5. ETHICAL AND LEGAL CONCERNS

Innovations and change create both opportunities and problems. This report does not identify all the ethical and legal problems arising from the application of genetics to health care, nor does it suggest how to resolve all those that are identified. It does attempt to demonstrate the range and importance of these issues, and it argues for the need to address them in the development and planning of genetic technologies and health services. We recognize that much work has already been done and is ongoing to identify and resolve ethical issues in genetics.[96] However, much still remains to be done.

Consideration of ethical issues should be integrated into development of genetic technologies and planning of services.

The issues surrounding human genetics will be difficult to distil into public policy for several reasons. The issues are complex and involve inherent conflicts. Attitudes toward many of the issues reflect the diversity of opinions and values among Canadians. There is no public consensus (and there may never be consensus) on issues such as prenatal diagnosis and termination of affected fetuses, or uses of genetic information. Any policies must accommodate a range of opinions.

The issues are complex, and there is often diversity of opinion.

But it is clear that genetic issues worry people. Serious concerns include:

- the potential for harm resulting from genetic engineering, including the ramifications of tampering with our essential "humanness";
- the possibility that information on personal risk of disease might be used to one's disadvantage; and
- the possibility that past eugenic abuses might be repeated, that genetic knowledge could again be used to justify claims of superiority or inferiority of races, or to discriminate against individuals.

Genetics deals with uncomfortable issues: genetic engineering, use of information, and possible eugenic abuses.

Genetic technologies can provide information about each of us, about our individual susceptibilities. Increasingly, our susceptibility to diseases can be diagnosed or predicted before we are able to use the information for our personal benefit. Moreover, we are accustomed to thinking of disease as an "outside enemy." The concept of genetic disease as an "internal" problem, resulting in part from our individual genetic make-up, requires us to change our thinking about disease.

On the one hand, not to apply genetics in health care will result in failure to develop and deliver many services beneficial to individual Canadians. On the other hand, failure to recognize relevant ethical issues may lead to inappropriate uses of genetic technologies and information. No satisfactory policies will emerge if public concerns about genetics in health care are not addressed. A process is needed to articulate these concerns, and the associated values and conflicts, and to work toward policies that allow a range of choices acceptable to most Canadians. If satisfactory policies are not developed, a backlash to the use of genetic technologies and health services may result.

No satisfactory policy will emerge until public concerns are addressed.

This chapter provides a brief overview of specific ethical issues associated with genetic knowledge, technologies, and health services.

Use of Genetic Technologies

The way in which genetic technologies will evolve and be applied will both affect and be affected by our social and moral structures. It is the view of the Science Council that the following principles must guide development and delivery of genetic technologies.

Genetic technologies should be available to treat or prevent genetic disease — not to improve the species.

- The primary objective of genetic applications in health care is to treat or prevent genetic disorders, not to reduce the cost of health care (although that may be an auxiliary benefit). Improving the human species is not an objective.

Genetic services should remain a voluntary option for individuals and families.

- Individuals and families should have access to beneficial technologies in order to make informed decisions about their own health care and reproductive options. The decisions should be based on reliable technical information and accurate, non-directive counselling. The individual's and family's decisions should be respected and supported.
- Genetic technologies should be used in the context of a caring society that values individuals and accepts human diversity and disability.

Individuals may choose not to avail themselves of genetic services. Participation is now, and should remain, a matter of free choice. Individuals should not be penalized (through reduced medical or social services, for example) for their reproductive or personal health care decisions.

Moral decisions regarding the use of genetic technologies should be made by individuals and society.

The "slippery slope" argument is often raised against the use of genetic technologies. The implication is that once initial steps are taken, there is no recognizable appropriate place to stop the use of genetic technology. The argument does not hold. Responsible distinctions can be made between a therapeutic application of a genetic technology, a trivial use, and the implementation of population eugenics. Moral decisions regarding the use of genetic technologies can and should be made by individuals and society.

Conflicts

Many ethical dilemmas result from differing interests and values.

Many of the ethical dilemmas associated with genetic knowledge and technologies arise from the conflicting interests of involved parties, conflicts between applications of competing ethical principles, and the range of opinion on specific issues. The involved parties include:

- individuals with genetic disorders or susceptibilities;
- their families;
- the fetus;
- society;
- future generations;
- geneticists and related researchers;
- health care delivery personnel;
- politicians and bureaucrats; and
- special interest groups.

The four basic principles of biomedical ethics are autonomy, beneficence, nonmaleficence, and justice.

The literature on biomedical ethics deals with the relationship of moral principles to rules and obligations, and is relevant to decision making regarding the applications of genetic technologies and information. The four basic principles of biomedical ethics are: autonomy, or respect for the wishes of competent persons; beneficence, or doing good; nonmaleficence, or doing no harm; and justice, or a fair distribution of benefits and harms. Related values include truthfulness, disclosing information to the patient, and confidentiality.

Among the areas of conflict to be resolved are:

- truthfulness versus perceived beneficence, in terms of disclosure of genetic information to patients;
- the interests of parents versus those of the fetus;
- the individual's right to confidentiality versus the information needs of family members at risk;
- the greater good of society versus the best interests of individuals;
- the interests of individuals alive today versus those of future generations; and
- the tension between the acceptance of disabled individuals and the provision of options to avoid birth of individuals with serious disabilities.

There are numerous areas of conflict to be resolved.

Accountability and Control

With genetic health care technologies changing rapidly, there is a growing need for accountability on the part of those involved in research, technology delivery, assessment of health care services, and use of information. But before the regulatory and legal system can address genetic issues, policies reflecting objectives and values are needed. The legal system should not be expected to set objectives and policies for genetic technologies.

Accountability is needed.

As noted by a Canadian expert in medical-legal issues:

> The approaches of ethics and of law to issues arising in medical care often result in conclusions which coincide, but the two disciplines are distinguishable, and their interaction merits attention. Both address questions of values, but the law must be constantly monitored to test whether it produces ethical effects.... One can identify circumstances, not only by reference to political oppression, in which the law may fail to protect significant ethical values.... There is an important sense in which law is a minimal ethic. When the law is not considered to be ethically deficient, its proper observance often discloses areas of unguided choice, where a legitimate discretion exists to act in different ways. The exercise of such discretion is a matter for ethical judgement and not for law.[97]

Genetic issues require both an ethical and a legal approach.

Some genetic issues — for example, the release of genetically engineered organisms into the environment, or access to medical information — are best served by regulatory control. However, most issues are best served by guidelines. Guidelines are more flexible and can result in more immediate and subtle responses to accumulating information and shifting social values. Guidelines have the further advantage of encouraging thoughtful decision making and assumption of responsibility. Awareness and understanding of ethical values is better achieved through the exercise of reasoned choice than through blind adherence to law.

Guidelines have advantages over regulations.

Finally, the setting of objectives for genetic technologies and the assessment of the need for guidelines or stronger regulatory instruments should be an ongoing process.

Box 21
Pre-Symptomatic Testing for Huntington Disease: Opinions of Three Individuals at Risk

"I think any at risk individual who wants the test should be able to have it. If he has been able to cope with the psychological hell of living at risk (and, believe me, it is hell), he should be able to cope with the knowledge he is carrying the gene. At least he can make plans for the future, whichever way the genetic dice have fallen."

"I consider it to be the height of irresponsibility on the part of doctors, lay groups, and even society to encourage the use of predictive testing to any at risk person no matter what this person says he wants to know, without an equally formidable medication that could offer hope. The repercussions will be staggering. If there's no hope, I say no test."

"Being at risk is a totally separate disease. Its symptoms and effects are far more widespread than HD is. It can limit or alter someone's entire adult life — not just the last 10 or 15 years. To free half the at risk people of both diseases in one test is worth it. More effective treatments cannot be far down the road."

Research

Scientists are responsible for ensuring the ethical conduct of research. They are also responsible for considering the effects of the potential applications of the research, and helping to set priorities and limitations.[98] However, it is not possible for scientists to anticipate all future uses of the information and related technologies.

Scientists are responsible for ensuring the ethical conduct of research.

Genetic research involving humans is subject to the same ethical considerations as other forms of medical research. The Science Council supports the Medical Research Council (MRC) guidelines for research involving human subjects (1987) and for research on gene therapy on humans (1990).[99]

Although the MRC guidelines address the issues thoroughly, only MRC-funded researchers are required to comply with them. (In addition, other research funding organizations, such as the Natural Sciences and Engineering Research Council, and some hospital research and ethics committees have chosen to adopt the guidelines.) There is a need to apply similar guidelines to all research involving gene therapy or experimentation with human subjects, irrespective of venue and funding. Local ethics review boards, already in place in hospitals, universities, and many private sector firms, could oversee compliance.

MRC guidelines are in place, but only MRC-funded researchers are required to comply with them.

Some issues associated with genetic research require additional or ongoing ethical and technical consideration. Such issues include the appropriate conditions for fetal research, use of fetal tissues, and anonymous testing for genetic diseases.

Genetic Health Services

Autonomy, counselling, informed consent, and confidentiality are the cornerstones of ethical delivery of genetic services. Some ethical issues related to genetic services have already been mentioned in previous chapters. Three major points:

Autonomy, counselling, informed consent, and confidentiality are the cornerstones of ethical delivery of genetic services.

- Genetic services should be initiated only if there are benefits such as disease prevention or treatment, or lifestyle or reproductive choices that can be made as a consequence. Opinions will vary on what constitutes a beneficial application (see Box 21).
- The importance of counselling individuals who are participating as subjects in human genetics research or in diagnosis and treatment programs should be recognized and accommodated.
- Follow-up health care and social support should be in place for individuals who have, or are at increased risk for, a genetic disorder.

Autonomy

The autonomy of individuals is a primary requirement in genetic services. Exceptions to this are children with serious diagnosable and treatable diseases, and mentally incompetent adults unable to make treatment decisions for themselves. For both groups, it must be demonstrable that the proposed services are in their best interests and improve their quality of life.

Autonomy of individuals is a basic requirement.

In the case of adolescents, genetic screening that conforms to recommended principles and practices has its advantages and benefits.[100] Adolescence is a period characterized by peer pressure and fragile self-image. Particular care is required in the conduct of such programs, and parental notification prior to screening is advisable.

Informed consent is fundamental to research and health care services.

The principle of informed consent is fundamental to all aspects of research and health care services. The consent of individuals should be obtained before undertaking research, conducting tests or treatments, releasing information on individuals, or before banking or using human tissues (including DNA).[101]

Prenatal Diagnosis and Pregnancy Termination

This report deals with the issue of pregnancy termination in a specific health care context. It does not address the wider issue of pregnancy termination: the rights of the fetus versus freedom of choice.

In cases of serious, untreatable genetic disorders, prenatal diagnosis and pregnancy termination should be valid health care options.

In the absence of effective disease prevention and treatment options, prenatal diagnosis of serious genetic disorders and pregnancy termination of affected fetuses should be valid health care options. The decision should rest with the individual woman. These diagnostic technologies are used primarily to help families at risk to have healthy children. Prenatal diagnosis should not be used to accommodate the preferences of parents on issues unrelated to serious health disorders (for example, to choose sex of offspring).[102]

These technologies help families at risk to have healthy children, but their use also implies value judgements on what kinds of life are worth living.

As more genetic conditions become detectable in the embryo or fetus, decisions will be required on which conditions are serious enough to warrant prenatal diagnosis. Some late-onset disorders or birth defects for which treatment is available (e.g., clinical depression or cleft palate) may be viewed differently by different families. The question remains as to who should make the decision whether societal resources should be used to make prenatal diagnosis available for such conditions. Ethicists recognize that individual and family decisions on pregnancy termination are in effect value judgements on what kinds of life are worth living.[103] These issues impinge upon our attitudes toward the disabled.

It should be kept in mind that prenatal diagnosis, although an important genetic service, does not contribute significantly to the number of pregnancy terminations. In 1984, for example, British Columbia had the highest pregnancy termination rate in Canada with 11 449 terminations and 43 911 live births; only 35 of these terminations were related to genetic problems diagnosed in the fetus. During 1984 almost 2000 genetic prenatal evaluations were done in British Columbia; 2.5 per cent of the evaluations showed abnormalities to be present.[104]

The search for better treatments must continue, even when effective prenatal diagnosis is possible.

The Science Council recognizes that the goal of genetics in health care is both to prevent disease and improve care. Therefore, the search for better treatment of genetic disease should continue, even for diseases where effective prenatal diagnosis is possible.

Responsibility and Liability

The physician has a general duty to know what a "reasonable" practitioner would know and to provide an acceptable standard of care. Provincial licensing bodies expect, and some require, that a physician keep up to date in knowledge.

This responsibility should extend to the delivery of services for dealing with genetic disease and susceptibility.[105] In other words, physicians should recognize the indications of genetic disease in individuals and families, incorporate appropriate diagnostic and treatment technologies into their practices, and refer patients and families to specialty genetic services as appropriate. For example, individuals at risk for familial bowel or breast cancer should be advised of precautions they should take to reduce their risk, and should be carefully monitored for early signs of disease.

The physician's responsibility to meet an acceptable standard of knowledge and care extends to dealing with genetic disease and susceptibility.

The issues surrounding prenatal diagnosis and pregnancy termination highlight the responsibilities of physicians and parents. Improved prenatal care and diagnostic technologies increase the responsibility and potential legal liability of those involved. The ethical and legal responsibilities of physicians and parents to the fetus are emotional, hotly debated issues.

Issues surrounding prenatal diagnosis highlight the responsibilities of physicians and parents.

In most contexts, the fetus is not afforded the legal rights of a person.[106] Therefore, it would seem that the wishes of the parents, and more specifically the woman carrying the fetus, generally take precedence in issues regarding *in utero* treatment and care. There is no legal obligation for a woman to accept *in utero* treatment.[107] This is not to say that parents do not have moral obligations. A woman carrying a fetus has a moral obligation to avoid wilfully harming the fetus through, for example, drug or alcohol abuse. However, she has no obligation either to carry a fetus to term or to terminate a pregnancy involving a disabled fetus. In this, as in other issues, the route to responsible, caring behaviour is through education and development of an ethical perspective, not through legal enforcement. There should be greater opportunity for education and counselling to ensure that prospective parents understand the effects of their lifestyles and choices on the unborn.

Physicians have a responsibility to advise parents on the health and health risks of the fetus, and on available diagnostic tests, the reliability of the tests, and the risks associated with testing procedures. A physician has the duty to advise clients as to the availability of these services, even if he or she does not agree with their use for technical or ethical reasons. Failure to inform is not responsible medical practice. In the United States, parents have launched "wrongful birth" court actions against physicians who failed to detect fetal abnormalities or advise the parents in sufficient time to offer the option of terminating the pregnancy.[108] However, a child born with such abnormalities has no legal grounds for claiming "wrongful life" against parents or physicians. The courts consider that a legal right not to be born would be a violation of the sanctity of human life.[109]

Physicians should advise clients of available carrier and prenatal diagnostic services.

Negligent, incorrect carrier testing of parents prior to conception and subsequent birth of a handicapped child is again actionable by the parents.[110] In these cases, judgements offering compensation to the child are now appearing. Compensation is based on restitution for pain and suffering rather than on the right not to be born.[111]

Information

The information that genetic technologies provide about an individual's risk for disease can be harmful as well as helpful. If misunderstood or misused, genetic information can result in unfair discrimination. Moreover, genetic information, even if used legitimately, could disadvantage individuals with or at high risk for

Genetic information can be harmful as well as helpful.

specific disorders, for example through exclusion from employment opportunities or insurance coverage.

Policies and action are needed to prevent misuse of genetic information.

There is a need to determine the desirable and acceptable uses of information on genetic disease or susceptibility, and a need for policies and action to control access to, and prevent misuse of, such information. Similarly, policies and action are needed to help individuals disadvantaged in some way because of knowledge about their genetic make-up.

Counselling and education are the essential partners of genetic information. Counselling helps individuals deal with their personal risk of disease; education helps individuals understand the implications of disease susceptibility for society, and creates acceptance and support of the disabled.

Genetic information should not be used to promote racist or discriminatory policies.

Genetic information should not be used to establish or promote racist or discriminatory policies. Genetic differences between individuals and between races and populations are normal, and genetics affects many aspects of human biology and behaviour; however, there is no evidence for the "inferiority" or "superiority" of one race over another. All races encompass a range of capabilities; the differences between individuals within races greatly exceed the differences between races. Moreover, behavioural traits are clearly the product of both environmental influences and genetic endowment.[112] Society's goal should be to assist all individuals to achieve their maximum potential.

Guidelines and, where necessary, legal instruments should be used to ensure the rights of individuals. The existing Charter of Rights and Freedoms and provincial human rights legislation are likely to be sufficient to protect individuals from discrimination on the basis of genetic knowledge.[113]

As a priority, the current and potential uses of genetic information should be reviewed with the objective of identifying possible problems and developing policies and controls. Issues to be considered include insurance and workplace access to information, disease registries, and DNA banks.

Confidentiality

Conflicts relating to the confidentiality of patient information can arise when disclosure could benefit other family members.

All personal medical information, including genetic information, is confidential. In the classic medical model, the individual with the symptoms is clearly the client, the person whose interests the physician must serve. But a potential conflict arises when information about one member of a family could be used to benefit other family members. Genetic diagnostic technology frequently produces information that could be beneficial to other family members since they share a common genetic heritage.

Counselling and public education on genetic diversity should gradually reduce the number of individuals who do not wish to share such information. However, if an individual remains unwilling to divulge information that could significantly affect the health or reproductive choices of other family members, the physician may still transmit the relevant information under certain circumstances:

The duty of confidentiality to an immediate patient can be overridden under certain circumstances.

A professional's ethical duty of confidentiality to an immediate patient or client can be overriden only if several conditions are satisfied:
(1) reasonable efforts to elicit voluntary consent to disclosure have failed;
(2) there is a high probability both that 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 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.[114]

These principles should be integrated into delivery of genetic health services in Canada.

Full Disclosure

Full disclosure of medical information to the patient is an appropriate objective. Yet an international survey of medical geneticists that addressed this topic and other counselling dilemmas demonstrates the complexity of the issues and the variation in attitudes among counsellors and cultures (see Box 22). For many geneticists there are circumstances where providing only the information required to ensure appropriate health benefits is preferable to providing the full truth.

Full disclosure of medical information to the patient is an appropriate objective, but not always considered the best course.

Prior to genetic testing, individuals and families should be informed that tests can reveal non-paternity, or the presence of disorders or disease susceptibilities unrelated to the original investigation. The question of whether such information is to be transmitted to the individual and to the family should be discussed and agreed upon in advance.

DNA Banking and Registries

DNA banking and disease registries will be of particular significance over the next few decades. Banked genetic material can be used for a multitude of research and diagnostic purposes including storage awaiting future technology, linkage analysis, genetic diagnosis, retesting using new technology, and sharing of material among genetic centres.

Genetic banks and registries facilitate patient services and advance research.

The establishment of banks and registries should be encouraged. But in conjunction with their development, it is essential that appropriate protocols be followed to ensure the consent and confidentiality of the individuals involved, and to ensure that participants understand the potential uses of the banked material and specify the uses to which they consent.[115] It should be made clear that individuals have full control over their level of participation, and that they can decline any or all participation without affecting their future access to improved clinical diagnosis or treatment. Appropriate operating procedures for DNA banking have been identified.[116]

Appropriate protocols to ensure confidentiality should be in place.

Property Rights

The potential commercial value of DNA material and of products derived from human tissues has led to debate (and lawsuits in the United States) over the rights of individuals to share in profits accruing from use of their tissues.[117] Are genes and genetic material "property"? What are the rights of the person who is the source of the material?

Box 22
Full Disclosure of Sensitive Information

Genetic testing can result in psychologically sensitive information that may harm the patient or family members. Should there always be full disclosure? The decisions involve a balance between the physician's duty to tell the truth (the patient's right to know) and the duty to do no harm.

The following examples from an international survey show how clinical geneticists in general, and Canadian geneticists in particular, handle these issues.

Problem 1:
Genetic testing has revealed which parent carries an abnormality (balanced translocation) that has caused Down syndrome in their child. Disclosure might enable the couple and relatives to use reproductive options to prevent the birth of another Down syndrome child. But the knowledge could also cause guilt in the carrier, and perhaps threaten the marriage.

How do geneticists handle this dilemma?
Fifty-four per cent of survey respondents (60 per cent in Canada) would disclose which parent is the carrier. An additional 43 per cent (40 per cent in Canada) would tell the couple that the information exists and give them the option of knowing.

Problem 2:
A woman is investigated for infertility. The investigation reveals that she has an XY (male) genetic make-up. Full disclosure could damage her self-image, but would resolve doubts about fertility.

How do geneticists handle this dilemma?
Fifty-one per cent of survey respondents (68 per cent in Canada) would disclose the XY status. The remaining 32 per cent of Canadian respondents, while offering an explanation of her infertility, would avoid full disclosure.

Problem 3:
During evaluation of a child with an autosomal recessive disorder, for purposes of genetic counselling, it is discovered that the husband is not the child's biological father.

How do geneticists handle this dilemma?
For 96 per cent of survey respondents (96 per cent in Canada) protection of the mother's confidentiality overrides disclosure of true paternity. Eighty-one per cent (87 per cent in Canada) would tell the mother in private. The primary reason given for not informing the husband was "preserving the family unit."

Problem 4:
Repeated maternal serum alpha-fetoprotein (AFP) tests of a patient are below the norm. Some studies have found low AFP values to be associated with Down syndrome, but geneticists do not agree on the interpretation of low values.

How do geneticists handle this dilemma?
Eighty-two per cent of survey respondents (94 per cent in Canada) would tell the patient that geneticists are not in agreement, but there may be a possibility of Down syndrome; they would discuss the risk of genetic abnormality, discuss the option and risk of prenatal diagnosis, and let the patient decide whether to use prenatal diagnosis.

It is not clear whether genetic material would qualify as personal property under Canadian law. The full range of ethical issues and available legal mechanisms warrant detailed consideration. For example, even if genetic material were deemed property, the donor's claim in any commercial profits might be limited to the value of the tissues when they were removed (i.e., the value before research or processing into the final commercial product). Such value would be extremely difficult to determine.

Whether or not an individual's genetic material is "personal property," it should not be sold...

The debate over whether genetic material is property should not be allowed to undermine the current Canadian philosophy of gift-based donorship; extension of the donor philosophy would mean that genetic material could not be sold, and donors would not have commercial interest in products developed using their tissues. However, it is critical that in all cases individuals have control over the use of their tissues, including use in research or in the development of commercial products. Consent should be obtained prior to conducting research using genetic material, even on tissues removed for diagnostic or therapeutic purposes and considered to be "abandoned."

...but in all cases the individual should have control over use of the material.

Eugenics

There are several definitions of eugenics:

- "The science which has for its object the production of fine offspring, especially in the human race."[118]
- "A term coined by Galton to denote practices and policies that tend to better the innate qualities of man and to develop them to the highest degree."[119]
- "A strategy of trying to orchestrate human evolution through programs aimed at encouraging the transmission of 'desirable' traits and discouraging the transmission of 'undesirable' ones."[120]
- "Any effort to interfere with individuals' procreative choices in order to achieve a societal goal."[121]

Eugenics was practised in many countries, including Canada.

Population eugenics was practised in this century, not just in Nazi Germany, but in different ways and to varying degrees in many countries, including Canada.[122] In Canada, eugenics was practised through sterilization of the "unfit" and certain immigration policies and practices (see Box 23). These official practices no longer exist. They were due to a combination of poor science, subversion of science to meet social objectives, and a disregard for basic human rights and ethical principles. The past abuses account for part of the public and political unease in addressing genetics and eugenics issues. However, medical geneticists in Canada today are clearly oriented toward individual and family needs and are not primarily concerned with the impact of parental reproductive choice on society, let alone the human species. Thus:

Medical genetics as practised today focuses on the needs of individuals and families.

> Medical geneticists in Canada and in other countries may vehemently and correctly reject any...link between their work and the reprehensible eugenic programmes of the 1930s and 1940s.... Vehement rejection of eugenic charges may not suffice over the next decade as the power of diagnostic technology increases. Medical geneticists and others may well have to engage themselves more explicitly than ever before in methodological and interdisciplinary reflection on the history of genetics and on the future course of genetics in an evolving society.[123]

Box 23
Historical Examples of Eugenics in Canada

Canadian eugenicists of the early 20th century believed the nation had to be protected against the racial degeneration (physical and mental) of its population. They attempted to influence policy development and legislation concerning control of reproduction among the "unfit" and restrictions on immigration.

Control of Reproduction

1912 A bill was presented to the Ontario legislature allowing sterilization of asylum inmates declared unfit to marry and produce children. Lack of public support for the bill induced its withdrawal.

1917 The Ontario government appointed a Royal Commission on the Care and Control of the Mentally Defective and Feeble-Minded. Its report of 1917 included restriction of marriage among its recommendations. World War I diverted attention from the report's findings.

1925 A Royal Commission on Mental Hygiene was appointed by the British Columbia government. The Commission's final report, issued in 1928, recommended sterilization as a policy option. It argued that sterilization would prevent the feeble-minded from passing their affliction on to their children. No immediate action followed the Commission's recommendations but they paved the way for later legislation.

1928 The United Farmers of Alberta government passed the Sexual Sterilization Act with the full support of organizations such as the United Farm Women of Alberta, the Imperial Order of the Daughters of the Empire, and the Women's Christian Temperance Union. Under the Act, the institutionalized mentally ill could be sterilized if this was approved by a Eugenics Board and consent was obtained from the patient or guardian. In 1937 the consent provision was removed.

1929 Ontario's Royal Commission on Public Welfare recommended that a policy of compulsory sterilization be adopted to decrease the numbers of the feeble-minded. Again the recommendations were not adopted by the government.

1933 The Conservative government of British Columbia passed the Sexual Sterilization Act with little opposition. Superintendents of relevant institutions could apply for approval of sterilizations to a Board of Eugenics. The Act applied to persons "likely to beget or bear children who by reason of inheritance would have a tendency to serious mental disease or mental deficiency." Consent was required from the inmate if capable, otherwise from the spouse, guardian, or Provincial Secretary.

1938 Ontario's Royal Commission on the Operation of the Mental Health Act recommended a sterilization policy. The Ontario government refused to act once more, partly because of personal opposition from the deputy minister of health and partly because the province's Roman Catholic minority opposed sterilization.

1972 The Sexual Sterilization Acts of Alberta and British Columbia were repealed.

Outcome

Between 1928 and 1971, 2822 cases were approved for sterilization in Alberta. No records remain for British Columbia, but the number of mentally ill and mentally deficient persons sterilized was probably in the order of a few hundred.

(continued on page 78)

The Science Council wishes to emphasize the following points.

- Genetic technologies should be used voluntarily; they should not be applied as an enforced form of population eugenics.
- There must be back-up health care services for individuals who do not, or cannot, avail themselves of available services to prevent, avoid, or treat genetic diseases.
- Genetic services and back-up health care services should be publicly funded, or a social and economic bias will result. For example, if publicly funded health services are not available for disabled children, there is an implicit economic pressure on lower-income families to avoid the birth of such children through prenatal diagnosis and pregnancy termination.
- We must ensure that availability of genetic services does not decrease our acceptance of the disabled.

Genetic technologies should not be applied as an enforced form of population eugenics.

Non-Medical Applications

Genetic technologies are used for purposes other than health care. Two major applications (workplace and insurance testing) are discussed separately here. Other potential non-medical uses include: to select the sex of offspring,[124] to prove kinship or paternity for legal or immigration purposes,[125] to conduct forensic investigations,[126] to develop agents for biological warfare (including agents effective on specific ethnic groups),[127] and to assess prospective immigrants for diseases or susceptibilities that could impose burdens on the health care system.

Non-medical applications of genetic technology include forensic investigations and biological warfare.

To prevent undesirable uses, all proposed applications should be subjected to technical and ethical review and to policies and regulatory instruments as appropriate.

Workplace Applications

Workplace screening is a one-time test of individuals, prior to employment, to determine whether they have genetic susceptibilities that would predispose them to occupational disease. Genetic monitoring entails periodic testing of employees to discover any genetic damage resulting from exposure to workplace mutagens.[128]

Genetic screening or monitoring programs can be beneficial if used to create a healthier work environment or to relocate high-risk individuals to safer jobs. But such programs could be considered discriminatory and in violation of workers' rights to security, integrity, and privacy if they are used to exclude or dismiss individuals from employment when the specific risk of disease is unrelated to workplace conditions or requirements.[129]

Genetic screening and monitoring programs have the potential to be used to the benefit or the disadvantage of employees.

Genetic screening in the workplace has been applied in the United States for more than 20 years. Although applications remain limited, employer interest is considerable.[130] But in the past, there have been some abuses and some misunderstanding of the risks of specific disorders. For example, individuals who were carriers of sickle cell gene were in many cases treated, incorrectly, as though they were sufferers of the disease and excluded from employment opportunities.[131]

Workplace applications of genetic screening remain limited, but there is considerable employer interest.

Box 23 (continued)

Although there was no enabling legislation, sterilizations of the mentally retarded were performed in Ontario. Sterilizations were clearly performed more frequently on specific groups. For example, during the last few years of the legislation's existence in Alberta over 25 per cent of sterilizations were carried out on Indians and Métis. These groups represented only 2.5 per cent of the Alberta population. There is no evidence that sterilization had any effect on the overall frequency of mental "deficiency."

Immigration Restrictions

1869 Canada's first Immigration Act prohibited the entry of "lunatics" and "idiots."

1901 Medical inspections were initiated at Canada's borders.

1910 A new Immigration Act divided undesirable immigrants into three major categories: mental defectives (including epileptics, idiots, the feeble-minded, imbeciles, and the insane); physical defectives (including the dumb and blind); and people with "loathsome" diseases or those deemed a risk to public health.

1928 By this time, the Department of Immigration was employing 28 medical examiners across Britain and the rest of Europe to screen immigrants and exclude unsuitable candidates.

1928 A federal Select Committee on Agriculture and Colonization submitted a report calling for stricter controls on immigration. The "hereditary deficiencies" of immigrant groups were an integral part of the discussions preceding the report. Stricter immigration controls were subsequently introduced but mostly as a result of the Depression rather than eugenic concerns.

Outcome

During the 1920s about 10 000 people were excluded from immigration to Canada for health reasons.

In Canada, employment law and the statutory and constitutional protection of individual rights are pertinent to genetic screening and monitoring in the workplace.[132] Following are items of particular relevance.

Employment law and statutory and constitutional protection of individual rights are pertinent.

- An employer is allowed to assess the skill, training, and medical status of a job candidate in relation to a specific job. Other than for positions that involve public safety (e.g., commercial airline pilots), the employer is not considered to be under a duty to determine if the potential employee is generally medically fit for the work.[133]
- Federal and provincial occupational health and safety statutes make employers responsible for ensuring the health and safety of their employees on the job. This responsibility makes it possible, perhaps even obligatory, for employers to establish genetic screening and monitoring programs.[134]
- Non-employment of genetically susceptible applicants or redeployment of susceptible employees should not be used as a substitute for improving the work environment.[135]
- An employer may impose "reasonable" screening tests on job applicants, that is, tests that are scientifically valid, reliable, and related to the job in question. The applicant can comply or withdraw the application. The rights of established employees with regard to genetic screening and monitoring are bound up in contract law and more complicated.[136] All these issues will probably be tested in Canadian courts within the decade.
- Exclusion from employment on the basis of genetic susceptibility may be considered discrimination based on handicap or disability. However, exclusion from employment may be permissible if the employer can show that the employee is unable or likely to be unable to substantially meet the essential requirements of the job because of the susceptibility, or can demonstrate that the susceptibility results in an unacceptable degree of risk for the employee, fellow workers, or the public.[137] It is not yet clear what kinds of risk are unacceptable or what kind of evidence is necessary.
- In some provinces employers have a responsibility to provide susceptible employees with alternative, safer employment (at equal pay).
- Finally, it should be remembered that every individual carries some form of genetic-based susceptibility to disease. However, that susceptibility may never express itself in disease.

Genetic screening is not a substitute for improving the work environment.

Genetic susceptibility is not necessarily reasonable grounds for exclusion from employment.

These issues point to the need to determine how genetic screening and monitoring should be used in the Canadian workplace, and then to ensure that appropriate legislation is in place.

Life and Disability Insurance

The application of reliable genetic diagnostic technologies has implications for the life and disability insurance industry and for individual Canadians.[138] At present, some disability income is provided by provincial governments and is available to all Canadians who qualify. In addition, many Canadians are covered by group or individual life and disability insurance policies offered by private firms or cooperatives. The purchase of life or disability insurance is not obligatory, and the right to buy such insurance is not guaranteed. Insurance is a contract and depends on good faith between the insurer and the person insured.

The application of genetic technologies in the current system of individually purchased life and disability insurance would allow an insurance company to set premiums that realistically reflected risk and to identify and avoid insuring individuals who were poor risks. The information would benefit individuals

Use of genetic screening for insurance purposes could result in a growing number of individuals deemed to be uninsurable.

who received a relatively clean genetic bill of health, but as diagnostic technologies became increasingly available would also result in a growing number of uninsurable individuals or, at best, individuals penalized for their personal biology.

Insurance companies are interested in identifying higher-risk individuals; however, applying genetic testing technologies is at present too complicated and expensive to have a major impact on the insurance industry. Still, some individuals with specific knowledge regarding their genetic health status do stand to be penalized.

There is a need to review options for providing life and disability insurance to such individuals.

Therefore, the time is now appropriate for a review of the insurance issues and alternatives. Is the purchase of life and disability insurance a "right," and if so how much should everyone have the right to purchase? What medical information should insurance companies have the right to request? How should insurance of high-risk individuals be accommodated? The options include "no-fault insurance," which averages out the risk and expense over the population; development of special high-risk insurance pools; or some form of basic insurance universally available at the same premium, with purchase of additional insurance optional and contingent on genetic information.

Representatives from the life and health insurance industry, consumer groups, and relevant government agencies should consider conducting a joint review to address the implications of emerging genetic information and technologies on life and disability insurance.