture or biological from environmental and cultural factors. "One of the dangers of biological determinism," warns Proctor, "is that

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47 *supra*, note 30 at 91.

48 *supra*, note 1 at 37. See also Hubbard & Wald, *supra*, note 8 at 36-37.

49 For example, see P. Aldhous, "Fast Tracks to Disease Genes: Two New Techniques for Scanning the Genome Promise: Great Advances in Tracking the Roots of Disorders Caused by Multiple Genes," (1994) 265 Science 2008.

50 F. Schachter *et al.*, "Genetic Associations with Human Longevity at the APOE and ACE loci" (1994) 6:1 Nat. Genet. 29; discussed by S. Watts, "New Year Heralds Life and Death Dilemmas: French Scientist Finds Genetic Clues to Long Life but Warns of Potential for Misuse" *The Independent* (1 January 1994) 1.

51 See J. Rennie, "DNA's New Twists," Scientific American (March 1993) 122-132.

the root cause for the onset of disease is shifted from the environmental (toxic exposures) to the individual (genetic defects)."[52]

III. Classification of genetic diseases

Genetic diseases are commonly thought of as clearly identifiable diseases carried over from one generation to the next and directly related to the transmission of genetic material. The traditional genetic diseases are caused by mutations in germ (sperm and egg) cells that are transmitted from parents to children. But other diseases, too, can be called "genetic." Somatic (not sperm or egg) cells can undergo changes during a lifetime. Mutations can occur either spontaneously or because of environmental interference. These mutations can provoke specific diseases, such as cancer, that are genetic, though not inherited. To complicate matters, disorders usually transmitted from parents to children sometimes originate in other ways. Congenital deafness is usually a recessive disorder, for example, but can be caused also by the drug streptomycin.[53]

For my purposes here, genetic diseases are classified as follows: (1) chromosomal aberrations; (2) single gene disorders (including susceptibilities); and (3) complex traits.

A. Chromosomal aberrations

These are major deviations from the chromosomal structure. They are usually established during fertilization but can occur later under environmental influence. A well-known example is Down's syndrome; the afflicted have extra copies of chromosome 21.

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52 Proctor, "Genomics and Eugenics" *supra*, note 23 at 80.

53 OTA, *Genetics Monitoring*, *supra*, note 8 at 194.

Chromosomal anomalies probably account for between 50%[54] and 60%[55] of spontaneous abortions. Moreover, according to the Office of Technology Assessment of the United States Congress, six newborns in every 1,000 are affected by chromosomal aberrations expressed in a variety of forms.[56] Prenatal tests have been developed to determine whether foetuses are affected by chromosomal diseases such as Down's syndrome.

Chromosomal anomalies under environmental influence are often associated with cancer. In cases of exposure to ionizing radiation, chromosomal analysis is used to establish the danger of lesion. Other chemical substances can influence the chromosomal structure and cause cancer. However, except in connection with ionizing radiation, efficient tests to control the influence of chemical agents on the chromosomal structure of employees have not yet been developed. According to the Office of Technology Assessment (OTA), controlling the influence of chemical substances through chromosome testing is difficult because it requires "that large numbers of individuals and cells be studied to detect a statistically significant increase in [chromosomal aberrations]. Detecting effects at low exposure levels or in small groups is not informative."[57] Chromosomal aberrations are a very important phenomenon in the workplace. Many workplace toxins are presumed to affect the chromosomes in cases of heavy exposure.

There are several problems in associating chromosomal mutations with disease. Those resulting from exposure to radiation or chemicals, for example, are very diverse. Some remain for a very long time after exposure, while others disappear very quickly. Many are not directly linked to disease. In some cases, effects are noticeable only several years after

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54 *Ibid.* at 195.

55 Science Council of Canada, *supra*, note 8 at 21.

56 OTA *Genetic Monitoring*, *supra*, note 8 at 196. The Medical Research Council of Canada keeps it at 5 per 1000 (mentioned in Privacy Commissioner of Canada, *Genetic Testing and Privacy* (Ottawa: Supply and Services, 1992) at 9.

57 OTA *Genetic Monitoring*, *supra*, note 8 at 62 [footnote omitted].

the initial exposure.[58] The clearest associations have been made between exposure to high levels of radiation and some forms of cancer. Connections between disease and exposure to low-level radiation or chemical substances often remains unclear.[59] Further study is underway in this area. Because chromosomal monitoring requires the co-operation of many workers, it could be argued that participation in monitoring programmes could be a condition for employment in certain industries.

B. Single-gene (or monogenic) disorders and susceptibilities

Because of their often severe character and early onset, single-gene disorders appeal most to the imagination. Although there are many of them – the Science Council of Canada mentioned in 1991 that 3,600 were already known[60] – they count for only a small part of all diseases.[61] A single-gene disorder is linked to one specific gene locus. It can either *dominant* or *recessive*. And it can be linked to either autosomal chromosomes (those that are not sex-linked) or sex chromosomes.

In *dominant genetic disorders*, only one copy of a defective gene is required to generate the disease. Heterozygotes for the trait normally have the disease. Even if only one parent is affected, the disease can be inherited. For every gene, children receive a copy from each parent. Heterozygous parents affected by a dominant disorder can transmit either the mutant or the normal copy. If only one parent is heterozygous for the trait, the child has a 50% chance of inheriting the disease.

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58 *Ibid.* at 55-71.

59 *Ibid.* at 60-62.

60 Science Council of Canada, *supra*, note 8 at 21.

61 L.B. Andrews, *et al.*, eds, *Assessing Genetic Risks: Implications for Health and Social Policy* (Washington: National Academy Press, 1994) at 62 [hereinafter *Assessing Genetic Risks.*]

Recessive genetic disorders are more common. In these diseases, the defective gene is usually neutralized by the presence of a normal counterpart. Heterozygotes for the trait carry the disorder and can transfer it to their offspring, but normal functioning of the gene is assured by the other copy. Recessive disorders are manifested only when two dysfunctional genes are transmitted and a person is homozygous for the trait. This is the case when a defective gene is inherited from both father and mother. Hence, children of two carriers are neither automatically affected nor automatically carriers of the disorder. If both parents are heterozygous, the children have a 25% chance of being affected (homozygous), a 50% chance of being unaffected and a 25% chance of being unaffected non-carriers (heterozygous). If one parent is homozygous (and thus affected) and the other carrier, their children have a 50% chance of being affected. If only one parent is a carrier, the children will not be affected personally. They have a 50% chance of being heterozygous, however, and thus carriers themselves.

Single-gene disorders linked to the sex chromosomes follow a somehow different pattern. No disease-causing mutations have been identified on the Y chromosome, which contains only a few genes. But *X-linked genetic disorders* are rather frequent. As I have noted, males have only one X-chromosome. Thus, X-linked recessive or dominant genes are expressed in males. They might or might not be affected by X-linked genetic disorders. They are never simply carriers of X-linked diseases. In females, much of what has been said regarding the difference between dominant and recessive disorders applies. Females can transmit recessive disorders to their children but remain asymptomatic because of compensating, second X-chromosomes. Sex-linked disorders such as muscular dystrophy, haemophilia and colour blindness are much more common in males, therefore, than in females.

Some of the single-gene disorders are more "determinant" than others. Those who have the mutant gene (or pair of mutant genes) usually develop the disease, although the exact time of its onset is often unpredictable. Huntington's disease is an autosomal dominant disorder. Those who receive a copy of the gene develop this fatal disease, usually between 30 and 50 years of age. Once the disease has expressed itself, it progresses steadily over a

period of 10 to 20 years. Tay-Sachs disease is a determinant recessive disorder. It affects the neurological system and inevitably leads to death in early childhood.

Other single genes lead to a significant increase in the risk of developing diseases. These can be classified as "susceptibility" genes. Women affected by autosomal dominant breast cancer have a very strong chance of developing the disease. Heterozygotes for one of the two breast cancer genes that have been identified, BRCA1 and BRCA2, have around an 87% chance of developing breast cancer before the age of 80.[62] In the case of autosomal dominant polycystic kidney disease, carriers of one of the two genes associated with it have a 50% chance of developing renal failure by the age of 70.[63] The same chances to have a heart attack by the age of 50 are incurred by male heterozygotes for familial hyper cholesterolemia. Women who are heterozygous for the trait have a 50% chance of suffering from a stroke by the age of 65.[64] Haemochromatosis is a treatable autosomal recessive disorder. It causes excessive iron deposits in the liver, heart, pancreas and other organs. This can lead to cirrhosis, heart failure, diabetes and liver cancer.[65] The disorder can be treated through frequent blood-letting to remove excessive iron. If treatment is started before the disease is clinically manifested, it can be completely cured. Tests now focus on detecting abnormal iron metabolism. No direct genetic test is available, although family-linkage tests can be done. Not all heterozygotes for the trait develop the disease.

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62 R. Wooster *et al.*, "Localization of a Breast Cancer Susceptibility Gene, *BRCA2*, to Chromosome 13q12-13," (1994) 265 Science 2089; see also D.E.C. Cole *et al.*, "Genetic Counselling and Testing for Breast, Ovarian and Colon Cancer Susceptibility: Where Are We Today?" in K.M. Taylor & D. De Petrillo, chairpersons, *Critical choices: Ethical, Legal and Sociobehavioural Implications of Heritable Breast, Ovarian and Colon Cancer, Background Paper for the International Research and Policy Symposium* (Toronto, April 28-30, 1995) 1-17.

63 *Assessing Genetic Risks*, supra, note 61 at 91.

64 *Ibid.* at 91.

65 *Ibid.* at 89-90.

Environmental factors might play a more important role in the development and time of onset of single-gene "susceptibilities" than in single-gene disorders such as Huntington's disease.

C. Complex traits

Complex traits have many causes, including the interaction between several genes and environmental factors. Most genetic diseases fall into this category. A complex trait can be defined as a genetic trait for which no single gene has been identified. In fact, the line between single-gene disorders and complex traits is often small.[66] Traits now classified as complex might eventually be reclassified as single-gene susceptibilities, if specific genes can be related to the diseases. Complex traits often include diseases that have single-gene variants of the same name. Breast cancer, for example, is in a minority of the cases (perhaps 5%)[67] connected to the presence of a single-gene mutation. Other cases of breast cancer are, as other forms of cancer in general, typical examples of complex traits. They are caused by the alteration of somatic cells that are not inherited. The development of these cancers is sometimes exacerbated by mutations resulting from specific life-styles. According to the Committee on Assessing Genetic Risks, "[o]ccasionaly, detection of a specific chromosomal or molecular abnormality is helpful in predicting the clinical severity of the cancer and in a few cases may aid in selecting the most appropriate treatment."[68]Other examples of complex traits are hypertension, diabetes and heart disease. In these diseases, the interaction of hereditary factors and environmental influences is often unclear. Predicting their development is complicated by the fact that, within any family, a different combination of

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66 In fact, classical single-gene disorders, such as sickle-cell anemia can also show complex patterns; see E.S. Lander & N.J. Schork, "Genetic Dissection of Complex Traits," (1994) 265 Science 2037.

67 Wooster, *supra*, note 62 at 2090; *Assessing Genetic Risks*, *supra*, note 61 at 93.

68 *Assessing Genetic Risks*, *supra*, note 61 at 96.

genes might be associated with a complex trait. Limited results might be obtained, therefore, with tests that take into consideration family patterns.

Several psychiatric diseases are now classified as complex traits.[69] Among them are manic depression, schizophrenia, Tourette's syndrome,[70] alcoholism (and smoking addiction[71]). In the cases of manic depression, schizophrenia and alcoholism, triumphantly announced findings, associating these conditions with a particular gene, could not be confirmed in subsequent studies.[72] Results of studies on twins, though, suggest that hereditary factors might play a role in these diseases.

A lot of controversy surrounds the studies that link genes with behavioral and psychiatric disorders. Some argue that hereditary factors play only a limited role and that genetic tests are unlikely to be of any benefit. Hubbard and Wald do not deny the genetic aspects of many of these diseases. After analyzing the studies on behavioral "disorders,"[73] however, they draw the following conclusions:

> With all this confusion, the presence of a genetic marker for a behavioural condition would not be particularly useful, even if it were found. Though the disease model or the genetic model can be helpful to some affected people, as with alcoholism, correlations between the conditions and specific base sequences of DNA do not add any useful information. Such correlations can neither predict the behaviour for specific individuals nor yield treatments. Identifying a "culprit"

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69 See *Assessing Genetic Risks*, *supra*, note 61 at 99, for example, and Science Council of Canada, *supra*, note 8 at 24-26.

70 Proctor, *supra*, note 23 at 80.

71 D. Carmelli, *et al.*, "Genetic Influence on Smoking: A Study of Male Twins," reported in "Twin Study Finds Genetic Influence on Smoking," (1993) 12 Brown U. Dig. of Add. Theory and Applic. 1-4.

72 See Kevles & Hood, *supra*, note 1 at 326-327; Hubbard & Wald, *supra*, note 8 at 66; Proctor, *supra*, note 23 at 80; and *Assessing Genetic Risks*, *supra*, note 61 at 99.

73 *supra*, note 8 at 93-107.

DNA sequence is just a fancier way of saying that the condition runs in the family.[74]

But for James Watson, former director of the U.S. National Institutes of Health's (NIH) genome project, it remains "pretty clear that manic depression has a genetic cause," "that alcohol bears some relationship to genes" and that the genes behind schizophrenia will one day be found. For the latter, he admits, the gene hunt will be difficult. But he argues that "it is still better to waste your money doing genetics because genetics lies at the heart of so much."[75]

Some employers might be particularly interested in testing for psychiatric disorders. As the Committee on Assessing Genetic Risks indicates, "[t]he implications of predictive testing for mental disorders raise even more problems than those for other complex medical diseases, because of the heightened potential for stigmatization and discrimination."[76]

D. Problems complicating the prediction of genetic disorders

1) Variable expressivity, incomplete penetrance, variable time of onset.

Genetic disorders can affect people to different degrees of severity, having extremely disabling effects on some individuals but leaving others hardly affected at all. This phenomenon is described as *variable expressivity* and is expressed in percentages ranking from 0% to 100%. Even when tests are available, they can seldom estimate the severity of their

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74 *Ibid.* at 104.

75 J. Watson, "A Personal View of the Project," in Kevles & Hood, *supra*, note 1 at 166-167.

76 *Assessing Genetic Risks*, *supra*, note 61 at 99.

expression.[77] Genetic disorders, especially late-onset ones, also diverge according to the time of onset. Those at risk can usually be told only that they are likely to develop the disease between certain years of age.

Though homozygous or heterozygous for a trait, some people never develop the corresponding disorder. This phenomenon is called *incomplete or reduced penetrance.*[78] It is unclear why this is the case. Possibly involved are environmental factors, life-style or the interference of other genes. At the moment, it is impossible to predict reduced penetrance.

Some examples can make clear how predictions are complicated by these phenomena. As I have observed, Huntington's disease is normally manifested between the ages of 30 and 50. But some people are affected at the age of 2 and others only at 80. Predicting the exact onset of Huntington's disease is still impossible, even though a link has been found with the number of triplet repeats present in the mutant gene and the age of onset. Myotonic dystrophy of Steinert, too, clearly indicates the problem of predicting genetic disorders. Myotonic dystrophy of Steinert is usually manifested between the ages of 20 and 30 and is characterized by progressive peripheral muscular weakness, atrophy and myotonia. Some people, though, remain free of signs or symptoms throughout their lives. Others experience only minor effects. The same is true for *neurofibromatosis.* Some people are affected by disfiguring tumours, while others develop only skin discolouration and minor tumours.[79]

2) Allelic and genetic heterogeneity.

More than one change in DNA can be responsible for the same genetic disorder. *Genetic heterogeneity* refers to a single disease associated with a variety of genes and chromosomal

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77 In some cases, severity of expression can be inferred from an expansion of the gene after transmission from parent to child. This is called "allelic expansion." See *Assessing Genetic Risks*, *supra*, note 61 at 63.

78 See OTA *Genetic Monitoring*, *supra*, note 8 at 194-195; Lander & Schork, *supra*, note 66.

79 OTA, *Genetic Monitoring*, *supra*, note 8 at 194.

locations. *Allelic heterogeneity* means that several mutations in the same gene can cause the disease.[80] Heterogeneity complicates genetic testing.

A clear example of allelic heterogeneity is *cystic fibrosis*. The discovery of the gene for this disease and the development of a diagnostic test were considered among the first success stories of the genome project. Cystic fibrosis is a recessive, single-gene disorder that affects one in 2500 Caucasians, of whom one in 25 is a carrier.[81] At one point, a diagnostic test seemed very promising. Soon after the gene was detected in 1990, though, it became clear that cystic fibrosis can be caused by a multitude of DNA changes[82] and that the frequency of variation differs from one population to another.[83] Obviously, variation complicates testing. For testing purposes, cystic fibrosis must be seen as a cluster of diseases.[84]

Genetic heterogeneity means that mutations in any one of several genes can cause an identically expressed disease. Genetic heterogeneity can be found in polycystic kidney disease and familial Alzheimer's.[85] Breast cancer, too, is characterised by a limited form of heterogeneity. As I have indicated, two breast-cancer genes have already been located and one or more might cause susceptibility to the disease.[86] Genetic heterogeneity seriously

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80 N. Wexler, "Clairvoyance and Caution: Repercussions from the Human Genome Project," in Kevles & Hood, *supra*, note 1 at 224; *Assessing Genetic Risks*, *supra*, note 61 at 62.

81 See S. Elias, G.J. Annas & J.L. Simpson, "Carrier Screening for Cystic Fibrosis: A Case Study in Setting Standards of Medical Practice," in Annas & Elias, *supra*, note 8 at 187; Wexler, *supra*, note 80 at 224-226.

82 More than 200 mutations have already been identified: *Assessing Genetic Risks*, *supra*, note 61 at 73; See also Wexler, *supra*, note 80 at 225 and Jones, *supra*, note 2 at 55.

83 The phenomenon of mutations within a single gene is called "allelic heterogeneity." See *Assessing Genetic Risks*, *supra*, note 61 at 62.

84 M. Barinaga, "Novel Function Discovered for the Cystic Fibrosis Gene," (1992) 256 Science 444; mentioned by Hubbard & Wald, *supra*, note 8 at 37.

85 Lander & Schork, *supra*, note 66.

86 Wooster *et al.*, *supra*, note 62 at 2090.

complicates testing. Some people are affected by mutations in one chromosomal region, some by mutations in another. A test that searches for only one of these mutations might suggest incorrectly, therefore, that someone is unlikely to develop the disease.[87]

3) Imprinting

The effects of a disordered gene can vary according to the person from whom the mutant gene is received. This phenomenon is called *genomic imprinting*.[88] Mothers and fathers put different stamps on the genes they transfer to their children. In the case of Huntington's disease, for example, imprinting by the father (that is, inheriting the disordered gene from him) seems to bring on the disease earlier than imprinting from the mother.

IV. Common problems in interpreting genetic information

A. Not one genetic disorder

The division made between these three categories of genetic disease indicates how difficult it is even now to speak in general terms about "genetic disorders." Not only are there several kinds of genetic disorder, but these are also difficult to compare because of fundamental differences. Some can be qualified as actual diseases (for example, some severe single-gene disorders), but others indicate only an increased chance of developing diseases (such as susceptibilities). Among the susceptibilities, there are single-gene disorders and complex traits. The risk factors of all these disorders vary significantly. Furthermore, the common name for a disease might cover several different types of disease. Some breast cancers are caused by a single gene, for instance, and others are complex traits. Finally, the predictive

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87 *Assessing Genetic Risks*, *supra*, note 61 at 38.

88 See Jones, *supra*, note 2 at 85-86 and *Assessing Genetic Risks*, *supra*, note 61 at 62.

value of tests, if available, varies widely. General guidelines might be developed, but they must be applied to specific diseases and in specific circumstances.

B. Susceptibility is not the same as being sick.

In most diseases attributed to the genomic constitution, detecting the presence of mutant genes allows physicians only to estimate the *risk* of developing them. This is particularly true in the case of complex traits, which account for most diseases. The available tests do not indicate the degree to which people will be affected or, in some cases, whether they will be affected at all. The tests indicate only the level of *susceptibility*. As for the time of onset, estimates provide no guarantee. As I have said, many factors contribute to the outcome. These include work, environment, diet and life-style. Genetic tests cannot take all these factors into consideration with any accuracy.

Does it make sense to classify people, through genetic testing, into risk groups? Why burden them because of inherited traits? Their life-styles might actually compensate for the presence of susceptibilities. Even in single-gene susceptibilities such as hypercholesterolemia, moreover, personal efforts in connection with diet and life-style can mitigate disorders.[89] Finally, every genetic test has a variable predictive value. Frequently, only a small number of those at risk can be identified by a test.

C. What does it mean to "have a genetic disorder"?

The onset of several genetic disorders occurs only later in life. People affected by some of the most severely disabling ones can lead normal lives for a long time. For some, the disorder causes only minor ailments. For others, normal functioning is not even affected. In

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[89] See Proctor, "Genomics and Eugenics," *supra*, note 23 at 81.

the absence of genetic tests, these people would be regarded as more or less healthy. They would certainly be distinguished from those substantially affected by disease. Genetic testing before the onset of a disease, of course, does not make this distinction. Testing has a declaratory function: it simply classifies people, without differentiation, as sick. In all these cases, people are considered to have "a genetic disorder." But a gene, even a mutant one, is not a disease.[90] Menzel points out that the use of computerized medical databanks within large companies can exacerbate this problem. Indeed, in such databanks, genetic information becomes a "medical fact" and it can easily be forgotten that this information requires further interpretation.[91]

Late-onset disorders and susceptibility traits raise interesting semantic questions about the meaning of words such as "disease," "normal" and "abnormal."[92] Moreover, genetic traits can often be associated with both susceptibility to some disorders and increased resistance to others. Heterozygotes for the sickle-cell trait, for example, have increased resistance to some forms of malaria.[93] Being carriers of the sickle-cell trait, therefore, actually offers a kind of selective advantage. That is why the trait is present so often in some populations at risk. As Robert Wachbroit rhetorically argues: "Therefore, one could say that

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90 B.M. Knoppers & C.M. Laberge, "DNA Sampling and Informed Consent" (1989) 140 C.M.A.J. 1023 at 1024; H. Guay, B. M. Knoppers & I. Panisset, "La génétique dans les domaines de l'assurance et de l'emploi" (1992) 52:2 R. du B. 185 at 320.

91 H.-J. Menzel, "Genomanalyse im Arbeitsverhaeltnis und Datenschutz" (1989) 33 Neue juristische Wochenschrifte 2041 at 2043.

92 For a discussion of this terminology in the context of genetics, see A. Caplan "If Gene Therapy Is the Cure, What Is the Disease?" in Annas and Elias, eds, *supra*, note 8, 128; P.J. Boyle "Genetic Grammar: 'Health,' 'Illness,' and the Human Genome Project" (1992) 22:4 Hastings Cent. Rep. S.1; P. Billings, M.A. Rothstein & A. Lippman, "Commentaries on 'But Is He Genetically Diseased?'" (1992) 22:4 Hastings Cent. Rep. S18-S20; S.D. Feenan, "Human Genes: Good, Bad and Abnormal," (1992) 81 Bulletin of Medical Ethics 16; Capron, *supra*, note 37 at 682-684; R. Wachbroit, "Making the Grade: Testing for Human Genetic Disorders" (1988) 16 Hofstra L. Rev. 583 at 588-589.

93 Science Council of Canada, *supra*, note 8 at 20 and 44.

the genetic make-up of people who do not have the sickle-cell gene is such that *if* they were in [...] so-called 'malaria-infested' environments, *then* they would be likely to develop malaria.[94] Non-carriers of the trait would be "susceptible" to malaria in that environment, not carriers.

Consider once more the remarkable association of two specific genes with longevity.[95] Many French centenarians carry genes that are associated with susceptibility to heart disease. Carrying susceptibility genes cannot be used to classify people as "sick," therefore, because it can actually confer an advantage.

Richard Epstein is rather sarcastic about the discussions of the normal-abnormal character of genetic traits. He argues that it "runs into the teeth of the current wave of fashionable political theory that disease, like everything else under the sun, is socially constructed."[96] For Epstein, however, "[t]he inescapable truth is that an abnormal trait, such as the gene for Huntington's disease, is a sign of fatal complications; it does not offer any hidden potential for personal gain."[97] Epstein's argument clearly distorts the genetic reality.[98] Genetic diseases are not so clear cut. Besides, he also takes to an extreme the arguments of those who, though acknowledging that genetic disorders can indeed be extremely severe, draw attention to the need for determining what "susceptibility" really means, what "risk" is and so on. Some genetic traits nearly always provoke disabling diseases, to be sure. Even so, variable expression and incomplete penetrance complicate the prediction of their development. Most genetic diseases are multifactorial, moreover, and their development is

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94 Wachbroit, *supra*, note 92 at 588.

95 See *supra*, note 50 and accompanying text.

96 R.A. Epstein, "The Legal Regulation of Genetic Discrimination: Old Responses to New Technology," (1994) 74:1 B.U.L. Rev. 1 at 6.

97 *Ibid.* at 7.

98 The statement about "hidden potential for personal gain" is obviously a personal value statement. It seems to me possible that people who are affected by such disease would contradict him.

very difficult to predict. In short, genes are not diseases, and people with genetic disorders are not always "sick" in the traditional sense of that word. Further developments in genetics, it could be argued, might show that nearly everyone has a genetic mutation and that nearly everyone could be classified as "susceptible" in one way or another.[99]

Social problems really can be caused by the perception and "construction" of disease. A Quebec court classified the gene for myotonic dystrophy as a "physical anomaly."[100] That is why it annulled the life-insurance contract of a man who knew that he had the mutant gene when he signed the contract but denied that he was suffering from a "physical anomaly." The disease was not expressed. The man was leading a normal life. He felt perfectly healthy. Several years later, he died in a car accident (that is, due to something unrelated to his disorder). Nevertheless, the court held that he had made a false statement when he concluded the insurance contract. The court annulled his contract *ab initio*.

Paul Billings and his group, who conducted research on the occurrence of genetic discrimination, mention another interesting case. A heterozygote for Gaucher's disease, a recessive disorder, was denied a government job because of his carrier status.[101] There was no doubt that this man was healthy and able to perform his job. The case indicates that ignorance can have dramatic effects in everyday life. Education about genetics is essential. Even that, however, is unlikely to solve every problem of perception. Authors such as Epstein seem to forget that we do not live in a perfectly rational world. Prejudices and

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99 Compare W.D. Matthewman, "Title VII and Genetic Testing: Can Your Genes Screen You Out of a Job?" (1984) 27 How. L.J. 1184 at 1217: "Furthermore, there is no such thing as a zero-risk individual. All individuals can be classified as "high risk" at some point in their careers." (footnote omitted)

100 See *Audet* v. *L'Industrie-Alliance* [1990] R.R.A. 500 (C.S.); discussed in Guay, Knoppers & Panisset, *supra*, note 90 at 209-210 and in T. Lemmens, "L'utilisation de l'information génétique par les compagnies d'assurance," Actualité Méd. (29 September 1993) 42 at 43.

101 P. Billings *et al.*, "Discrimination as a Consequence of Genetic Testing" (1992) 50 Am. J. Hum. Genet. 476 at 478-479.

impressions must be taken into account. These impressions are culturally "constructed," as much as Epstein's perception of reality is.

D. The limits of scientific understanding and popular interpretation

It should be clear by now that new developments in genetics do not provide us with infallible diagnostic tools. It is still unclear whether one gene is responsible or many, very often, and whether environmental or social factors are significantly involved. Nevertheless, genetics is a scientific endeavour. Such endeavour is, according to Jerome R. Ravetz,

> "an organized human effort to understand the natural world. As such, it has cultural, social and economic determinants. These determinants may interfere with achieving understanding. They may aid it. To deny their existence by excising scientific effort from its social context and comparing it to some ultra-utopian ideal is to mistake a stereotype of science for reality."[102]

As a scientific venture, genetics is based on interpretation of observations, formulation of hypotheses, confirmation and falsification. History indicates how often people draw incorrect conclusions about natural phenomena. Scientific mistakes can have serious consequences when it comes to public policy. Examples are easy to find. In one study of direct importance for any discussion of the workplace, it was found that the ability to metabolize lung carcinogens was genetically inherited. But subsequent studies rejected this conclusion.[103] Workers could have been excluded on the basis of this study if tests had been introduced prematurely. More controversial and stigmatizing were the use of both the theory that *XYY syndrome* is linked to criminal behaviour and sickle-cell screening.[104]

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102 J. Ravetz, *Scientific Knowledge and Its Social Problems* (Oxford, 1971), cited by H. Eddy, *Regulation of Recombinant DNA Research: A Trinational Study: A Discussion Paper* (Ottawa: Science Council of Canada, 1983) at 21.

103 Proctor, "Genomics and Eugenics," *supra*, note 23 at 80, note 94 and reference.

104 See *infra* at 38-41.

Science does not exist in isolation from other human endeavours. Economic interests do intervene and can influence the applications of science. Popular demands, often stimulated by irresponsible journalists, can obscure scientific facts and lead to inappropriate uses.

1) Journalism and genetics

We should be prudent when interpreting sensational announcements about the discoveries of new genes "causing" specific diseases and the future availability of tests. Some of the most sensational announcements on "genetic discoveries" have been based on family studies, especially on twins. The co-inheritance of specific traits among monozygotic twins, for instance, is a good indicator of that trait's genetic origin. In some studies, identical twins are compared to fraternal twins, the aim being to see whether disorders or behaviours are shared more often by identical twins than by the latter. Ideally, these studies include twins separated in early life; this minimizes the effects of cultural and environmental factors. But the studies are not always very reliable. For one thing, they are often performed on a relatively small scale.[105] In addition, it is often difficult to establish the role of social, emotional and environmental factors. These studies might be interesting enough to formulate a hypothesis. And that, in turn, might be explored further through detailed and focused research on DNA fragments. Taken separately from further research, however, studies of twins are of limited scientific value. So, the results should be used with extreme caution. Limited twin studies

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105 D. Nelkin & L. Tancredi, "Classify and Control: Genetic Information in the Schools." (1991) 27:1-2 Am. J. Law & Med. 51 at 54.

were used, for example, to establish a genetic cause of homosexuality[106] and even "the tendency to divorce."[107] These announcements often received uncritical attention in the press.

Even when disease-causing genes have been identified, moreover, they seldom cover all manifestations of diseases. Breast cancer, as I have observed, is a clear example.[108] In the popular press, a lot of attention has been paid to the discovery of "the" breast cancer gene. As I have pointed out, though, two genes (associated with only a minority of breast cancers) have been located, and researchers suspect that at least one more gene might be a cause of hereditary breast cancer.[109] The wrong impression is being created. Not all breast cancers are hereditary. What happens to women who have cases of breast cancer in the family? What if they believe, wrongly, that they are at very high risk? They can be pressured into taking preventive action, such as participating in preventive trials, such as the controversial tamoxifen breast cancer preventive trial. It should be made clear that most cases of breast cancer are not understood. They are certainly not cured by the discovery of one gene and the availability of a test. Nevertheless, existing tests can be useful for medical purposes by helping those affected to make medical decisions. The fact that only a few cancers are covered by this or that test, though, might render it inappropriate for other purposes. At any

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106 R.C. Friedman & J.I. Downey, "Homosexuality," (1994) 331:14 N.Engl.J.Med. 923 at 927-928 and references; R. Hubbard & E. Wald, "Looking for Gay Genes," (1993) 8:5-6 GeneWatch 1.

107 See "Le divorce pourrait s'expliquer par les gênes" *La Presse [de Montréal]* (8 December 1992) B1.

108 For an extensive critique of "genetization" and especially of the misleading statistics on breast cancer, see Hubbard & Wald, *supra*, note 8 at 86-90.

109 For example, see *Newsweek* (6 December 1993) 46-52: "Family Matters: The Hunt for a Breast Cancer Gene"; *The [Montreal] Gazette* (31 January 1994) C1/2: "Finding the Breast Cancer Gene: Its Discovery Seems Imminent. But What Will Knowing Mean for Women at Risk?" and *The [Montreal] Gazette* (18 March 1994) A10: "Cancer Gene Puts Women at 100% Risk, Researchers Say." In fact, scientists have now identified two different loci: one on chromosome 17q21 (BRCA1) and one on chromosome 13q12-13: see Wooster *et al.*, *supra*, note 62.

rate, it is difficult to justify the exclusion of people from jobs on the basis of a test that is applicable to so few.[110]

The extent to which genes are involved in some other diseases is even less clear. The Science Council of Canada estimates that the genetic basis of Alzheimer's disease range "from 10 to 100%."[111] The Committee on Assessing Genetic Risks of the Institute of Medicine of the U. S. National Academy of Sciences estimates that roughly 5% of the Alzheimer's cases are transmitted as an autosomal dominant disorder.[112] Therefore, statements about the genetic causes of and the future availability of a test for Alzheimer's, as recently made in the media in relation with the discovery of a gene for hereditary Alzheimer's, are misleading. Mentioning that a test for familial Alzheimer's may be developed (as the Canadian Privacy Commissioner has done) can lead to misunderstanding.[113] It is essential to make clear that this test would cover only a minority of the cases.

Meanwhile, newspapers and magazines continue to announce spectacular "new insights" offered by genetics.[114] Many scientists are aware of the limited explanatory power of their studies and the possible impact of incomplete results. But they cannot control the

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110 See *infra*, Part 2, IV.

111 Science Council of Canada, *supra*, note 8 at 22.

112 *Assessing Genetic Risks*, *supra*, note 61 at 87.

113 Privacy Commissioner of Canada, *supra*, note 56 at 12. Markers for familial Alzheimer have indeed been identified on chromosome 21 (Science Council of Canada, *supra*, note 8 at 22) and family studies indicate that the disease indeed "runs in families."

114 See, for example, Kevles & Hood, *supra*, note 1 at 327; the authors mention a newspaper article citing Harvard psychologist Kagan, who suggests that shyness and hay fever have the same genetic origin. See also "Les gènes gagnants," *La Presse (de Montréal)* (28 February 1994) B1. The article is accompanied by a picture of Olympic heroin Myriam Bédard in action. Scientists suggest that their search for "winning genes" might be useful some day for the detection at birth of talented athletes. The article discusses preliminary results of a study funded by the National Institute of Health. It contains self-evident statements about the importance of biological factors in athletic performance but covers it now all under the umbrella of genetics.

ways in which these studies are reported and the ways in which they are perceived by the public. As Daniel Kevles and Leroy Hood note:

> It was front-page news in 1990 when researchers . . . announced that . . . they had detected a gene for alcoholism. (It was page-ten news in *The New York Times* when, in December 1990, scientists at the National Institutes of Health reported that they could not confirm the UCLA/Texas results). Reporters often take as firm conclusions what scientists announce as tentative conclusions, yet scientists are complicitous in the process when they hold press conferences to proclaim attention-getting results in the behavioral area, however fragile they may be.[115]

They predict an increase in controversial and speculative discoveries with the expansion of available genome data. With that in mind, they propose the development of an ethics for scientists and journalists dealing with value-laden genetic information.[116]

2) Economic interests and the pressure for tests.

It could be argued that tests should not be developed on the basis of such preliminary, uncertain and incomplete results. Even though incomplete tests offer some diagnostic advantages, moreover, it could be argued that they should not be used to classify people in the workplace or anywhere else. Many geneticists brush aside warnings about the danger of predictive testing for, among other things, behavioral tendencies, by arguing that the scientific links between genes and behaviour are too weak. Indeed, that should be a good enough reason to wait. The market is governed by the discovery and even creation of new needs, however, not by scientific rationality. Genetic tests will become less costly. Inexpensive tests and effective marketing by multinational companies, obviously interested

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115 *supra*, note 1 at 327 [footnote omitted.]

116 *Ibid.*

in this promising billion-dollar industry,[117] might convince some employers. According to Larry Gostin, the market for genetic tests has already become so important that it might be the "single greatest factor motivating genetic testing."[118] Corporate penetration into academic science is also a reason for concern.[119]

The critical mass for questioning the validity of tests might soon be lacking. The special Committee on Assessing Genetic Risks of the Institute of Medicine of the U.S. National Academy of Sciences argued that "[b]ecause of their wide applicability, it is likely there will be strong commercial interests in the introduction of genetic tests for common, high-profile complex disorders. Strict guidelines for efficacy therefore will be necessary to prevent premature introduction of this technology."[120] Personnel testing has already become an industry. Companies can now choose from a wide range of psychosocial and drug tests (not to mention those based on graphology, astrology, numerology and so forth). Pseudo-spiritual training programs are followed with great interest by the executives of respectable enterprises. The efficacy of these tests and training programmes is often much more dubious than the predictive value of genetic tests, but employers prefer to be on the safe side. Playing it safe has become very easy in a society with a surplus in the workforce. Moreover, public authorities and scholars in all fields often run ahead of employers, proposing avant-garde measures on the basis of premature or badly understood research results.

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117 See Proctor, "Genomics and Eugenics," *supra*, note 23 at 68-70; K. Nolan, "First Fruits: Genetic Screening" (1992) 22:4 Hastings Cent. Rep. S2 at S3; D. Nelkin & L. Tancredi, *Dangerous Diagnostics: The Social Power of Biological Information* (New York: Basic Books, 1989) at 33-36.

118 L. Gostin, "Genetic Discrimination and the Use of Genetically Based Diagnostic Tests by Employers and Insurers" (1991) 17 Am. J.L. & Med. 109 at 116.

119 See S. Krimsky, "The Corporate Capture of Academic Science and its Social Costs." in A. Milunsky & G.J. Annas, eds, *Genetics and the Law III* (New York: Plenum Press, 1985) 45; *Id.* "Corporate Academic Ties in Biotechnology: A report on Research in Progress" (September-December 1984) GeneWatch 3-5.

120 *Assessing Genetic Risks*, *supra*, note 61 at 10.

3) Sickle cell and XYY syndrome or, How scientific theories can harm.

Two examples in recent history, the XYY anomaly and sickle-cell trait, should warn us about scientific theory as the basis for social policy. In the former case, infringements on privacy and serious discrimination were recommended. Moreover, ethically questionable research was undertaken. In the latter case, employment and insurance discrimination and restrictions of personal liberty emerged.

The XYY saga originated in an Edinburgh study of patients at a high-security mental institution. It was published in a 1965 edition of *Nature*. Apparently, a disproportionably high number of patients in this institution were carriers of an extra Y chromosome.[121] This study concluded that the high frequency of XYY carriers could be related to aggressive behaviour, mental deficiency or a combination of both. The hypothesis that extra Y chromosomes might predispose people to unusually aggressive behaviour was quickly interpreted as a solid medical fact by the general public. It was suggested that screening should be introduced to keep these people under surveillance.[122] A study of 1976, however, concluded that people with the XYY anomaly were <u>not</u> more inclined to violence than others; they simply had a lower-than-average intelligence. It took more than ten years for the first hypothesis to be refuted. During that time, erroneous interpretations of facts were used in public debates about control over human lives. Fortunately, no screening programmes were established.

Sickle-cell anemia is a single-gene recessive disorder that affects 1 in 500 black Americans, those who received two copies of the sickle-cell gene; 1 in 10 has a single sickle-cell gene and is a carrier of the trait. Populations of Mediterranean origin, too, have a higher than average incidence. Carriers are not affected by the disease. In the seventies, several states introduced massive screening programs of newborns, schoolchildren and marriage

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121 See Suzuki & Knudtson, *supra*, note 8 at 123-141; Kevles, *supra*, note 21 at 277-278 and N.A. Holtzman, *Proceed with Caution: Predicting Genetic Risks in the Recombinant DNA Era* (Baltimore: Johns Hopkins University Press, 1989) at 113.

122 Kevles, *supra*, note 21 at 278, references at note 19.

applicants.[123] Their aim was to diminish the devastating appearance of the disease among blacks. At first, support for these screening programmes was found within the black community.[124] Very soon, though, it began to be said that screening was used as a way to discriminate against blacks. In some states, for example, mandatory screening became a condition for marriage licence. Because this affected mainly African Americans, screening was perceived as a form of genocide.[125] Some employers required the screening only of blacks, even though the trait can be found in other ethnic groups, some of which are also at high risk.[126]

The National Sickle Cell Anemia Control Act provided federal funding for states that fulfilled the requirements of the Act. One of these was that the screening had to be voluntary, thus stressing that it was in the interest of those being tested. But the damage had been done: sickle cell became a reason for discrimination in employment and insurance.[127] Those carrying the sickle-cell trait, though not affected by anemia themselves, were considered sick. Even the legislation's preamble confused being a carrier with having the disease.[128] This confusion was exacerbated by the theory that carriers could have sickling episodes when confronted with exceptionally low levels of oxygen. During these episodes, dizziness and fainting can occur. But this theory has not been confirmed by reliable research

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123 For an overview of the sickle-cell controversy, see Draper, *Risky Business: Genetic Testing and Exclusionary Practices in the Hazardous Workplace* (Cambridge: Cambridge University Press, 1991) at 92-94; Hubbard & Wald, *supra*, note 8 at 33-35; Jones, *supra*, note 2 at 165-167; Kevles, *supra*, note 21 at 255-256 and 278; Matthewman, *supra*, note 99 at 1204-1208; Nelkin & Tancredi, *supra*, note 117 at 98.

124 Kevles, *supra*, note 21 at 255.

125 *Assessing Genetic Risks*, *supra*, note 61 at 40-42 and 258.

126 Suzuki & Knudtson, *supra*, note 8 at 145.

127 See Draper, *supra*, note 123 at 103 and Nelkin & Tancredi, *supra*, note 117 at 98-100.

128 Kevles, *supra*, note 121 at 278.

and is now seriously questioned.[129] Nevertheless, the U.S. Air Force refused to use sickle-cell carriers as pilots.[130] Discrimination took place in the chemical industry as well. Du Pont, for example, performed sickle-cell screening on employees and prevented carriers from working with nitro and amino compounds.[131] From being a medical prevention programme, sickle-cell screening came to be perceived more and more as discrimination. In reaction to that, several states introduced anti-discrimination legislation.

To avoid even more questionable tests from being used to select employees, it might be necessary either to develop a strict system of validity and quality control in connection with tests on the market[132] or to work out forms of protection for the people likely to be tested. The examples demonstrate a need for solid science in connection with every public policy on genetic testing. It makes clear, in addition, how quickly conclusions are drawn on the basis of preliminary results.

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129 The controversy continues. A 1974 report from the National Academy of Science concluded that the scientific evidence was lacking (OTA *Genetic Monitoring*, *supra*, note 8 at 42). For Hubbard & Wald (*supra*, note 8 at 34), it is an unproven assumption; Suzuki and Knudtson (*supra*, note 8 at 144) write that there is no reliable evidence; but Jones (*supra*, note 2 at 216) opposes them.

130 Hubbard & Wald, *supra*, note 8 at 34; OTA 1990 at 42-43 and Nelkin & Tancredi, *supra*, note 117 at 99.

131 See Council For Responsible Genetics, *Position Paper on Genetic Discrimination* (Boston, s.d.) at 7; the paper refers to C. Reinhart, "Chemical Hypersusceptibility" (1978) 20 Journal of Occupational Medicine 319-322; see also M.S. Henifin & R. Hubbard, "Genetic Screening in the Workplace," (1983) 1 GeneWatch 5 at 6 and Nelkin & Tancredi, *supra*, note 117 at 200.

132 For a discussion on this topic, see *Assessing Genetic Risks*, *supra*, note 61 at 118-145.

V. Conclusion Part 1: The particularity of Genetic Information

A. Uncertainty

I have devoted so much space to science for a reason. Any discussion of genetics in the workplace requires an assessment of its possible applications. The overview makes it clear that uncertainty is not solved by genetic testing. In most cases, genetic testing allows for only an estimate of risk. It does not provide information about actual health. The results can be used by employers to divide employees into risk groups without telling them very clearly who might develop a genetic disorder or when. Moreover, genes are not the only causes of disease. They account for only a part of all diseases.[133] Even when a genetic mutation is clearly connected to a disease, it often explains only some cases of the disease. It seems unreasonable, therefore, to use a genetic tests as selection tools when they identify only a few of those at risk. In these cases, it would be very difficult to justify on the basis of necessity.

As I have said, moreover, uncertainty can take many forms. With some single-gene disorders, such as Huntington's disease, sickle-cell anemia and cystic fibrosis, people are affected when they have, respectively, one or two mutant alleles. In these cases, they are said to "have the disease." Even then, however, phenomena such as variable expressivity and variable penetrance can affect its development. When and how severely the lives of these people will be affected, therefore, remains unclear. Other single-gene diseases involve susceptibilities. Only a percentage of those affected actually become sick. Hereditary breast cancer has earlier been mentioned as an example. Although women who carry one of the two identified genes for breast cancer are at very high risk for developing the disease, much uncertainty remains. Indeed, these women have eithty-seven per cent chance of becoming sick before the age of 80. But that gives the disease still a lot of leeway:

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[133] The Science Council of Canada, *supra*, note 8 at 21 argues that available figures are conservative and that during their life time 60 percent of the population will experience a disease that in some cases has a genetic component to its cause" (footnote omitted). This statement is very vague. How many cases are really genetically determined? And what does "a genetic component" mean?

some of the "affected" women become sick only later in life, and 13% of them do not develop the disease at all. To measure the risk comprehensively, one would have to compare it with other risk factors.

The cases of autosomal dominant polycystic kidney disease and familial hypercholesterolemia are more extreme. Even so, a 50% chance of developing renal failure by the age of 70 or of having a heart attack by 50 (for males) or 65 (for females) cannot be considered the same as diagnosing someone with the disease. Not all people would want to be informed about a vague threat for disease, especially if there is no therapy.

But even in clearly treatable diseases, problems arise because of all the uncertainty. Those at risk must decide whether they want to start treatment or follow preventive diets. In the case of haemochromatosis, the preventive treatment (frequent blood-letting) does not involve major risks and the choice is not very difficult. For women at risk for breast cancer, "treatment" decisions are far more cumbersome. Regular mammograms could lead to early detection. Much more distressing is the mutilation resulting from (bilateral) mastectomy and the anxiety over participation in potentially harmful trials such as the tamoxifen breast cancer prevention trial.[134]

Many factors determine the development of complex disorders. The presence of mutant genes is a good indicator of risk but no more than that. Disordered genes interrelate with personal life-style and daily living conditions, including the working environment. Genetic tests cannot account adequately for these "external" factors, which can be as important as or even more important than inborn characteristics. In fact, people at risk can seriously reduce the risk of developing multifactorial diseases when informed of their genetic constitutions. They might follow an appropriate diet, say, or undergo preventive screening. Those who are not "genetically disordered," on the other hand, might jeopardize their health in connection with carefree life-styles. In short, appearance (created by genetic testing for complex diseases) can be deceptive.

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[134] On the controversy surrounding this trial, see Hubbard & Wald, *supra*, note 8 at 89 and C. Weijer, "Our Bodies, Our Science" *The Sciences* (May/June 1995) 41-45.

Uncertainty is caused in addition, of course, by the limitations of both science and the techniques based on it. Genetic tests are rarely 100% accurate.[135] Some disclose only some of the cases. The sensitivity[136] and specificity[137] of tests vary widely. Tests using genetic markers, in particular, are not totally reliable. Markers provide only statistical probabilities based on the presumption (sometimes incorrect) that people have inherited genes with the identified markers.[138] Both false positives[139] and false negatives,[140] create ethical problems.[141] When do these tests become reliable tools? For what purposes? How many errors are acceptable?

Compared to other ways of predicting health, these tests represent great improvement. Genetic tests are much more reliable than many family studies undertaken by insurers (and sometimes by employers) on the basis of which important decisions are made. Even so, we should be aware of the remaining uncertainty and the problems generated by it. Although the information might be of use for those who want to reduce the risk of developing specific

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135 Wachbroit, *supra*, note 92 at 585; For a good discussion on the reliability of tests, see Nelkin & Tancredi, *supra*, note 117 at 43-48.

136 The sensitivity of a test refers to the probability that all those affected will be identified (Science Council of Canada, *supra*, note 8 at 48). A distinction can be made between clinical sensitivity and allelic sensitivity. Clinical sensitivity is the ability to detect all those who have or will have a genetic disorder. Allelic sensitivity means the ability of a test to detect mutations (*Assessing Genetic Risks*, *supra*, note 61 at 37).

137 The specificity of a test refers to the probability that it will identify all those who are not affected (Science Council of Canada, *supra*, note 8 at 48).

138 Suter, *supra*, note 34 at 1863.

139 Tests are false positive when they indicate erroneously the presence of genetic conditions.

140 Tests are false negative when they when they suggest erroneously the absence of a genetic condition.

141 See M.J. Mélançon, "Les marqueurs génétiques: les dilemmes éthiques du savoir/non-savoir sur la condition génétique pour les personnes et familles à risque" in G. Bouchard and M. DeBraekeleer, eds, *Histoire d'un génome* (Sillery: Les Presses de l'Université du Québec, 1991) 545 at 647-648.

diseases, it might be of less use to employers. The following statement of Neil Holtzman can be applied to many genetic tests: "For the vast majority of people affected by heart disease, cancer and the like, the origin is so complex that it's a gross oversimplification to think that screening for a predisposing gene will be predictive."[142]

B. The relevance of genetic information for families

A major characteristic of genetic information is that, unlike most other forms of medical information, it seems to exceed the boundaries of personal autonomy.[143] People are connected by their genomes with families and communities.[144] In fact, genetic information reveals information not only about those tested but about their families as well.[145] It has been argued that this undermines a traditional legal and ethical approach based on personal autonomy and individual rights.[146] Although family relevance is not really a new development – information on diseases "running in the family" has, to a certain extent, always been available –its predictive value makes genetic information particularly important for both living members of the family and future generations.[147] The results can be either beneficial or harmful.

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142 Cited by Proctor, "Genomics and Eugenics," *supra*, note 23 at 81.

143 See Capron, *supra*, note 37 at 694.

144 B.M. Knoppers, "Le génome humain: un patrimoine universel, personnel et communautaire," in Mélançon & Lambert, eds, *supra*, note 8 at 108.

145 For the legal implications, see J. Miller, "Physician-Patient Confidentiality and Familial Access to Genetic Information" (1994) 2 Health L.J. 141; Suter, *supra*, note 34; B.M. Knoppers, "Human Genetics: Parental, Professional and Political Responsibility" (1993) 1 Health L.J. 13, in particular at 16-17.

146 See for example D.C. Wertz & John C. Fletcher, "Privacy and Disclosure in Medical Genetics Examined in an Ethics of Care" (1991) 5:3 Bioethics 213.

147 See Knoppers, *supra*, note 145 at 16-18.

On the one hand, family members might find it extremely beneficial to learn in this way about increased risks. They can use the information in making decisions about reproduction, for instance, or careers. In the case of treatable or preventable diseases, moreover, they can look for preventive measures or avoid exposure to workplace hazards.[148] On the other hand, they might find it extremely harmful. Employers or insurance companies could find genetic information through the test results of relatives. As I have already pointed out, people could be denied jobs or insurance coverage because of family information. Then, too, discovering information of this kind can be very harmful psychologically.

Genetic information can disturb family relations. John Phillips, a molecular biologist, mentions the case of a widow who was approached by a woman claiming that the deceased husband was the father of her two children and that these children had rights of inheritance. Genetic tests indicated the extremely high probability of paternity and were used to support her claim.[149] In the past, claims of this kind could have been proved only with difficulty and thus rejected easily. Although this seems unfair, it promoted greater social stability. Genetic tests now disturb these paternity presumptions and make it much easier to undermine familial ties. The case mentioned by Phillips might have been rare, but there are many circumstances in which the absence of genetic ties could become very awkward. In screening for familial disorders, for instance, geneticists often discover that children are not biologically related to their fathers.[150] The social stability created by the legal presumption of fatherhood within marriage, is clearly undermined by such discoveries. What should be done with this knowledge? On the one hand, it does not belong to geneticists. It belongs to those who are tested. They have a right to information about themselves, unless such information could endanger their health. On the other hand, genetic tests are not done with this kind of

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148 Wachbroit, *supra*, note 92 at 590-596.

149 J. Phillips, "Molecular Biology and the `New Genetics'" in J.A. Lowden, chairman, "Genetics Issues in Insurance: Proceedings of a Seminar, Arlington, Virginia, Feb. 7-9, 1993" (1993) J. Ins. Med. (Supp. B) 200 at 205.

150 For a discussion of the ethical problems of such cases, see Wertz & Fletcher, *supra*, note 146 at 216-219.

situation in mind. Many people would prefer not to know about family secrets. Clear information should be given to people about the risk of making unwanted discoveries. And they should be asked to indicate whether they want to be informed or not. A survey of Canadian geneticists showed that only 12% of the respondents would require a pre-test agreement on whom to inform about non-paternity. Up to 75% per cent of them agreed with the requirement that couples should be informed of the possibility that non-paternity might be discovered. And 49% of them would warn the mother privately and in advance.[151]

Family co-operation is often necessary in order to detect genetic problems. If a gene has not yet been identified and markers are used, for instance, the genetic patterns of family members, ideally spread over different generations, must be established to determine who is affected by the disorder or carrier of it.[152] This makes it difficult or impossible to respect fully the confidentiality of those tested. Not only must family members be required to participate, they must also agree that information about their genetic constitutions will come to light.[153] This could conflict with the wish of family members not to be informed about the risk of developing a genetic disease. If people have generally the right to refuse medical tests, could they be forced to participate in a testing procedure for the benefit of others? On the other hand, it could be argued that there is at least a moral obligation to assist others by being tested, especially if the information would enable others to prevent disease.

Genetic information can also be important for future generations. Researchers have indicated interest in setting up large DNA banks. Information would be brought there and

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151 D. Wertz, "Canadian Geneticists' Views: A Survey of the CCMG and CAGC," paper presented at the 5th Annual Conference of the Canadian Bioethics Society (Ottawa, November 18-21, 1995).

152 See M.J. Seller, "Genetic Counselling," in R. Gillon and A. Lloyd, *Principles of Health Care Ethics* (Chichester, Eng.: John Wiley, 1994) 961 at 967; Wexler, *supra*, note 80 at 227-228; Mélançon, *supra*, note 141 at 548-549. Until recently, this was the case for Huntington's. For the legal implications, see C.L. Becker, "Legal Implications of the G-8 Huntington's Disease Genetic Marker," (1988-89) 39 Case W. Res. L. Rev. 273 at 280-281.

153 Seller, *supra*, note 152 at 967.

stored – even after the individuals themselves have died.[154] This could be of particular interest when genetic markers must be used. The collaboration of even non-affected family members would be essential.

Clearly, genetic testing raises some difficult ethical and legal questions. Is there a duty to inform family members about the existence of risk? If so, what is the threshold of risk? Is it relevant that the chances of having a disease are greater for dominant single-gene disorders than for recessive ones?[155] What if no treatment is available? Does a duty fall only on those being tested or also on their genetic consultants and physicians? Is there a legal liability for informing family members who do not want to be informed? Can pressure be used to make people participate in family studies? Can people be obliged to provide DNA samples for the benefit of family members?[156] How can we protect data collections of families with genetic problems? Past abuses of data files on families affected in this way should not be forgotten.[157]

C. The relevance of genetic information for populations

Genetic information links the members not only of families but also of whole communities. Genetic diseases are often over-represented in racial and ethnic groups or even in specific local communities.[158] Tay-Sachs disease, for example, is particularly common among Ash-

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154 For the importance of these data banks, see Science Council of Canada, *supra*, note 8 at 31-33.

155 Becker, *supra*, note 152 at 296.

156 See Suter, *supra*, note 34 at 1855 and 1864-1866; Capron, *supra*, note 37 at 684; and Shapiro, *supra*, note 8 at 173.

157 See Harper, *supra*, note 21.

158 For some examples, see Draper, *supra*, note 123 at 84; for a general discussion, see *ibid.* at 83-96; Gostin, *supra*, note 118 at 111; and Rowinski, "Genetic Testing in the Workplace" (1988) 4 J. Contemp. Health L. & Pol'y 375 at 398.

kenazi Jews and French Canadians.[159] Among the former, 1 in 30 carries a gene for this very severe recessive disorder that affects 1 in 3600 of their infants. In Canada, an effective screening programme, supported by the Ashkenazi community, has seriously reduced the occurrence of the disease. Many Ashkenazi Jews are also carriers of Gaucher's disease. As I have mentioned, the sickle-cell trait has a very high incidence among Africans and people of African origin.[160] In America, from 8 % to 10% of black people are carriers, and 1 in 400 to 600 has sickle-cell anemia.[161] Several genetic disorders are said to be prevalent in the Saguenay-Lac-Saint-Jean region of Quebec.[162] But the very intense genetic research on some populations could exaggerate the presence of problems. For example, Gérard Bouchard, the founder a sophisticated genetic data-bank of the Saguenay-Lac-Saint-Jean region (BALSAC), stresses that no serious genetic comparison between this region and other parts of Canada has been undertaken.[163]

The prevalence of genetic disorders can add stigmatization to groups that are already affected by racial or ethnic discrimination.[164] They might face genetic discrimination in

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159 Science Council of Canada, *supra*, note 8 at 42.

160 See *supra* at 39.

161 According to the Science Council of Canada (*supra*, note 8 at 20), one in every 625 black newborns has sickle cell-anemia.

162 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: JCL, 1994) 17; M. Perron, "Les maladies héréditaires au Saguenay-Lac-Saint-Jean: Responsabilité individuelle ou collective," in *id.* 43-51 and M. De Braekeleer, "The Ethics of Cystic Fibrosis Carrier Screening: Where do we stand?" (letter to the editor), (1990) 47:3 Am. J. Hum. Gen. 581-582.

163 G. Bouchard, "Les problèmes de droit et d'éthique reliées à l'exploitation d'un fichier de population à des fins génétiques", in Mélançon, ed., *supra*, note 162 at 39.

164 See H.T. Greely, "Health Insurance, Employment Discrimination, and the Genetics Revolution" in Kevles & Hood, eds, *supra*, note 1, 274; M.R. Natowicz, J.K. Alper & J.S. Alper, "Genetic Discrimination and the Law" (1992) 50 Am. J. Hum. Genet. 465; For a discussion of American law in relation to discrimination and workplace screening, see Gostin, *supra*, note 118 at 120-134; E.F. Canter, "Employment

addition. Screening programmes and government interventions designed to help people are sometimes interpreted as evidence of racism, especially when they lead to exclusion from employment or insurance. I have already discussed the controversy surrounding sickle-cell screening. This affected mainly African Americans and was perceived to be discriminatory.[165] Other types of discrimination might be provoked by the use of genetic testing.[166]

Fear for stigmatization and discrimination could affect the willingness of these groups to co-operate with genetic research or with preventive screening programs.[167] Willingness to co-operate with extremely revealing genetic research can generate a backlash against participants and actually aggravate the stigma of belonging to a particularly "diseased" group. Although genetic traits can be more common in isolated regions than elsewhere, intense scientific research might exaggerate the problem. Specific groups could thus become victims of their scientific importance. This has been perceived as unfair, especially because they often serve as testing grounds for scientific studies that are of great value for the entire population.[168]

Discrimination; Implications of Genetic Screening in the Workplace under Title VII and the Rehabilitation Act" (1984) 10(3) Am. J.L. & Med. 323; Matthewmann, *supra*, note 99; M.A. Rothstein, "Employee Selection Based on Susceptibility to Occupational Illness" (1983) Mich. L. Rev. 1379 at 1436-1466.

165 *Assessing Genetic Risks*, *supra*, note 61 at 40-42 and 258.

166 See *infra*, at 105.

167 Bouchard, *supra*, note 141 at 40; Lemmens, *supra*, note 100 at 43; Rowinski, *supra*, note 158 at 409 and Miller, *supra*, note 145 at 151.

168 Bouchard, *supra*, note 163 at 39-40.

D. The absence of cure

The genome project is still in its infancy. Spectacular discoveries are often made, but they involve mainly the development of new diagnoses, new links between genes and disease. These discoveries have given us valuable tools for determining whether people are at risk or not. Although experimental genetic treatment has begun, however, no real cures have been offered for most of the genetic diseases. According to the Science Council of Canada, "at present our ability to identify an individual at risk for genetic diseases exceeds our ability to prevent or treat the disease."[169] Predictive screening can frequently help people prevent or delay the onset of disease, but it cannot help them once they are sick. Genetics is now useful mainly for reproductive decisions:[170] people can be tested to determine whether they are carriers of mutated genes and to calculate the risk of giving birth to affected children. Newborn screening, too, is applied to determine the presence of genetic anomalies. The information is never used as a cure. Very often, the only "cure" is prevention of birth by means of either contraception or abortion.

But this is not always the case. Phenylketonuria, for example, is a genetic disease characterized by a liver-enzyme deficiency.[171] This deficiency leads to serious mental retardation unless affected children follow a strict diet. With the introduction of general screening programmes for phenylketonuria in Canada, mental retardation due to it has nearly disappeared.

The absence of cures for most genetic diseases presents ethical problems.[172] It has been argued that the pressure for screening (leading to contraception or abortion) is a subtle form

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169 Science Council of Canada, *supra*, note 8 at 7; see also C.T. Caskey, "DNA-Based Medicine: Prevention and Therapy" in Kevles & Hood, eds, *supra*, note 1, 112-135.

170 *Ibid.* at 129.

171 See Science Council of Canada, *supra*, note 8 at 40-41.

172 See L. Skene, "Mapping the Human Genome: Some Thoughts for Those Who Say: 'There Should Be Law on It'" (1991) 5(3) Bioethics 233 at 237-241.

of eugenics.[173] The provision of screening and counselling services in connection with particular diseases presupposes a value judgement: contraception or abortion are legitimate alternatives to the birth of children with genetic diseases. So, it is misleading to claim that "[g]enetic counselling is . . . non-directive."[174] Simply providing genetic testing and counselling is directive. The development of screening devices and the cutback in support available to parents of disabled children can influence the social perception of disability. It might become increasingly difficult to accept the idea that people do not always control health or that responsible parents would produce genetically abnormal children. This does not mean that genetic screening and counselling are wrong. It is possible to argue that screening involves a value judgement about "avoidable life," one that could have a negative impact on our perception of disability, but still agree that there are good reasons to offer it for specific diseases. The nature of the disease might be a factor worth serious consideration. Is it humane to prevent extremely burdensome diseases such as Tay-Sachs, thalassaemia and cystic fibrosis? This does not necessarily mean that those affected have less worth or "dignity." It might simply reflect the view that some diseases have a very detrimental impact on both infants and families and that avoiding the conception of children with such disease is an acceptable option.

Some challenge the "directive character" of genetic screening and counselling for reproductive decisions. Others, especially legal scholars, argue for the concept of "prenatal torts." In that context, parents could be sued for giving birth to children with genetic problems[175] or for exposing foetuses to hazards while knowing about the risks.[176] Disabled

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173 Hubbard and Wald, *supra*, note 8 at 23-38.

174 Seller, *supra*, note 152 at 962.

175 M.W. Shaw, "The Potential Plaintiff: Preconception and Prenatal Torts," in Mulinsky & Annas, eds, *supra*, note 4 at 225-232; cited by Hubbard & Wald, *supra*, note 8 at 25-26.

176 J.A. Robertson, "Procreative Liberty and the Control of Conception, Pregnancy and Childbirth," (1983) 69 VA. L. Rev. 405-464; cited by Hubbard and Wald, *supra*, note 1 at 26-27.

children would have legal recourse against parents who declined to use available genetic screening services or who decided not to abort. Legalistic arguments reveal eugenic tendencies based on the notion that there is a norm, or standard, by which to judge worthiness of life. Legal liability is introduced to compensate for deviation from the norm.

In the absence of cure, the possibility that parents would be held liable for giving birth to disabled children is of particular importance to workplace testing. If liability were introduced, it would become very difficult for workers either to refuse screening aimed at detecting genetic susceptibility to workplace hazards or to continue working where they might be at high risk.

More direct psychological problems are also produced by the impossibility of curing major genetic diseases. Being informed that one is affected by a genetic condition can be extremely disturbing, especially in connection with incurable diseases such as Huntington's.[177] Huntington's is a severe genetic disorder characterized by degeneration of neurons in the brain. This has serious physical and psychological consequences. It is described, in fact, as "l'une des maladies héréditaires les plus éprouvantes pour les individus et leur famille."[178] Those affected gradually lose control over their bodily movements and suffer from memory loss, personality changes, depression and so on. The disease inevitably leads to total physical disability and, 15 to 20 years after its onset, to death. A positive test result is like a death sentence.[179] Some studies indicate that suicides in families at risk for

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177 For an in depth ethical, see Melançon, *supra*, note 141. This article was written before the gene was identified. A more reliable test is now available. Even so, much of what is discussed remains nevertheless. For a description of the disease, see Becker, *supra*, note 152 at 277-279 and references there; also Shapiro, *supra*, note 8 at 173-177.

178 Mélançon, *supra*, note 141 at 546.

179 N. Wexler *et al.*, "A DNA Polymorphism for Huntington's Disease Marks the Future," (1985) 42 Arch. of Neurology 20 at 22.

Huntington's are more frequent than in the general population and that many consider suicide an option.[180]

If so, should people even be told be told that they will develop the disease? Would a "best interest" approach imply that they should not?[181] Some people would prefer not to know. They might prefer not even to be tested. Others, though, might prefer to make realistic plans. They might want to change their reproductive plans, for example. They might even decide to get involved in the struggle against this disease and build meaningful lives around it.[182]

But imagine the relief experienced by those with negative test results. Even then, psychological counselling is probably essential, as these people might suffer from "the guilt of the survivor." They are members of families, after all, in which others are likely to be affected.[183] In short, genetic testing should be considered carefully and, if implemented, be accompanied by professional support.

It is easier for employers to exclude susceptible workers than to adapt the work environment. Genetics does not provide any direct remedy to reduce risks. Those at risk could minimize the impact of workplace hazards by reducing risk factors in their personal lives. They could stop smoking, wear better protective equipment, follow diets and so forth. But doing these things would not necessarily reverse the potential impact of hazards. The most effective remedy, of course, is simply to avoid a hazardous workplace. Genetic screening has been criticized because it distorts the real causes of workplace-related dis-

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180 Mélançon, *supra*, note 141 at 554, referring to Craufurd & Harris, "Ethics of Predictive Testing for Huntington's Chorea: The Need for More Information," (1986) 293 B. M. J. 249 at 250.

181 Wachbroit, *supra*, note 92 at 590; the author argues that "denying people access to their own test results would not appear to be morally acceptable" [footnote omitted].

182 Nancy Wexler, who performed most important genetic research in the area of Huntington's, seems to have done so; see Shapiro, *supra*, note 8 at 165-177.

183 See Wexler *et al.*, *supra*, note 179 at 22.

eases.[184] Employers tend to blame the genes of individual workers. These, they say, are the "culprits." Their solution, therefore, is to remove the employees. A less desirable solution from their point of view, perhaps, would be to clean up the workplace.

Part 2: Genetic Testing in the Workplace

I. Types of genetic testing in the workplace

A. Genetic screening and genetic monitoring.

There are two forms of genetic testing: screening and monitoring.[185] Screening is a one-time testing of employees and is usually part of a selection process. The aim is to identify particular inherited traits, disorders or susceptibilities to specified workplace hazards.[186] It provides information about the pre-existing genomic constitution of each employee.[187] Screening can indicate susceptibility to specific hazards, for example, risk for developing a complex

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184 See Draper, *supra*, note 123 at 37-61, 181-182 and id., "*High Risk Workers or High Risk Work*" (1986) 6:4 Int. J. Sociol. & Soc. Pol'y 12-28; K. Marshall, "The Impact of Advances in Genetics on Workplace Policy" in R.S. Brown & K. Marshall, eds, *Advances in Genetic Information: A Guide for State Policy Makers* (Lexington: The Council of State Governments, 1992) 65 at 66. See also further.

185 OTA, *Genetic Monitoring*, *supra*, note 8 at 3-6; Privacy Commissioner of Canada, *supra*, note 56 at 10-13; Rowinski, *supra*, note 158 at 380-381.

186 International Labour Office, *supra*, note 22 at 55.

187 *Ibid.*

disorder or the likelihood of being affected by a single-gene disease. Accuracy varies widely according to the type of test.

Monitoring occurs periodically and is applied on groups of workers. It "involves the periodic evaluation of employees for either the effects of a toxic substance or its byproducts."[188] The aim is to determine whether there have been any mutations that could be attributed to toxic agents in the workplace. There are two forms of genetic monitoring. Genuine monitoring detects any changes that have been taking place in the molecular structure of DNA. Cytogenic monitoring, through blood and urine testing,[189] detects major structural changes in the chromosomes. The latter has long been used in the atomic industry to identify the effect of exposure to radiation. Neither form of monitoring is used in selecting employees.

The results of monitoring can be used to prevent further detrimental exposure of individual employees or to protect employees in general by removing or reducing toxic agents.[190] Genetic monitoring could be used either to exclude workers or to assess the safety of a workplace. Changes in the genetic structure of enough employees would surely signify a hazardous working environment. The evidence could convince employers to improve their safety measures.

B. Screening before and during employment; voluntary and mandatory screening.

Fear of genetic testing in the workplace is based primarily on the potential for discrimination and breaches of confidentiality. Fear of discrimination could be reduced by prohibiting the use of genetic screening as a selection tool. That would protect people from exclusion because of inherited conditions over which they have no control. In some industries, genetic

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188 OTA, *Genetic Monitoring*, *supra,* note 8 at 55.

189 See Nelkin & Tancredi, *supra*, note 117 at 95.

190 International Labour Office, *supra*, note 22 at 56.

testing for pre-existing hypersusceptibility might still be defensible on medical grounds: to protect workers from serious harm. Ideally, it would work like this: people would be hired first, then tested and then informed of their condition and the risk involved when exposed to hazardous material. Alternative jobs could be offered to them. The confidentiality of their medical records could be guaranteed, but two problems would remain.

First, this system might be possible only in big companies. Only they would be flexible enough to offer alternative jobs without jeopardizing their financial structure. In smaller companies, prohibiting genetic tests for selection purposes but permitting them for employees might do nothing more than delay the exclusion of hypersusceptible employees, perhaps to the detriment of both them and their employers. It might be better for hypersusceptible workers to find more appropriate working environments, ones in which they are either not at risk in the first place.

Second, genetic testing would be useful mainly in connection with high-risk jobs. According to Elaine Draper, high-risk jobs are better paid than low-risk ones for which the same skills are required.[191] Most of those willing to take high-risk jobs, though, are unskilled workers. What alternatives, after all, do they have? These people are mainly interested in high-risk jobs because of the better pay and because of the limited opportunities open to people with their level of education or training. Transferred to jobs that pay less than the high-risk ones, they consider themselves victims of discrimination.

Murray identifies four purposes for genetic screening in the workplace: (1) diagnosis; (2) research; (3) information; and (4) exclusion.[192] The latter two are discussed in terms of being either voluntary or mandatory (which is to say, in terms of testing to provide employees with information and testing to exclude them from the workplace). Voluntary

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191 *Supra*, note 123 at 126.

192 T.H. Murray, "Warning: Screening Workers for Genetic Risks" (1983) 13:1 *Hastings Cent. Rep.* 5-8. According to Murray, genetic screening for diagnostic or research purposes does not raise novel ethical questions: diagnostic testing is submitted to the guiding principles of medical diagnosis and treatment and genetic research on a cohort of workers has to respect the guidelines for research with human subjects.

screening is likely to be perceived in a much more positive way, of course, than mandatory screening.[193] Many would probably be interested in knowing whether they are susceptible to illnesses linked to workplace hazards. Voluntary screening respects the freedom of individuals to make decisions about their own health. These programs are obviously medical in nature. Their function is clearly to inform employees about the risks involved in their work. What they do is up to them. They can decide to be cautious, for instance, and prevent the onset of disease. This voluntary approach corresponds to current medical theory. It is clearly established among physicians that no treatment should be given to competent patients without consent. Voluntary testing respects this choice: genetic testing is preventive medicine, not economic discrimination. Though voluntary testing seems more acceptable than mandatory testing, the success of voluntary programs depends on other factors, such as the guarantee of confidentiality.

C. Is genetic testing currently undertaken?

Due partly to past controversies over sickle-cell testing, employers' organizations have not yet taken official positions on screening.[194] Nevertheless, two surveys by the Office of Technology Assessment, undertaken in 1982 and 1989, indicate that genetic testing has been conducted in the United States.[195] In 1989, it was found that 20 of the 500 biggest companies either were conducting genetic tests or had done so in the previous 19 years.[196] Only 1 company was conducting a program of genetic monitoring, though 5 had done so in the past. During the years separating these two surveys, screening programmes increased in number

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193 Whether consent is a sufficient condition for genetic testing is discussed further. *Infra*, at 112.

194 International Labour Office, *supra*, note 22 at 62.

195 *Ibid.* at 59-60 and OTA, *Genetic Monitoring*, *supra*, note 8 at 23-24.

196 *Ibid.*at 175. It was found that 12 companies were actually conducting screening, and 8 had done so in the past.

just slightly; monitoring programmes actually decreased. Companies in both surveys were asked about plans for genetic testing programmes. Answers did not differ much from one survey to the next; slightly fewer companies were planning to introduce genetic screening or monitoring in 1989 than in 1982.[197]

There are no reports of genetic testing in the Canadian workplace. In 1990, the Canadian Manufacturers Association and the Canadian Labour Congress told the Canadian Privacy Commissioner that they were not aware of any genetic screening by Canadian companies.[198] According to the Science Council of Canada, too, no genetic screening programmes are being conducted in Canada.[199] At an annual meeting of the Canadian Bioethics Society, in 1994, Dorothy Wertz discussed a survey by Canadian Genetics and Genetic Counsellors. Only 1% of them reported being confronted with patients who had been refused employment.[200]

D. The validity and accuracy of genetic tests.

1) Genetic monitoring

The validity of technologies for genetic testing was discussed at length in a 1983 report of the Office of Technology Assessment, "The Role of Genetic Testing in the Prevention of Occupational Disease."[201] Its conclusions were confirmed in the report of 1990.[202] Serious

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197 *Ibid.* at 178.

198 Privacy Commissioner of Canada, *supra*, note 56 at 16.

199 SCC, 1991, p.103

200 D. Wertz, *Canadian Geneticists' View: A Survey of the CCMG and CAGC*, presented at the Canadian Bioethics Society, ...

201 U.S. Congress, Office of Technology Assessment, *The Role of Genetic Testing in the Prevention of Occupational Disease* (Washington DC: U.S. Government Printing

research difficulties remain when it comes to establishing a causal link between workplace exposure and chromosomal aberrations. These difficulties are caused by the fact that other variables interfere: age, life-style, smoking and so forth. Even common diseases such as influenza or the common cold[203] can interfere.[204] Mutations resulting from exposure to radiation or chemicals can be very diverse. Some remain for a very long time. Others disappear very quickly after exposure has been discontinued. Many mutations are not linked directly to diseases. In some cases, effects are noticeable only years after the initial exposure.[205] The report's general conclusion is that tests can reveal exposure to toxic substances, the absorption of these, the presence of mutagens or molecular changes. In general, though, tests do not indicate reliably the effects of exposure on the health of individual people. More research is required.

The clearest links have been made between exposure to high levels of radiation and some forms of cancer. But the connection between cancer and exposure to low-level radiation or chemicals remains unclear.[206] According to OTA, "[m]ost analysts agree that interpretation of cytogenetic results at the individual level is questionable and recommend that until the relationship between cytogenetic damage and disease is better understood, interpretation should be maintained at the population level. In addition, cytogenetic

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Office, 1983).

202 OTA 1990, at 58-71.

203 M.S. Henifin & R. Hubbard, "Genetic screening in the workplace" Nov.-Dec. 1983 GeneWatch 5 at 7.

204 OTA 1990 at 69; Royal Commission on New Reproductive Technologies, *supra*, note 8 at 270-273; J.V. Neel, "How can we best evaluate, and compensate for, genetic hazards in the environment and workplace", in Milunsky & Annas, eds, *Genetics and the Law III*, *supra*, note 119, 465.

205 OTA 1990 at 55-71.

206 OTA 1990 at 60-62.

monitoring of human populations is expensive and time-consuming."[207] New genetic techniques are being developed that could become much more effective in measuring individual risk and thus preventing disease. For example, oncogene detection is likely to become the major technique for early diagnosis of cancer.[208] When activated, oncogenes stimulate the development of cancerous tissue. Monitoring could establish whether these oncogenes have been activated by radiation or by other chemicals. Further studies are required before monitoring can be introduced effectively. OTA concludes: "Until the health effects of exposures are better understood, monitoring can only provide a gross indication that genetic changes have occurred and that adverse health effects could follow. . . . New methods may provide better estimates of the health effects of low doses of some mutagen, as well as providing qualitative data on the nature of mutation."[209]

Further research is being undertaken and is likely to result in more adequate genetic monitoring. One of the major research programmes on genetic monitoring for carcinogenic agents is being carried out by the Finnish Institute of Occupational Health in collaboration with several Nordic countries.[210] The Canadian Royal Commission on New Reproductive Technologies, in its final report, recommended that programmes to monitor employees for workplace hazards be established.[211]

2) Genetic screening

Genetic screening in the workplace can be classified in two groups: (1) tests indicating that susceptibility to workplace hazards might be directly relevant for the workplace; and (2) tests

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207 OTA 1990 at 62 (note omitted).

208 OTA 1990 at 68-69.

209 OTA 1990 at 71.

210 OTA 1990, at 48 and Conditions of Work Digest, at 218.

211 Royal Commission on New Reproductive Technologies, *supra*, note 8 at 298.

indicating the presence of single-gene disorders or complex traits that might interest employers as much as the general health and fitness of their employees. The accuracy of these tests depends on factors that have already been mentioned. One has to bear in mind the specificity of genetic information. When tests indicate the presence of a deleterious gene, that does not necessarily indicate the presence of disease itself. This is so in the case not only of "susceptibility genes" but also of some determinant single-gene diseases. Variable expressivity and incomplete penetrance can be very substantial. Moreover, as I have observed, various techniques are used in genetic testing. The highest level of accuracy is reached when genes associated with diseases or with susceptibility to them have been identified and direct tests are available. Genetic markers are less reliable.

The use of genetic markers generates several problems.[212] Genetic linkage maps are established by comparing the DNA of both affected and non-affected members of a family. To discover whether someone is affected, the co-operation of at least two family members is required. This creates problems of confidentiality. A more practical problem is the inaccuracy. Tests using genetic markers are less accurate than direct tests; there is a higher margin of error. Also, the specificity and sensitivity of tests using markers is lower; this produces more false negatives and false positives.[213] Both direct tests and those using genetic markers, of course, are subject to errors at the laboratory.[214]

It is impossible to discuss the accuracy of genetic testing in general terms. Test results are very diverse. The following pages can give only an impression of the difficulties in assessing the importance of test results.

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212 For a general discussion of the practical and ethical issues of the use of markers, see Mélançon, *supra*, note 141.

213 Science Council of Canada, *supra*, note 8 at 45-46 and 48; Suter, *supra*, note 34 at 1863, in particular note 59.

214 *Assessing Genetic Risks*, *supra*, note 61 at 37-38.

a) Tests for susceptibility to occupational hazards

Susceptibility tests aim at identifying those who are predisposed to be adversely affected when confronted with specific hazards in the workplace. The 1990 report of OTA states that there are 50 genetic traits that would affect susceptibility to specific environmental agents, many of which are listed and discussed in the report.[215] But for many of them, increased susceptibility is hypothetically asserted, not scientifically confirmed. In some cases, increased susceptibility is found among so many people that it ceases to mean very much. Three examples from the report show how difficult it can be to make a general statement about the validity of these tests: (1) sickle cell; (2) acetylation phenotype; and (3) ataxia telangiectasia.

Sickle-cell is the most controversial example. Limited studies have suggested that carriers are more vulnerable than others to health problems when exposed to low levels of oxygen or to chemicals such as nitrogen dioxide and chlorite. This trait is listed as one of the genetic factors affecting susceptibility to such environmental agents. But "[n]either the experimental [n]or epidemiological evidence has confirmed the hypothesis that persons with sickle cell trait are at increased risk when exposed to several chemicals."[216] And scientists are not certain that the low level of oxygen at high altitudes increases the risk for carriers.

More clearly established is the susceptibility of those who carry the "slow acetylation gene."[217] Acetylation refers to the detoxification of many substances. An identified gene is involved in the process, producing the necessary enzyme for this process. People are either slow or fast acetylators. Studies indicate that slow acetylators are susceptible to bladder cancer when exposed to the chemical arylamine. But can we really speak of an "increased susceptibility" to arylamine? After all, the report says that 50% of Americans, both blacks and whites, are slow acetylators!

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215 OTA, *Genetic Monitoring*, *supra*, note 8, at 83-87.

216 *Ibid.*, *supra*, note 8 at 85; see also Henifin & Hubbard, *supra*, note 131 at 5-6.

217 OTA, *Genetic Monitoring*, *supra*, note 8, at 85.

Ataxia telangiectasia is an autosomal recessive genetic disorder that predisposes individuals to immune deficiencies and certain types of cancer.[218] Homozygotes for the trait usually die in early adulthood. Their risk of cancer is 100 times as great as that of control groups. Studies have indicated that heterozygotes run a risk of dying from cancer 5 times as high as that of the general population. More importantly for workplace testing, research now suggests that heterozygotes are considerably more susceptible as well to cancer resulting from exposure to radiation. Heterozygous status can actually be identified through genetic testing. Because many Americans –according to OTA, 6 million of them –are heterozygotes of the trait, the test could become important for jobs involving exposure to radiation.

In conclusion, susceptibility tests can indicate increased chances of developing workplace- related diseases. But tests do not indicate clearly who will develop these. Although tests might be of value to employees, allowing them to make well-informed decisions about exposure, inaccuracy would support the argument against employers who want to impose tests as a way of protecting their health. If some hypotheses are confirmed, nevertheless, systematic screening could be of substantial benefit in specific industries. Employees might find it extremely important to know that they are carriers of the ataxia telangiectasia trait, for example.

b) Tests for other genetic traits

Employers might be interested in tests for non-occupationally-related genetic diseases. Is it ethical or even rational to perform these tests in the workplace or to obtain information about them in a working context? I will discuss that later. For the time being, I want to focus attention on the scientific reliability of tests that could be of interest to both employers and employees. In that respect, two types of non-occupational screening should be distinguished: (1) testing for single-gene disorders; and (2) testing for complex traits.

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[218] *Ibid.* at 86-87.

Single-gene disorders can have a serious impact. There are already a few genetic tests for late-onset single-gene diseases that might interest employers. The U.S. Committee on Assessing Genetic Risks mentions the following examples of late-onset genetic disorders for which tests are either available or likely to become available in the near future: Huntington's disease, Alzheimer's disease, haemochromatosis, familial hypercholesterolemia, polycystic kidney disease and inheritable cancer.[219] As I noted earlier, though, statements of this kind must be analyzed very carefully. For example, a potential test for Alzheimer's would be able to detect only about 5% of the cases, only those transmitted as an autosomal dominant trait. Breast cancer is often characterized as a genetic disease, even though no more than 5% of the cases might be linked to the identified genes. The predictive value of these tests varies according to the type of disorder. A test for Huntington's is very accurate; those who test positive usually develop the disease. But the test for breast cancer, once again, is less accurate. Not all carriers of the gene develop this disease; many women who are not carriers, on the other hand, do develop it.

The success rate of testing for complex traits varies considerably. For most of the latter, reliable tests are lacking because of the unpredictable and non-yet-understood interaction of many factors. But even if tests were developed, their success rate could be very low. The case of insulin-dependent diabetes indicates how limited the predictive value of tests can be.[220] Genes on chromosome 6 have been associated with this condition. Family tests were developed to determine susceptibility. Only 25% of those identified as being at risk developed clinical diabetes. Another example is heart disease.[221] High cholesterol levels are associated with it. But many individuals with high cholesterol are never affected by heart problems; others, with normal cholesterol, are. The Committee on Assessing Genetic Risks predicts that a "small battery of tests" for the major susceptibility genes and environmental interaction will be developed. Screening might thus become more reliable. Still, a battery

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219 *Assessing Genetic Risks*, *supra*, note 61 at 87-94.

220 *Ibid.* at 97.

221 *Ibid.* at 97.

of tests is likely to detect only some of the high-risk individuals, those who might subsequently take precautionary measures.

Future tests might indicate as well increased susceptibility to cancers of complex origin or to hypertension. These are only a few examples of diseases that might be involved in the context of work. But as Holtzman remarks, "[f]or the vast majority of people affected by heart disease, cancer and the like, the origin is so complex that it's a gross oversimplification to think that screening for a predisposing gene will be predictive."[222] The inherent problem with tests for complex disorders is the fact that they can indicate only risk factors that interact with many other elements and do not indicate the actual presence of diseases. People who are called "carriers" might never develop the diseases linked to their genes. They often compensate for increased susceptibility by reducing hazardous environmental influences. "The influence of environment remains the wild card in most cases," concludes OTA, "because possession of the genetic predisposition alone may not be sufficient to cause disease. It is likely that for some time modern science will be more successful in identifying the genes and the markers than in identifying the environmental agent(s) necessary for activation of the predisposing genes."[223]

Particular caution is recommended for psychiatric diseases because of their highly stigmatizing character.[224] Studies have tried to link genes to schizophrenia, manic depression and alcoholism. Although these have not been confirmed, genetic factors probably do play a role. Other psychiatric conditions, such as panic disorders and Tourette syndrome, are thought to be partly genetic. But the role that genes and environment play, respectively, in the development of all these diseases remains unclear. And it is likely to remain unclear.

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222 N. Holtzman, cited in Proctor, "Genomics and Eugenics" *supra*, note 23 at 81 (footnote omitted).

223 OTA *Genetic Monitoring*, *supra*, note 8 at 88.

224 *Assessing Genetic Risk*, *supra*, note 61 at 99.

3) Validity of genetic tests in comparison with other tests

Genetic tests should not be judged only on their internal validity. Attention should be paid to other factors as well, ones that might affect the health of employees or their capacity to perform on the job. Are genetic factors the only ones that can influence health and performance? If not, how important are the other factors? Can the latter be detected easily or not?

Answering these questions can be extremely important from the legal perspective if genetic testing is judged to infringe on individual autonomy, say, or to be a form of discrimination. Either case might involve a proportionality assessment. Liberty-restricting practices are often defended when the interests of other individuals or of the public are at stake. Excluding a disabled employee might be defended, for instance, as a *Bona Fide Occupational Requirement.*[225] It would be difficult to argue for necessity, of course, if there are other health or performance-affecting factors and if employers do not test for these factors, especially if tests are readily available.

Mark Rothstein shows how factors other than genetic ones can influence the health of employees and their ability to work.[226] Among these are previous drug use, exposure (of employees or their parents) to hazards, geography, diet, life-style, musculoskeletal constitution and prior illness. Although some of these elements can be detected through genetic testing, most cannot be. In fact, no tests are available for most of them. Risk factors can be established only on the basis of information given by the people concerned.

Some researchers argue that genetic risk factors are more important than others – housing, food, drugs, sleeping habits and so on. But eating a lot of broccoli, Brussels

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225 A bona fide occupational requirement is an employment requirement that is imposed on an employee and that is reasonably related to the task that this employee would have to fulfil in a specific company. An employer who is accused of discriminatory practices in hiring employees can defend himself by proving that an exclusionary practice constitutes a reasonable requirement.

226 *Supra*, note 164, at 1391-1405.

sprouts, cabbage, garlic and olive oil can reduce susceptibility to certain types of cancer.[227] Why not question employees about their eating habits, for instance, when applying for jobs that increase their chances for developing cancer? Even living in high risk areas can increase susceptibility to cancer. As Rothstein remarks, "a new employee who grew up in New Jersey, (the state with the highest cancer rate) would be more likely to develop bladder cancer than an employee who grew up in Kentucky or Utah. Could such a hypothesis lead an employer whose employees were exposed to benzidine or some other bladder cancer-causing substance to refuse to hire applicants who grew up in New Jersey?"[228] William Matthewman indicates that nutritional status can affect susceptibility to chemicals. He suggests rhetorically that "an employer could argue that a selection process removing all applicants who live in poverty is job-related since poor individuals have poor nutritional habits and, therefore, are prone to certain pollutants."[229] In short, the justification for genetic testing might depend on the existence and validity of other tests.

Comparing with other tests is important in discussing the intrusiveness of genetic ones. According to many human rights codes, practices that have discriminatory results or infringe on individual privacy must be submitted to proportionality tests. Under a proportionality assessment, that I will discuss further, the importance of the final goal is weighed against the intrusiveness of the tests. One should always wonder whether there is no less restrictive way of attaining the same result. This kind of analysis is based on the belief that even fundamental rights are limited by the interests of others. Two conditions must be met: (1) the interests of others (whether individuals or communities) must be legitimate ones; and (2) there must be no less-intrusive way of protecting the interests of these others.

I continue, therefore, with a discussion of interests that frequently collide when it comes to genetic testing in the workplace. This will be followed by a discussion of the

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227 *Ibid.* at 1398.

228 *Ibid.* p.1398 and footnote 140. [footnote omitted]

229 *Supra*, note 99 at 1217.

ethical theories that might be used to balance these interests. I propose that, in stead of balancing
harms and benefits, important values should be taken into consideration.

II. Interests in genetic testing

A. How interests shape judgment

According to Elaine Draper, employers and employees have opposing views on the validity of genetic screening or monitoring because of competing interests, shaping their perceptions of reality.[230] Employers favour screening as a way of selecting employees but oppose monitoring. Labour unions and employees, on the other hand, vehemently oppose screening but favour further research on monitoring. The support of employers for screening reflects their interest in arguing that health problems are due to genes, not the workplace. This would reduce their responsibility, of course, for illness among their employees. This focus on susceptibility obscures the potential impact of workplace hazards even on "normal" employees. In the short run, at any rate, excluding workers seems more cost-effective than cleaning up the workplace.[231]

Others, including consumer groups, support Draper's argument.[232] According to Karen Messing, a biologist who conducted research on genotoxic effects on the health of employees, industrial interests explain the lack of funding for research on hazards in the

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230 *Supra*, note 123 at 175-188; *supra*, note 184; and "Genetic Secrets: Social Issues of Medical Screening in a Genetic Age" (1992) 22:4 Hastings Cent. Rep. S15.

231 Draper, *supra*, note 123, in particular at 58-61 and *id.*, *supra*, note 184.

232 See e.g. Proctor, "Genomics and Eugenics" *supra*, note 23 at 80-81; M. Gibson, *Workers' Rights* (Rowman & Allanheld: Totawa, 1983) at 22-23; K. Brokaw, "Genetic Testing and Employer's liability" (1990) 23 Colum. J.L. & Soc. Probs. 317 at 318; Marshall, *supra*, note 184 at 66.

workplace.[233] At a hearing of the Royal Commission on New Reproductive Technologies, a representative of the British Columbia Federation of Labour said that "[e]mployers have been more energetic in excluding workers at risk from the work site than they have been in reducing hazards."[234] The reason for this approach seems clear. Fierce competition pushes employers to find cost-saving procedures, ones that do not necessarily protect employees. According to Dorothy Nelkin and Laurence Tancredi, "economic rationality has encouraged industry to place responsibility for health on the individual worker rather than on the firm."[235] Employers do not want to harm their employees, but they do want to save money. It is in their interest to screen out susceptible employees, not to clean up the workplace.

Employees, on the other hand, do not want to lose their jobs or be classified in high-risk groups. It is in their interest to see the source of harm in the outside world, not in their own constitutions. They favour genetic monitoring, because they fear chemical hazards. But employees do not always oppose genetic testing. Not all workers' organizations, at any rate, have opposed it. Many recognize the potentially beneficial applications of genetic technology. A Danish law that restricts genetic testing by employers was opposed, for instance, by the Danish trade unions. Instead of prohibiting genetic screening, they argued, the state should control access to genetic information. So, the Union acknowledged that genetic screening could be beneficial.[236] In the United States, the AFL-CIO supported research projects on genetic testing but stressed the importance of confidentiality.[237] But the Union of Swiss Trade Unions categorically condemned genetic screening.[238] As a matter of

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233 K. Messing, "Union-initiated Research in Genetic Effects on Workplace Agents" (1990) 6:4-5 Genewatch 8-14.

234 Royal Commission on New Reproductive Technologies, *supra*, note 204 at 274.

235 *Supra*, note 117 at 84.

236 International Labour Office, *supra*, note 22 at 62.

237 *Ibid.* at 62.

238 *Ibid.*

principle, it argued, decisions about obtaining and using medical information should be made only by individual employees. Anthony Mazzochi, former vice-president of the American Oil, Chemical, and Atomic Workers Union, argues that "workers have to have total control of industrial hygienic, medical, and all other scientific capability at the point of production."[239]

In conclusion, Draper's view that employers and employers have opposing views, by definition, is incorrect. Nevertheless, she is correct in warning us that genetics can be used to oversimplify the cause of workplace-related diseases. In fact, there is a danger of scientific research shifting "from a search for mutagens in the environment to biological defects in the individual."[240] Several authors have expressed their concern. According to Kevles, "[b]laming biology lets society or its constituents off the hook; it permits them to segregate problems rather than to deal with them."[241] With the workplace in mind, Hélène Guay, Bartha Maria Knoppers and Isabelle Panisset warn that "on ne saurait privilégier la privation d'un emploi à un candidat ou à un employé aux dépens de la modification de l'environnement de travail, de l'élimination des éléments dommageables au patrimoine génétique ou de l'élimination des facteurs qui affectent plus particulièrement certaines personnes en raison de leur susceptibilité."[242] Finally, Matthewman argues that "[e]mployers should not be allowed to utilize genetic screening as a substitute for cleaning up the workplace. It is clearly less expensive to exclude a few "susceptibles" than to make the workplace safe for all employees. Public policy is best served by requiring the employer to make the industrial workplace safe for everyone."[243]

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239 "Trade Unionist Speaks Out" *GeneWatch (november-december 1983)* at 8.

240 Proctor, "Genomics and Eugenics," *supra*, note 23 at 80.

241 *Supra*, note 25 at 276.

242 *Supra*, note 90 at 321.

243 *Supra*, note 99 at 1217.

B. The interests of employees

Genetic tests were developed originally for medical purposes. They are intended primarily to benefit those being tested. For instance, tests can help people make rational decisions about reproduction. They can warn people of the need for preventive measures, such as low-risk jobs, healthy diets, medications, protective clothing and tools to avoid disabling diseases.

In the future, it might be possible to determine whether workers are at a lower than average risk for developing specific workplace-related diseases. This, too, would influence work-related decisions. Some of these people might ask for well-paid jobs that involve serious exposure to toxins.

What might be in the interest of individual workers, though, might be against those of other workers. As Draper and others have said, genetic screening might be too easy a solution for employers. The fact that some people face high risks when exposed to toxins does not mean that other people face no risks; excluding the former does nothing to help the latter, who still need to work in safety.[244] Besides, the fact that some susceptibilities have been discovered does not mean that there are no other, that still have to be detected; genetic screening for known susceptibilities could become an excuse for not reducing exposure to other substances, the long-term effects of which are not yet known.

The bias of some employers' protective policies can be illustrated by the U.S. Supreme Court case of Johnson Controls.[245] Was this producer of batteries discriminating against women with its policy of protecting foetuses? The company excluded women –except those who could prove their inability to bear children –from all jobs involving exposure to lead. The Supreme Court rejected the defense that this was a benign policy and therefore not discriminatory. According to the decision, Johnson Controls "does not seek to protect the unconceived children of all its employees. Despite evidence in the record about the

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244 Gibson, *supra*, note 223 at 22-23.

245 *International Union* v. *Johnson Controls* (1991) 113 L Ed 2d 158.

debilitating effect of lead exposure on the male reproductive system, Johnson Controls is concerned only with the harms that may befall the unborn offspring of its female employees."[246] The Court further stressed that "[t]itle VII [of the Civil Rights Act[247]] plainly forbids illegal sex discrimination *as a method of diverting attention from an employer's obligation to police the workplace*."[248]

But employees, as a group, can benefit substantially from genetic monitoring that aims at controlling the impact of hazardous substances on their health. Because efficient monitoring requires the participation of many people, it could be argued that participation should be required. Monitoring is frequently undertaken for research purposes.[249] The fact that "non-interested" researchers conduct them, according to some experts, diminishes the importance of confidentiality and consent.[250] When it comes to high-risk professions, they argue, the importance of further genetic research on monitoring might justify participation as a condition of employment. But is research important enough to bypass the fundamental requirements of informed consent and confidentiality? On the contrary, these requirements are essential preconditions for research involving human subjects. Therefore, if, in a given industry, monitoring is considered so important that employees could be required to participate, adequate information should be provided before offering employment and submitting workers to monitoring.

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246 *Id.* at 173.

247 Title VII of the Civil Rights Act prohibits sex-based classifications in terms and conditions of employment and other employment decisions.

248 *Id.* at 180 [my italics].

249 Murray, *supra*, note 192.

250 Rowinski, *supra*, note 158 at 385 referring to statements made by T.H. Murray.

C. The interests of employers

Employers can use genetic tests for several reasons: to increase productivity, to assure safety, to reduce the cost of health care, to reduce costs in general, to protect employees and so on. In the literature, the reasons discussed most often are those that conflict with the interests of employees.[251] Medical tests are seen mainly as a potential source of discrimination. But this approach is simplistic. It is at least possible that some employers actually care about the health of those who work for them.[252] They might provide genetic screening to foster public health,[253] for example, or to protect highly susceptible workers from hazards and toxins. Employers might use screening to identify vulnerable employees, to be sure, but might offer them safer jobs as well. I will return to the question of whether or not decisions of this kind should be left to employers.

Genetic screening can be implemented to determine whether candidates have required physical (or even psychological) capacities. In that case, it could be seen in the context of ordinary medical examinations given to candidates for jobs. Even healthy people, after all, might be unsuitable for physically demanding jobs. The problem is that genetic screening identifies not only those who *are* impaired but also those who *might become* impaired. More than money is at stake.[254] Moreover, the existence of other medical selection procedures does not necessarily justify genetic screening. After all, both the former and the latter might be unjustifiable. "What is" should not be used as a basis for "what ought to be."

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251 See, for example, Nuffield Council on Bioethics, *Genetic Screening; Ethical Issues* (London: Nuffield Council, 1993) at 56. The Canadian Privacy Commissioner's report also approaches the issue from the perspective of conflicting interests: "Without compelling arguments to the contrary, genetic screening for the benefit of the employer is inappropriate. Screening might, of course, benefit employees or applicants." Privacy Commissioner of Canada, *supra*, note 56 at 31.

252 Brokaw, *supra*, note 232 at 326; Rowinski, *supra*, note 158 at 387.

253 Natowickz, Alper & Alper, *supra*, note 164 at 467.

254 Nuffield Council, *supra*, note 251 at 55.

Economic interests can be very great in implementing genetic testing, a fact that concerns employees as well as employers. Shapiro suggests wisely that "some balance must be struck between compassion on the one hand and cost on the other."[255] I have already noted, however, that employers could use genetic screening as a way of avoiding costly changes in the workplace. According to one trade unionist, the introduction of screening can have value from the perspective of public relations: "[M]anagament benefits from genetic screening because it creates a public consciousness that says: it's not the polluted workplace that's to blame for occupational health problems, it's the makeup of the workers."[256]

The overall health of employees has a monetary value. Healthy employees are cheaper.[257] The productivity of people with genetic problems might be impaired, after all, and cause them to use more sick leave.[258] Sometimes, moreover, temporary replacements must be hired, trained and equipped. Employers invest in their employees. When skilled and experienced, the latter cannot be replaced easily. But sick leave and early retirement need not be too costly to employers, especially if the state provides pensions and disability insurance to those who stop working for health-related reasons. In some cases, moreover, the age even of healthy people can be a serious disadvantage. But this, too, need not be a problem for employers. The early retirement of construction workers, for example, allows them to maintain young workforces.

Holtzman makes a related argument in connection with the U.S. health care and pensions. When workers live longer, he says, they increase the pension costs of their

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255 Shapiro, *supra*, note 8 at 173.

256 "Trade Unionist Speaks Out" *GeneWatch* (Nov.-Dec. 1983) 8.

257 Natowickz, Alper & Alper, *supra*, note 164 at 467 and Nuffield Council on Bioethics, *supra*, note 251 at 56.

258 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*, International Colloquium, Lausanne, 14th April 1994, Publications of the Swiss Institute of Comparative Law 25 (Zürich: Schulthess Polygraphisher Verlag, 1994) 129 at 132.

employers. Pensions cost much more than life insurance. Therefore, he argues, the cost of pension plans could be reduced by hiring workers likely to die at the age of 65.[259] Although this argument has some theoretical value, it is not very convincing. It presupposes the existence of diseases that have no affect on job performance, do not kill before the age of 65 and do so without costing much. It also obscures the fact that life and health insurance costs would probably increase, which would mitigate the decrease in pension costs. Arguments about the long-term cost-effectiveness of hiring workers at risk indicate the fundamental difficulty of pure "economic" reasoning. Apart from the fact that these arguments do not always seem very ethical, they can go both ways.

Of financial interest to employers are not only tests that reveal physical abilities but also tests that reveal physical assets. Employers are inclined to use cost-effective tests, especially under a system of private health insurance as in the United States.[260] There, employers pay at least a part of the health insurance premiums of their employees. Three different methods are used: community-rating,[261] experience rating and self-insurance. Under the latter two systems, disabled employees can be very costly. With experience rating, insurers calculate their premiums on the average cost of employees during the previous year. Under self-insurance, employers pay directly for the health care of their employees. The more employees are sick, under these systems, the higher the costs for employers. Self-insurance has become the major system of health insurance for American companies.[262] This undoubtedly pushes employers to screen out potentially costly employees.

Universality of health care makes the Canadian system fundamentally different. But universality is now being questioned. And it has already been affected. In some provinces, moreover, a parallel but private system is being developed. Additional health insurance has

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259 Holtzman, *supra*, note 121 at 205.

260 See Greely, *supra*, note 164.

261 In the system of community rating, an insurer charges to an employer a premium that corresponds to the average cost of the insurer for employees in that region.

262 Greely, *supra*, note 164 at 269.

grown in importance and has become a major expenditure for employers, who frequently pay an important part of the premiums. Problems in the United States, therefore, deserve the attention even of Canadians. A public health care system removes many of the incentives for the exclusion of employees with genetic disorders or susceptibilities. When decisions are made about universal health care in Canada, this should be considered very carefully.

Employers introduce screening for financial reasons. This is clear in connection with testing for drug use. Though justified with references to the safety of others, including the public, the underlying motive is often money. Studies have indicated a correlation between the use of drugs and both the level of productivity at work and the frequency of absence from work. Even when drug testing does not reveal actual impairment, it does reveal the identity of those likely to become efficient employees.[263]

For the same reasons, employers might be interested in genetic screening for monogenic diseases or multi-factorial diseases that are unrelated to the workplace. It would certainly be in their interest to know whether one of two candidates for employment is more likely than the other to have heart disease by the age of 50.

Some problems are associated with testing for psychiatric disorders. In all likelihood, most employers would be interested in these tests. As I have observed, future tests might be developed for schizophrenia, manic depression and alcoholism. At least some employers would surely be tempted to use inaccurate tests. Even now, many employers submit prospective employees to all kinds of psychological tests, the scientific validity of which are sometimes questionable.[264] It is surprising how many employers use graphology tests for the selection of employees; a report of the International Labour Office gives the following national percentages: 47.8% in France, 13.3% in Germany, 6.3% in Italy and 2.6% in the United Kingdom.[265] Mental diseases have a bad connotation; they are often misunderstood

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263 See T. Lemmens, "Dominium Bank's Drug Testing Program: Not Discriminatory, but Intrusive." (1995) 1:2 Canadian HIV/AIDS Policy & Law Newsletter 4-5.

264 For a discussion of different forms of tests, see International Labour Office, *supra*, note 22.

265 *Ibid.* at 75.

and feared. The stigmatizing character of psychiatric disorders is such that people are often afraid of those who are classified in this way. Consequently, employers would prefer to exclude employees at risk.

D. The interests of third parties and the community at large

Others, too, can benefit in several ways from the genetic monitoring or screening of employees. Two categories should be distinguished: (1) family members of tested employees; and (2) other third parties and the public at large.

1) The interests of family members

I have said that genetic information, more than any other kind of medical information, is closely related to the family. After all, family members (those who are related by blood) share genetic material.[266] When it comes to testing, contradictory interests might be involved. If tests reveal genetic disorder or susceptibilities, family members might want to know that they, too, are at risk. They might also worry about confidentiality. Genetic information reveals potential risk factors that could be used by other employers, by insurance companies and so forth.

It has been argued that the right to be free from bodily intrusion and to take important decisions about one's health includes "the right *not* to know whether one carries a disease gene."[267] This right is surely not absolute and compelling interests can supersede it.

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[266] Knoppers, *supra*, note 145 at 16-18.

[267] Suter, *supra*, note 34 at 1893 (footnote omitted). See also Privacy Commissioner of Canada, *supra*, note 56 at 30 and N. Park & B. Dickens, "Legal and Ethical Issues in Genetic Prediction and Genetic Counselling for Breast, Ovarian and Colon Cancer Susceptibility" in Taylor & De Petrillo, *supra*, note 62 at 70. Others do not define this as a "right" but acknowledge that many people do not want to be informed by their risk of developing an incurable condition: see Miller, *supra*, note 145 at 153 and references

Mandatory testing can be imposed for reasons of public health, for example to control the spread of contagious diseases. In some cases, though, it seems reasonable though, to give individuals the choice of being informed about their actual health or future illness, especially if others cannot be infected and informing the patient will have no effect on the disease.[268] This "right not to know" can be infringed by indirect disclosure of risk factors through job refusal. People could be excluded from work by information that employers obtained by testing family members. They could thereby be informed about their susceptibility.

Some other interests should be mentioned here. Consider future descendants. Damage to the germ cells of employees could affect their health in significant ways. Although the exact effect of toxic substances on reproduction is unclear, studies have associated sperm abnormalities with exposure to various metals, insecticides and solvents.[269]

There is also a more remote reason for family members to be concerned about monitoring or screening. They might be financially dependent; the results of health problems among employees could be measured by their families in financial terms as well as emotional ones. Then, too, family members might file liability claims related to inappropriate conducting of genetic monitoring or screening.

2) The interests of other third parties

People belong to communities. Their actions are related to others. Communities are webs of social relations in which everyone plays a specific role. The well-being of individuals, therefore, is of interest to the community. This is particularly true where nearly everyone

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[268] For a discussion of the right to refuse and mandatory testing, see *Ibid.* at 1897-1905. For a discussion of compelling interests that would justify workplace testing, see *infra* at 118.

[269] OTA, *Genetic Monitoring*, *supra*, note 8 at 62 and references there.

contributes money to support systems of public health care and worker's compensation.[270] When people are involved in potentially harmful work, the entire community must pay for the consequences. Damaged employees need treatment, take early retirement, pay less toward the health care of others and so on. The actions of some can have a greater impact, of course, than those of others. As I have just noted, for example, many employees have dependents.[271] But the problem concerns everyone, not only family members. Society itself might have to step in and take over the care of these dependents. In short, the health of individuals can easily become a social problem. This is true in private systems, too, such as the American one. Disease and poverty affect the community as much as (or even more than) they do in public systems, albeit less directly.

But modifying the workplace is more costly than excluding the disabled. Companies with higher costs are less competitive. Some are forced to close. And that creates unemployment. In short, as Shapiro argues, money spent to make jobs more accessible takes money away from other things, including health care and research.[272]

Communal interests do not necessarily outweigh individual ones. They should not be given absolute priority when it comes to the regulation of screening and monitoring. I will return to the question of how to balance individual and communal interests. A more controversial question is whether genetic screening or monitoring should be required in order to ensure public safety (or at least contribute significantly to it). Employees affected by genetic disorders or susceptibilities might represent a serious danger to others. This argument was invoked by the US Army to exclude carriers of the sickle-cell trait from flight

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270 W.K. Viscusi, *Risk By Choice: Regulating Health and Safety in the Workplace* (Cambridge Mass.: Harvard University Press, 1983) at 42.

271 Viscusi, one of the most prominent defenders of the idea that the free market is the best tool to solve problems of health and safety in the workplace, acknowledges that the existence of family members might make a difference. However, in Viscusi's perfect market, family members will only affect the level of risk an individual is willing to accept. The market will regulate the risk because individuals will simply require a higher premium before accepting the job. *Ibid.* at 41.

272 *Supra*, note 8 at 173.

and diving occupations.[273] Similar exclusions were introduced in the private sector. It was suggested that carriers, though not ill, could enter sickling periods and loose consciousness due to lack of oxygen. Loss of consciousness by pilots, who are often exposed to low levels of oxygen, could indeed result in disaster. But the suggestion that carriers of the sickle-cell trait are subject to sickling periods has remained controversial; it has not yet been demonstrated scientifically. In the meantime, carriers suffered from discrimination. Several states intervened, eventually, prohibiting employment discrimination on this basis.

The public-safety argument could be invoked to justify other types screening, even if links between the test and the danger of harm to others are unclear – which is usually the case. At the 1994 Annual Meeting of the Canadian Bioethics Society, for instance, one participant expressed serious concern over the fact that someone identified as a carrier of the gene for Huntington's was a professional truck driver. This disease is characterized by the gradual increase of uncontrollable bodily movements. Though a monogenic dominant disorder, which implies that carriers will ordinarily develop the disease, the test reveals nothing about current health. As the Danish Council of Ethics indicates, there is no reason to exclude from work those who are potentially but not actually sick. Those predisposed to Huntington's disease represent no danger for the workplace. A regular check-up, according to the Danish Council, is the best way to test for ability to perform without risk to others.[274] Once symptoms appear, of course, additional steps must be taken.[275]

A survey of Canadian geneticists, presented at the same conference, brought up the issues of public safety and confidentiality. Geneticists were asked if they would inform their employers that a bus driver has familial hypercholesterolemia if the patient refused both to disclose the condition and to retire. People with familial hypercholesterolemia are at high risk for heart attack or stroke. According to the survey, 24% of the geneticists would tell

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273 Rothstein, *supra*, note 164 at 1385-1386.

274 See Danish Council of Ethics, *Ethics and the Mapping of the Human Genome* (Copenhagen: Danish Council of Ethics, 1993) at 83.

275 Becker, *supra*, note 152 at 301.

their employers. Another 20% would warn their employers without identifying the employee. It is worth noting that 35% had been confronted with similar cases.[276]

Several questions should be raised in connection with testing at the workplace. Do employees who will become sick at some unspecified moment in the future, and to an unspecified degree, represent such a danger to others that they should be screened out? What are the chances of a risk being materialized? Is screening the most appropriate way of assessing risk and preventing risk to others? Is there another way of assuring public safety? In answering the latter question, attention should be paid to other risk factors and ways of dealing with them. The public might be at much greater risk of being struck by a flying truck wheel than of being injured by a healthy driver with a genetic susceptibility. Unfortunately, it is usually the latter that seems most disturbing in the imagination. This could provide another example of the way in which finding faults in the genome can obscure other problems, creating an illusion of safety.

Many employers are enthusiastic about drug testing and invoke public safety or the security of other workers to defend themselves.[277] They might use the same arguments to defend the screening of employees for diseases linked to frequent impairment or behavioral problems. Even the risk of heart disease or alcoholism could be used to justify not hiring people as drivers, pilots or train conductors. And "the gene for schizophrenia" might be used to justify not hiring people as law enforcers.

Viscusi mentions another public interest. Hazards in the workplace can be parts of larger problems. Testing employees could show that toxins are dangerous not only to employees, after all, but also to the surrounding environment.[278] Those who live near nuclear plants, for example, might be reassured if employees, even closer to the source of danger, are routinely monitored. I have already mentioned that genetic screening and monitoring can be undertaken for research purposes. Insights on the effects of toxins in the workplace can help

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276 Wertz, *supra*, note 151.

277 See Lemmens, *supra*, note 263.

278 *Supra*, note 270 at 41-42.

the public, not only employees, by contributing to a scientific understanding of both genetics and occupational hazards on health. The interest of society in genetic research is an important argument for the need to protect confidentiality. If confidentiality is not guaranteed, after all, people could become reluctant to participate in genetic research?[279]

E. Self-regulation or state involvement: the interests of the market as absolute value?

Some defenders of self-regulation argue that government should not intervene at all in the relations between employers and employees. The market, they argue, is the best guarantee of both fairness and prosperity. At the very least, they oppose stringent health and safety regulations in the workplace. For Viscusi, market mechanisms fairly balance the risks and benefits of dangerous jobs, assuring better protection than "rigid policies that mandate the objective of equal risk for all."[280] His arguments are based on the idea that informed workers are equipped best to correlate the risks they want to take and the income they want to earn. Few would want jobs that involve a great deal of risk –unless, of course, they pay a great deal of money. What could provide employers with a better reason to improve the workplace than the absence of people willing to work there? According to Viscusi, intervention should focus on the provision of risk information, not on regulation.[281]

Though Viscusi acknowledges the existence of other interests, he argues "that these interests are difficult to quantify, so one cannot ascertain whether the inadequacies of the [economic] analysis are critical or of only technical interest."[282] So, elements that cannot be expressed in measures and compared may be discarded. This is a weak argument. Talking

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279 See supra, note 167.

280 *Supra*, note 270 at 135. For an interesting critique of Viscusi, see Draper, *supra*, note 123 at 119-128.

281 *Supra*, note 270, in particular at 156-168.

282 *Ibid.* at 42.

about health hazards involves much more than economic rules and quantifiable elements. Above all, it involves human lives. Economic efficiency is one element that must be taken into account when making decisions, to be sure, but it is hardly the only one. Values and interests cannot be measured in numbers.

Other defenders of the free market have written more explicitly about genetic testing. For them, employers should have the right to test their own employees and exclude them on the basis of genetic traits. Labour, they believe, is part of a stable economic system. It can run smoothly only if the game is played according to rules. One rule involves a perfect contractual relationship in which autonomous parties make decisions on the basis of accurate information. So, employers should be allowed to gather all the information that might be relevant for their decision. If information is concealed, they are harmed. Not revealing genetic information to a potential employer, therefore, amounts to fraud.[283]

Epstein argues this way. He does not reject the need for accommodating genetically disabled people. But he claims vigorously, with a mixture of economic and moral arguments, that the free market should not be disturbed by the anti-discrimination legislation that now protects employees. For Epstein, the only legitimate way to accommodate their needs would be through the introduction of subsidies. Three main arguments are invoked to defend this view. First, anti-discrimination laws do not lead to the equal distribution of burdens. On the contrary, they lead to concentration of genetically disabled people within industries. Second, anti-discrimination laws entail higher costs than direct subsidies. When direct subsidies are provided, tax-payers have a clear view on the costs of accommodation. They will not accept substantial increases in taxes for accommodation. As a result, spending on accommodation will be sealed off at an earlier stage than with anti-discrimination laws. Third, anti-discrimination laws that promote the reduction of workplace hazards, not the exclusion of susceptible workers, are too costly. The problem with these arguments is that they are based on a very dubious premise: above all, respect the market. Each of Epstein's

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[283] See Epstein, *supra*, note 96 at 12-13.

arguments is based on a cost-benefit analysis; each can be calculated in purely financial terms.

To demonstrate the last argument, for example, he compares the costs and benefits of improving the workplace with those of discriminating against susceptible workers. These costs and benefits are expressed in numbers. Nothing is said, though, about what they represent. Do we really have to include pain, suffering, death, meaning, social relations, communal solidarity and so on as calculable benefits that can be expressed adequately in dollars? Like Viscusi, Epstein would probably dismiss all these things as non-quantifiable and, therefore, irrelevant. Epstein's conclusion is predictable: it can cost a great deal of money to improve the workplace, but doing so can benefit only a small group of individuals. If only susceptible workers are excluded, however, the harm to the remaining workers will be relatively small and no expenses will be incurred. The relation between costs and benefits is clearly better if disabled people are excluded and the workplace not adapted.

In his second argument, Epstein admits that charity does not necessarily compensate for the harshness of the economic system and will not necessarily help disabled employees. In fact, he argues, the public will look away if accommodating the disabled costs too much. For Epstein, of course, this is the way things should be: "Although that outcome might not please advocates of the disabled, it should please those who have a more disinterested view of proper social decision making; that is, those who think that the commitment to eradicate genetic discrimination can be too large as well as too small."[284] In other words: if the community decides it, according to the rules of the market, morality is guaranteed and proper social decisions are made. But who, precisely, are these "disinterested" policy makers?

Remarkably, Epstein suggests that charity –disinterested support for the less fortunate by the more fortunate – should be given leeway in business. He criticizes the anti-discrimination approach, because it "forsakes the language of charity and embraces the language of rights by holding that private parties must disregard in business settings the same conditions, (i.e. impairments) that in informal social contexts prompt a compassionate

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[284] *Supra*, note at 21.

response."[285] Indeed, he says, charity should be the correcting mechanism. After all, charity does not disturb the market. Unfortunately, people are not always in the mood for charity.

By limiting his argumentation to a cost-benefit analysis, Epstein clearly demonstrates the amoral character of economics. In an anonymous system, based on cost-benefit analyses, there is no place for direct compassion toward those who suffer, duty to identifiable others, self-realization through work and so on. For Epstein, the economic order is a moral one, not merely an instrumental one. Simply making the economic system work is moral. And disrupting it through social policy is not only irrational and counter-productive but immoral as well. Not surprisingly, Epstein is clearly disturbed by the fact that anti-discrimination laws do not search for moral culpability in the cause of disability. On the contrary, he calls the argument that alcoholics should receive no coverage for health care because "their misbehavior renders them less deserving" an "eminently sensible position."[286] From all this, I conclude that combining an absolutely free economy with an absolutely blind trust in charity would make our society less humane and less moral.

Communal life involves more than financial rights and obligations. It involves values. Ethical standards are a part of every value system. In the context of my study, these include protecting the weak, integrating the disabled, respecting the autonomy of individuals, preserving privacy, striving for equality, studying the consequences of genetic screening or monitoring and so forth. The potentially damaging consequences to society of the latter should be included in any discussion of genetic testing in the workplace. These values will now be discussed.

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285 *Ibid.* at 5.

286 *Ibid.* at 4-5, note 16, with reference to A.H. Moss & M. Siegler, "Should Alcoholics Compete Equally for Liver Transplantation?" (1991) 265 J.A.M.A. 1295.

III. Ethical Issues involved in genetic testing in the workplace

In the last few decades, there has been an explosion of subdisciplines in ethics. These include bioethics, business ethics, environmental ethics and even computer ethics. This is not the place to discuss the value and underlying philosophical assumptions of each. Their mere existence, however, raises some questions. Could genetic testing in the workplace be submitted to more than one form of ethical reasoning, for instance, and thus to more than one ethical standard? Could the results be influenced by who does the testing or who is being tested? Should the purpose of testing determine the type of ethics to be applied? Should the level of confidentiality vary, for example, according to whether testing is done for diagnostic purposes by independent physicians or for selection purposes by physicians in the pay of employers?

These considerations should not produce different answers to the same problem. The angle from which problems are approached, however, can influence the way they are perceived. Even calling a problem "workplace-related" or "medical" can have a specific connotation. It expresses a view of what the legitimate purpose of testing should be. Patients are supposed to know that physicians act in their best interest, either to heal them or to relieve their suffering. Calling a problem "medical," even if it is related to labour, moves the issue beyond the contractual relation between employer and employee: of primary importance is the health of employees. Calling the problem "workplace-related" suggests that something else is involved. Consequently, it might be acceptable for employees to be tested for non-medical purposes, for genetic testing to be used as a selection device and so on. The latter approach, of course, would not be defended by everyone.

In the following pages, I present an examination of ethical principles developed in the specific field of bioethics. I do so, in the first place, on principle. I believe that genetic testing should serve medical and research purposes. As Kuitert argues, "[o]btaining information about an individual's genome is a health care matter: its use is aimed at

preventing a disease or if a disease cannot be prevented, at early intervention, if possible."[287] Because genetic information is considered medical information, medical standards should apply to its use. The fact is, nevertheless, that medical tests, whether genetic or not, can be used for other purposes. Although I do not reject their uses by insurance companies and employers out of hand, I insist on submitting these to the type of ethical reasoning that is applicable to the main purpose for which the tests were designed. Clearly, my approach is based on ethical reasoning. It reflects a vision of the necessarily instrumental character of a "free market" system according to which economic forces may be manipulated for the protection of health, for example, and privacy. An economy, as such, can be neither ethical nor unethical. Only human actions can. As I will mention, this is a view that is not shared by everyone.

I have also chosen bioethics for practical reasons. In the first place, bioethicists have written a great deal about this topic and closely related ones. Bioethics has most thoroughly dealt with the kind of dilemma presented by genetic testing, and it has generated a system of decision making on the basis of well-known ethical notions. Finally, the principles continually invoked in that field are closely linked to legal concepts. Law and bioethics have often met each other in court.

What principles within bioethics can be used in this context? Since Beauchamp and Childress published their *Principles of Bioethics*[288] in the seventies, traditional bioethics has focused attention on four basis principles: (1) autonomy; (2) beneficence; (3) non-maleficence; and (4) justice. This "principle-based" approach has been challenged. Critics believe it is based too heavily on individual autonomy and liberalism. As Renée C. Fox remarks, "[U.S. bioethics] downplays communal values and qualities of the heart, like

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[287] H.M. Kuitert, "Using Genetic Data: A Moral Assessment of the Direct Social Consequences" in *The Social Consequences of Genetic Testing*, Proceedings of a Conference on 16-17 June 1988 (The Hague, Netherlands Scientific Council for Government Policy, 1990) 31 at 40.

[288] T.L. Beauchamp & J.F. Childress, *Principles of Bioethics*, 3rd ed. (Oxford University Press: New York, 1989). For a recent discussion of the four principles in all fields of health care and bioethics, see Gillon & Lloyd, eds, *supra*, note 152.

caring, kindness, devotion, compassion, generosity, service, altruism, sacrifice, and love. These values involve recognizing and responding to close and distant others in a self-transcending way–to 'neighbours' and 'strangers,' members of future generations in distant lands, as well as 'sisters' and 'brothers' who inhabit this time and this familiar place."[289] New bioethical approaches have emerged: feminist, phenomenological, narrative and hermeneutical –the latter being described by Leder as "the very space wherein [all] these perspectives are articulated and engage in dialogue."[290] Although I do not discuss these approaches in detail, I have been influenced by them. Apart from anything else, I acknowledge that a strict focus on autonomy cannot offer consistent guidelines for testing in the workplace. By analyzing the problems and pointing out the presuppositions of *every* approach, I come closest to hermeneutical analysis. But I cannot discuss any of these in depth. The following is an introduction. It calls for further inquiry. It is, in short, a description of the issues at stake.

The following discussion of bioethical principles indicates that the use of genetic information presents specific ethical problems. If genetic testing in the workplace is allowed, these should be taken into consideration. At the very least, observers should ask whether testing in the context of employment promotes or undermines important values.

A. Autonomy

In our society, autonomy is often seen as one of the most essential attributes, if not the most essential one, of all persons. Autonomy is the condition for individual morality. The development of this notion has been associated with Kant. According to Kant, rational and

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[289] R.C. Fox, "The Entry of U.S. Bioethics into the 1990's. A Sociological Analysis." in E.R. DuBose, R. Hamel & L.J. O'Connell, *A Matter of Principles? Ferment in U.S. Bioethics. (Trinity Press International: Valley Forge, 1994) 21 at 53.*

[290] D. Leder, "Toward a Hermeneutical Bioethics," in DuBose, Hamel & O'Connell, *supra*, note 289, 240 at 253.

self-determining agents should be treated as ends in themselves, not merely as means. We owe others, as persons, respect for their capacity to make decisions as rational agents. Autonomy is a deontological principle.[291] It is not valued in terms of its consequences but because it is the essence of being a person with the potential for choice and thus with moral responsibility. A minimal level of autonomy is deemed essential for holding people accountable for their acts.

Feinberg's description of autonomy includes two aspects that have been translated into legal rights.

> The kernel of the idea of autonomy is the right to make choices and decisions –what to put into my body, what contacts with my body to permit, where and how to move my body through public space, how to use my chattels and physical property, what personal information to disclose to others, what information to conceal, and more. Some of these rights are more basic and more plausible treated as indispensable than others. Put compendiously, the most basic autonomy-right is the right to decide how one is to live one's life, in particular what skills and virtues to cultivate, what career to enter, whom or whether to marry, which church to join, whether to have children, and so on.[292]

Feinberg's definition is particularly powerful for this discussion of genetic testing in the workplace. He recognizes the importance of autonomous, self-determining beings, to make "life choices." This includes making decisions about health, work (career) and reproduction (children).

This way of thinking has been translated into concrete rights and obligations in the context of health care:[293] the right of patients to refuse treatment and the obligation to obtain informed consent from patients or their representatives; the obligation to accept decisions made by patients even when these seem unwise; and the obligation to keep medical

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[291] See H.T. Engelhardt, *The Foundations of Bioethics* (New York: Oxford University Press, 1986) at 81-83.

[292] J. Feinberg, *The Moral Limits of the Criminal Law, Part III: Harm to Self* (New York: Oxford University Press, 1986) at 68.

[293] See R. Gillon, "Medical Ethics and the Four Principles." preface of Gillon & Lloyd, eds, *supra*, note 152 at xxii-xxiii.

information confidential. Two different aspects of autonomy can be distinguished here. First, autonomy implies that people have the right to make decisions about their own health and cannot be subjected to treatment or testing without consent. Then, too, autonomy presupposes the existence of a private sphere. Some aspects of life are considered so private that people, as autonomous persons, should retain complete control over who knows about them.

1) Privacy

The word "privacy" is a general term that refers to a realm of intimacy. It also suggests the transfer of information. Several definitions have been introduced to describe privacy.[294] Parent defines it as "the condition of not having undocumented personal knowledge about one possessed by others. A person's privacy is diminished exactly to the degree that others possess this kind of knowledge about him."[295] The right to privacy aims at protecting wrongful invasions into this private sphere.

For George J. Annas, privacy includes both the classical common-law right to be let alone and the more recent right of "informational privacy."[296] Legally, in fact, privacy serves two masters. It "involves a condition of limited access to a person" as well as "the right of individuals . . . to have some element of their person or personal life free from intrusion by others."[297]

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[294] For an overview, see W.A. Parent, "Privacy, Morality, and the Law" in J.C. Callahan, ed, *Ethical Issues in Professional Life* (New York: Oxford University Press, 1988) 215.

[295] *Ibid.* at 216. "Undocumented" refers to what has not already been made public in the media or through other sources. Parent rejects the often-used notion of privacy as "the right to be let alone" or the right to control significant personal matters, because these definitions would confuse privacy with liberty.

[296] G.J. Annas, "Rules for Gene Banks; Protecting Privacy in the Genetics Age" in T.F. Murphy & M.A. Lappé, eds, *Justice and the Human Genome Project* (Berkeley: University of California Press, 1994).

[297] Rothstein, *supra*, note 258 at 133.

Intimate information about someone's medical condition falls under the category of privacy. And this, of course, is what matters in the context of genetic testing in the workplace. Genetic information refers to very essential aspects of a person.[298] As the Danish Council of Ethics expresses it, "[t]he unique genetic blend is an essential contributing factor in making a person what and who he is."[299] Alexander Morgan Capron describes genetic information in the same way as "*inherent in* –and, indeed, one might say, *constitutive of*– an individual."[300] Never before has it been possible to determine so much about health and prospects for the future on the basis of tests performed on human tissue. Indeed, the volume of very intimate personal information now available might present very specific problems.[301] Many now fear the possibility that even psychological traits and behavioral tendencies might be discernable through genetic testing. For many, this would be an invasion of the most intimate aspects of life for both them and their families. Hence the call for control.

There are many reasons why people might not want information about their health freely distributed. Consider the fear that genetic information could lead to stigmatization and discrimination. Consider also the desire that anonymous others –or even family members –not be informed about health and other private matters.

But is the fear of stigmatization or discrimination a good enough reason to make of privacy an absolute value? Hiding genetic information, after all, could accentuate fears and prejudices. Proper genetic education might make people realize that we all have unique genetic constitutions and that most of us carry some abnormal genes. Secrecy makes it impossible to give genetic disability a presence in society. When "everyone realises that he

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[298] See Rowinski, *supra*, note 158 at 407; M.A. Lappé, "Justice and the Limitations of Genetic Knowledge" in Murphy & Lappé, eds, *supra*, note 296, 153 at 155 and L.B. Andrews & A.S. Jaeger, "Confidentiality of Genetic Information in the Workplace" (1991) 17:1-2 Am. J.L. & Med. 75 at 77.

[299] Danish Council of Ethics, *supra*, note 274 at 61.

[300] *Supra*, note 37 at 685.

[301] *Ibid.* at 63.

or she is a carrier there can be no stigma."[302] Hidden diseases are more frightening than visible ones, moreover, and those suspected of being affected are often treated harshly. The history of AIDS suggests that absolute privacy is counterproductive from this point of view. Actually, inherited disorders are made socially acceptable when represented publicly by real people. The Nuffield Council on Bioethics mentions that most participants in a study on cystic fibrosis carriers were in favour of testing and that they did not feel stigmatized by the results. Most of those affected talked about it with family and friends.[303] The Council also cites a submission of The Fragile X Society, which stated: "no family has said that it has experienced this (stigmatization) as a problem; on the contrary, many have found their children easier to accept and deal with once they have an explanation for their problem."[304]

It is true that privacy can be particularly important in connection with against the use of genetic information by anonymous third parties, those who have no emotional commitment to the people being tested. In this context, it is worth noting the development of large computerized genetic registers (with information on individual carriers, families and even entire populations).[305] There is a very good reason for concern about this: insurance companies could exclude people from coverage on the basis of information from employers. Future employers, moreover, might seek genetic information. But pointing out the fact that personal information might be used by others is not a justification of the need for protection. The question remains: do others, such as employers, have a legitimate interest in this information? I will discuss the matter later. For the time being, I note merely that our society's interest in protecting privacy is well established. Genetic information, being intimate medical information that reveals more about someone's condition than any other

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[302] J. Burn, "Screening for cystic fibrosis in primary care" (1993) 306 B.M.J. 1558 cited in Nuffield Council on Bioethics, *supra*, note 251 at 79.

[303] *supra*, note 251 at 78-79.

[304] *Ibid.*

[305] See in general: Annas, *supra*, note 296 at 75; A. DeGorgey "The advent of DNA databanks: implications for information privacy" (1990) 41 Am. J.L. & Med. 381-398; see also: Billings *et al.*, *supra*, note 101 at 481; Harper, *supra*, note 24 at 463.

information, clearly belongs to the domain of privacy. But under what circumstances, if any, might privacy be limited?

2) Confidentiality

Although confidentiality and privacy are related, especially in the context of medicine, they should not be confused. Confidentiality implies the existence of a bond, very often in a professional context. It is based on a relation of trust. People reveal information about which they want no one else to know. Sissela Bok puts it nicely: "Confidentiality refers to the boundaries surrounding shared secrets and to the process of guarding these boundaries."[306] The subject of a confidential exchange might be considered "private," the kind of information that is protected, but it might not be. Confidential information can be merely trivial, not personal. Essential in the notion of confidentiality is the obligation not to violate someone's trust, the obligation to keep something secret.

This is well established in the physician-patient relationship. The Hippocratic oath already imposed on physicians the duty not to speak about information given to them by their patients. According to its Code of Ethics, The Canadian Medical Association puts physicians under an obligation to "keep in confidence information derived from a patient or a colleague regarding a patient, and divulge it only with the permission of the patient except when otherwise required by law."[307] An authoritative American report, that of the President's Commission for The Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Screening and Counselling for Genetic Disorders, recommends the same thing: genetic information should be kept confidential and divulged to others only with the consent

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[306] S. Bok, *Secrets: On the Ethics of Concealment and Revelation* (New York: Random House, 1983) at 119.

[307] Art.7 Code of Ethics, Canadian Medical Association, reprinted in J. Downie & F. Baylis, comps, *Codes of Ethics: Ethics Codes, Standards and Guidelines for Professionals Working in a Health Care Setting in Canada* (Toronto: Department of Bioethics, Hospital of Sick Children, 1992) at 35.

of those who have been tested (or in a few other specific circumstances).[308] The Professional and Ethical Guidelines of the Canadian College of Medical Geneticists is more precise about potential exceptions to the rule. Geneticists must respect the confidentiality of information obtained from their patients "unless it can be shown this is likely to produce significant detrimental effects to the health of other individuals, currently or in the future."[309]

Because the duty of confidentiality involves a special relation of trust, it is necessary to examine the context of testing. What applies to the relationship between physicians and patients does not necessarily apply to that between employers and employees. Physicians who act as agents of employers, it has been argued, are not in a relation of care with other employees. According to some, there would be no physician-patient relationship in these circumstances and no legal duty of confidentiality toward employees.[310] Guay, Knoppers and Panisset argue convincingly, particularly in relation to genetic information, that privacy should be guaranteed in this case as well. Even though employees must transmit some personal information to their employers, the latter do not have an unlimited interest in the health of their employees. Consequently, information should not be required of employees unless it is directly linked to work. That way, a core of intimacy would be protected.[311]

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[308] President's Commission for The Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Screening and Counselling for Genetic Disorders: A Report on the Ethical, Social and Legal Implications of Genetic Screening, Counseling and Education Programs* (Washington: U.S. Government Printing Office, 1983) at 42 [hereinafter President's Commission], mentioned in Rowinski, *supra*, note 158 at 408. For a discussion on the issue of "consent" see *infra* at 112.

[309] Canadian College of Medical Geneticists, Professional & Ethical Guidelines, reprinted in Downie & Baylis, compls, *supra*, note 307 at 31.

[310] Rowinski, *supra*, note 158 at 409 and Office of Technology Assessment, U.S. Congress, *The Role of Genetic Testing in the Prevention of Occupational Disease* (Washington: U.S. Government Printing Office, 1983) at 118. Some argued that occupational physicians are not bound by professional secrecy; G.P. Dancosse & B. Winters "Le médecin de l'entreprise et le secret professionel" (January 1983) Médecin du Qué. 87, referred to by Guay, Knoppers & Panisset, *supra*, note 90 at 290.

[311] Guay, Knoppers & Panisset, *supra*, note 90 at 291.

An American court also affirmed that employers should not know the details about employees' health. In *Horne* v. *Patterson*, the Alabama Supreme Court had to settle the claim of an employee who sued his physician for disclosing without consent information about his health to his employer. This disclosure had resulted in his dismissal. The court, affirming that the physician had a duty of confidentiality, noted: "Nor can it be said that an employer is necessarily a person who has a legitimate interest in knowing each and every detail of an employee's health."[312]

The Code of Ethics of the International Commission on Occupational Health goes in the same direction. It proclaims that "[i]ntegrity in professional conduct, impartiality and the protection of confidentiality of health data and of the privacy of workers are part of these obligations [of the occupational-health professionals]."[313] It states explicitly that "[t]he results of the examinations . . . must only be conveyed to management in terms of fitness of the envisaged work or of limitations necessary from a medical point of view in the assignment of tasks or in the exposure to occupational hazards."[314] The importance of keeping medical files confidential is stressed, but, with regard to access to these files, reference is made to national laws and regulations.

No professional code of ethics can prevent employers from obtaining access to files kept by their "health agents" unless prohibited from doing so, in addition, by law. If genetic information is to be kept confidential, strict rules must be established to regulate the context in which testing can take place and/or to establish by law the duty of confidentiality.

The issue of the confidentiality of medical information is very important when it comes to genetic testing. I cannot discuss this matter in detail here. It should be kept in mind, however, that explicit protection of the genetic information kept in medical files is essential if we want to offer protection against inappropriate use of it by employers. It is not enough

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[312] *Horne* v. *Patterson* (1973), 287 So. R. (2d) 824 at 830-831; also discussed by Becker, *supra*, note 152 at 299-300.

[313] International Labour Office, *supra*, note 22 at 102.

[314] *Ibid.* at 101.

merely to prohibit employers from requiring tests, after all, if they still have access to medical files that contain the same information.[315]

3) Informed consent

This application of autonomy, too, is well established. In the context of genetics, it has become very important to ensure that people maintain at least some control over what happens to them. It has been argued that autonomy calls for "voluntary testing based on autonomous choice, with the participants having full information."[316] This implies that employees should not be submitted to genetic testing without consent and that they must make their own decisions on the basis of test results.

On the basis of autonomy, of course, individuals may refuse to be tested. This could be of major importance in the case of genetic disorders that can be neither treated nor prevented. Many would prefer not to be informed about any predisposition. As I have already observed, genetic information can be very disturbing, especially when it refers to fatal diseases.

The right to make treatment decisions includes the right to refuse even life-saving treatments. In Canada, this has been recognized in *Malette* v. *Schulman*.[317] In this case, the Ontario Court of Appeal declared that a physician who imposed a blood-transfusion on a Jehovah's witness, knowing very well that she would refuse it if she were conscious, was liable to the charge of battery. A Québec court, too, recognized the right of a patient to be disconnected from a respirator on which she was dependent.[318]

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[315] For an overview of "strategies for protection" in the context of the workplace, see Andrews & Jaeger, *supra*, note 298; Rothstein, *supra*, note 258 at 138-141 and Greely, *supra*, note 164 at 276-280.

[316] B.M. Knoppers & R. Chadwick, "The Human Genome Project: Under an International Ethical Microscope," (1994) 265 Science 2035.

[317] *Malette* v. *Schulman*. [1990] 67 D.L.R. (4th) 321 (Ont. C.A.).

[318] *Nancy B.* v. *Hôtel-Dieu de Québec* (1992), 86 D.L.R. (4th) 385 (Q.S.C.)

If even life-saving treatment may be refused, it could be argued, surely employees may choose working environments in which they are merely at risk of being harmed. But one important distinction can be made. In cases of treatment refusal, the right to refuse is based not only on respect for autonomy as "choice" but also on the idea that forcing treatment is intrusive. The right to refuse treatment seems to become more forceful when the chances of recovery are diminishing and the degree of bodily invasion is increasing.[319] As to genetic testing in the workplace, the idea of futility is absent. In many cases of treatment refusal, courts deal with patients who are already seriously ill and have often only a limited chance of surviving anyway, or even nothing more than a chance of prolonging life for a short period of time. The situation is clearly different with employees who are actually healthy but choose to run a risk.

One particular feature of the cases on treatment refusal can be invoked for the debate on testing in the workplace. As I say, courts have taken into consideration the degree of bodily invasion in order to determine the right to refuse treatment: the deeper the invasion of bodily integrity, the stronger the justification must be. Employees submitted to involuntary genetic testing would be in a situation very similar to that of patients on whom treatment is forced. This would surely invade bodily integrity. After all, genetic testing requires body tissue. It might not be as obviously invasive as an obligatory rectal examination,[320] but it is still invasive. To be allowed, such testing would require a more substantial justification than, for example, a general health check.

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[319] T. Lemmens, "Treatment Refusal, Assisted Suicide and Euthanasia in the United States and Canada" (1995) 52:2 British Medical Bulletin (forthcoming).

[320] See e.g. *R.* v. *Greffe* [1990] 1 S.C.R. 755, in which the a majority of the Supreme Court held that, under the circumstances of this case, a rectal examination was unjustified, given its intrusiveness and the impact on human dignity and bodily integrity.

4) Genetics and the challenge to autonomy

Although the notion of autonomy (including the right of people to make treatment decisions and to protect their own privacy) seems to be very important in the context of genetics, the fact is that genetics also challenges it. For good reason, Capron points out the importance of one question in particular: "[I]in light of the genetic connections that bind people to one another, in terms not only of inheritance but also of molecular diagnostics, what are the proper meaning of 'autonomy' and 'privacy'?"[321] Although genetic constitution –that is, the entire combination of base pairs –is unique, genes taken separately are not. Specific parts of the genome are inherited from one parent and shared with other family members. Mutations are most frequently parts of familial, ethnic and racial patterns. These mutations tell us much about others. As a result, they can be of crucial importance for allowing others to make appropriate health care decisions. In a way, then, genes are part of the "public domain."[322] This compelling interest of others in matters related to personal health could be invoked to challenge the right of informed consent and the duty of confidentiality.

As I mentioned before, family co-operation is often necessary to determine whether people are affected by genetic disorders. This is the case when genetic markers are used to establish the genetic patterns of family members.[323] It could be argued that family members have a duty to participate in such testing. This would clearly affect their right of informed consent and might undermine the confidentiality of medical information.

The compelling interest of others might also establish a duty to warn others –especially in connection with preventive measures and reproductive decisions. This issue is not new. Two things, however, are new: the amount of information available and the number of interests others might have in anyone's genetic constitution. For Bok, the dilemma "resembles all the choices through the ages about whether or not to reveal to intimates and

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[321] Capron, *supra*, note 37 at 694.

[322] See Danish Council of Ethics, *supra*, note 274 at 61-62.

[323] See *supra*.

future spouses that someone suffers from incurable venereal disease, sexual problems, a recurring psychiatric condition, or a degenerative disease as yet in its early stages. But it has taken a new frequency because there is now so much more information, especially of a genetic nature. . . . With increased knowledge of risks, therefore, the collective burden of confidentiality has grown as well."[324]

Since the case of *Tarasoff* v. *Regents of the University of California,*[325] it has been argued often that when there is a clear and serious danger to third parties, physicians have a duty to disclose confidential medical information.[326] This duty has received a lot of attention in connection with the disclosure of HIV status to the sexual partners of patients.[327] Many recognize that the interests of others can justify disclosure but prefer to talk about a "privilege to warn."[328] Sonia M. Suter argues that, in the context of genetics, counsellors have a conditional privilege to warn family members about the risk of being affected by a genetic disorder but that "courts or legislators should never compel them to do so."[329] She points out, correctly, that the degree of risk and the potential source of harm vary from one

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[324] Bok, *supra*, note 306 at 235.

[325] *Tarasoff* v. *Regents of the University of California*, (1976) 551 P. Rep. (2d) 334 (Cal.S.C.). In *Tarasoff*, the California Supreme Court held that a psychotherapist had a duty to warn others of serious dangers, even if this involved divulging confidential information obtained in the physician-patient relation. For the Court, the therapist breached his duty of care by not informing Tatiana Tarasoff that his patient had expressed his intention of killing her.

[326] Miller, *supra*, note 145; for an in depth discussion of the issue of disclosure, see Andrews & Jaeger, *supra*, note 298 at 87-106; see also Suter, *supra*, note 34 at 1874-1877.

[327] Suter, *supra*, note 34 at 1877 and references there.

[328] See, for example, H.P. Glenn *et al.*, *HIV Infection, AIDS and Privacy, Working Paper* (Montreal: McGill Centre for Medicine, Ethics and Law, 1990) at 76; Becker, *supra*, note 152 at 295. For a good discussion in the context of genetics, see Suter, *supra*, note 34 at 1877-1887.

[329] *Ibid.* at 295.

genetic disease to another. In the case of problems involving genes, unlike those involving violence or contagion, the behaviour of patients presents no foreseeable harm. The only risk is that family members are unaware of having a mutant gene.[330] Not being informed does not endanger them directly. At worst, it would deprive them only of opportunities to prevent or slow down the onset of disease. In the case of diseases such as Huntington's, informing family members has no direct health benefit. On the contrary, harm can result from disclosure of the risk factor. In many of the most severe disorders, close family members are often aware of being at increased risk. For Suter, the privilege to disclose takes on importance only "if there is a clear imbalance of harm in favour of disclosure."[331]

Wertz and Fletcher argue that "[a]n ethics of care more accurately reflects geneticists' decision-making in actual practice than does an ethical view derived from basic ethical principles."[332] The ethics of care implies that patients should be approached "in terms of interactive relationships"[333] The duty to disclose genetic risks has its place under such approach. For Wertz and Fletcher, disclosure should not be limited to immediate family members. According to them, there is an ethical obligation to inform all family members who are at risk for a condition.[334]

The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Screening and Counselling for Genetic Conditions states also that the duty of confidentiality can be overridden–but only if "(1) reasonable efforts to elicit voluntary consent to disclosure have failed; (2) there is a high probability both that the harm will occur if the information is withheld and that the disclosed information will actually be used to avert harm; (3) the harm that identifiable individuals would suffer

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[330] *Ibid.* at 1883. This is also argued by Park & Dickens, *supra*, note 267 at 71.

[331] *supra*, note 34 at 1883.

[332] Wertz & Fletcher, *supra*, note 146 at 214.

[333] *Ibid.* at 213.

[334] *Ibid.* at 222.

would be serious; and (4) appropriate precautions are taken to ensure that only the genetic information needed for diagnosis and/or treatment of the disease in question is disclosed."[335]

In conclusion: whether disclosure seems acceptable and appropriate depends on various factors that must be determined case by case. The following factors are particularly important for genetic disorders: (1) whether family members are closely related and, therefore, easily identifiable; (2) how severe the disorder is; (3) whether disclosure could result in the prevention of harm; and (4) whether disclosure could result in serious harm to the person being tested.

It is difficult to determine the extent of the duty of confidentiality. This is another reason to limit genetic testing to the context of health care. The relationship between employers and employees is defined primarily by work and economic interests. This is not the appropriate context to deal with tension between the duty of confidentiality (for the benefit of employees) and the duty of protection (for the benefit of those who have no relationship with the employers). How can anyone either impose the duty or grant the privilege of disclosing very intimate and complex health information to people who are not even in a relation of care with those being tested?

B. Beneficence and Non-maleficence

The principle of beneficence reflects the purpose of every medical treatment: promoting the health and well-being of patients. Non-maleficence imposes the duty of not harming them. "Whenever we try to benefit others," writes Raanan Gillon, "we inevitably risk harming them –so in the context of health care, which is committed to benefiting others, it is essential to

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[335] President's Commission, *supra*, note 308 at 44; discussed by Becker, *supra*, note 152 at 295-296 and Wertz & Fletcher, *supra*, note 146 at 222.

consider the principles of beneficence and non-maleficence together."[336] It has been argued that beneficence is contingent and non-maleficence absolute. Beneficence would be an imperfect moral duty, then, involving an obligation toward only some people; after all, we cannot benefit everyone. Non-maleficence, on the other hand, would be a perfect duty; we can agree not to harm anyone.[337] This approach has been criticized cogently by Nicholson. Actions can be seen as harmful to others even when not immediately visible and even if those harmed remain unknown.[338]

In exercising medical care, the potential for improvement must be balanced against the risk for harm. Non-maleficence imposes caution on health-care professionals: in striving for the good and taking risks, there must be a positive balance. Although it is often impossible to exclude every form of risk, a net benefit must result from the intervention. This immediately indicates the problem in applying these principles: it is often very difficult to balance the risks for harm against the probabilities of benefit. Medical treatment nearly always involves risk, but it can also provide the greatest possible benefits.

Clearly, genetic testing in the workplace can be helpful to employees. It can be used to prevent medical problems. It can be used to inform people of their susceptibilities. It can be used to help employees make well-informed decisions for the protection of their health. The principle of beneficence requires that counselling be provided when necessary. Non-maleficence prohibits physicians from performing medical procedures that expose employees to harm without the expectation of benefit. It could be argued that this is precisely what happens when testing is performed to exclude people from work, especially if exclusion is unnecessary for the health of those being tested. Test procedures themselves are seldom

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[336] Gillon, *supra*, note 293 at xxiii.

[337] R. Gillon, *Philosophical Medical Ethics* (John Willey: Chichester, 1984) cited by R.H. Nicholson, "Limitations of the Four Principles" in Gillon & Lloyd, eds, *supra*, note 152 at 269-270.

[338] *Ibid.* at 268; see also *supra*.

risky, to be sure, but the results of testing can be seriously harmful.[339] That is the reason behind a comment by Knoppers and Chadwick: "[T]here is consensus that predisposition testing should be limited to diseases that are treatable or preventable."[340] This would mean that no testing should be provided for diseases such as Huntington's. Moreover, it could be argued, testing for the sole purpose of excluding specific employees could be considered a harm in itself. Some even argue that "to offer an individual a contract on condition that he sacrifices his privacy conflicts with not doing harm as the minimal requirement for every pre-contractual situation."[341]

It has also been argued that systematic screening should be offered only to those who are at risk for serious genetic disorders.[342] Because health resources are limited, choices must be made about the accessibility of genetic testing and the implementation of systematic testing programmes. Counselling is usually necessary both to explain precisely what the results mean[343] and to provide support. The principles of beneficence and non-maleficence could be invoked to complement an overly stringent application of autonomy, imposing a duty on those who perform genetic tests to provide adequate support. Many people would feel very uncomfortable about making decisions totally on their own; they would benefit greatly from guidance.

Beneficence and non-maleficence are products of the typical doctor-patient relationship. They have been very useful in limiting the power of physicians to conduct clinical research on patients. The ultimate factor in doctor-patient relationships should always be: what can be of benefit for the patients and is not disproportionately risky.

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[339] This limits the autonomy of those who, unlike many others, really want to know what the risks are? The beneficence and non-maleficence principles can conflict with autonomy.

[340] Knoppers & Chadwick, *supra*, note 316 at 2035.

[341] Kuitert, *supra*, note 287 at 40.

[342] Knoppers & Chadwick, *supra*, note 316 at 2035.

[343] *Ibid.*

Genetic research, however, has broken down the exclusive relationship between physicians and patients. Other parties have become involved. As soon as beneficence and non-maleficence are introduced, the problem pops up again: how to balance personal benefits, which often have an impact on others, and societal benefits? When the public good is involved, these principles –autonomy, beneficence and non-maleficence –cannot resolve the moral dilemmas.

C. Justice

Of the four principles to be discussed here, justice is probably the most all-encompassing and the most ill-defined. It includes the duty to promote communal well-being. This is usually understood to require the fair distribution of benefits. It includes as well the duty to promote equality. The notion of justice can be applied in many ways to defend many views. It could be invoked by employers to argue that they alone should not have to bear the cost of hiring disabled people.[344] It could be invoked by others, however, to argue that employers should take their share of responsibility for employing people with disabilities.

Could the principle justify exclusionary practices in case of susceptibility to workplace hazards? After all, susceptible workers would burden others unduly as a result of their choices? As I have said before, the health of employees has an impact on others, especially when it comes to public health. Could they not be submitted to obligatory testing and even be excluded from the workplace in the name of justice? Epstein seems to suggest this. He considers it "immoral" for employees to take a job knowing that they have genetic disorders that might entail costs for their employers but without informing them.[345] One of his

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[344] See Epstein, *supra*, note 96.

[345] *Ibid.*at 11: "I think that in the case of Huntington's disease it is immoral for a person to marry (or even take a job) and conceal the condition from the potential spouse or employer. The conclusion is valid in commercial settings as well as marital ones so long as the concealment results in selective knowledge to one side that is denied to the other."

arguments in favour of exclusion on the basis of genetic traits, remember, is that the absence of testing leads to an unequal distribution of burdens in the industry.

This way of thinking should be rejected. Epstein's argument is flawed if it is meant to be universally applicable, because it is not as relevant in a system of public health care. The argument cannot offer a moral basis for policy decisions, moreover, because it is purely economic. Otherwise, human relations amount to nothing more than an efficient economy. According to Justice Sopinka of the Canadian Supreme Court, "Human Rights values cannot be over-ridden by business-expediency alone."[346]

Finally, Epstein's argument lacks any nuance, any realistic assessment of the costs and burdens borne by people with genetic disorders. In fact, it does not seem necessarily relevant economically for employers to know that employees will be affected, at some unforeseeable moment, by disease.

Justice is infringed when people are excluded from work simply on the basis of their genotype even though they are perfectly fit for work.[347] In that case, they are treated unequally without reasonable justification. There is no difference in actual health, after all, between the carriers of recessive traits and non-carriers. As I have said, moreover, genetic disorders can have variable expressivity and reduced penetrance. Justice could be infringed if the "asymptomatic ill"[348] were excluded solely because of genotype.

The notion of justice is present, too, in the prohibition of discrimination against people on the basis of traits for which they are not responsible.[349] Exclusionary practices on the basis of genetics can be related to at least four kinds of discrimination.[350] (1) Being affected by a genetic disorder or being carrier of a trait can be seen as a handicap. Excluding a person

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[346] *Zurich Insurance* v. *Ontario* [1992] 2 S.C.R. 321 at 349.

[347] Rothstein, *supra*, note 258 at 134-135.

[348] See Billings, *et al.*, *supra*, note 101 at 479.

[349] See Greely, *supra*, note 164 at 275: "[P]eople should not be "punished" for things that are beyond their control."

[350] See Gostin, *supra*, note 118 at 137-142.

for this, therefore, could be seen as tantamount to discrimination on the basis of handicap. (2) Then, too, genetic traits are often racial or ethnic. Distinctive treatment in connection with the sickle cell trait, for example, could be interpreted as discrimination by race. (3) Moreover, toxins in the workplace could endanger the reproductive system. Excluding either women or men, however, could be interpreted as discrimination on the basis of sex. (4) Finally, it has been suggested that genetic testing could give rise to the creation of a "new social category, a "genetic proletariat."[351] For Gostin, "[d]iscrimination based on genetic factors can be as unjust as that based on race, gender, or disability. In each case, people are treated inequitably, not because of inherent abilities, but solely because of pre-determined characteristics. The right to be treated equally and according to one's abilities in all the diverse aspects of human endeavour is a core social value."[352]

In a recent essay on justice and the human genome project, Marc Lappé says that genetics will increasingly reveal that "genes are not randomly distributed among groups of individuals with disparate ancestry (ethnic origins)"[353] but, on the contrary, follow ethnic and social lines. A big challenge for social policy, therefore, will be whether and how these differences can be taken into consideration without accentuating ethnic, racial and other differences. Several major questions would be raised. Can genetic differences be taken into consideration in a "just" society by compensating for genetic disadvantages but without leading to stigmatization and discrimination? Can differentiating on the basis of genetic traits be used to promote good health but without necessarily requiring genomic conformity?

Social policy should be able to guide the use of genetics so that (1) genetic differences are not embedded in existing racial, ethnic or other biases and (2) scientific discoveries do not increase pressure for genetic conformity. For Timothy F. Murphy, there are several major questions: "[W]ill the genomic project cast a hermeneutic of suspicion over all people

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[351] *Heredity, Science and Society: On the Possibility and Limits of Genetic Testing and Gene Therapy*, Report submitted by a Committee of the Health Council of The Netherlands (The Hague, 1989) at 147.

[352] Gostin, *supra*, note at 112.

[353] *supra*, note 298 at 160.

and especially children? How many tests will a man have to pass to be judged for employment and the resultant social and personal benefits? How many tests will a woman have to pass to buy health or life insurance? How many tests will a child have to pass to be wanted, born and loved?"[354] Without the acceptance of difference, it could be argued, genetics will lead to a decrease in justice. Integration of "genetic diversity" in essential aspects of public life, such as labour, could be very important.

The principle of justice is now one of the major issues in health care. How should we deal with those who need treatment, taking into consideration both limited resources and the needs of others? Should we spend so much money on mapping the human genome? Why not spend the money on more immediate ways of fighting disease?

The justice principle is associated with the future, moreover, not only the present. After all, current actions affect future generations. Think of the analogy with irresponsible use of natural resources, environmental pollution or government spending that undermines the financial stability of a country and thus endangers health care for the next generation. Economic inequality creates gulfs not only between the rich and poor of our own society but also between industrial and non-industrial societies.[355] Here, people wonder if technology is prolonging life unnecessarily; elsewhere, the technology is not available even to do so adequately. Not surprisingly, genetics is still of little use in many countries. Few of the latter have genetic screening programmes that respond even to the most basic needs of inhabitants. Consider the worldwide distribution of geneticists: there are 3,291 in developed countries (serving a total population of 733,928,000) and 989 in undeveloped countries (serving a total population of 3,574,133,000).[356] Even if gene therapy were more successful than it is, undeveloped countries would not be able to afford it.

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[354] T.F. Murphy, "The Genome Project and the Meaning of Difference" in Murphy & Lappé, eds, *supra*, note 296, 1 at 9.

[355] Nicholson, *supra*, note 337 at 270.

[356] Wertz, *supra*, note 151.

Murphy argues convincingly that "[t]here is no reason . . . why serious arguments against the genome project could not be raised on grounds of resource allocation."[357] He stresses that the genome project, more than any other research programme of its magnitude, will be of use primarily to future generations. A major questions for Murphy, therefore, is this: "[W]hat is the moral argument to be offered that the suffering of people here and now can be sacrificed to expected benefits in the future?"[358] This brings me back to genetic testing in the workplace. Is testing useful only to select future employees? What about the needs of current employees who suffer from health hazards in the workplace? Should research not focus on reduction of these instead?

D. Values in context

This short description of the four principles that prevail in bioethics should give some idea of the issues at stake when it comes to genetic testing in the workplace. They do not, however, give a clear-cut answer on the approach to be taken. After all, these principles often contradict each other. What could be perceived as beneficent to some people could be perceived as extremely harmful to others. The blood transfusion that most people consider a way of saving lives are considered by Jehovah's Witnesses a form of rape that could exclude them from eternal life. Either way, perceptions fit into coherent schemes of values.

As I have observed, moreover, position in society influences perceptions of risk and benefit. Even communal consensus on what is "good" does not necessarily mean that everyone wants to act accordingly. People are rational in some ways and non-rational or even irrational in others. They are clearly influenced not only by reason but also by emotions, preferences, impulses, cravings and so forth. Consider autonomy and beneficence. Some people choose dangerous or unhealthy jobs. On the basis of autonomy, their choice

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[357] Murphy, *supra*, note 354 at 5.

[358] *Ibid.* at 3.

should be accepted. On the basis of beneficence, however, it must be rejected. Or consider autonomy and justice. The latter is a balancing principle, which imposes limits on autonomy. But what are the limits? Justice itself must be understood in the context of a given society and its culture. How far can the demands of justice go in limiting the exercise of autonomy?

People interpret and apply ethical principles in the context of pre-existing values. According to Weinreb, justice is an unattainable ideal, a desert. A completely just human society would have no room for self-determination. If everything were as it should be, after all, why would anyone ever have to make choices? "All being always and everywhere exactly what is just, there would be no space for the exercise of freedom."[359] Justice is about attempts to find a balance between liberty and equality. "The idea of equality affirms that the conditions for the exercise of liberty have also a value attached to them and that some conditions are more acceptable than others."[360] The central questions remain. How do we find the balance? On what basis do we balance these notions?

I argue that the content given to justice (as well as to other ethical notions) depends on perceptions of what it means to be an autonomous person, what it means to live in a specific society and culture. And I suggest that law, being an instrument to build and support society, should enable self-determination and safeguard a framework in which shared values can flourish. One crucial element in the process of self-determination is liberty, as it is expressed in the notion of autonomy. Autonomy, as I say, seems to have at least some content. It implies that self-determining persons have identifiable bodies over which they exercise a minimal level of control. Without bodily identity, there is no person. Respecting the liberty of people means, among other things, respecting the decisions they make about their bodies. In addition, it means respecting their integrity – including their genetic integrity. The Canadian Supreme Court clearly adopted this view in *R.* v. *Dyment*, in which it stated that

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[359] L.L. Weinreb, *Natural Law and Justice* (Cambridge: Harvard University Press, 1987) at 221.

[360] *Ibid.* at 183.

"the use of a person's body without his consent to obtain information about him, invades an area of personal privacy essential to the maintenance of his human dignity."[361]

But liberty is more than the right to be left alone and to make free choices. Liberty is not a final goal or an independent value. People value it as a way of defining themselves in relation to others. For Charles Taylor, liberty must be seen in a broader context. It has meaning only in relation to other important values. The significance of every choice is determined by the value attached to it by the community. In *The Malaise of Modernity*, Charles Taylor describes liberty in the following way:

> "It may be important that my life be chosen, as John Stuart Mill asserts in *On Liberty*, but unless some options are more significant than others, the very idea of self-choice falls into triviality and hence incoherence. Self-choice as an ideal makes sense only because some *issues* are more significant than others."[362]

Taylor also argues convincingly that equality, to have any content at all, requires us to recognize the existence and value of some commonly shared properties. Other people, for instance, are recognized as "beings capable of reason, or love, or memory, or dialogical recognition."[363] Others share a common core of values with us and participate in a similar societal project, even if the exercise of individual liberty often differs.

It is essential, though, that participants in a community of shared values dispose of the essential tools for self-determination. They must be able to invent themselves in relation to others, and they must see their choices recognized by others. It seems then, that real self-determination requires the opportunity to make choices that will be recognized as valuable by others. People are "judged" by their contributions to the community. Indeed, supporting shared values is essential for the recognition of value in any choice.

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361 *R.* v. *Dyment* [1988] 2 S.C.R. 417 at 432. In this case, the Supreme Court dealt with the question whether taking bodily fluids of a person without consent constituted an "unreasonable search or seizure" in terms of S.8 of the Charter.

362 C. Taylor, *The Malaise of Modernity* (Concord: Anansi 1991) at 39.

363 *Ibid.* at 51.

Interestingly, some of the core values that Taylor identifies as characteristic of our culture are important elements in the discussion on genetics and the workplace. For Taylor, our culture is focussed on "affirmation of the ordinary life" or "the sense that the life of production and reproduction, of work and the family, is what is important for us."[364] Active participation is an essential part of meaningful liberty. In our culture, being an "active member" is connected to labour (in the wide sense of that term). Self-realization through labour has been given a central place. Work has become essential as a core value of "the ordinary life." For Kuitert, "[w]ellbeing means a fair chance of getting a job, of playing part [sic] in society, of being treated with respect."[365] Work has been recognized even as a "fundamental right" in The Universal Declaration of Human Rights, the source par excellence to discover what is actually recognized as a major value of our civilization. Then, too, the importance of work is expressed in the Canadian Human Rights Act; the Canadian Human Rights Act is one of the basic mechanisms that protect citizens against employment discrimination. Section 2 of the Act contains the following statement of purpose, "The purpose of this Act is to extend the laws in Canada to give effect . . . to the principle that every individual should have an equal opportunity with other individuals *to make for himself or herself the life that he or she is able and wishes to have, consistent with his or her duties and obligations as a member of society*, without being hindered in or prevented from doing so by discriminatory practices . . ."[366]

Decisions about reproduction, too, are considered essential in the exercise of self-determination. Neither nature nor culture decide any longer that children should be born. Procreative decisions have become personal ones. According to the American Supreme Court, "[i]f the right to privacy means anything, it is the right of the individual, married or single, to be free from unwarranted governmental intrusions so fundamentally affecting a

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[364] *Ibid.* at 104.

[365] Kuitert, *supra*, note 287 at 42.

[366] S.2 Canadian Human Rights Act, R.S.C. 1985, c. H-6. My italics.

person as the decision whether to bear or beget a child."[367] This right to make reproductive decisions has a particular importance in the context of the workplace. As I have said in relation to the *Johnson Controls* case, protection of future children has been invoked to exclude some employees (so far, mainly women) from the workplace.[368] If the decision to reproduce or not is a fundamental part of individual self-determination, it is not obvious why employers should be allowed to impose health standards for the protection of a future generation.

The principles of liberty and equality can be interpreted in view of these elements. Social policies, in other words, can help people develop themselves within a framework of values. "A harmonious community," writes Weinreb, "will subscribe to principles of liberty and equality that are congruent and give a coherent shape to its members' conceptions of themselves as self-determining actors within a determinate social order."[369] Any coherent regulation of workplace relations ascribes value to both self-determination and interconnectedness. Self-determination does not take place within a vacuum. People depend on society as much as it depends on them. This means that the impact of individual actions on family, neighbours and distant others must be taken into consideration. If necessary, regulations must balance procreative liberty and its consequences for others. Workplace policies should take into consideration that respecting equality, to have any significance at all, involves respecting a variety of choices. It seems that choices related to job and family are among the most important for people's self-determination. Regulations in the workplace should enable them to make these choices. They should not merely enable free choices, however, but also support a framework of values within which to make choices.

In short, regulating labour relations should focus attention on the integration of workers and on the inclusion of as wide a variety of employees as possible. Respecting equality should mean, whenever possible, respecting their capacity to participate in valued labour.

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[367] *Eisenstadt* v. *Baird* (1972) 405 U.S. 438, cited by Holtzman, *supra*, note 121 at 222.

[368] *International Union* v. *Johnson Controls* (1991) 113 L Ed 2d 158.

[369] Weinreb, *supra*, note 359 at 233.

Market mechanisms have no value independent of the society and the individuals they should serve. Why should productivity be given more respect, after all, than other values?[370]

IV. Guidelines for decision making.

A. Importance of individual decision making: is consent a sufficient condition?

I have stressed the importance of making decisions, especially those affecting health. The liberty to make these could be used in two ways when it comes to genetic testing in the workplace: (1) consent could be invoked by employers as a shield against liability for exposing employees to health hazards; or (2) consent could be used to legitimate genetic testing as a condition of employment. It could be argued, therefore, that respecting the full autonomy of employees implies respecting the contractual choices they make.

But the exercise of choice never occurs in a vacuum. Once again, it should be seen in connection with a horizon of significance. If some choices are considered more valuable forms of self-determination than others, of course, society should encourage the former and discourage the latter. Consent is an important form of self-determination, to be sure, but is it the most valuable? The answer can be given only in specific circumstances.

This approach is not taken by everyone. At this point, I want to discuss the "law and economics" theory of authors such as Richard Posner. Analyzing this theory is interesting for two reasons. For one thing, it approaches ethical and legal problems in the context of economy. So, of course, does genetic testing in the workplace. Many arguments in the debate over this are based on the way markets function. Even those who give only partial support to this school of thought recognize the importance of economic interests. Then, too, many "law and economics" arguments are present in traditional legal approaches toward this type of problem. By criticizing them, the proposed "law and values" approach becomes

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[370] See Guay, Knoppers & Panisset, *supra*, note 90 at 290.

clearer. My point is that autonomy (represented by the legal notion of "consent") has meaning only in the context of values.

Posner is the clearest representative of an approach that accentuates ways in which respect for the free market fosters personal autonomy.[371] According to this theory, promotion of autonomy is the highest moral goal. The market is based on several things: contractual relations between free, consenting individuals; institutions that support these relations; and the wealth-maximizing transfers between these economic actors. Because these transfers promote autonomy, they are morally attractive. Posner defends an "ethic of free choice" in which government has hardly any role to play.[372] Consent is the basis of transactions that promote both a moral and an economic order. People find greater autonomy and well-being by the exercise of choice. Consent seems to Posner the moral basis of societal interactions, because it promotes autonomy and the distribution of wealth.

This approach is based on an unrealistic view on the autonomy of individuals and the motives that underlie their exercise of choice. Posner gives moral validity to actions simply because they involve choices. However, as Robin West argues, "[c]onsensual acts of commerce, labor, or sexual intercourse are not morally good simply because they are not coerced: a bad trade is still bad, even if it is not theft; a bad job is still bad, even if it is not slavery; and bad sex is still bad sex, even if it is not rape."[373]

Posner states that "whether a worker consents to work in a dangerous environment depends on whether he is paid to do so or tricked into doing so (the dangers may be

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[371] An interesting debate on this issue took place between West and Posner in the Harvard Law Review. See R. West, "Authority, Autonomy, and Choice: The Role of Consent in the Moral and Political Visions of Franz Kafka and Richard Posner." (1985) 99 Harv. L. Rev. 384 [Hereinafter: West, Autonomy]; R.A. Posner, "The Ethical Significance of Free Choice: A Reply to Professor West." (1986) 99 Harv. L. Rev. 1431 and R. West, "Submission, Choice, and Ethics: A Rejoinder to Judge Posner" 99 Harv. L. Rev. 1449 [Hereinafter: West, Submission]. Others share Posner's concern for the economic market without giving it an overtly moral significance: see Epstein, *supra*, note 96 and Viscusi, *supra*, note 270.

[372] See *supra*, note 371.

[373] "Authority," *supra*, note 371 at 399.

concealed)."[374] In the former case, he would argue that truly free choices make the transactions ethical. In the latter case, there is no real consent and the transaction is inefficient; it does not promote the interests of two parties, one being involuntary. But for Posner, law recognizes fraud or duress as a defence against the enforcement of contracts. The application to genetic testing in the workplace is clear. Government should not interfere in undertakings between free agents. Knowing the consequences either way, employees can either give or withhold their consent. The rules of the market supply employees. If employers are too severe in their selection, they will have difficulties finding employees and will have to pay high wages for the happy few that are not screened out. Employers would not be forced to make the workplace less harmful. Government could, however, assure that employees are informed about the existence of harm. Employees could choose freely, in short, and be compensated for any risks by high wages. Under these circumstances, genetic testing is no problem at all. The problem is solved by consent. This idea is expressed in the legal maxim "*volenti non fit injuria.*"

For West, the voluntary character of transactions does not give them the status of moral perfection. People can give consent for many reasons. Society can have a moral obligation to intervene even in consensual relations, which certainly do not always promote well-being. As West argues, "assumption of risk is the very antithesis of autonomy when it entails abandonment, not enrichment, of personal responsibility."[375] She does not claim that choice is necessarily "coercive" even when it amounts to acceptance of serious risk. Indeed, "[i]n the entrepreneurial context as well, risk-taking may or may not be antithetical to the ideal of personal autonomy."[376] She accentuates only the various influences on choice, especially emotions. The latter are constitutive parts of all people. Sometimes, they enrich experiences and choices, and sometimes they render these problematic or even morally questionable. Due to its fluctuating nature, consent should not be seen as a moral value as such. "If we are

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[374] *supra*, note 371 at 1442 (footnote omitted).

[375] "Authority," *supra*, note 371 at 412.

[376] *Ibid.* at 413.

motivationally complex," she writes, "then we cannot delegate to any ambiguously motivated human act such as consent the task of moral legitimation. We cannot infer that a consensual world leaves every individual better off (and is therefore morally superior) simply because all affected parties have consented to it. . . ."[377] So, restriction of contractual liberty can be a valid moral choice in some cases.

This analysis can be linked to that of Draper, which has already been discussed. Draper shows that employees are not necessarily free in choosing a harmful environment. High-risk jobs, for which genetic testing might be of primary importance, are characterized by low turnover. Usually, they are held by relatively unskilled people with few alternatives – certainly not jobs that offer the same wages and benefits.[378] Under these circumstances, consent might be based on economic necessity more than self-determination. Is the "choice to be harmed" of those struggling to earn a living no different from that of people wanting to earn extra money over the summer vacation?

Volenti non fit injuria has absolute moral validity only in a Posnerian universe. Unfortunately, very few people (if any) live in that kind of universe. Their choices are free to some extent, but that does not mean these choices cannot harm them. Regulatory intervention seems necessary to correct an imbalance in power between employers (who provide harmful environments) and employees (who seldom have good alternatives and seldom are in a position to demand better safety standards or genetic monitoring).

Employers should not be allowed to invoke consent as a way of freeing themselves from the obligation to establish healthy work environments. This is recognized by various occupational health and safety laws and by regulations connected to these acts. Ontario's Occupational Health and Safety Act,[379] for instance, provides for a regulatory structure under

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[377] *Ibid.* at 425.

[378] Draper, *supra*, note 123 at 125-128.

[379] *Occupational Health and Safety Act*, R.S.O. 1990, c.0.1.

which health and safety standards are imposed on employers.[380] It requires employers to create health and safety committees, to allow the inspection of work sites and to provide employees with information about potential hazards and how to prevent them. The use of specific chemicals is regulated. Some toxic agents are prohibited. Exposure to others is limited. In fact, whole industries are regulated.

In Quebec, the *Loi sur la santé et la sécurité du travail*,[381] which is of public order, imposes similar obligations on employers.[382] Employers have a general duty to provide their employees with safe work environments. As in other provinces, some industries are submitted to specific occupational health and safety regulations. The law provides for obligatory medical examinations in connection with high-risk jobs, obligatory pre-employment examinations and, in some settings, periodic testing. Clearly, the contractual freedom of both employers and employees is limited.

Although health and safety regulations provide for some forms of obligatory testing and monitoring, this does not mean that employers may, on their own initiative, submit employees to all forms of testing. Consent may not be invoked to defend unlimited testing. Once again, employees are not powerful enough to reject genetic testing as a screening device. This is particularly so in times of high unemployment.[383] Consent offers neither moral legitimation for allowing employees to choose a harmful workplace nor moral justification for submitting potential employees to genetic testing. The relations among employers, employees and employment market create a fundamental imbalance of power, which taints the character of consent. For Guay, Knoppers and Panisset, for example, "[c]ompte tenu de cet élément de contrainte –le seul choix étant pour l'individu de refuser

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[380] See M. Grossman, *The Law of Occupational Health and Safety* (Toronto: Butterworths, 1994) at 6.6-6.7.

[381] *Loi sur la santé et la sécurité du travail*, L.R.Q., c. S-2.1.

[382] For a general discussion of the law in relation to medical testing, see Guay, Knoppers & Panisset, *supra*, note 90 at 257-264.

[383] K.Y.I.J. Adelmund, "The Role of Employees" in Rigter *et al.*, eds, *supra*, note 287, 61 at 63.

l'emploi ou l'avantage retiré du contrat d'emploi – on peut douter de la liberté du consentement."[384] Kuitert also argues that "[f]or the employee or the aspiring policy holder, voluntary screening is never really voluntary; it is obligatory by implication."[385]

In many reports and recommendations on genetic testing, screening for employment purposes is rejected with no distinction made between voluntary and mandatory testing. The Committee on Assessing Genetic Risks, for example, proposes legislation "to limit the type of medical testing employers can request and to ensure that the medical information they can collect is job related."[386] It acknowledges that there might be reasons to test employees, but it makes clear that consent, in itself, does not justify all types of testing. The Canadian Privacy Commissioner, too, recommends that "[e]mployers should in general be prohibited from collecting personal genetic information about job applicants or employees through mandatory *or voluntary* genetic screening [or monitoring]."[387] In its recommendations on workplace testing, the Nuffield Council on Bioethics says that genetic testing should be allowed only for specific policy reasons. It does not say that consent, in itself, can justify testing.[388]

Consent is not a sufficient condition for submitting people to genetic tests. But when tests are done, consent is, in general, a necessary condition. I have already noted that genetic information is highly personal, because it shapes identity and that genetic testing involves

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[384] Guay, Knoppers & Panisset, *supra*, note 90 at 272, referring to G. Nadeau, "L'incidence des chartes canadienne et québécoise sur les contrôles obligatoires en milieu de travail" in Meredith Memorial Lectures, *Le contrat de travail: problèmes et perspectives* (Cowansville: Yvon Blais, 1988) 35.

[385] *supra*, note 287 at 37; see also Adelmund, *supra*, note 383 at 65: "The employee may not be placed in such a position that he is pressured into consenting to genetic screening."

[386] *Assessing Genetic Risks*, *supra*, note 61 at 24.

[387] Privacy Commissoner of Canada, *supra*, note 56 at 86 [my italics].

[388] The fact that no references are made to consent is not the result of neglect. Informed consent is mentioned in most of these documents as a condition when screening is discussed in a medical context.

the invasion of bodily integrity. If self-determination has any significance, testing must involve informed consent. Québec's Code de déontologie des médecins acknowledges this as a fundamental obligation by imposing on occupational physicians the duty to inform every patient of the goal underlying any examination.[389]

So, consent alone justifies neither testing itself nor allowing employees to chose harmful jobs. Some questions remain. Can anything else justify genetic testing? If so, can anything justify testing without informed consent? And what safeguards should be adopted to ensure privacy?

B. Policy considerations justifying genetic testing.

Only very important policy considerations can justify the imposition of genetic testing. When they do, regulations must take into account, as far as possible, the importance of making personal decisions concerning labour, health and reproduction. The potentially damaging aspects of genetic information too, must be considered.

Given the specific character of genetic information and the values at stake, I propose four minimum requirements. (1) Genetic testing should have a sound scientific basis. Governmental quality control might be essential to assess the "scientific merit and efficacy" of new tests before they can be used.[390] Every test should be analysed and judged separately. And every one of these should be able to indicate, at the very least, a clear association between the presence of a genetic mutation and the development of a genetic disorder.[391] The

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[389] R.R.Q., c. M-9, r. 4, art. 2.03.31a); cited by Guay, Knoppers & Panisset, *supra*, note 90 at 273.

[390] *Assessing Genetic Risks*, *supra*, note 61 at 273 and at 292-295; see also recommendation 16 of the Privacy Commissioner of Canada, *supra*, note *56* at 90.

[391] See Nuffield Council on Bioethics, *supra*, note 251 at 64.

latter's occurrence, moreover, should be highly probable.[392] Complex disorders are less likely to meet this requirement than single-gene disorders or single-gene susceptibilities. Tests revealing only slightly higher-than-average risks should not be used to exclude employees. The results of these tests might be important for employees, but they alone should decide what to do about the risks presented by their jobs. (2) There should be no other way to gather the desired information. If a mere fitness test is sufficient to guarantee public safety, genetic tests would be unacceptable. (3) Testing should be allowed only if they are related directly to identified and accepted purposes. The latter should be discussed and established through public debate. Testing should not be allowed as a general way of determining the qualification of employees or potential employees. 4) Health information should remain confidential, also when testing is performed in the workplace. Occupational health workers should have a duty of confidentiality towards employees. They should inform workers about specific health problems and risks. As the Canadian Privacy Commissioner recommended: employees should control genetic information and be able to make their own decisions on the basis of these results.[393] Only in exceptional cases should occupational physicians transfer information to employers, and only the kind of information needed by the latter to make decisions that are recognized as important.

What could acceptable purposes be? As I have already indicated, genetic testing is above all a medical procedure. Two purposes, therefore, are legitimate: (1) ensuring the health of employees; and (2) preventing harm to others.

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[392] Guay, Knoppers & Panisset, *supra*, note 90 at 266.

[393] Privacy Commissioner of Canada, *supra*, note 56 at 31-34 and 86-87: "Recommendation 3: Employers should in general be prohibited from collecting genetic information about job applicants or employees through mandatory or voluntary genetic screening. However, employers should be permitted to screen employees or applicants who volunteer for the screening if the employees or applicants retain absolute control over the genetic samples and any related personal information." (see also recommendation 4 on genetic monitoring and recommendation 5 on the control of information).

1) Health of employees

Existing health and safety regulations concerning high-risk industries already require pre-employment tests and regular monitoring. Genetic monitoring might actually be essential for protecting employees. When reliable monitoring programmes are available for specific toxins, at any rate, employers should be obliged to institute them. It seems reasonable that employees be required to participate if they want to work in these industries. The participation of all might be required in order to establish clear links between chromosomal changes and workplace hazards. Because monitoring requires the participation of many workers and contributes to overall safety, it may be imposed by regulation.

In these cases, however, monitoring should be accompanied by counselling. If serious risks are discovered, employees and governmental authorities dealing with occupational safety should be informed. Employees should be removed from exposure. And control should be exercised to ensure that they can return to work safely.[394] In no case should genetic monitoring or genetic screening be an alibi for not taking all possible measures for making the workplace safer. Safeguards should be established to guarantee the confidentiality of information.

When a clear link has been established between some genetic mutation and susceptibility to a specific workplace hazard, the introduction of genetic screening can also be a reasonable response. Due to the nature of genetic information, though, screening should be an exceptional measure. Regulations should stipulate that the purpose and importance of testing be discussed by all concerned. Testing should be motivated by the need to protect health. Therefore, testing should be part of general health examinations. Genetic tests should be allowed only if they indicate significant susceptibilities to hazards particularly prevalent in specific industries.[395] Testing to find out if people are heterozygous for ataxia telangiectasia,

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[394] *Preussag Métal Inc.* v. *M.U.A., s.l. 8800*, T.A., SA 85 04 292, April 18, 1985 (C. Lauzon), cited by Guay, Knoppers & Panisset, *supra*, note 90. See also other references there.

[395] See Canter, *supra*, note 164 at 325, referring to Drs. Stokinger & Scheel.

say, could be important in occupations involving exposure to radiation (heterozygotes for the trait being considerably more susceptible to cancer as a result of exposure to radiation). Testing for heart disease, on the other hand, would be unacceptable in these industries. It has been argued that "le devoir de protection ne pourrait s'étendre à un droit de procéder à une "fouille" génétique."[396]

Should employees be required to abstain from taking on jobs if they are at risk? Considering the importance of individual decision-making in the area of health, the specificity of genetic information, the importance of work and the danger of systematic discrimination against "high- risk" populations, exclusion on the basis of susceptibility is acceptable only in exceptional cases. People should be free to make their own decisions about risk. Although public agencies may encourage individuals to live in healthy ways, they may not impose healthy ways (unless unhealthy ones endanger the community). People are not prohibited from engaging in dangerous sports, eating fat, drinking alcohol. Nor are they forced to engage in physical exercise or live in healthy areas. Unless the risk is much higher than average, people should be allowed to choose where they want to work.

If the risk is much higher, most people are willing to accept prohibitions –especially when "public" activities are involved. Motorcyclists and some hockey players, for example, are required to wear helmets. For the same reason, some employees are required to wear protective masks or other special clothing.

Regulation of risks in the workplace is particularly important because of the power imbalance. As I say, employees do not always consent willingly to high-risk jobs. The establishment of health and safety regulations is one of the most important developments in the protection of workers. The goal is to impose on employers respect for safety standards instead of discriminating against susceptible employees.

It has been suggested that genetic screening for the protection of employees be permitted in exceptional cases but only after they have been hired. This would prevent discrimination against susceptible applicants. Once they are hired and found susceptible, their employers

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[396] Guay, Knoppers & Panisset, *supra*, note 90 at 262.

should accommodate their needs. This has been proposed by an Interdepartmental Working Group of the Dutch Ministry of Health.[397] Although the approach is valuable in many situations, it seems unrealistic to impose it as a general rule. Big companies can afford to make the necessary accommodations, after all, but small ones would have more difficulties.

In exceptional circumstances – when the risk involved is both direct and serious – removing the right to choose a harmful environment can be justified. The decision should not, at any rate, be left entirely to employers; it should involve employers, employees and interested governmental agencies. Testing should be justified by an important public interest in health. Moreover, employees should be excluded only if reasonable accommodation is impossible and if general workplace safety is at stake. The duty to provide a safe workplace should not be limited to excluding only the employees that are most at risk. Why test for specific susceptibilities, after all, if every employee is at considerable risk?

2) Risk of harm to others

Autonomy is not an absolute value. The actions of one person have an impact on others. Living in a society, therefore, requires the acceptance of limitations on liberty. A second argument invoked to support genetic testing in the workplace, then, is the risk of harms to others. These "others" include fellow employees, people who are served by the employee and the public in general. This has been used as an argument to support testing for drugs, alcohol and HIV/AIDS.[398] Few people would find it unreasonable that airline pilots must take medical examinations and are regularly tested for overall fitness; that train and truck drivers are not allowed to drive while drunk and can be tested for visual capacity; that those

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[397] Cited in *Heredity, Science and Society*, *supra*, note 351 at 145.

[398] The rationality of alcohol and, particularly, drug testing for reasons of public safety is often questioned. For a rigorous discussion, see Ontario Law Reform Commission, *Report on Drug and Alcohol Testing in the Workplace* (Toronto: Ontario Law Reform Commission, 1992). Different forms of testing are discussed in International Labour Office, *supra*, note 22.

with serious psychiatric problems may not guard nuclear weapons or to enter the police force. The importance of integration in the workforce and the right to make health-care decisions do not imply that people should have the freedom to take on jobs in which they endanger others.

Can this argument be invoked to justify genetic testing in the workplace? No general statement about the rationality and acceptability of testing can be made. The merits of every genetic test must be established independently. Ideally, no genetic test should be allowed that is not approved by a government-controlled body.

3) Bona fide occupational requirements and undue hardship

The criteria for determining whether genetic tests may be introduced or not could be inspired by the notions of "Bona Fide Occupational Requirement" (BFOR) and "Undue Hardship." These have been developed by the courts in case law on discrimination in the workplace.[399] Beyond my scope here would be a detailed analysis of either all human-rights provisions or all relevant examples of case law. Worth pointing out, though, are the criteria developed by courts for examining cases of discrimination in the workplace. These indicate what should constitute the reasonable use of genetic testing.

Several codes (including the Canadian Human Rights Act, the Ontario Human Rights Code and the Québec Chartre des droit et libertés de la personne) prohibit discrimination in employment based on grounds such as sex, race, colour, ethnicity, marital status and handicap. A distinction has been made between direct and indirect discrimination. The former refers to situations in which employers refuse to hire people on the basis of characteristics specified in the codes. The latter refers to situations in which employers introduce requirements that people in these categories can seldom meet. Generally speaking,

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[399] For an interesting discussion of discrimination in the workplace and human rights legislation in Canada, see D. Proulx, *La discrimination dans l'emploi: les moyens de défence* (Cowansville: Yvon Blais, 1993). He focuses on the Canadian Human Rights Act and the Quebec "Chartre des droits et libertés de la personne" but refers to case law of other provinces.

the burden of proof is heavier in cases of direct discrimination. Nevertheless, employers accused of direct discrimination can be defended successfully if their practice constitutes a BFOR. Those accused of indirect discrimination can be defended successfully if they are unable to offer reasonable accommodation.[400] They must prove that accommodation would create undue hardship for them.

What constitutes a BFOR? In *Ontario Human Right Commission* v. *Etobicoke*, Justice McIntyre spoke for the majority in defining it as follows:

> To be a *bona fide* occupational qualification and requirement a limitation . . . must be imposed honestly, in good faith, and in the sincerely held belief that such limitation is imposed in the interests of the adequate performance of the work involved with all reasonable dispatch, safety and economy, and not for ulterior or extraneous reasons aimed at objectives which could defeat the purpose of the Code. In addition, it must be related in an objective sense to the performance of the employment concerned, in that it is reasonably necessary to assure the efficient and economical performance of the job without endangering the employee, his fellow employees and the general public.[401]

Courts and jurisprudence have specified the various elements in a BFOR defence.[402] To be judged "reasonably necessary," an allegedly discriminatory requirement must be demonstrably rational and proportional. An employment requirement is rational when its final goal is acceptable and when the required abilities have a direct and substantial link with this goal.[403] The health and safety of employees and the risk to others have been recognized as justifiable grounds for stringent workplace requirements. It is unlikely that courts will

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400 Under the Ontario Human Rights Code, the duty to accommodate is a part of the overall assessment of a BFOR.

401 *Ontario Human Right Commission* v. *Etobicoke* [1982] 1 S.C.R. 202 at 208.

402 See Proulx, *supra*, note 399 at 30-66.

403 See *Ibid.* at 40-41.

accept purely economic reasons as justifications for discrimination.[404] To be rational, as McIntyre suggests, workplace requirements must be focused on the specific nature of the "employment concerned." Employers must prove that their requirements are necessary for specific tasks in their company. Discriminatory requirements are judged case by case. This approach is essential for judging the acceptability of genetic testing in the workplace.

The proportionality requirement contains two elements: (1) the fact that there is no other reasonable and non-discriminatory way of getting the same result; and (2) the duty to evaluate every person individually. So, proportionality includes a duty to judge every case on its own merits. As Proulx maintains, the Supreme Court and human rights courts insist on the need for individual evaluation of employees. For Proulx, rejecting general exclusions based on group characteristics is respectful of the spirit of anti-discrimination legislation. People have the right to be measured according to their individual abilities, not on the basis of presumed characteristics.[405] In relation to genetic testing, it is essential that a proportionality assessment take into account the specific nature of genetic testing: its intrusiveness and its potentially detrimental and stigmatizing effect on individuals, family members and even risk-groups.

Some workplace requirements are technically non-discriminatory but have discriminatory results. Employers must indicate that they cannot reasonably be expected to alleviate the latter. Every case is judged on its own merits. According to the Ontario Human Rights Commission, "[t]he essence of accommodating people with disabilities is individualization. . . . There is no formula for accommodation to alleviate the barriers which confront people with disabilities. Each person's needs are unique and must be considered afresh when a barrier is encountered."[406] When people are genetically at risk, as I have pointed out, they

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[404] See *Etobicoke* at 209 and *Zürich Insurance Co.* v. *Ontario* [1992] 2 S.C.R. 321 at 349 (Sopinka); cited by Proulx, *supra*, note 399 at 38.

[405] *Ibid.* at 52.

[406] "Guidelines for Assessing Accommodation Requirements for Persons with Disabilities under the Ontario Human Rights Code," Introduction, N., [hereinafter: Guidelines] reproduced in B.A. Grosman & J.R. Martin, *Discrimination in Employment in Ontario*

could be assigned to tasks that do not expose them to specific toxins. The Ontario Law Reform Commission, too, is of the opinion that "[a]ccommodation may include transfer of the employee to another job in which the employee can safely perform the essential requirements of the work, or authorized leave from employment for the purpose of receiving medical treatment."[407]

Employers may be relieved of their duty by proving that accommodation would cause undue hardship. This refers to excessive costs, as well as to the safety of either employees or the public (or both).[408] Accommodation may not be required if economic survival would be jeopardized or even if economic stability would be seriously undermined. A mere increase in costs, of course, would not be enough to qualify as undue hardship. Accommodation almost always increases costs. Big companies almost always find it easier than small ones, as I have said, to accommodate the needs of employees at risk by providing an alternative tasks. This is explicitly recognized by the federal Human Rights Commission[409] and the Quebec Commission des droits de la personne,[410] both of which suggest that size be taken into account in establishing what constitutes undue hardship or "une contrainte excessive."

It has been argued that companies should not invoke the future costs of accommodating disabled employees. The Ontario Human Rights Commission states in its Guidelines, for

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(Aurora: Canada Law Book, 1994) at 363-364.

[407] Ontario Law Reform Commission, *supra*, note 398 at 108 (footnote omitted).

[408] For an overview of legislation and guidelines in relation to reasonable accommodation, see Proulx, *supra*, note 399 at 93-105.

[409] Commission canadienne des droits de la personne, Direction générale des programmes antidiscriminatoire, J.G. Savard, directeur général, *Directive procédurale: Mesures d'adaptation raisonnables et contraintes excessives*, 19 July 1993; cited by Proulx, *supra*, note 399 at 99.

[410] Commission des droits de la personne, *Guide d'application de la charte des droits et libertés de la personne à l'intention des employeurs, Mieux gérer en toute équité*, feuillet supplémentaire: *Discrimination indirecte et mesures d'adaptation*, December 1992; cited by *Ibid.* at 101.

instance, that "the current abilities of a person with a disability and the situation's current risks are to be taken into account, rather than abilities or risks which may arise in the future. Where the person has a condition which may cause deterioration of ability over time, the unpredictable nature and extent of future disability cannot be used as a basis for assessing needs in the present."[411] Genetic tests nearly always refer to the future possibility of disease. As anti-discrimination doctrine suggests, the potential costs of accommodating employees who might be affected by a disabling disease in the future should not be used to exclude those who can perform their jobs and require no accommodation in the present.

Sometimes, disabled workers are offered accommodation that does not diminish the risk. Exceptionally, accommodation might even create additional risks. The criteria used for measuring these risks are similar to those of the BFOR defence. The main question is always the same: how much risk do we estimate as acceptable?

It is now well established that minimal risks are not enough to justify (directly or indirectly) discriminatory practices.[412] Risks must constitute good enough reasons to override the prohibition on discrimination. Three elements can been distinguished in measuring the importance of a risk: (1) the nature and seriousness of the risk created by a particular employment; (2) the probability that this risk will materialize; and (3) the scope of this risk (who and how many people could be harmed?)[413] The Canadian Human Rights Tribunal indicated in *Robinson* v. *Canada*[414] how important it is to consider the nature of every job. It found that someone who suffered from epilepsy could be prevented reasonably by the Canadian armed forces from flying an airplane but that he could not be refused work,

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[411] Guidelines, *supra*, note 406 at 366.

[412] For the development of the case law with respect to the BFOR, see Proulx, *supra*, note 399 at 44-50.

[413] See Guidelines, *supra*, note 406 at 375. The Guidelines distinguish four different factors. It seems difficult to distinguish its first two factors. The Canadian Human Rights Tribunal identified only three factors in *Robinson* v. *Canada*, (1992) 15 CHRR D/95, par.95 (see the discussion by Proulx, *supra*, note 399 at 47-48).

[414] *Robinson* v. *Canada* (1992) 15 CHRR D/95, par.95

among others, as a truck driver. The tribunal argued that imposing very strict requirements for airline pilots was reasonable but that the same requirements for truck drivers was unreasonable. It looks like the seriousness of the consequences of risk-realization and the number of people who could be harmed were important elements in the distinction.

In assessing the rationality of exclusion, it is important to compare with other risks. In the *Robinson* case, for example, the probability of a medically controlled epileptic having a crisis was compared to the probability of an average person having the same sort of crisis. The same Tribunal compared the risk of HIV/AIDS transmission among marines with other risks accepted by the same employer.[415] Another interesting comparison was made by the American Supreme Court in the *Johnson Controls* case.[416] The Court noted that there was no reason to distinguish between risk for the male and female reproductive systems. Justice Blackmun, speaking for the majority, stated that "[t]he bias in Johnson Controls' policy is obvious . . . because it does not apply to the reproductive capacity of the company's male employees in the same way as it applies to that of the females."[417]

An interesting comparison of accepted and non-accepted risks was given by the Ontario Human Rights Commission.[418] The Commission argued convincingly that in assessing the risk of employing disabled workers, employers should measure other risks that are accepted in our society. These include risks caused by the general physical condition of normal employees; more common, overall workplace risks; and risks that are present in society or in similar industries.

It seems wise to bear in mind these words of the Commission:

> Many sources of risk exist in the workplace. . . . All employees assume everyday risks that may be inherent in a work site, or in working conditions, or which may be caused by a co-worker's fatigue, temporary inattentiveness, hangover, or stress. Employers have recognized that not all employees are 100% productive every day by

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[415] See Proulx, *supra*, note 399 at 48-49 and references.

[416] *International Union* v. *Johnson Controls* (1991) 113 L Ed 2d 158; see *supra*.

[417] *Ibid.* at 172-173.

[418] Guidelines, *supra*, note 406 at 373-374.

providing counselling programs or other means of coping with financial problems, emotional difficulties, or addiction to alcohol or other substances. Risks from these situations are factored into the level of safety that we all accept in our lives every day."[419]

Conclusion

I have shown how genetic testing can be used in the workplace, whose interests might be at stake and what ethical and social issues are involved. To do so, I first explained some basic aspects of genetics and of genetic testing in the workplace and distinguished different forms of genetic diseases. This introduction noted the particular problems that genetic information creates in relation to families, for example, and ethnic or racial groups. I pointed out how uncertainty and absence of cure nowadays characterizes genetic testing and how few specifically workplace-related tests are actually available.

I have proposed a specific framework of values, according to which all forms of workplace testing, and genetic testing in particular, should be judged on their merits. Genetic testing, I have argued, should be permitted only in exceptional circumstances. No statements about the validity of genetic testing in general can be made. Every genetic test should be evaluated on its scientific validity and submitted to rigorous supervision.

I have supported the idea that the existence of unequal bargaining power in the workplace limits the validity of consent as basis for policy making. I proposed instead two very specific justifications for genetic testing in the workplace: the protection of health and the avoidance of harm. Finally, I have shown how existing anti-discrimination legislation and case law could be useful sources for examining the rationality and proportionality of genetic testing in the workplace.

These guidelines are obviously not sufficient to prevent employers from accessing genetic information on employees from other sources and from using it. Further research is

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[419] *Ibid.* at 374.

needed on how to protect those who are affected by genetic disorders and their families, from being excluded from the workplace. I believe that genetics can lead to the reduction of the quality of life and the cutback in life choices and opportunities for those who, on the contrary, should benefit from the improved health care that genetics can bring. Everything should be done to avoid social stigmatization of those who already suffer from the possibility of developing a genetic disease. Instead of excluding them, they should be integrated in social life. An important aspect of this life is the workplace. Genetic progress should be accompanied by a greater acceptance of diversity and should not be used as a way of imposing social or biological uniformity.

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