Government of Canada
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A BRAVE NEW WORLD:

Where Biotechnology and Human Rights Intersect

Conclusion and Glossary

Canada

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Conclusion

The purpose of this project has been to examine select applications of biotechnology within the framework of human rights and identify any gaps in rights protection. The project examined biotechnology, jurisprudence and legislation at a particular point in time. Advances in biotechnology occur at such a rapid pace that there may have been significant developments since the time of writing that are not reflected in the chapters.

In many cases, the authors attempted to look to the future and speculate as to what situations might arise as a result of advances in biotechnology. This meant that many of the issues that arose were novel and it was difficult to determine how the courts might address them. The goal at the start of the project was to devise a human rights framework for the application of biotechnology. It soon became apparent that a single framework could not be developed that would address the diverse applications of biotechnology and the spectrum of human rights issues that arose.

The application of biotechnology often raises difficult moral and ethical issues, as well as novel legal issues. The United Nations ("U.N.") human rights instruments are of limited guidance. This is not surprising considering the difficulties of reaching international consensus on many of the human rights issues raised by biotechnology. The U.N. treaties provide only a basic minimum of guidance in terms of rights protection in this area. Many of the issues raised by biotechnology are multi-dimensional and value laden, and as such, the task of achieving consensus between states on the wording of an international treaty addressing these issues would be extremely difficult. The courts may find more guidance from UNESCO declarations that, while of a non-binding nature, offer more concrete guidance on these issues.

In Canada, the *Charter* provides protection for rights and freedoms in the event of government action or interference. The most oft engaged *Charter* rights with respect to assisted human reproduction technologies would be those found in section 7. The lack of jurisprudence in this area will present challenges to the courts. In addition, the status of the *in vitro* embryo and whether it possesses any rights is an issue that has not yet been addressed by the courts. The issues outlined in Chapter 7 relating to indigenous peoples and possible rights to protect and use their traditional knowledge have not yet come before the courts in Canada. The courts may be forced to craft novel solutions to these difficult issues.

Waiting for the judiciary to provide guidance is always a slow and often unsatisfactory approach. The gaps that emerge from the review and analysis may be best addressed through a variety of mechanisms ranging from legislative provisions to regulations to codes of practice, rather than through amendments to human rights legislation. Canada should consider whether to proactively address gaps in human rights protection through appropriate mechanisms rather than waiting for the courts to decide these matters.

Not every application of biotechnology was examined. For example, the creation of genetically modified foods, nanotechnology and pharmacogenetics were not explored. However, that does not mean that these matters are

unimportant and should not be the focus of future work. The technologies likely raise novel ethical and legal issues, and likely raise human rights issues, that should be considered. Furthermore, not all of the applications of assisted human reproduction were explored. The issues relating to surrogacy motherhood and as well, other questions relating to the application of assisted reproduction technologies were not examined. The following questions were not addressed: Do children have a right to have two biological parents of the opposite sex? Does a child have a right to have a "normal" or "natural" genetic origin? Do parents have the right to have a child conceived using their own genetic material, even if this means using the genetic material from three biological parents?

A major issue that was not explored regarding indigenous rights and traditional knowledge relates to the fact that indigenous communities are sometimes viewed as a good source of raw materials for human genetic research since they often represent a homogenous gene pool. Indigenous peoples have expressed concerns that they may be targeted for discrimination during or as a result of such research. One such concern relates to the possibility that the results of such research may be used to determine who is a member of a particular indigenous community.

This project began by examining human rights issues of an intensely personal and private nature that may arise in the area of human reproduction and ended with an examination of issues of a "collective" nature. It is clear that not every application of biotechnology is best addressed through a human rights framework. The project papers illustrate, however, that certain applications of biotechnology raise human rights issues that could be addressed through legislative amendment or regulation. Protecting individual rights and the interests of collectives would help to ensure that society as a whole continues to benefit from responsible scientific progress.

Glossary

A

AHR
assisted human reproduction

artificial insemination (AI)
The introduction of semen into the vagina other than by coitus.

azoospermia
Absence of living sperm in the semen.

B

BRCA1 gene
A tumor suppressor gene on chromosome 17 at locus 17q21, isolated in 1994; encodes p53 protein, which prevents cells with damaged DNA from dividing; carriers of germline mutations in BRCA1 are predisposed to develop both breast and ovarian cancer.

BRAC2 gene
A tumor suppressor gene indentified in 1995 on chromosome 13 at locus 13q12-q13; a large gene; encoding a protein of 3418 amino acids; carriers of germline mutations in BRCA2 have an increased risk of developing breast cancer and a moderately increased risk of ovarian cancer; BRCA2 families also exhibit an increased incidence of male breast, pancreatic, prostate, laryngeal, and ocular cancers.

blastocyst
An early pre-implantation embryo which consists of an inner and an outer cell layer surrounding a fluid-filled central cavity. The surface cells will give rise to extra-embryonic tissues, and the inner cells will become the fœtus.[1]

blastomere
One of the cells into which the egg divides after its fertilization.

C

CBD
Convention on Biological Diversity

CEDAW
Convention on the Elimination of All Forms of Discrimination Against Women

CERD
International Convention on the Elimination of All Forms of Racial Discrimination

CRC
Convention on the Rights of the Child

[1] Webster's Online Dictionary, online: http://www.websters-online-dictionary.org/definition/english/ga/gamete.html (date accessed: 25 March 2004).

cloning

1. Growing a colony of genetically identical cells or organisms *in vitro*.

2. Transplantation of a nucleus from a somatic cell to an ovum, which then develops into an embryo; many identical embryos can thus be generated by asexual reproduction.

D

donor insemination (DI)

Artificial insemination with semen from a donor who is not the woman's husband.

Medical indications for donor insemination include azoospermia, oligospermia or the presence of a genetic disease in the male partner's sperm.

E

ESHRE

European Society of Human Reproduction and Embryology

EPC

European Patent Convention

EPO

European Patent Office

embryo

In humans, the developing organism from conception until approximately the end of the second month; developmental stages from this time to birth are commonly designated as fœtal.

eugenics

1. Practices and policies, as of mate selection or of sterilization, that tend to better the innate qualities of progeny and human stock.

2. Practices and genetic counselling directed to anticipating genetic disability and disease.

F

fœtus

The product of conception from the end of the eighth month to the moment of birth.

G

gamete

A mature sexual reproductive cell having a single set of unpaired chromosomes.[2]

gamete intra-fallopian transfer (GIFT)

A method of treating infertility by removing eggs from a woman's ovaries, combining them with sperm from her partner or a donor in the laboratory, and placing the eggs and sperm together in one of her fallopian tubes, where fertilization can occur.[3]

gene

A functional unit of heredity that occupies a specific place on a chromosome, is capable of reproducing itself exactly at each cell division and directs the formation of an enzyme or other protein. As a functional unit, the gene consists of a discrete segment of a giant DNA molecule containing the purine (adenine and guanine) and pyrimidine (cytosine and thymine) bases in the correct sequence to code the sequence of amino acids of messenger-RNA formed on the chromosome with the gene acting as a template.

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2 Webster's Online Dictionary, online: http://www.websters-online-dictionary.org/definition/english/ga/gamete.html (date accessed: 25 March 2004).

3 Hyperdictionary, online: http://www.hyperdictionary.com/medical/gamete+intrafallopian+transfer (date accessed: 25 March 2004).

germ cell
The sex cells — ovum or sperm cells.

H

Human Genome Project
The Human Genome Project is a global, collaborative, scientific effort consisting of a number of national and international programs that began in the mid-1980s with the objective of mapping and sequencing the entire human genome.[4]

I

IACHR
Inter-American Convention on Human Rights

ICCPR
International Covenant on Civil and Political Rights

ICESCR
International Covenant on Economic, Social and Cultural Rights

IGC
Intergovernmental Committee on Genetic Resources, Traditional Knowledge and Folklore

ILO
International Labour Organization

implantation
Attachment of the fertilized ovum (blastocyst) to the endometrium, and its subsequent embedding in the compact layer, occurring 6 or 7 days after fertilization of the ovum in humans.

intra-cytoplasmic sperm injection (ICSI)
A procedure in which a single sperm cell is injected into the ovum during *in vitro* fertilization.

in vitro
In an artificial environment, referring to a process or reaction occurring therein, as in a test tube or culture media.

***in vitro* fertilization (IVF)**
A process whereby (usually multiple) ova are placed in a medium to which sperm are added for fertilization, the zygote thus produced then being introduced into the uterus and allowed to develop to term.

O

OAS
Organization of American States

Oligospermia
A subnormal concentration of sperm in the penile ejaculate.

P

PIPEDA
Personal Information Protection and Electronic Documents Act

PGD
Pre-implantation genetic diagnosis. Genetic diagnosis performed on the *in vitro* embryo.

parthenogenesis
A form of nonsexual reproduction in which eggs are subjected to electrical shock or chemical treatment in order to initiate cell division and embryonic development.[5]

pluripotent cell
Primordial cells that may still differentiate into various specialized types of tissue elements.

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4 Allyn L. Taylor, "Globalization and Biotechnology: UNESO and an International Strategy to Advance Human Rights and Public Health" (1999) 25 Am. J. L. and Med. 479 at 5 (Lexis Nexis).

5 The President's Council on Bioethics, "Human Cloning and Human Dignity: An Ethical Inquiry" (Washington, July 10, 2002) at 132 http://www.bioethics.gov/reports/cloningreport/fullreport-print.html.

S

somatic cell
The cells of an organism other than the germ cells.

somatic cell nuclear transfer
A process whereby the nucleus of a human egg is removed and replaced with the nucleus from a donor cell. The egg is artificially stimulated and it begins to develop as an *in vitro*.[6]

stem cell
1. Any precursor cell.

2. A cell whose daughter cells may differentiate into other cell types.

sterilization
The act or process by which an individual is rendered incapable of fertilization or reproduction.

T

TK
traditional knowledge

TRIPS
World Trade Organization's Agreement on Trade-Related Aspects of Intellectual Property Rights

totipotent cell
An undifferentiated cell capable of developing into any type of body cell.

U

UDHR
Universal Declaration of Human Rights

UNCTAD
United Nations Conference on Trade and Development

UNESCO
United Nations Educational, Scientific and Cultural Organization

W

WHO
World Health Organization

WIPO
World Intellectual Property Organization

WTO
World Trade Organization

Z

zygote
The diploid cell resulting from union of a sperm and an ovum.

6 *Ibid.* PresidentÕs Council.