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# A BRAVE NEW **W**ORLD:

Where Biotechnology  
and Human Rights Intersect

## Chapter 3

Pre-Implantation  
Genetic Diagnosis

Canada

A Brave New World: Where Biotechnology and  
Human Rights Intersect

July 2005

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## Pre-Implantation Genetic Diagnosis

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Judy Hunter

### 3.1 Introduction

*The temporal implications of genetic technology will require international human rights organizations to revisit issues surrounding the rights of the unborn that persist despite the abortion debate.*<sup>1</sup>

The ability of scientists to fertilize a human egg with sperm outside the body of a woman was hailed as a feat of technology that would enable the infertile to have children. Since the late 1970s, medical and scientific research in this area has focused on improvements in assisted human reproduction (“AHR”) procedures and technologies. An example of a recent technological development in this area is pre-implantation genetic diagnosis (“PGD”) which allows the detection of a genetic anomaly in the *in vitro* embryo.<sup>2</sup>

In 1989, the Government of Canada appointed the Royal Commission on New Reproductive Technologies (“Commission”) to inquire into and report on the current and potential medical and scientific developments relating to new reproductive technologies. The Commission’s mandate was very broad; it was asked to consider the social, ethical, health, research, legal and economic implications of such technologies.<sup>3</sup>

In 1993, the Commission issued its final report, entitled “Proceed With Care: Final Report of the Royal Commission on New Reproductive Technologies” (“Final Report”).<sup>4</sup> With respect to PGD of the *in vitro* embryo,<sup>5</sup> the Commission concluded:

Preimplantation diagnosis is an experimental form of prenatal diagnosis involving *in vitro* fertilization...the

available data indicate that preimplantation diagnosis is a difficult, invasive, expensive, and inefficient technique with very limited indications.<sup>6</sup>

With respect to prenatal diagnosis, the Commission noted that during its Canada-wide consultations:

... most people in Canada think that the choice of whether to have prenatal diagnosis when at risk for a serious disorder, and whether to have an abortion if a disorder is diagnosed, should be left to each woman or couple in accordance with their own values and circumstances.<sup>7</sup>

The public would likely express the same viewpoint if asked about a prospective parent’s right to choose whether to conduct PGD of their *in vitro* embryos when at risk for

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<sup>1</sup> Maha F. Munayyer “Genetic Testing and Germ-Line Manipulation: Constructing a New Language for International Human Rights” (1997) 12 Am. U.J. Int’l L. & Pol’y 687 at 10 (Lexis Nexis).

<sup>2</sup> An “*in vitro* embryo” is one that has been created and exists in a Petri dish, i.e., outside a woman’s body. An “*in utero*” or “*in vivo* embryo” is one that has been conceived and exists within the woman’s body.

<sup>3</sup> Royal Commission on New Reproductive Technologies, *Proceed With Care: Final Report of the Royal Commission on New Reproductive Technologies* (Ottawa: Minister of Government Services, 1993) at 2.

<sup>4</sup> See Chapter 2 of the project paper for a more detailed discussion of the Royal Commission.

<sup>5</sup> “foetus” is defined as the unborn human more than eight weeks after conception (Concise Oxford Dictionary, 10th Ed.). “Embryo” is defined as the unborn human in the first eight weeks following fertilization or conception (Concise Oxford Dictionary, 10th Ed.). “*In utero*” means within the mother’s uterus or womb. “*In vitro*” refers to outside the human body and in a glass dish.

<sup>6</sup> *Supra* note 3 at 824.

<sup>7</sup> *Ibid.* at 788.

a serious genetic disorder, and to select only disease-free *in vitro* embryos for reproductive purposes.

In Canada, access to PGD is currently controlled by the medical profession. The decision as to whether an individual or couple should undergo *in vitro* fertilization and PGD is a private one made by an individual or couple in consultation with their physician.

This chapter will identify and examine the human rights issues that arise with respect to PGD of an *in vitro* embryo. The chapter begins with a general discussion of PGD, a background section briefly explaining the science and technology, and a section identifying the relevant human rights issues. The rest of the chapter is organized under the following headings: (1) the relevant international law and principles, (2) the law in other jurisdictions, (3) the relevant Canadian law, (4) academic or other commentary, (5) discussion, and (6) conclusion.

### 3.2 PGD

In the late 1980s, PGD was developed and made available to prospective parents in the United Kingdom (“U.K.”).<sup>8</sup> In April 1990, Handyside and Hannersmith Hospital reported the first established pregnancies from biopsied human pre-implantation embryos.<sup>9</sup>

PGD permits the detection of specific genetic disorders and the sex of the embryo (to avoid a sex-linked disease). It allows the selection of only those *in vitro* embryos that are free of a genetic predisposition to disease (or selection by sex for a sex-linked disease) for transfer into the woman. At present, tests are only available to detect single-gene disorders, such as cystic fibrosis. Although PGD can confirm the presence of a genetic anomaly, it cannot predict the extent to which the *in vitro* embryo, if transferred into the womb and born alive, would be affected as a child or adult.

This technology could be viewed as increasing reproductive choice for individuals who might otherwise forego parenthood because of their risk of passing on a genetic disease or disorder to their offspring.<sup>10</sup> Prior to the development of PGD, once the woman was pregnant and

prenatal testing revealed that the *in utero* embryo or foetus had a genetic disease or disorder, the choices available to the woman or couple were limited. The woman or couple could choose a “genetic abortion,”<sup>11</sup> which often resulted in physical and emotional trauma, as well as feelings of guilt for the parent,<sup>12</sup> or they could choose to complete the pregnancy with the possibility of raising a seriously ill or disabled child. PGD allows the embryo to be tested *in vitro*, and only those embryos that are believed to be free of a particular genetic disease are transferred to the womb in the hopes of a pregnancy.

Today, the number of world-wide centres offering PGD is on a steady increase.<sup>13</sup> In 2000, the European Society of Human Reproduction and Embryology (“ESHRE”) PGD Consortium began collecting statistics from participating fertility centres around the world with respect to the use of PGD.<sup>14</sup> ESHRE’s three published reports (1999, 2000 and 2001) reveal a steady increase in referrals for and use of PGD.<sup>15</sup>

<sup>8</sup> Anuja Dokras, M.D.Ph.D. (Department of Obstetrics and Gynaecology, Yale University School of Medicine, U.S.), Pre-Implantation Genetic Diagnosis, Vol. 1 No.5 at 1 (<http://www.hygeia.org>).

<sup>9</sup> A.H. Handyside et al., “Biopsy of Human Preimplantation Embryos and Sexing by DNA Amplification” (1998) February 18 *Lancet* 347-49; A.H. Handyside et al., “Pregnancies from Biopsied Human Preimplantation Embryos Sexed by Y-Specific DNA Amplification” (1990) 344 *Nature* 768-70.

<sup>10</sup> Joint Canadian Fertility and Andrology Society/Society of Obstetricians and Gynaecologists of Canada, “Policy Statement: Ethical Issues In Assisted Reproduction” (1999) *Journal SOGC* 4 at 32.

<sup>11</sup> “Genetic abortion” is the term given in the literature for an abortion on the basis of medical information about the genetic status of the fetus.

<sup>12</sup> Jason Christopher Roberts, “Customizing Conception: A Survey of Preimplantation Genetic Diagnosis and the Resulting Social, Ethical, and Legal Dilemmas” (2002) *Duke L. & Tech. Rev.* at 12.

<sup>13</sup> ESHRE, “Preimplantation Genetic Diagnosis Consortium: Data collection III” (May 2001) at 233.

<sup>14</sup> *Ibid.* (ESHRE); On February 16, 2004, Dr. Joyce Harper, Senior Lecturer in Human Genetics and Embryology at the UCL Centre for Preimplantation Genetic Diagnosis (London, England) announced that she has information that 86 centres worldwide are now conducting PGD (<http://www.ucl.ac.uk>).

<sup>15</sup> ESHRE, “Preimplantation Genetic Diagnosis Consortium: preliminary assessment of data from Jan. 1997 to Sept. 1998” (1999) 14 *Human Reproduction* no. 12, at 3138-3148; ESHRE, “Preimplantation Genetic Diagnosis Consortium: Data collection II” (May 2000), (2000) 15 *Human Reproduction* no. 12, at 2673-2683; ESHRE “Preimplantation Genetic Diagnosis: Data collection III” (May 2001), (2002) 17 *Human Reproduction* no. 1, at 233-246. NOTE: Canada is not contributing to this data collection since we only have one fertility centre performing PGD.

The increased use of PGD can be explained in part by the success of the Human Genome Project,<sup>16</sup> as well as improvements in the technology which have made PGD more reliable. In addition, individuals and couples in certain countries have started using PGD for non-medical reasons, such as selecting *in vitro* embryos on the basis of sex for social or cultural reasons.<sup>17</sup>

The most recent ESHRE report (2001) noted that PGD is now being used for selecting *in vitro* embryos that have the potential of becoming a donor child.<sup>18</sup> PGD allows for the selection of *in vitro* embryos that have the exact genetic traits needed to provide a cell transplant for an existing sibling with a genetic disease. Once the donor child is born, stem cells can be retrieved from his or her umbilical cord and placenta (tissues that would normally be discarded), and donated for transplant to the sibling.

### 3.3 Background

#### The Science

PGD of an *in vitro* embryo includes the use of several different technologies and processes.

First, an *in vitro* embryo must be created. The woman is given large doses of hormones to hyperstimulate her

ovaries into producing a number of ova (eggs) in a single cycle, as opposed to the usual single egg in a typical cycle. Following hyperstimulation, as many eggs as possible are retrieved from the woman's ovary. These are either mixed with her partner's or a donor's sperm in a Petri dish or a single sperm is selected and injected into the egg, to create an *in vitro* embryo.<sup>19</sup>

Second, the resulting *in vitro* embryos are grown in the lab until they reach the eight-cell stage, approximately three days after fertilization. At that point, the *in vitro* embryo is biopsied by removing one or two blastomeres<sup>20</sup> (cells) for molecular analysis. Blastomeres are totipotent cells which are capable of developing into any cell type or into an embryo.<sup>21</sup> The biopsy is not believed to adversely affect the further development of the *in vitro* embryo, which continues in the lab while the biopsied blastomere cells undergo analysis.<sup>22</sup>

Third, to perform molecular analysis on the cell, the genetic information must be extracted from the nucleus of the isolated blastomeres. Two different types of genetic information can be obtained, i.e., chromosomal and gene. Chromosomal is the most common type of information obtained.

<sup>16</sup> 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 (Allyn L. Taylor, "Globalization and Biotechnology: UNESCO and an International Strategy to Advance Human Rights and Public Health" (1999) 25 Am. J. L. and Med. 479 at 5 (Lexis Nexis)). The Project involves compiling information on genetic and physical features of the human genome, mapping the DNA sequences and understanding the interactions between human genes. The Project began officially in 1990 as an international research effort with the objective of discovering the estimated 60,000 to 100,000 human genes, and mapping the genes onto each chromosome. It will have a significant impact on the development of prenatal and preimplantation genetic testing. (Alastair T. Iles, "The Human Genome Project: A Challenge to the Human Rights Framework" (1996) 9 Harv. Hum. Rts. J. 27 at 2-3 (Lexis Nexis)). The project is intended to provide researchers with the genetic information to locate the genes responsible for various genetic diseases and disorders. It is predicted that eventually the emphasis will shift from disease treatment to disease prevention. (Wendy E. Roop, "Not in My Womb: Compelled Prenatal Genetic Testing" (2000) 27 Hastings Const. L.Q. 397 at 2-3 (Lexis Nexis)). On June 26, 2000, a first draft of the human genome was presented at a White House ceremony. By that time over 7,000 genes had been traced to specific chromosomes. The project has increased scientific knowledge with respect to single gene mutations that cause disease (including late-onset diseases) (Kay Chung, *Designer myths: the science, law and ethics of preimplantation genetic diagnosis* (London: Progress Educational Trust, 1999) at 11. In February 2001, two competing groups (one public and one private) published their more

complete analyses of the human genome. Both papers indicate that the human species possesses 30,000 or so genes, not the 100,000 that many predicted (just 11,000 more than the laboratory roundworm (Gerard Magill, PhD "The Ethics Weave in Human Genomics, Embryonic Stem Cell Research, and Therapeutic Cloning: Promoting and Protecting Society's Interests" (2002) 65 Alb. L. Rev. 701 at 4 (Lexis Nexis); Southern California Center for Reproductive Medicine, "ART Preimplantation Genetic Diagnosis" November 2003 at 2 (<http://www.socalfertility.com/art/PGD.shtml>)).

<sup>17</sup> A. Malpani and D. Modi, "Preimplantation sex selection for family balancing in India" (Opinion: European Society of Human Reproduction and Embryology (ESHRE)) at 11.

<sup>18</sup> ESHRE, *supra* note 13 at 234; These children have been coined "saviour children" by the media in the UK because they have been selected from among a number of healthy *in vitro* embryos for reproductive purposes based on their potential ability to provide a cure for an existing sibling who is ill.

<sup>19</sup> For more details, see Chapter 2 of the project paper at 2 to 3.

<sup>20</sup> "Blastomeres" are totipotent cells which have the potential of giving rise to any cell type or to a human embryo (including all of its tissues and organs) and as well the fetal portion of the placenta (The President's Council on Bioethics, Human Cloning and Human Dignity: An Ethical Inquiry" (Washington, July 10, 2002) (<http://www.bioethics.gov/reports/cloningreport/fullreport-print.html>); The Concise Oxford Dictionary, 10th Ed.

<sup>21</sup> The President's Council on Bioethics, Human Cloning and Human Dignity: An Ethical Inquiry" (Washington, July 10, 2002) (<http://www.bioethics.gov/reports/cloningreport/fullreport-print.html>); The Concise Oxford Dictionary, 10th Ed.

<sup>22</sup> Dokras, *supra* note 8 at 1.



## Chromosomal

The nucleus of each cell in the body, except for the sperm and ovum cells (“sex cells”), contains forty-six chromosomes. The nucleus of the sex cells contains twenty-three chromosomes. When the nucleus of a sperm and egg fuse during fertilization, the resulting embryo has forty-six chromosomes: half of the chromosomes come from each parent. Chromosomes are made up of as many as 30,000 genes,<sup>23</sup> which are specific stretches or regions of double-stranded deoxyribonucleic acid (“DNA”).<sup>24</sup>

The most common use of PGD is to examine the genetic information at the chromosomal level. For example, some diseases and disorders are X-linked (such as haemophilia and Duchenne muscular dystrophy), which means that while the disease is carried by a healthy woman on the sex chromosomes, only her male children would be affected.<sup>25</sup> In the case of an X-linked disorder, instead of testing for mutations in the gene, the sex of the *in vitro* embryo is identified and only female embryos are transferred into the woman.<sup>26</sup>

The presence of additional, or the absence of certain, chromosomes can be indicative of a number of different diseases, such as Down’s Syndrome, which results when the cell’s nucleus has three copies of Chromosome 21 instead of two.<sup>27</sup> (This abnormality appears more frequently as the maternal age increases past 35 years.)<sup>28</sup>

## Gene

The second and more complex use of PGD is to detect the presence or absence of a specific gene mutation in a chromosome within the cell’s nucleus. The individual or couple who requires this type of information may be fertile but may carry a genetic mutation that could result in a particular disease or disorder in their offspring. These individuals undergo PGD to select for transfer (into the womb) only those *in vitro* embryos that do not have the particular gene mutation.<sup>29</sup>

The number of diseases known to be caused by a single gene mutation is growing as scientists learn more about the composition of the human genome.<sup>30</sup> To date, the most commonly tested single-gene disorders are cystic fibrosis, beta-thalassaemia and Huntington’s disease. In addition, as knowledge of the human genome increases,

tests for adult or late-onset diseases may be developed, such as those cancers with a genetic component.<sup>31</sup>

The director of the Human Genome Project, Francis Collins, predicted that by 2010, genetic tests will be available to diagnose diseases, to predict future risk for most of the common diseases, such as cancer, heart disease, mental disorders, and possibly to detect susceptibility to infections. In the future, it may be possible to screen for multifactorial diseases, such as asthma and the more complex cancers.<sup>32</sup>

It should be remembered, however, that genetic tests can currently only reveal whether an *in vitro* embryo is likely to have a genetic disease or disorder, but not the degree to which the condition will affect the future person.<sup>33</sup>

The use of PGD is not without controversy. In order to conduct PGD, an *in vitro* embryo must be created and manipulated. As noted earlier, the two blastomeres which are removed from the *in vitro* embryo for testing are totipotent, which means that they theoretically have the ability to develop into an embryo on their own if they were maintained under the proper conditions. Performing PGD on the blastomeres destroys them. For those individuals who consider the embryo to be human life, PGD would likely raise ethical and moral concerns.

<sup>23</sup> A gene is a section of a deoxyribonucleic acid molecule that codes for or directs the production of protein products used by the organism to build up and repair its various parts, catalyze metabolic processes, or even regulate the activity of other genes. The genes are arranged along rod like structures called chromosomes. (Anne Lawton, “The Frankenstein Controversy: The Constitutionality of a Federal Ban on Cloning” (1998/99) 87 Ky. L.J. 277 at 3 (Lexis Nexis).

<sup>24</sup> Wendy E. Roop, “Not in my womb: Compelled Prenatal Genetic Testing” (2000) 27 Hastings Const. L.Q. 397 at 2-3 (Lexis Nexis).

<sup>25</sup> Kay Chung, *Designer myths: the science, law and ethics of preimplantation genetic diagnosis* (London: Progress Educational Trust, 1999) at 10 to 11.

<sup>26</sup> *Ibid.* at 11.

<sup>27</sup> Southern Calif Centre for Reproductive Medicine, “ART Preimplantation Genetic Diagnosis” (November 2002 at 2. Online: <http://www.socalfertility.com/art/pgd.shtml>

<sup>28</sup> Royal Commission, *supra* note 3 at 847.

<sup>29</sup> Peter Braude (B.Sc., M.A., Ph.D. (Clinical Director of the Guy’s and St. Thomas’ Centre for Preimplantation Genetic Diagnosis, U.K.), “An overview of preimplantation genetic diagnosis” (presented at the Preimplantation Genetic Diagnosis Study Day (October 17, 2001)) at 1.

<sup>30</sup> *Supra* note 27.

<sup>31</sup> Chung, *supra* note 25 at 11; Trudo Lemmens “Why Regulate New Genetics?” (Spring 2004, *Innovate*, 14-17).

<sup>32</sup> Denise Avard and Bartha Maria Knoppers, “Screening and Children Policy Issues for the New Millennium” (ISUMA, autumn 2001) at 47.

<sup>33</sup> Munayyer, *supra* note 1 at 3 (Lexis Nexis).



Furthermore, PGD allows for the selection of embryos that are believed to be free of genetic disease, or that have certain desirable genetic traits, for transfer into a woman while the remaining *in vitro* embryos are discarded. This use of PGD raises concerns among many individuals regarding the practice of eugenics.<sup>34</sup>

### 3.4 Issues

Three issues that arise with respect to the use of PGD have been selected for discussion in this chapter. The first two issues discussed are from the perspective of the would-be parents, while the third issue is discussed from the perspective of an *in vitro* embryo.

The first issue considers whether prospective parents, at risk of passing on a serious genetic disease to their offspring, have a right to access PGD to make a decision concerning reproduction. The second issue examines whether prospective parents have a right to use PGD to select, for reproduction, only those *in vitro* embryos that have certain preferred genetic traits, such as a certain sex or the gene for deafness. The final issue examines whether the *in vitro* embryo has a right to life and whether it has a fundamental right to be born as a child with a sound mind and body.

### 3.5 Issue 1: The right to access PGD for medical reasons

Although there is no specific right to access PGD or information respecting one's embryo or foetus in international or regional human rights instruments, there are certain obligations imposed on State Parties in those instruments that suggest that women and perhaps couples have a right to reproductive freedom. Reproductive freedom could be viewed as containing two equal but opposite rights: the right to reproduce and the right not to reproduce. One could argue that information about the genetic status of one's *in vitro* embryos is essential for reproductive autonomy. Such information may be necessary for some persons to assist in their decision-making regarding reproduction. For example, if PGD revealed that one's *in vitro* embryos carried a genetic anomaly that would likely result in the child being born with a severely debilitating disease, one might choose not to reproduce.

### 3.5.1 International and Regional Instruments

As noted in Chapter 2, there is no specific reference to assisted human reproduction in international instruments. Neither is there a specific reference to PGD. There are, however, a number of international instruments that provide a right to "found a family."<sup>35</sup> This right is contained in the *International Covenant on Civil and Political Rights*<sup>36</sup> ("ICCPR") which Canada has ratified. The Human Rights Committee ("HR Committee"), which oversees the implementation by State Parties of the provisions of the ICCPR, provided its interpretation of the right to found a family in *General Comment 19*. The HR Committee noted that the right implies, in principle, the possibility to procreate and live together.<sup>37</sup>

Canada has ratified the *Convention on the Elimination of All Forms of Discrimination against Women*<sup>38</sup> ("CEDAW"). It obliges states to ensure that women have access to information and advice regarding "family planning" (Article 10(1)(h)).<sup>39</sup> Article 16(1)(e) obliges states to ensure that women have the right to decide freely the number and spacing of their children and ensure their access to the "information, education and means" to exercise these rights.<sup>40</sup> In 1993, the CEDAW Committee adopted the

<sup>34</sup> "Eugenics" may be defined as the science of controlled breeding to increase the occurrence of desirable heritable characteristics in a population (Concise Oxford Dictionary, 10th ed.).

<sup>35</sup> *Universal Declaration of Human Rights*, GA Res. 217 (III), UN GAOR, 3rd Sess., Supp. No. 13, UN Doc. A/810 (1948), article 16; *European Convention for the Protection of Human Rights and Fundamental Freedoms*, article 12; *International Covenant on Civil and Political Rights*, 19 December 1966, 999 U.N.T.S. 171, entered into force 23 March 1976, article 23.

<sup>36</sup> *Ibid.*

<sup>37</sup> GC No. 19/38 on article 23 of the ICCPR, UN Doc. CCPR/21/rev.1/Add.2 at para. 5. See Chapter 2 for a more in-depth discussion.

<sup>38</sup> *Convention on the Elimination of all Forms of Discrimination against Women*, G.A. res. 34/180, 34 U.N. GAOR Supp. (No. 46) at 193, U.N. Doc. A/34/46 (entered into force September 3, 1981).

<sup>39</sup> *Ibid.* — article 10(h):

States Parties shall take all appropriate measures to eliminate discrimination against women in order to ensure to them equal rights with men in the field of education and in particular to ensure, on a basis of equality of men and women: (h) Access to specific educational information to help to ensure the health and well-being of families, including information and advice on family planning. [emphasis added]

<sup>40</sup> *Ibid.* — article 16(1)(e):

1. States Parties shall take all appropriate measures to eliminate discrimination against women in all matters relating to marriage and family relations and in particular shall ensure, on a basis of equality of men and women: (e) The same rights to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights.

only authoritative interpretation of the right to family planning in *General Recommendation 21*.<sup>41, 42</sup>

The CEDAW Committee noted that the responsibilities of bearing and raising children affect women's right to access education, among other things, and place an unequal burden of work on women. For these reasons, women are entitled to decide the number and spacing of their children.<sup>43</sup> Recommendation 21 stated that a woman's decision to have or not to have children should not be limited by a spouse, parent, partner or government. Women must have information about contraceptive measures and family planning services.<sup>44</sup>

The CEDAW Committee's interpretation, outlined in Recommendation 21, reinforces the view that women have a right to procreational autonomy. Some commentators argue that the right to found a family and the positive element of the right to family planning are related to an individual's or couple's right to have a child and thus implicitly guarantee a right to procreate or reproduce.<sup>45</sup>

At the international level, however, there are multiple interpretations of a right to procreate or reproduce.<sup>46</sup> There is uncertainty as to whether such a right would include a right to obtain information about the status of the foetus or, in the case of AHR, the status of the *in vitro* embryo in order to decide whether to procreate.

The CEDAW states in article 5(a):

Article 5 – States Parties shall take all appropriate measures:

(a) To modify the social and cultural patterns of conduct of men and women, with a view to achieving the elimination of prejudices and customary and all other practices which are based on the idea of the inferiority or the superiority of either of the sexes or on stereotyped roles for men and women;

The CEDAW Committee has not issued recommendations regarding article 5 that would assist with its interpretation or to further inform States Parties of their obligations.

With respect to regional instruments, the Council of Europe's *Convention on Human Rights and Biomedicine*<sup>47</sup> ("*Convention*") provides the following in Articles 12 and 14:

#### Article 12 – Predictive genetic tests

Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to a disease may be performed *only for health purposes* or for scientific research linked to health purposes, and subject to appropriate counselling. [emphasis added]

#### Article 14 – Non-selection of sex

The use of techniques of medically assisted procreation shall not be allowed for the purpose of choosing a future child's sex, except where serious hereditary sex-related disease is to be avoided.

The Explanatory Report<sup>48</sup> to the *Convention* notes in paragraph 83 that "Article 12 as such does not imply any limitation of the right to carry out diagnostic interventions at the embryonic stage to find out whether an embryo carries hereditary traits that will lead to serious diseases in the future child."<sup>49</sup>

<sup>41</sup> *Convention on the Elimination of all Forms of Discrimination against Women*, Recommendation 21, Equality in marriage and family relations (Thirteenth session, 1992), Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies, U.N. Doc. HRI/GEN/Rev. 1 at 90 (1994).

<sup>42</sup> Maja Kirilova Eriksson, *Reproductive Freedom: In the Context of International Human Rights and Humanitarian Law* (The Hague, The Netherlands: Kluwer Law International, 2000) at 185.

<sup>43</sup> Recommendation 21, *supra* note 39 at para. 21.

<sup>44</sup> *Ibid.* at para. 22.

<sup>45</sup> Eriksson, *supra* note 42 at 188; M. Tardu, "Relationships between human rights and population issues" (1990) Population and Human Rights UN New York at 55; Statens Medicinsk-etiska Rad, *Assisterad befruktning*, Stockholm 19 April 1995 at 15; J.A. Frowein & W. Peukert, *Europäische MenschenRechtsKonvention*, Kehl 1996 at 424.

<sup>46</sup> See Chapter 2 of the paper for a detailed discussion.

<sup>47</sup> *Convention for the protection of Human Rights and dignity of the human being with regard to the application of biology and medicine: Convention on Human Rights and Biomedicine* (Oviedo, 4.IV.1997) (Council of Europe, European Treaty Series, No. 164).

<sup>48</sup> *Explanatory Report to the Convention on Human Rights and Biomedicine* (Council of Europe, European Treaty Series, No. 164.) (<http://conventions.coe.int/Treaty/en/Reports/Html/164.htm>) (hereinafter Exp Report).

<sup>49</sup> *Ibid.* (Exp Report) at para. 83, page 15.

With respect to Article 14, the Explanatory Report notes that "...it is not permissible to use a technique of medically-assisted [*sic*] procreation in order to choose a future child's sex, except where serious hereditary sex-related disease is to be avoided."<sup>50</sup> Paragraph 94 of the Explanatory Report notes, however, that it is up to the law of each country to determine what will be considered a "serious hereditary sex-related disease".<sup>51</sup>

In the spring of 1996, Canada was granted observer status on the Council. Although the *Convention* is open to signature by non-member states, Canada has not signed. Articles 12 and 14 of the *Convention* could, however, be introduced in a Canadian court as indicative of how European countries have dealt with these issues.

### Conclusion

The provisions of the ICCPR and CEDAW could not form the basis of an action in a Canadian court, but they could be cited, along with the *Declaration*, to support a particular interpretation of the *Canadian Charter of Rights and Freedoms*<sup>52</sup> ("*Charter*") or of domestic legislation. The lack of jurisprudence at the international level regarding the right to found a family makes it difficult to predict how these provisions would be interpreted by a Canadian court.

### 3.5.2 The Law in Other Jurisdictions

The following will outline the law regarding the right to access PGD in the United States ("U.S."), Germany and the UK. These countries were chosen because they provide examples of three distinct state approaches to the practice of PGD.

#### The U.S.

In the U.S., there is no federal legislation respecting PGD. Fertility clinics are free to conduct PGD within the limits set by the laws of each state.<sup>53</sup> Only a handful of states explicitly address the use of PGD. Ten out of fifty states prohibit embryo research but six of those exempt PGD and thus allow it.<sup>54</sup> The other four states restrict the use of PGD to those situations where it can be shown to be beneficial, and without risk, to the *in vitro* embryo.<sup>55</sup>

It may be that the degree of control exercised by a state over the use of PGD correlates with the state's view of the moral and legal status of the *in vitro* embryo. This appears

to be the case in Louisiana, which is one of the four states that prohibit PGD. It assigns rights to the *in vitro* embryo from the moment of conception. Under the Louisiana *Civil Code*, the *in vitro* embryo is protected and is deemed to be a juridical person who can sue and be sued, until such time as it is implanted in a woman's womb.<sup>56</sup> Louisiana prohibits PGD, unless it can be demonstrated that the procedure would benefit and be risk-free for the *in vitro* embryo. Both of these criteria would arguably be difficult to meet since PGD is never without risk to the *in vitro* embryo and, as a result of PGD, any *in vitro* embryos with a genetic anomaly would most likely be left to perish.

American jurisprudence has recognized that women have a constitutionally protected right to terminate a pregnancy up to the point of foetal viability, under the right to privacy and to liberty in the First, Fourth, Fifth and Fourteenth Amendments<sup>57</sup> to the *U.S. Constitution*. At the point of

<sup>50</sup> *Ibid.* (Exp Report) at para. 93, page 16.

<sup>51</sup> *Ibid.* (Exp Report) at para. 94, page 16.

<sup>52</sup> *Constitution Act, 1982*, Schedule B, 1982, c.11, *Canadian Charter of Rights and Freedoms*, entered into force on April 17, 1982.

<sup>53</sup> Chung, *supra* note 25 at 15.

<sup>54</sup> Timothy Stoltzfus Jost, "Rights of Embryo and foetus in Private Law" (2002) 50 Am. J. Comp. L. 633 at 640; June Coleman, "Playing God or Playing Scientist" (1996) 27 Pac. L.J. 1331 at 1354 (The ten states are: Mass., Mich., N.H., N.M., N.D., R.I., LA., Minn., PA., and ME.) (Lexis Nexis).

<sup>55</sup> *Ibid.* (Coleman) at 11 (The four states that limit the conduct of PGD are: Louisiana, Minnesota, Maine, and Pennsylvania.) (Lexis Nexis).

<sup>56</sup> Jost, *supra* note 54 at 633; Louisiana Civil Code § 26 (1988).

<sup>57</sup> "Privacy": Although the *U.S. Constitution* does not specifically provide a right to privacy, the court has held that it originates in the First, Fourth and Fifth Amendments to the *Constitution* (Sklar A Sherwood "Don't Hate Me Because I'm Beautiful... And Intelligent... And Athletic: Constitutional Issues in Genetic Enhancement and the Appropriate Legal Analysis" (2001) 11 Health Matrix 633 at 5-6 (Lexis Nexis)). The courts have held that the rights secured by this guarantee to privacy are fundamental rights. For example, the right to procreate and the right not to procreate were both derived from the guarantee of privacy and thus they are considered fundamental. These rights are fundamental because they are located within areas of such a personal nature that unwarranted governmental intrusion is improper; these rights are not easily restricted by the state. Fundamental rights are granted the highest protection under the law. However, they are not limitless: the state can infringe on a fundamental right but only if it has a compelling reason and the infringement is accomplished through the least restrictive means. "Liberty": The Fourteenth Amendment extends to the states the Fifth Amendment Due Process Clause's guarantee that "no person shall be deprived of life, liberty, or property without due process of law." The Due Process Clause of the *U.S. Constitution* includes a substantive component, which provides heightened protection against government interference with individual liberty interests under the First and Fourteenth Amendments. "Liberty denotes more than freedom from bodily restraint, but also the right of the individual to contract, to engage in any of the common occupations of life, to acquire useful knowledge, to marry, establish a home, and bring up children... and generally to enjoy these privileges long recognized... as essential to the orderly pursuit of happiness by free men [and women]." (Kelly M. Plummer "Ending Parents' Unlimited Power to Choose: Legislation is Necessary to Prohibit Parents' Selection of Their Children's Sex and Characteristics" (2003) 47 St. Louis L.J. 517 at 5 (Lexis Nexis).)

foetal viability, the state's interest in the developing foetus may be such that the state can impose limitations on a woman's right to terminate the pregnancy.<sup>58</sup>

In the case of prospective parents who are at risk of passing on a serious genetic disorder or disease to their offspring, there would be an obligation on the attending physician to advise them of the risks and to recommend either PGD (if legal in the state) or prenatal genetic testing. The information from such testing might be viewed by the prospective parent as crucial to the making of an informed decision regarding reproduction. In those instances where the physician failed to inform the parent of the risk or failed to advise them regarding genetic testing and a seriously affected child was born, the parent might be in a position to sue the physician on the basis of negligence. In a majority of cases, these actions are in the nature of a tort framed as either "wrongful birth," when it is a court action taken by the parents, or "wrongful life," when it is a court action taken on behalf of the child.

The Supreme Court of California held in *Turpin v. Sortini*,<sup>59</sup> an action for wrongful life, that:

...in deciding whether or not to bear such a [disabled] child parents may properly, and undoubtedly do, take into account their own interests, parents also presumptively consider the interests of their future child. Thus, when a defendant negligently fails to diagnose a hereditary ailment, he harms the potential child as well as the parents by depriving the parents of information which may be necessary to determine whether it is in the child's own interest to be born with defects or not to be born at all.<sup>60</sup>

There has been some jurisprudence in those states that prohibit foetal experimentation where the courts have linked a constitutional right to information with reproductive freedom. In *Margaret s. v. Treen*<sup>61</sup> ("Margaret s. II"), there were multiple issues before the Court relating to provisions of a Louisiana state law regarding abortion. One issue was whether the legislative provision prohibiting *in utero* and *in vitro* foetal experimentation was constitutional. The plaintiffs alleged that the provision would have the effect of catching procedures

involving the foetus which might be considered "experimentation" but which would be therapeutic to a pregnant woman. In addition, the plaintiffs argued that the provision unconstitutionally burdened a doctor's right to conduct medical and scientific research.<sup>62</sup>

The U.S. District Court held that the prohibition respecting foetal experimentation, which carried substantial criminal penalties, unconstitutionally burdened a woman's right to an abortion and infringed on the rights of physicians to participate in foetal research.<sup>63</sup> In reaching these conclusions, the Court stated:

The decision whether or not to beget or bear a child is at the very heart of this cluster of constitutionally protected choices recognized as the right of privacy...*The Court finds that this statute unduly limits the medical information obtainable through experimentation in that it deprived women of information concerning the likelihood of fetal deformity in their future pregnancies.* Such experimentation which might be therapeutic to the woman would be prohibited by [the statute] because it would not be therapeutic to the aborted, dead fetus. The right of women to make reproductive choices free of undue burdens imposed by the state is further violated by [the statute] in that the information needed to improve the accuracy and reliability

<sup>58</sup> *Roe v. Wade*, 410 U.S. 113 (1973).

<sup>59</sup> *Turpin v. Sortini et al.*, 31 Cal. 3d 220; 643 P.2d 954; 182 Cal. Rptr. 337; 1982 (Supreme Court of California) (Lexis Nexis).

<sup>60</sup> *Ibid.* at 10 (Lexis Nexis).

<sup>61</sup> *Margaret s. v. Treen*, 597 F. Supp 636, 673 (E.D. La. 1984) (District Court) (QL).

<sup>62</sup> *Ibid.* at 31 (QL).

<sup>63</sup> *Ibid.* at 33 (QL). The right of physicians to engage in their profession, although not recognized as a fundamental right, nonetheless is entitled under the Constitution to protection from arbitrary infringement. The court defined "liberty" to include "the right to engage in any of the common occupations of life." The court noted that "[a] state law will not be permitted to deny a person the right to pursue his occupation (including the physician class in this case) unless it is rationally related to the achievement of a legitimate state interest...The state's interest in protecting fetal life does not continue past the death of the fetus...There is no Louisiana law that prohibits experimentation on a deceased human being and, in fact, such experimentation is conducted during autopsies which are routinely performed...Under [Louisiana] statute, a mother could donate the body of her child to medical science for [education, research or the advancement of science]...purposes, but the criminal penalty imposed by [this statute] would effectively prohibit the donation of a mass of aborted tissue. This statute draws a distinction between a dead fetus and a deceased human being. There is no rational basis to draw such a distinction."



of amniocentesis and other pre-natal diagnostic methods is dependent on the use of aborted fetal tissue for experimentation.<sup>64</sup> [emphasis added]

The District Court held that because fundamental rights encompass the entire process surrounding abortion, the prohibition on foetal experimentation, which could include diagnostic testing, violated the constitutionally protected right of women to make reproductive choices.<sup>65</sup> Presumably, the fundamental right to reproductive choice is not limited solely to a decision respecting abortion, but extends to encompass decisions respecting child bearing and contraception.<sup>66</sup>

The decision of the District Court was appealed to the Fifth Circuit Court,<sup>67</sup> which criticized the District Court for avoiding the real constitutional issue raised: whether a statutory ban on experimentation would inevitably limit the kinds of tests available to women and their physicians and thus could not help but infringe on a woman's fundamental rights.<sup>68</sup> The Fifth Circuit Court noted that every medical test that is now "standard" was once an "experiment." The Fifth Circuit Court, concurring with the District Court, held that the statute's prohibition on foetal experimentation was unconstitutionally vague.<sup>69</sup>

In *Jane L. v. Bangerter*<sup>70</sup> ("Bangerter"), the Tenth Circuit Court was asked to review a Utah statute that permitted discretionary experimentation aimed at acquiring genetic information about the embryo or foetus. A lower court upheld the statute as constitutional by narrowly interpreting the term "experimentation" to mean "tests or medical techniques which are designed solely to increase a researcher's knowledge and are not intended to provide any therapeutic benefit to the mother or child."<sup>71</sup>

The Tenth Circuit Court disagreed, finding that the lower court had "blatantly" rewritten the statute in an attempt to provide clarity. The Court held that the word "benefit" was also ambiguous and pondered "if the mother gains knowledge from a procedure that would facilitate future pregnancies but inevitably terminate the current pregnancy, would the procedure be deemed beneficial to the mother?"<sup>72</sup> Since the statute was found not to provide clear boundaries to distinguish permissible acts from

those that are criminal, the Court deemed it unconstitutional and invalid.<sup>73</sup>

In *Lifchez v. Hartigan*<sup>74</sup> ("Lifchez"), the District Court of Illinois considered the scope of the constitutionally protected right to procreational autonomy. The issue before the Court was whether s. 6(7) of the Illinois *Abortion Law*, which prohibited the sale of or "experiment" on a foetus unless the experiment was "therapeutic" to the foetus, offended due process principles in the Fourteenth Amendment of the *U.S. Constitution* by being so vague.

The Court found that the undefined terms "experiment" and "therapeutic" in the Illinois *Law* rendered it vague and thus violated the plaintiff's due process rights under the *Constitution*. The Illinois *Law* contained a provision purporting to exempt *in vitro* fertilization. However, the Court noted that, given the vague wording, PGD could be viewed as an experimental procedure that is not therapeutic to the *in vitro* embryo, and a procedure that could fall outside the *in vitro* fertilization exemption.<sup>75</sup>

In addition, the Court asked itself whether the Illinois *Law* impinged on a woman's right of privacy and reproductive freedom as established in *Roe v. Wade*.<sup>76</sup> The Court found that s. 6(7) was unconstitutional since it impermissibly restricted a woman's fundamental right of privacy; in particular, a woman's right to make reproductive choices free of government or state interference.<sup>77</sup>

<sup>64</sup> *Ibid.* at 32 (QL).

<sup>65</sup> *Ibid.*; Roberts, *supra* note 12 at 10 (Lexis Nexis).

<sup>66</sup> *Supra* note 61 at 1078-79.

<sup>67</sup> *Margaret s. v. Edwards*, 794 R.2d 994 (5th Cir. 1986) (Fifth Circuit Court).

<sup>68</sup> *Ibid.* at 999-1002.

<sup>69</sup> *Ibid.* at 999.

<sup>70</sup> *Jane L. v. Bangerter*, 61 F.3d 1493 (10th Cir. 1995).

<sup>71</sup> *Jane L. v. Bangerter*, 794 F. Supp. 1528 (D. Utah 1992).

<sup>72</sup> *Supra* note 70 at 1502.

<sup>73</sup> *Ibid.*

<sup>74</sup> *Lifchez v. Hartigan*, 1990 U.S. Dist. Lexis 4947 (United States District Court). (Lexis Nexis) Dr. Lifchez challenged the *Law* because he, along with other Illinois physicians, was concerned that the vague wording in its provisions, including s. 6(7), could be interpreted to apply to procedures, such as amniocentesis or chorionic villi sampling, undertaken to obtain information about the embryo or foetus. If that was the case, physicians who performed such procedures could be charged under the statute's criminal sanctions.

<sup>75</sup> *Ibid.* at 6-7 (Lexis Nexis).

<sup>76</sup> *Roe*, *supra* note 58.

<sup>77</sup> *Lifchez*, *supra* note 74 at 15 (Lexis Nexis).

In support of its decision, the Court referred to the following passage from *Carey v. Population Services International*:<sup>78</sup>

The decision whether or not to beget or bear a child is at the very heart of this *cluster of constitutionally protected choices*. That decision holds a particularly important place in the history of the right of privacy, a right first explicitly recognized in an opinion holding unconstitutional a statute prohibiting the use of contraceptives...and most prominently vindicated in recent years in the context of contraception...and abortion.<sup>79</sup> [emphasis added]

The Court held that s. 6(7) intruded on this “cluster of constitutionally protected choices” which included activities such as chorionic villi sampling (which provides information about the foetus) and embryo transfer (an AHR procedure). The Court noted:

Embryo transfer is a procedure designed to enable an infertile woman to bear her own child. It takes no great leap of logic to see that *within the cluster of constitutionally protected choices that includes the right to have access to contraceptives, there must be included within that cluster the right to submit to a medical procedure that may bring about, rather than pregnancy*. Chorionic villi sampling is similarly protected. The cluster of constitutionally protected choices that includes the right to abort a fetus within the first trimester must also include *the right to submit to a procedure designed to give information about that fetus which can then lead to a decision to abort*. Since there is no compelling state interest sufficient to prevent a woman from terminating her pregnancy during the first trimester...there can be no such interest sufficient to intrude upon these other protected activities during the first trimester.<sup>80</sup> [emphasis added]

The Court concluded that s. 6(7) was unconstitutional “by encroaching upon this protected zone of privacy.”<sup>81</sup> In *Lifchez*, the Court commented on AHR procedures, noting that the woman’s decision to undergo a particular AHR procedure was a fundamental personal and private reproductive choice into which the state could not intrude. State intrusion or interference with a woman’s access to such procedures, designed to provide information necessary for reproductive choice, would restrict her

constitutionally protected right of privacy as articulated in the landmark Supreme Court decision of *Roe v. Wade* and *Carey v. Population Services International*.<sup>82</sup>

### Summary

In both *Margaret S.* and *Lifchez*, the court dealt with rights related primarily to information about an *in utero* foetus or embryo. The courts were concerned that overly broad statutory limitations on foetal experimentation might include foetal testing which could provide information necessary for the woman to make informed decisions about reproduction. In *Margaret S.*, the courts were willing to expand a woman’s fundamental right to make reproductive decisions to include the right to information obtained from testing the *in utero* and *in vitro* foetus. The courts were of the view that testing the dead foetus could provide the necessary information to the woman to allow her to make future reproductive decisions. The Court in *Lifchez* held that the AHR procedure of embryo transfer, a process developed to allow an infertile woman to bear a genetically related child, falls within the “cluster of constitutionally protected choices” that are part of the fundamental right to procreative autonomy.

It may be that American courts would consider the information obtained from the testing of an *in vitro* embryo equally important for reproductive decision-making by women and would thus fall within a constitutionally protected sphere. At least one court has held that a decision to submit to an AHR procedure in order to procreate is similarly protected under the woman’s right to procreational autonomy. It may be that both *in vitro* fertilization and PGD would be found by the courts to be fundamental choices that warrant constitutional protection.

### Germany

In 1990, Germany passed the *Law for the protection of embryos*<sup>83</sup> (“*Embryo Protection Law*”). The *Embryo Protection Law* grants legal protection to life (including the *in vitro*

<sup>78</sup> *Carey v. Population Services International*, 431 U.S. 678, 52 L.Ed. 2d 675, 97 S.Ct. 2010 (1977).

<sup>79</sup> *Ibid.* at 685; *Lifchez*, *supra* note 74 at 15 (Lexis Nexis).

<sup>80</sup> *Lifchez*, *supra* note 74 at 16 (Lexis Nexis).

<sup>81</sup> *Ibid.* at 15-16 (Lexis Nexis).

<sup>82</sup> *Ibid.* at 15 (Lexis Nexis).

<sup>83</sup> *Law for the protection of embryos*, Bundesgesetzblatt, Part I, 19 December 1990, pp. 2746-2748).

embryo) before birth.<sup>84</sup> Some interpret the Law as conferring on an *in vitro* embryo human rights from the moment of fertilization.<sup>85</sup>

The objective of the legislation is to preserve and protect *in vitro* embryos. The selection of an *in vitro* embryo on the basis of its sex, disability or tissue typing<sup>86</sup> would be prohibited under the Law. Under the legislation, the only activities permitted with respect to the *in vitro* embryo are those designed to benefit or to ensure its preservation. PGD is prohibited in Germany presumably because it involves the identification and selection of only those *in vitro* embryos that are “healthy,” while discarding those that have a genetic anomaly.

Under section 3 of the *Embryo Protection Law*, the fertilization of an egg with sperm selected solely on the basis of their sex chromosome is prohibited. An exception is made, however, to permit sperm selection solely to avoid a serious sex-linked genetic disease.<sup>87</sup> Some pressure has been brought to bear on the government to permit PGD since the German position appears contradictory.

On the one hand, Germany allows prenatal testing of the foetus. If the foetus is found to have a particular genetic disease, the woman or couple are able to choose a genetic abortion without fear of prosecution by the state. Although abortion is illegal, the German Constitutional Court has specified that if a woman decides to have an abortion, she will not be prosecuted under the law as long as she visits a pregnancy counsellor prior to the abortion and she is less than fourteen weeks pregnant at the time of the abortion.<sup>88</sup>

And yet, on the other hand, the *Embryo Protection Law* prohibits the use of PGD which is conducted on the *in vitro* embryo prior to a pregnancy. PGD could eliminate the need for a genetic abortion by pre-selecting for transfer into the woman only those *in vitro* embryos that are free of a genetic predisposition to a particular disease.<sup>89</sup>

In Germany, there are individuals and groups, including women’s groups that support the *Embryo Protection Law*, including the prohibition on PGD. These groups are concerned that widespread use of PGD to prevent disability and handicap would lead to negative attitudes

in society towards those individuals who are chronically ill or disabled.<sup>90</sup> The German view is not surprising given the eugenics practiced by the Nazis in Germany before and during World War II.

### The U.K.

PGD is a regulated activity under the U.K.’s 1990 *Human Fertilisation and Embryology Act*<sup>91</sup> (“HFE Act”). It is permitted when the individual or couple are at risk of passing on a genetic disease or when the woman is over the age of 35 years. Practitioners require a licence from the Human Fertilisation and Embryology Authority (“HFE Authority”) to create an *in vitro* embryo, and further approvals to conduct PGD.

The *HFE Act* provides that a licence is required to undertake any “practices designed” to ensure that *in vitro* embryos are in a “suitable condition to be placed in a woman.”<sup>92</sup> PGD has been determined to be such a practice and thus a clinic that wishes to undertake PGD must have a licence from the HFE Authority.

In addition to a licence, the clinic must apply to the HFE Authority for an approval to use PGD to diagnose or screen *in vitro* embryos for a particular genetic disease. Licences are not issued to undertake PGD on every genetic disease or disorder. Instead, a committee of the HFE Authority decides whether to issue an approval to

<sup>84</sup> Ecumenical Dialogue, *Biomedicine and Genetic Engineering* (1998) ([http://www.ikd.de/dialogue/22396\\_3375.html](http://www.ikd.de/dialogue/22396_3375.html)).

<sup>85</sup> Chung, *supra* note 25 at 15.

<sup>86</sup> “Tissue typing” refers to a test to determine whether tissues are immunologically compatible with one another.

<sup>87</sup> *Supra* note 83.

<sup>88</sup> Eriksson, *supra* note 42 at 289; Questions and Answers about Germany: Health Care, Health Issues and Social Welfare. Online: [http://www.germany-info.org/relaunch/info/facts/facts/questions\\_en/he.../healthissues3.htm](http://www.germany-info.org/relaunch/info/facts/facts/questions_en/he.../healthissues3.htm)

<sup>89</sup> Stephan Mueller, Ph.D. (Research Centre Biotechnology & Law, University of Lueneburg, Lueneburg, Germany), “Ethics and the regulation of Preimplantation diagnosis in Germany” (1997) 7 *Eubios Journal of Asian and International Bioethics* 5 at 5. Online: <http://www.biol.tsukuba.ac.jp/~macer/EJ71D.html>.

<sup>90</sup> Gabriele Pichlhofer and Sigrid Graumann, Frauen Forum Fotpflanzungsmedizin, Statement ReproKult, *The role of women in biomedical research*. Online: [http://www.reprokult.de/posit\\_e.html](http://www.reprokult.de/posit_e.html).

<sup>91</sup> *Human Fertilisation and Embryology Act 1990* (c. 37). Online: [http://www.legislation.hms.gov.uk/acts/acts1990/Ukpga\\_19900037\\_en\\_1.htm](http://www.legislation.hms.gov.uk/acts/acts1990/Ukpga_19900037_en_1.htm).

<sup>92</sup> *Ibid.* at section 1 (Schedule 2).



undertake PGD testing for a particular disease or disorder on a case-by-case basis.

Section 44 of the *HFE Act* extends section 1 of the *Congenital Disabilities (Civil Liability) Act 1976* to cover infertility treatments. This extension means that parents of children born disabled in the U.K. are permitted to sue physicians or clinics for their negligent performance of or their failure to undertake PGD on the *in vitro* embryo to detect a genetic disease.

Under the *HFE Act*, the use of PGD for the purpose of social sex selection is prohibited. In December 2003, the HFE Authority announced the results of public consultations regarding sex selection for social reasons. Approximately 80% of those who responded were in favour of retaining the legislative prohibition.<sup>93</sup>

The HFE Authority decided to issue licences allowing the use of *in vitro* fertilization, PGD and tissue typing to transfer only those *in vitro* embryos that are a genetic match for an existing sibling with a serious disease. The HFE Authority's decision was not without controversy and was challenged by Josephine Quintavalle, acting on behalf of a group whose purpose was to focus debate on ethical issues arising from AHR. One of the group's central tenets was absolute respect for the human embryo. Ms. Quintavalle sought judicial review of the HFE Authority's decision to licence tissue typing to select between healthy embryos.<sup>94</sup>

In *Quintavalle v. Human Fertilisation and Embryology Authority*<sup>95</sup> ("*Quintavalle*"), the High Court of Justice held that the phrase "practices designed to secure that embryos are in a suitable condition to be placed in a woman," in s. 1 (Schedule 2) of the *HFE Act*, permitted the HFE Authority to issue licences for PGD and tissue-typing. The Court held that PGD and tissue-typing were permitted under the *HFE Act* in order to secure an embryo, from among other healthy embryos, in a suitable condition for transfer, i.e., a tissue-type match for an already existing sibling who had a serious genetic disease.<sup>96</sup>

The Court, arguably, gave an expansive reading to the phrase "in a suitable condition" to allow PGD and

tissue-typing. A narrow interpretation of the phrase might have restricted permissible practices to only those intended to ensure the health and safety of embryos.

In the U.K., clinics and practitioners must be licensed to perform PGD. To undertake tissue-typing to create an *in vitro* embryo that could become a tissue donor, an approval must be obtained from the HFE Authority. Approvals are granted only on a case-by-case basis.

### 3.5.2.1 Conclusion

It appears from a review of the laws in Germany, the U.S. and the U.K., that state legislation governing the practice of PGD closely mirrors the society's predominant view of the moral and legal status of the embryo. In those jurisdictions where the dominant view of the embryo is that of a developing human being or person, the state restricts testing and experimentation and/or assigns an embryo certain legal rights (Germany and Louisiana). In other jurisdictions, where the embryo is not considered a human being but may rather be viewed as *sui generis*, i.e., deserving of respect but not legal rights, the use of PGD is either unrestricted by the state or subject to state regulation, rather than state prohibition (the U.K. and the majority of states in the U.S.).

### 3.5.3 Academic Literature and Commentary

Despite the lack of jurisprudence with respect to PGD, there is no shortage of academic commentary on the subject, much of it from the U.S.

For many American academics, reproductive choice is viewed as part of the constitutionally protected right to procreational autonomy within the right to liberty. It is broad enough to encompass the right to choose to undergo an AHR procedure, as well as the right to choose to have the resulting *in vitro* embryos undergo PGD. Procreative autonomy is considered to include the choice

<sup>93</sup> BioNews "HFEA rules out social sex selection" (November 12, 2003). Online: <http://www.bionews.org.uk>.

<sup>94</sup> *Quintavalle v. Human Fertilisation and Embryology Authority* [2003] E.W.J. No. 2533 (England and Wales Court of Appeal (Civil Division)) at 4 (QL). It is my understanding that *Quintavalle* is being appealed to the House of Lords.

<sup>95</sup> *Ibid.*

<sup>96</sup> *Ibid.* at 15.

to have healthy children, as well as the right not to have unhealthy children.<sup>97</sup>

Academics argue that procreative autonomy includes the right to obtain and use genetic information to make a reproductive choice. If individuals are free to decide whether to procreate, and if information as to the presence or absence of a genetic anomaly will affect that decision, it is obvious that prospective parents should be free to obtain and use the genetic information to assist in their decision-making.<sup>98</sup> These commentators are not suggesting that the right to obtain genetic information is a positive right or obligation on the state to provide genetic testing, but rather it is a negative right to access genetic testing free from government interference.<sup>99</sup>

Other commentators have argued that parents have a fundamental right, based in natural law, to make decisions respecting the care and upbringing of their children. With respect to genetic intervention, this fundamental right would enable parents to protect the health and bodily integrity of their children by making crucial decisions for their children at all stages of development.<sup>100</sup> Commentators suggest that this fundamental right would allow parents to make decisions, based on genetic information, to screen out disabling disease at the earliest stage of procreation, the embryonic stage. This right would allow parents to choose non-life, over disabled life, for their future child by choosing testing and by selecting for transfer only those *in vitro* embryos that are free of a genetic disease or disorder.<sup>101</sup>

There are, however, a number of academics who believe that the state must place some restrictions on the use of PGD, given the possible implications for society that may result from the unrestricted use of this technology. At least one commentator proposes a complete ban on PGD in the belief that it will lead to societal discrimination against persons born with disabilities.<sup>102</sup>

Commentators opposed to PGD often argue that the rejection of an embryo based on the possibility of disability is discriminatory, and that it is based on a misunderstanding of the nature of disability which devalues persons living with disabilities.<sup>103</sup> They further argue that if genetic diseases and disorders come to be viewed as

avoidable, genetic testing, such as PGD and genetic therapy, would likely encourage narrow, socially determined standards of “health” and “normality” to prevail in society. These standards would reinforce existing prejudices against individuals with disabilities or physical characteristics that do not live up to a cultural ideal.<sup>104</sup>

Such standards could also generate social animosity toward parents who allow their children to be born “defective,” despite knowledge of a potential genetic condition. As a result, the social focus might shift from encouraging tolerance of human diversity to developing methods to avoid or eradicate diversity.<sup>105</sup>

Furthermore, it is possible that PGD could be used to identify genetic traits beyond those that may cause severe genetic disorders or disease and thus transform PGD from a useful reproductive technique into a tool for eugenic purposes. By preventing the birth of at least some children with inherited disabilities, the use of PGD may reinforce discriminatory social attitudes towards disabled people in general.<sup>106</sup>

### 3.5.4 The Law in Canada

In Canada, a physician would likely recommend PGD where there is evidence that the individual or couple are at risk of passing on a severe genetic disease to their offspring, or when the maternal age is greater than

<sup>97</sup> John Robertson, “Genetic Selection of Offspring Characteristics” (1996) 76 B.U.L. Rev. 421 at 1.

<sup>98</sup> *Ibid.* at 2.

<sup>99</sup> Megan A. Jellinek, “Disease Prevention and the Genetic Revolution: Defining a Parental Right to Protect the Bodily Integrity of Future Children” (2000) 27 Hastings Const. L.Q. 369 at 16 (Lexis Nexis).

<sup>100</sup> *Ibid.* (Jellinek) at 4 (Lexis Nexis); Rebecca Knox, “Preimplantation Genetic Diagnosis: Disease Control or Child Objectification?” (2003) 22 St. Louis U. Pub. L. Rev. 435 at 3-7 (Lexis Nexis).

<sup>101</sup> *Ibid.* (Jellinek).

<sup>102</sup> Jodi Danis, “Sexism and ‘The Superfluous Female’: Arguments for Regulating Pre-Implantation Sex Selection” (1995) 18 Harv. Women’s L.J. 219 at 3 (Lexis Nexis).

<sup>103</sup> Jost, *supra* note 54 at 641; Robertson, *supra* note 97.

<sup>104</sup> Danis, *supra* note 102.

<sup>105</sup> Munayyer, *supra* note 1 at 4 (Lexis Nexis).

<sup>106</sup> Joint Canadian Fertility and Andrology Society/Society of Obstetricians and Gynaecologists of Canada, *Policy Statement: Ethical Issues In Assisted Reproduction* (1999) Journal SOGC 4 at 33-34.

35 years.<sup>107</sup> At the present time, Canada has only one centre providing PGD which is located in Montreal, Quebec.

### The AHR Act

On April 22, 2004, certain portions of the federal *Act Respecting Assisted Human Reproduction and Related Research*<sup>108</sup> (“AHR Act”) were proclaimed in force. Under the AHR Act, some uses of PGD are prohibited while others will be regulated as controlled activities. The Act permits the use of PGD for selecting only those *in vitro* embryos of a particular sex for medical reasons, i.e., to prevent, diagnose or treat a sex-linked disease or disorder. However, the Act prohibits the use of PGD, as well as other technologies, to identify the sex of *in vitro* embryos in order to select, for social or cultural reasons, only those of a certain sex for reproductive purposes (s. 5(1)(e) of the AHR Act). A person who contravenes this prohibition, depending on the type of offence, could be liable to a substantial fine and/or imprisonment.

The offence provisions in the AHR Act are based on the federal criminal law head of power in s. 91(27) of the *Constitution Act, 1867*. Section 60 of the Act provides that a person convicted of committing a prohibited act would, depending on the type of offence, be liable to a maximum fine of \$250,000 to \$500,000 and /or a maximum jail term of 4 to 10 years. A person who is convicted of contravening any of the regulations made under the Act would, depending on the type of offence, be liable to a maximum fine of \$100,000 to \$250,000 and/or a maximum jail term of 2 to 5 years (section 61).

The AHR Act provides the Governor in Council with an extensive regulation-making authority, as well as the authority to create the future Assisted Human Reproduction Agency of Canada (“Agency”). The use of PGD, for reasons other than social sex selection, will most likely be the subject of regulations under the Act, and physicians and/or clinics will most likely be required to obtain a licence from the Agency to conduct PGD. Furthermore, the Agency, once created would have authority to attach conditions to each licence, further controlling the practice of PGD.

### The Charter

In order to invoke the application of the *Charter*, there must be a government action that arguably deprives a person of one of the protected rights or freedoms. Section 7 provides the interests and rights that would most likely be implicated in a situation where state action prevented a woman from accessing information about her *in vitro* embryo that would be necessary for her to make a reproductive decision.

The section 7 analysis undertaken by the courts could be viewed as a three-step process. First, the courts look to see whether there has been a state deprivation of one of the rights in section 7, i.e., life, liberty or security of the person. Second, the courts identify and define the relevant principle of fundamental justice. Third, the courts determine whether the state deprivation was in accordance with the principles of fundamental justice and if it was, then the state action would be found constitutional. If the deprivation was not in accordance with the principles of fundamental justice, then it would be either be found unconstitutional or the court would determine whether the state could justify the deprivation under section 1 of the *Charter*.

### Case law

In Canada, the courts have recognized a woman’s right to reproductive autonomy. This right, like all other rights, is not absolute. It can be limited by the state through legislation or regulations. Any state limitation would have to accord with the principles of fundamental justice and be justifiable. The following Supreme Court cases discuss reproductive autonomy.

<sup>107</sup> Canadian physicians currently look to either the Joint Policy Statement of the Canadian Fertility and Andrology Society and the Society of Gynaecologists of Canada (“Canadian Policy Statement”) (Joint Canadian Fertility and Andrology Society/Society of Obstetricians and Gynaecologists of Canada, *Policy Statement: Ethical Issues In Assisted Reproduction* (1999) Journal SOGC 4 at 32.) or to the professional guidelines established by the Ethics Committee of the U.S. American Society of Reproductive Medicine (“U.S. Guidelines”) (Ethics Committee of the American Society of Reproductive Medicine, *Sex selection and Preimplantation genetic diagnosis* (1999) 72 (No. 4) Fertility and Sterility 595.) for guidance with respect to providing PGD services.

<sup>108</sup> The *Act Respecting Assisted Human Reproduction and Related Research*. Third Session, Thirty-seventh Parliament, 52-53 Elizabeth II, 2004 (passed 12 March 2004 and certain sections proclaimed in force on 22 April 2004). Online: <http://www.parl.gc.ca>.

In *R. v. Morgentaler*<sup>109</sup> (“*Morgentaler*”), a majority of the Supreme Court struck down the impugned provisions of the federal *Criminal Code* dealing with abortion, on the basis that the provisions restricted a woman’s access to a therapeutic abortion and thus violated her section 7 *Charter* right to security of the person. The majority held that the *Criminal Code* provisions could not be justified by the government under section 1 of the *Charter*.

Section 7 of the *Charter* provides:

Everyone has the right to life, liberty and security of the person and the right not be deprived thereof except in accordance with the principles of fundamental justice.

Section 1 of the *Charter* states:

The *Canadian Charter of Rights and Freedoms* guarantees the rights and freedoms set out in it subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society.

In *Morgentaler*, there were three majority opinions and one dissenting opinion from the Court. Justice Wilson, writing one of the majority opinions for herself alone, based her reasons for decision on the section 7 *Charter* right to liberty and to security of the person. In her view, the liberty interest protected by section 7 is concerned not only with physical liberty but also with the fundamental concepts of human dignity, individual autonomy and privacy.

Wilson J. stated “[A]n aspect of the respect for human dignity on which the *Charter* is founded is the right to make fundamental personal decisions without interference from the state. This right is a critical component of the right to liberty.”<sup>110</sup> In her view, section 7 grants women a degree of autonomy such that in the early stages of pregnancy, the woman has an unrestricted right to make personal decisions regarding her pregnancy free from state interference.<sup>111</sup>

Both Justice Beetz, writing one of the majority opinions on behalf of himself and Justice Estey, and Justice Wilson

suggested, in *obiter*, that the state’s interest in a developing human life could become compelling when the foetus reached the point of viability, i.e., the point at which the foetus could survive outside the mother’s womb without artificial aid. They both noted that foetal viability might be a basis on which the state could draft valid legislative limits on a woman’s right to an abortion.

Justice Wilson expanded on the suggestion as follows:

It would be my view and I think it is consistent with the position taken by the United States Supreme Court in *Roe v. Wade*, that the value to be placed on the foetus as potential life is directly related to the stage of its development during gestation. The undeveloped foetus starts out as a newly fertilized ovum; the fully developed foetus emerges ultimately as an infant...in balancing the state’s interests in the protection of the foetus as potential life under s. 1 of the *Charter* against the right of the pregnant woman under s. 7 greater weight should be given to the state’s interest in the later stages of pregnancy than in the earlier.

[...]

A developmental view of the foetus...supports a permissive approach to abortion in the early stages of pregnancy and a restrictive approach in the later stages. *In the early stages the woman’s autonomy would be absolute: her decision, reached in consultation with her physician, not to carry the foetus to term would be conclusive. The state would have no business inquiring into her reasons. Her reasons for having an abortion would, however, be the proper subject of inquiry at the later stages of her pregnancy when the state’s compelling interest in the protection of the foetus would justify it in prescribing conditions...It seems to be, however, that it might fall somewhere in the second trimester.*<sup>112</sup> [emphasis added]

<sup>109</sup> *R. v. Morgentaler*, [1988] 1 S.C.R. 30. It is important to note, however, that the Supreme Court left open the possibility that the government could impose restrictions on abortion after the foetus reached the point of viability outside the womb.

<sup>110</sup> *Ibid.* at 166.

<sup>111</sup> *Ibid.* at para. 260.

<sup>112</sup> *Ibid.* at para. 259 and 260.



In Justice Wilson's view, the state interest in the foetus would only become compelling in the later stages of a pregnancy, sometime in the second trimester, and would be based on foetal viability. However, she found that the woman's autonomy would be absolute during the early stages of a pregnancy, when the developing foetus exists as a newly fertilized ovum (an embryo).

Since *Morgentaler*, women in Canada have had the ability to terminate a pregnancy without fear of criminal sanction. This right would arguably apply whether the woman conceived through sexual reproduction or through an AHR procedure.

Although it did not raise any *Charter* arguments, the case of *Winnipeg Child and Family Services (Northwest Area) v. G.(D.F.)*<sup>113</sup> ("Winnipeg") provides comments from the Supreme Court regarding the *Charter*-protected liberty interest in section 7. In *Winnipeg*, the Court was asked whether it could exercise its *parens patriae* jurisdiction to protect an unborn child by ordering the mother into custody because of her glue-sniffing addiction. A majority of the Supreme Court held that the court does not have *parens patriae* jurisdiction over an unborn child and thus cannot make a custody order for the mother for the purpose of preventing harm to the unborn child.<sup>114</sup>

The majority decision was delivered by Justice McLachlin. In her reasons, she canvassed the law of tort and the scope of the court's *parens patriae* jurisdiction. Justice McLachlin noted that extending the *parens patriae* jurisdiction to the unborn would affect a broad range of liberty interests. It would allow the courts to make fundamental decisions for the pregnant woman, such as where to live and what medical treatment to undergo. She noted that the court's *parens patriae* jurisdiction has never been invoked as a basis for making such decisions on behalf of competent women, whether they are pregnant or not. In the majority's view, the extension of power sought in this case would have the effect of seriously intruding on the rights of women.<sup>115</sup>

Recent jurisprudence from the Supreme Court has since expanded and clarified to some extent the liberty interest in section 7. In *Godbout v. Longueuil (City)*,<sup>116</sup> ("Godbout") the Supreme Court was asked whether a municipal by-law

restricting where an employee of the municipality could reside infringed the right to liberty under section 7 of the *Charter*. La Forest J. reiterated Justice Wilson's comments in *Morgentaler*, *supra*, regarding the section 7 liberty interest. He stated that in his view, the liberty interest in section 7 grants the individual a degree of autonomy in making decisions of fundamental personal importance.<sup>117</sup>

He emphasized that section 7 protects:

...the right to an irreducible sphere of personal autonomy wherein individuals may make inherently personal choices free from state interference...this sphere of autonomy...[is not] so wide as to encompass any and all decisions that individuals might make in conducting their affairs...individuals cannot, in any organized society, be guaranteed an unbridled freedom to do whatever they please...the autonomy protected by the s. 7 right encompasses only those matters that can properly be characterized as fundamentally or inherently personal such that, by their very nature, they implicate basic choice going to the core of what it means to enjoy individual dignity and independence.<sup>118</sup>

The following cases illustrate that the *Charter* rights in section 7 can now be invoked outside the penal context in those situations where government action engages the justice system and its administration. In addition, the cases provide further insight into the scope of liberty under section 7 and into the scope of the section 7 right to security of the person.

In *New Brunswick (Minister of Health and Community Services) v. G.(J.)*<sup>119</sup> ("G(J)"), Chief Justice Lamer, writing for

<sup>113</sup> *Winnipeg Child and Family Services (Northwest Area) v. G.(D.F.)*, [1997] S.C.J. No. 96 (File No.: 25508) (QL). (A judge of the superior court held that the court could exercise its *parens patriae* jurisdiction over the unborn and ordered the mother into custody. The Court of Appeal held that the existing law of tort and *parens patriae* could not support such an order and overturned the decision of the superior court judge.)

<sup>114</sup> *Ibid.* at 2.

<sup>115</sup> *Ibid.* at para.56.

<sup>116</sup> *Godbout v. Longueuil (City)*, [1997] 3 S.C.R. 844.

<sup>117</sup> *Ibid.* at para. 65.

<sup>118</sup> *Ibid.* at para. 66.

<sup>119</sup> *New Brunswick (Minister of Health and Community Services) v. G.(J.)*, [1999] 3 S.C.R. 46.

a majority of the Supreme Court, expanded the application of section 7 from the penal context to situations where state action engaged the justice system and the administration of justice. In *G(J)*, section 7 was held to apply in the context of a child protection/custody hearing. The Supreme Court was asked whether a parent has a constitutional right to state-funded counsel when the government sought an order to suspend a parent's custody of their child.

The majority held that not all state interference with the parent-child relationship would constitute an infringement of a parent's *Charter* right to security of the person. Rather, only those state actions that cause a "serious and profound effect on a person's psychological integrity" would qualify as a deprivation. The resulting psychological stress suffered by the parent must be more than "ordinary stress or anxiety."<sup>120</sup>

In finding that the government's act of removing the appellant's children violated her security of the person interest under section 7 of the *Charter*, the majority considered whether the state restriction was in accordance with the principles of fundamental justice.<sup>121</sup> The majority noted that the principles of fundamental justice respecting child protection hearings are both substantive and procedural. The custody hearing, while administrative rather than criminal in nature, remains adversarial. Without counsel, the appellant could not effectively participate in the hearing.<sup>122</sup> The majority concluded that the potential restriction of the appellant's section 7 rights would not have been in accordance with the principles of fundamental justice if the appellant had not been represented by state-funded counsel and the infringement would not have been saved by section 1 of the *Charter*.<sup>123</sup>

In *Gosselin v. Quebec*<sup>124</sup> ("*Gosselin*"), the Supreme Court restricted the application of section 7 to those situations where state action engaged the administration of justice. In *Gosselin*, the Court was asked whether the section 7 *Charter* right to security of the person includes the right to receive a particular level of social assistance from the state.<sup>125</sup> McLachlin C.J., writing for the majority, noted that "the dominant strand of jurisprudence on section 7 sees its purpose as guarding against certain kinds of deprivation of life, liberty and security of the person, namely, those that occur as a result of an individual's

interaction with the justice system and its administration."<sup>126</sup>

The Chief Justice stated that section 7 does not protect against all activities that might infringe on life, liberty and security of the person. Rather, it only protects against those activities that can be attributed to state action implicating the justice system or the administration of justice. The administration of justice does not refer solely to processes operating in the criminal law. It can be implicated in a variety of circumstances, such as human rights processes, parental rights in relation to state-imposed medical treatment, parental rights in custody proceedings, and liberty to refuse state-imposed addiction treatment.<sup>127</sup> McLachlin C.J. noted that, to date, section 7 has been implicated in those situations where the state has deprived people of the right to life, liberty and security of the person. She stated that, in the future, section 7 may be interpreted to impose positive obligations on the state. However, since the case at bar did not involve a state action resulting in a section 7 deprivation, the majority held that the plaintiff's action failed.<sup>128</sup>

In *R. v. Malmo-Levine; R. v. Caine*,<sup>129</sup> the Supreme Court was asked, among other questions, whether the laws respecting the possession and trafficking of marijuana under the federal *Narcotic Control Act* violated section 7 of the *Charter*. One of the appellants alleged that the legislative provisions infringed his personal liberty under section 7. The other appellant alleged that the potential imprisonment for conviction of possession was not in accordance with the principles of fundamental justice.<sup>130</sup>

A majority of the Court held that the availability of imprisonment for the offence of simple possession was

<sup>120</sup> Chapter 2 of the project paper at 30.

<sup>121</sup> *G(J)*, *supra* note 119 at 18.

<sup>122</sup> *Ibid.* at 21.

<sup>123</sup> *Ibid.* at 23.

<sup>124</sup> *Gosselin v. Quebec*, [2002] 4 S.C.R. 429. Online : <http://www.lexum.umontreal.ca>

<sup>125</sup> *Ibid.* at 28.

<sup>126</sup> *Ibid.* at 28.

<sup>127</sup> *Ibid.* at 29.

<sup>128</sup> *Ibid.* 29-30.

<sup>129</sup> *R. v. Malmo-Levine; R. v. Caine*, [2003] SCC 74. Online : <http://www.lexum.umontreal.ca>.

<sup>130</sup> *Ibid.* at para. 81 and 82.

sufficient to trigger scrutiny under section 7. The majority noted that the *Charter* cannot be stretched to protect every activity a person defines as central to their lifestyle. Rather than protecting these types of lifestyle choices, the *Charter* serves to protect those basic choices that go to the core of what it means to enjoy individual dignity and independence.<sup>131</sup>

The majority held that the risk of jail is another matter; such a risk engages the appellants' liberty interest.<sup>132</sup> In this case, is the risk of a deprivation of liberty in accordance with the principles of fundamental justice?

The appellants agreed that the state may act to prohibit harm to others without violating the principles of fundamental justice. However, they argued that because marijuana is not harmful, it serves no state interest in depriving them of their liberty to possess marijuana and consequently the infringement of their liberty interest is not in accordance with the principles of fundamental justice.<sup>133</sup>

The Court rejected the appellants' argument that the principle of fundamental issue in the case was the "harm principle." Instead, the Court held that the valid state interest in this case was one of "avoidance of harm."<sup>134</sup> The law will not be found to be arbitrary or irrational when the state determines that the harm to be prevented is not *de minimis* or insignificant and the law is not grossly disproportionate to the state interest.<sup>135</sup>

A decision whether to reproduce or not would most likely be found by the courts to constitute a decision of fundamental personal importance and thus would qualify for *Charter* protection under section 7. The courts would most likely find that a choice to reproduce sexually or to reproduce through assisted reproduction technology falls within the *Charter*-protected sphere of personal decision making. The courts might adopt the American approach which broadened the scope of reproductive autonomy to include a right to access medical information about the *concepti* that was considered necessary for reproductive decision making. On the other hand, the courts in Canada might adopt a narrow approach and limit *Charter* protection only to the decision to reproduce or not to reproduce.

This seems unlikely since it could be argued that information about the foetus in the mother's womb is often necessary to allow women to make a reproductive choice, and thus it follows that information about the status of the *in vitro* embryo is equally important to allow women autonomous decision making. In fact, there may be compelling arguments that information regarding the genetic status of an *in vitro* embryo is more important to the woman since it allows her to make a reproductive decision prior to becoming pregnant and thus may avoid the physical and psychological risks that accompany abortion.

The following cases are important with respect to a discussion of one's right to access a particular medical therapy or treatment. In *Rodriguez v. British Columbia (Attorney General)*<sup>136</sup> ("*Rodriguez*"), the Supreme Court was asked whether section 241(b) of the *Criminal Code* infringed the appellant's section 7 *Charter* rights to life, liberty and security of the person by making it a criminal offence for another person to assist Ms. Rodriguez to commit suicide. The appellant was suffering from amyotrophic lateral sclerosis, a terminal disease that would eventually cause her to lose the ability to speak, swallow, walk and move without assistance.<sup>137</sup>

Once she could no longer enjoy life, she wanted a physician to set up the technological means whereby she could end her life at the time of her choosing, and the physician providing assistance would not be subject to a criminal prosecution.<sup>138</sup> The majority reviewed other relevant cases starting with *Morgentaler, supra*, and concluded that security of the person encompasses: (1) personal autonomy, i.e., the right to make choices concerning one's own body, (2) control over one's physical and psychological integrity, and (3) basic human dignity, free from state interference in the form of criminal prohibitions.<sup>139</sup>

<sup>131</sup> *Ibid.* at para. 86.

<sup>132</sup> *Ibid.* at para. 89.

<sup>133</sup> *Ibid.* at para. 90 to 92.

<sup>134</sup> *Ibid.* at para. 130.

<sup>135</sup> *Ibid.* at para. 133 to 135.

<sup>136</sup> *Rodriguez v. British Columbia (A.G.)*, [1993] 3 S.C.R. 519.

<sup>137</sup> *Ibid.* at 520.

<sup>138</sup> *Ibid.*

<sup>139</sup> *Ibid.* at 588.



The Court noted that, in *Morgentaler, supra*, security of the person was found to include a right of access to beneficial medical treatment for a condition representing a danger to life or health without fear of criminal sanction.<sup>140</sup>

A five-person majority of the Supreme Court held that although the prohibition infringed her rights to security of the person and liberty, it did not do so in a manner contrary to the principles of fundamental justice. Thus, the *Criminal Code* prohibition on assisted suicide was found to be constitutional.<sup>141</sup>

In *R. v. Parker*<sup>142</sup> (“*Parker*”), the Ontario Court of Appeal was asked whether prohibitions under two federal statutes regarding the cultivation and possession of marijuana violated the respondent’s section 7 *Charter* rights to security of the person and liberty.<sup>143</sup> Parker alleged that the prohibitions interfered with his health and therefore his security of the person and liberty interests.

The Court of Appeal noted that *Morgentaler, supra*, is the leading case where medical treatment and the criminal law intersect. In that case, state interference with bodily integrity and state-imposed psychological stress, at least in the criminal law context, constituted a breach of security of the person. This view of the right to security of the person was adopted in *Rodriguez, supra*, and *G(J), supra*.<sup>144</sup>

The Court of Appeal relying on the Supreme Court’s comments in *Morgentaler* and *Rodriguez* held that:

...deprivation by means of a criminal sanction of access to medication reasonably required for the treatment of a medical condition that threatens the life or health constitutes a deprivation of security of the person ... Depriving a patient of medication in such circumstances, through a criminal sanction, also constitutes a serious interference with both physical and psychological integrity.<sup>145</sup>

And later in the decision:

...the constitutional right to security of the person must include some protection from state interference when a person’s life or health is in danger... There must be state intervention for “security of the person” in s. 7 to be violated. If a rule of criminal law

precludes a person from obtaining appropriate medical treatment when his or her life or health is in danger, then the state has intervened and this intervention constitutes a violation of that man’s or woman’s security of the person. *Security of the person must include a right of access to medical treatment for a condition representing a danger to life or health without fear of criminal sanction.* If an Act of Parliament forces a person whose life or health is in danger to choose between, on the one hand, the commission of a crime to obtain effective and timely medical treatment and, on the other hand, inadequate treatment or no treatment at all, the right to security of the person has been violated.<sup>146</sup> [emphasis added]

### 3.5.4.1 Conclusion

The cases above illustrate that the courts consider some individual decisions or choices to be so fundamentally personal that they fall within a protected sphere. Not every choice will qualify for protection; the choice must relate to a matter that by its very nature goes to the core of what it means to enjoy independence and dignity.

### 3.5.5 Discussion

There is no jurisprudence in Canada dealing with whether a woman has a right to information about the medical or genetic status of her unborn child, let alone her *in vitro* embryo.

### International Arena

As noted earlier, certain international human rights instruments contain articles that address family formation and planning and have been interpreted as providing women with reproductive autonomy. One commentator has suggested that an international right to reproductive

<sup>140</sup> *Ibid.* at 587.

<sup>141</sup> *Ibid.* at 583.

<sup>142</sup> *R. v. Parker* (July 31, 2000).

Online: <http://www.canlii.org/on/cas/onca/2000/2000onca359.html>.

<sup>143</sup> At trial, the judge held that the prohibitions violated the respondent’s *Charter* rights under s. 7 to life, liberty and security of the person and were contrary to the principles of fundamental justice. Instead of striking down the prohibition, the trial judge read in an exemption for persons cultivating or possessing marijuana for their personal medically-approved use.

<sup>144</sup> *Ibid.* at 18.

<sup>145</sup> *Ibid.* at 20.

<sup>146</sup> *Ibid.* at 22.

autonomy can be found “using traditional human rights analysis, drawing upon existing international treaties and charters.”<sup>147</sup> In her view, support for a human right to reproductive freedom can be found in three basic principles of international law: privacy, equality and health.<sup>148</sup>

It is important to note that the CEDAW does not limit reproductive autonomy to the right to terminate a pregnancy. Rather, it could be interpreted as providing a broad right that includes rights relating to family planning, such as the right to decide the number and spacing of one’s children. These rights appear to exist independently of a pregnancy. One could argue that the international right to reproductive autonomy, inferred from these instruments, encompasses and protects all decision making related to reproduction, such as decisions respecting genetic testing.

The international instruments and commentary could be used to inform the court’s interpretation of the scope of reproductive autonomy under the liberty interest in section 7 of the *Charter* and any domestic legislation.

The courts could also be referred to the Council of Europe’s *Convention* as an example of how other countries have dealt with PGD and genetic information. The *Convention* provides that genetic testing may be undertaken to determine the presence of a gene responsible for disease (article 12). The accompanying Explanatory Report notes that article 12 in no way limits diagnostic testing of the embryo to determine the presence of a gene that could lead to a serious disease in the future child.

### Other Jurisdictions

The courts have been known to turn to American constitutional jurisprudence to inform its interpretation of the human rights and freedoms under the *Charter*. Some U.S. state courts have broadened the constitutionally protected right to procreational autonomy to include a right to access information that would assist a woman in making a decision regarding reproduction. Furthermore, at least one state court has held that the constitutionally protected right to procreational autonomy includes the right to choose to submit to an AHR procedure to become pregnant.

### The Charter

The section 7 *Charter* right to liberty could be viewed as one of the basis for reproductive autonomy in Canada. One could argue that at the very least reproductive autonomy is comprised of two equal but opposite rights: the right to reproduce and the right not to reproduce.

Justice Wilson was of the view that the liberty interest in section 7 was concerned with more than just physical liberty; it also encompassed the concepts of dignity, autonomy and privacy. She considered that an essential component of human dignity was the right to make certain fundamental personal decisions without interference from the state. She concluded that this aspect of the liberty interest provided women with a degree of autonomy to make decisions regarding reproduction, at least in the early stages of a pregnancy. In practical terms, this gave women the right to carry on with the pregnancy and reproduce, or terminate the pregnancy and not reproduce, at least during the early stages of the pregnancy.

It is important to note that Justice Wilson did not suggest that women had unlimited autonomy, but rather a degree of autonomy. She also restricted the woman’s decision-making autonomy to the early stages of pregnancy, prior to foetal viability. Both she and Justice Beetz (and Estey J.) considered that at some point in the pregnancy, the state’s interest in the developing foetus would become compelling such that the state could limit the woman’s rights.

Justice Wilson’s interpretation of the section 7 liberty interest could be viewed as consistent with the articles in the CEDAW that provide women with rights to decide freely the number and spacing of their children. The CEDAW Committee’s comments regarding these articles also supports such an interpretation. It states that a

<sup>147</sup> Elizabeth K. Spahn “Reproduction, Rights, and Reality: How Facts and Law Can Work for Women: Waiting for Credentials: Feminist Theories of Enforcement of International Human Rights” (1995) 44 Am. U.L. Rev. 1053 at 5 (Lexis Nexis).

<sup>148</sup> *Ibid.* “Privacy” has been recognized as an international human right since 1948 — in the *Universal Declaration of Human Rights*, article 12, and in article 8(1) of the *European Convention on Human Rights* (1950); “Equality” United Nations Charter, article 1(3) and the preamble — fundamental freedoms for all without distinction as to sex; and “Health” *Universal Declaration of Human Rights*, article 25(1) (Lexis Nexis).

woman's decision respecting reproduction should not be limited by her spouse, parent or government.

The reproductive autonomy rights enunciated by Wilson J. in *Morgentaler, supra*, were with respect to a pregnant woman. Now that biotechnology has provided alternative means of conception, can reproductive autonomy be extended to protect decision-making with respect to an *in vitro* embryo?

### **Pregnant women and genetic testing of the embryo/fœtus**

Pregnant women in Canada routinely undergo ultrasound tests during their pregnancy. These tests allow the physician to monitor the progress of the pregnancy and to detect abnormalities in the developing fœtus. In the case of women or couples who have a history of genetic disease, or when the woman is over the age of 35 years, physicians routinely recommend more sophisticated, invasive testing, such as chorionic villi sampling or amniocentesis, in order to detect the presence of any genetic anomaly in the fœtus.

These genetic tests are fundamentally private matters that provide crucial information about the health of the pregnant woman and of the fœtus that she carries. In Canada, pregnant women, in consultation with their physician, are able to choose to undergo such tests. If the tests revealed that the woman's health is at risk because of the pregnancy, or that the embryo or fœtus is severely deformed or carries a gene for a serious disease, the woman is free to choose to terminate the pregnancy and that right extends past the point of foetal viability.

In the event that the state prohibited such prenatal genetic testing, an argument could be made that the woman's liberty and security of the person interests, under the *Charter*, would be engaged. A woman's section 7 right to security of the person protects her physical and psychological integrity. A state prohibition could deprive her of crucial information about the health and genetic status of the fœtus. In those instances where a woman knows she is at risk of passing on a serious genetic disease to her child, the prohibition would arguably engage her psychological integrity by causing her profound and serious stress and anxiety. It would also interfere with her right to make a

decision regarding the pregnancy. One could conclude that such a prohibition would engage the woman's liberty and security of the person interests under the *Charter*. Of course it would be open to the courts to determine that the prohibition was in accordance with the principles of fundamental justice, in which case there would be no *Charter* violation.

### **A woman and her *in vitro* embryos**

The relevance of human rights is arguably more obvious and straightforward in the case of a pregnant woman whose body is implicated in the pregnancy. It may not be so clear, however, when the pregnancy has not yet begun and the embryo exists outside the woman's body, i.e., *in vitro*.

*If the state prohibited a woman's right to access genetic information about her in vitro embryos through the use of PGD, would it raise any human rights issues?*

One could argue that a prohibition on using PGD to obtain information necessary to make a decision about reproduction would engage the woman's liberty and the security of the person interests in section 7 of the *Charter*.

Recent Supreme Court jurisprudence has established that the right to autonomy to make decisions of a fundamentally personal nature, within the liberty interest, extends beyond the sphere of human reproduction to encompass a range of subject matters. Advances in biotechnology and assisted human reproduction make it possible for women to gain information about her embryos prior to pregnancy. Consequently, one could argue that an expanded liberty interest protects medical tests, such as PGD, on an *in vitro* embryo undertaken to provide the woman with critical information necessary for her to make a decision regarding reproduction. These activities undertaken on the very early embryo could be considered to fall within a "cluster of constitutionally protected choices."<sup>149</sup>

It is likely that genetic testing of one's *in vitro* embryos to select for reproduction only those that appear disease-free would qualify as a matter of fundamental personal importance that goes to the core of individual dignity and independence. This would be especially so if the person

<sup>149</sup> *Lifchez, supra*, note 74 at 15; *Carey, supra*, note 78 at 685.

or couple were at risk of passing a genetic disease to their offspring. One could argue that a prohibition on the use of PGD would engage the woman's section 7 *Charter* right to liberty and to security of the person.

***What principle of fundamental justice would the court identify as a standard against which to measure the state's deprivation of the woman's section 7 rights?***

In *Morgentaler, supra*, the Supreme Court identified procedural and substantive principles of fundamental justice against which to measure the state's deprivation of a woman's right to liberty, and found the deprivation breached the principles. The Court proceeded to consider whether the state could justify the deprivation under section 1 of the *Charter*. It is likely that the courts would proceed directly to the analysis under section 1 in the event of a challenge to the constitutionality of a prohibition on PGD.

***Does the state have a compelling interest in the *in vitro* embryo that could justify infringing on a fundamental right?***

Justice Wilson, in *Morgentaler, supra*, noted that the foetus is potential life from the moment of conception. However, in balancing the state's interest in the protection of the foetus as potential life under section 1 of the *Charter* against the woman's rights under section 7, she held that greater weight should be given to the state's interests in the later stages of the pregnancy. In fact, she noted that in the early stages of a pregnancy the state's interest in the developing embryo would be non-existent, while the woman's right to autonomy would be absolute.

Based on Wilson J's view of the foetus as potential life from the moment of conception, one could argue that the *in vitro* embryo is potential life, however at this point the *in vitro* embryo could not be considered viable (it could not survive without artificial means).

An argument could be made that the use of PGD, as a diagnostic tool, would not engage the same compelling state interests as the use of prenatal diagnostic testing on the foetus. If prenatal testing revealed a gene for disease in the foetus, the woman could decide to terminate the pregnancy. If the foetus had reached the point of viability, the state might argue that it has a compelling interest in the

foetus as potential and viable human life. However, PGD is conducted on an *in vitro* embryo that is only two or three days old. If PGD detected the presence of a gene for disease in the *in vitro* embryo, the woman could decide to let it perish. The *in vitro* embryo is clearly not viable; it is maintained through technology in a laboratory setting. In order to become viable, a woman must consent to transfer it into her womb and carry it into the second trimester of pregnancy.

The state may have an interest in the *in vitro* embryo as potential life, but since it is not viable, it is likely not sufficient or compelling enough to justify infringing on a woman's right to reproductive autonomy.

An argument could be made that the woman's right to physical and psychological integrity would be engaged by a prohibition on PGD. If a woman was denied access to PGD to obtain information as to the genetic status of her *in vitro* embryos, i.e., before pregnancy, her options would be restricted to sexual reproduction and prenatal testing of the foetus once she is pregnant. If the prenatal testing indicates that the developing foetus has a gene for a serious disease, the woman's choices are limited to a genetic abortion or the possibility of coping with a seriously ill or disabled child. The state prohibition on PGD could arguably cause her profound and serious psychological stress and anxiety implicating her security of the person interest. It could also interfere with her physical integrity, since there is an element of risk to the woman's physical integrity inherent in any abortion procedure. One might argue that the woman has been prohibited access by the state to what could be considered a beneficial medical procedure, i.e., PGD.

### **3.5.5.1 Conclusion**

It is difficult to predict whether the provisions in international human rights and regional instruments could be referenced to support a broad definition of the right to reproductive autonomy under the *Charter*. The fact remains that, at the international level, procreational rights are not well defined. There are, however, basic principles and norms of international law that the courts could look to for assistance, such as privacy, equality and health. The courts might also be informed by U.S.



jurisprudence on reproductive autonomy developed under the *Bill of Rights*.

The Supreme Court has recognized that the liberty interest in section 7 of the *Charter* provides a degree of autonomy under which individuals are able to make decisions of fundamental personal importance without state interference.<sup>150</sup> A prohibition which deprived a woman, especially one at risk of passing on a genetic disease to her offspring, of the right to choose a procedure that would provide her with essential information to make an informed decision regarding reproduction would arguably engage her section 7 liberty interest.

Women would be limited to prenatal testing once they are pregnant as the only source of information with which to make a reproductive choice. Prenatal testing, such as amniocentesis, is invasive and presents risks to both the mother and the foetus, and could deprive the woman of her physical and psychological integrity. One could argue that the state prohibition on PGD would also engage a woman's section 7 *Charter* right to security of the person. A woman's options would be limited to prenatal testing, no testing, or a decision not to reproduce.

### 3.6 Issue 2: The right of parents to use PGD to select *in vitro* embryos based on certain favoured genetic traits

In the future, it may be possible for a parent to select an *in vitro* embryo based on certain traits that the embryo would exhibit as a child, such as hair or eye colour, height, and intelligence. Is the right to reproductive autonomy broad enough to protect a woman's choice of PGD to select *in vitro* embryos on the basis of certain favoured genetic traits?

The following discussion is limited to three genetic traits that science is currently able to identify through PGD. These traits are: (1) a gene for deafness, (2) a desired sex, and (3) genetic compatibility to donate to a sibling who has a life-threatening disease.

#### 3.6.1 A Gene for Deafness

If one has the right to use PGD to select only those *in vitro* embryos that are disease free, does one have a corresponding right to choose PGD to select for reproduction an *in vitro* embryo because of the presence of a certain genetic anomaly? In 2002, the *Journal of Medical Ethics* reported that a deaf lesbian couple in the U.S. used sperm from a donor with five generations of deafness in his family to self-inseminate with the objective of giving birth to a deaf child.<sup>151</sup>

The article questions whether there might be some good reasons for allowing couples to select for disability. The author notes that in the case above, there were no ethical issues raised because the couple had the right to reproduce with whomever they chose. They chose to reproduce with a man who had a long family history of genetic deafness.

Not everyone would agree that this act is devoid of ethical considerations. The fact that the women consciously selected a sperm donor with a long family history of deafness in the hope of creating a deaf child might, for some individuals, raise significant ethical and moral issues.

Julian Savulescu, as well as other commentators, questions whether a woman or couple have caused any harm when they make such a choice. In the view of one commentator, to be harmed, the child would have to be put in a worse condition than it would have otherwise been in.<sup>152</sup> However, if the child had not been chosen by the women for reproduction on the basis of deafness, he or she would not have been born.<sup>153</sup> The article notes that there are other deaf couples who would like to choose PGD to select a deaf child. For these prospective parents,

<sup>150</sup> *Morgentaler*, *supra* note 109. The Supreme Court, in three separate majority decisions, found that both security of the person and liberty (the decisions of Beetz and Wilson) included rights to make decisions affecting one's physical and psychological integrity, and the right to make decisions of fundamental personal importance free from state interference.

<sup>151</sup> Julian Savulescu, Director, Oxford Centre for Applied Ethics "Deaf lesbians, "designer disability," and the future of medicine" (2002) *Journal of Medical Ethics* 325 at 1 (<http://jme.bmjournals.com>).

<sup>152</sup> Shaun D. Pattinson "Wrongful Life Actions as a Means of Regulating Use of Genetic and Reproductive Technologies (1999) 7 *Health L.J.* 19 at 5 (Lexis Nexis).

<sup>153</sup> *Ibid.* at 3 (Lexis Nexis).

deafness is not considered a disability but rather as a distinct culture that welcomes deaf children.<sup>154</sup>

The purpose of genetic testing is generally to offer individuals or couples the opportunity to select the child with the “best life prospects.” Who decides, however, what are the best life prospects? Whose value judgements should prevail? In at least one author’s opinion, reproductive freedom and respect for autonomy are such that the value judgements of the parents should prevail, as long as their decision does not harm the child.<sup>155</sup>

Not all commentators agree. Some argue that because there are significant disadvantages associated with many disabilities, it is unethical to allow parents to deliberately choose a characteristic or trait in a child that is treated by society as a disability or disadvantage.<sup>156</sup>

However, on close analysis, this argument is flawed. The deaf women who chose to use PGD to select from among their *in vitro* embryos only those with the gene for deafness, were not engineering deafness in the embryo but rather were selecting for reproductive purposes only those *in vitro* embryos that already possessed the gene for deafness. If the *in vitro* embryo had not been selected for reproduction, it would not have experienced life. The question remains: Is the child worse off being born deaf or never having been born at all?

If the state prohibited the use of PGD for such a purpose, would it raise any human rights issues? The answer to this question depends very much on the scope given by the courts to reproductive autonomy under section 7 of the *Charter*. If the courts considered that the information obtained from PGD as essential to allow the woman to make a decision respecting reproduction, then the prohibition could arguably be found to engage a woman’s section 7 liberty and security of the person interests.

Such a prohibition might also raise human rights issues related to equality under section 15 of the *Charter*. Section 15(1) provides that:

Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in

particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or *physical disability*. [emphasis added]

The deaf women might argue that the state prohibition on PGD to select *in vitro* embryos because they have a particular genetic anomaly, in this case deafness, is discriminatory on the basis of an enumerated ground, i.e., physical disability. Other women in Canada can choose to undertake PGD to select only those *in vitro* embryos for reproduction that are without the gene for deafness. An argument could be made that the state prohibition on PGD impacts negatively on the deaf woman’s human dignity.

The concerns and analysis might be much different if a woman wanted to choose genetic engineering to create deafness in an *in vitro* embryo. A discussion of the possible human rights issues relating to genetic engineering have not been addressed in this paper.

### 3.6.2 A Desired Sex

The desire to have some control over the gender of one’s offspring has existed far longer than AHR technologies, such as PGD. However, the use of these technologies (developed to assist the infertile to reproduce) for social sex selection raises for some individuals both moral and ethical concerns.<sup>157</sup>

In Canada, the Royal Commission’s national survey noted that, with respect to sex-selection:

...contrary to what has been found in some other countries, a large majority of Canadians do not prefer children of one sex or the other. Many interveners... assumed that Canadians have a pro-male bias with regard to family composition; we found that this assumption appears to be unfounded...<sup>158</sup>

<sup>154</sup> Savulescu, *supra* note 151 at 2.

<sup>155</sup> *Ibid.* at 4.

<sup>156</sup> Rebecca Knox “Preimplantation Genetic Diagnosis: Disease Control or Child Objectification?” (2003) St. Louis U. Pub. L. Rev. 435 at 6-7 (Lexis Nexis).

<sup>157</sup> Ethics Committee of the American Society of Reproductive Medicine, “Sex Selection and Preimplantation Genetic Diagnosis” (1990) 72 (No. 4) Fertility and Sterility 595 at 597.

<sup>158</sup> *Supra* note 3 at 889.

The AHR Act prohibits the use of PGD to select for reproduction purposes *in vitro* embryos of a particular favoured sex (section 5 (1)(e)). The Act does permit the use of PGD to select embryos on the basis of sex when the intent is to prevent a sex-linked disorder or disease; this activity will be controlled under the Act.

As noted earlier, in the U.K., selecting an *in vitro* embryo on the basis of its sex for non-medical reasons is prohibited under the *HFE Act*.

The Ethics Committee of the American Society of Reproductive Medicine (“Committee”) provides standards of practice for physicians and obstetricians. Compliance with the standards is voluntary. In 2002, the Committee restated its position with respect to the use of PGD for social sex selection.

The Committee recommended that: (a) initiating *in vitro* fertilization and PGD for the purposes of social sex selection of *in vitro* embryos in the case of a first born should be discouraged by physicians; and (b) initiating *in vitro* fertilization and PGD for social sex selection in order to create gender variety in a family should also be discouraged.<sup>159</sup> The Committee did not go so far as to recommend that such practices be prohibited by state or federal law. This may be because the Committee subscribes to a broad interpretation of the constitutional right to procreational autonomy.

There are women and couples who would like to use PGD to select for reproduction only those *in vitro* embryos that are of a particular sex. Some of the reasons given by Canadians, and others, for selecting *in vitro* embryos on the basis of sex include: to bear and raise children of the culturally preferred sex; to ensure economic usefulness within the family; to achieve gender balance or variety among children in a given family; and to determine a gendered birth order.<sup>160</sup> Proponents of social sex selection argue that it is a logical extension of the right to procreate and reproductive autonomy.

Some argue that selecting for sex is a lesser evil than the alternative of prenatal genetic testing of the foetus followed by an abortion, and far better than the alternative of infanticide, which is still practiced in some countries.<sup>161</sup> In addition, there are those who argue

that the use of PGD for sex selection could contribute to population control.<sup>162</sup>

At least one commentator has argued that the ability to use PGD to select only those *in vitro* embryos of a particular sex might be a useful tool in family planning and population control. If parents were able to select a child of each sex, they might not continue to reproduce in the hope of having a child of a particular sex.<sup>163</sup>

Some commentators have argued that the legal doctrine of informed consent with respect to medical treatment may justify a woman’s claim to information relating to the sex of the foetus she bears. This argument might also apply to give a woman a legal right to the information concerning the sex of the *in vitro* embryos being transferred into her for the purpose of reproduction. The stated counter argument is that such a right to information should be restricted to only the information necessary to make a choice on medical grounds, such as the genetic health of the foetus.<sup>164</sup>

Opponents of this use of PGD cite the following concerns: the practice will result in gender discrimination and gender bias in society as a whole; the appropriateness of expanding control over nonessential characteristics of offspring; and the relative importance of sex selection when weighed against medical and financial burdens to parents and against multiple demands on limited medical resources.<sup>165</sup> They argue that procreational autonomy and privacy rights should not be extended to include a parent’s right to choose PGD to select the sex of their children. These rights should not be considered fundamental by the court, so as to ensure that the state can prohibit and regulate such practices. The state could likely establish that such a prohibition or regulation is rationally related to a legitimate government purpose.<sup>166</sup>

<sup>159</sup> Roberts, *supra* note 12 at 6.

<sup>160</sup> *Supra* note 157.

<sup>161</sup> Rebecca J. Cook, Bernard M. Dickens and Mahmoud F. Fathalla, *Reproductive Health and Human Rights* (New York: Oxford University Press, 2003) at 367.

<sup>162</sup> *Supra* note 157 at 596.

<sup>163</sup> *Ibid.* at 595.

<sup>164</sup> Cook, *supra* note 161 at 367.

<sup>165</sup> *Supra* note 157 at 596.

<sup>166</sup> Kelly M. Plummer “Ending Parents’ Unlimited Power to Choose: Legislation is Necessary to Prohibit Parents’ Selection of Their Children’s Sex and Characteristics” (2003) 47 St. Louis L.J. 517 at 4 (Lexis Nexis).



Furthermore, opponents are concerned that social sex selection could psychologically harm children selected on the basis of their sex since it would place high expectations on them. It is argued that this practice would reduce a child to a consumer product. Selecting a child on the basis of sex is not a proper criterion: children should be valued for their own sake, and not selected and valued primarily because of their sex.<sup>167</sup> In addition, opponents argue that if widely practiced, it could lead to an overall change in the human sex ratio which would be detrimental to the future of society.<sup>168</sup>

One could argue that the prohibition on PGD for non-medical sex-selection in the AHR Act denies a woman access to information necessary for her to make a decision regarding reproduction, and thus engages her liberty and security of the person interests under section 7 of the *Charter*. A distinction could, however, be made between accessing information as to the sex of the embryo and accessing information as to the presence of a gene for disease in the *in vitro* embryo. The courts might find that only the latter type of information can be categorized as central to a person's decision regarding reproduction and thus protected. With respect to information as to the sex of a future child, the court may consider decisions based on this type of information as more of a "lifestyle" choice,<sup>169</sup> than a decision respecting a matter that goes to the core of individual dignity and independence.

The provisions regarding the right to found a family and family planning in the CEDAW and the ICCPR might inform the courts when it interprets the scope of the *Charter* right to reproductive autonomy. The courts might be particularly influenced by the non-discrimination provisions in article 5(a) of CEDAW when interpreting the scope of reproductive autonomy, at least with respect to non-medical sex selection. The courts may find that a state prohibition against sex selection for social or cultural reasons is in accordance with the principles of fundamental justice or is justifiable by the state under section 1 of the *Charter*.

### 3.6.3 A Donor Child

Through the use of PGD and tissue-typing, it is possible to select for and transfer only those *in vitro* embryos that

have certain traits needed to provide a cell or tissue transplant for a seriously ill sibling, without harming the donor child.

It has already been noted that, under the UK's *HFE Act*, parents can access both *in vitro* fertilization and PGD to create a donor child. The UK court has held that the HFE Authority has the power under the *HFE Act* to issue licences for this procedure. It should be noted that each case is considered on its merits by the HFE Authority before it issues an approval for a particular procedure and there have been cases where the HFE Authority has refused to issue a licence.<sup>170</sup>

The AHR Act does not prohibit the use of PGD or tissue-typing. Until such time as the Agency is created and able to inspect, only those fertility clinics that conducted PGD in the year preceding the Act's coming into force can continue to do so without a licence. Once the Agency is created, a physician or clinic would have to obtain a licence from the Agency to perform *in vitro* fertilization and perhaps a second licence or approval to conduct PGD with tissue-typing. The procedure would most likely be regulated under the Act.

Some commentators argue that creating a child to be a future donor is unethical and represents an immoral objectification and commodification of the child. In addition, the child may suffer psychological harm on learning that they were created and chosen in order to save a sibling.<sup>171</sup>

<sup>167</sup> *Ibid.* at 15 (Lexis Nexis).

<sup>168</sup> *Supra* note 157 at 596; Susan M. Faust "Baby Girl or Baby Boy? Now You Can Choose: A Look at New Biology and No Law" (2000) 10 Alb. L.J. Sci. & Tech. 281 at 5 — The author cites the results of a recent survey in Ohio that suggest the preference for male babies may be weakening. Although the survey finds some support for a sex preference in the birth order of children, the majority of participants indicated that they had no preference for a boy or girl as the first-born child. She notes that as almost 50% of pregnancies in the U.S. are unplanned, it is likely that only a minority of couples would actually use sex selection and this minority would be unlikely to create a significant sex ratio imbalance.

<sup>169</sup> *Marmo-Levine, supra*, note 129 at para. 86.

<sup>170</sup> RG Edwards (Editor), Reproductive BioMedicine Online "Ethics of preimplantation diagnosis: recordings from the International Symposium on Preimplantation Genetics" 2002 at 3. Online: <http://www.rbmonline.com>.

<sup>171</sup> Knox, *supra* note 156 at 8-9.

Other academics point out that parents have always had reasons for creating children, many of which could be viewed as selfish, such as to provide companionship, to assist with a family business, or to care for parents as they age. Creating a child to save the life of an existing sibling is no more psychologically damaging to the child than other more common reasons for procreation. Many parents have conceived a second child without the use of technology in the hopes that the child will be a tissue match for an already existing sibling who is ill. The use of *in vitro* fertilization and PGD to create such a child could be viewed simply as eliminating a large part of the uncertainty and stress for these parents.<sup>172</sup>

It is interesting to note that the UK Court in *Quintavalle*, *supra*, interpreted the *HFE Act* in a broad manner such that the HFE Authority has the power to authorize the creation of a donor child. The UK Court's decision was not based on the parent's right to procreational autonomy; rather it was the result of the application of principles of statutory interpretation to the *HFE Act*.

An argument could be made that a prohibition on the use of PGD to obtain information to select an *in vitro* embryo to become a donor child is more than just a decision respecting a lifestyle choice, it deprives the woman of critical information to make a decision relating to reproduction. Not only would the prohibition engage the woman's section 7 liberty and security of the person interests, it would arguably engage the interests of the ill sibling to life and security of the person under section 7. The state prohibition would prevent the existing sibling from accessing a beneficial medical treatment, e.g. a transplant of histocompatible stem cells from a saviour child, for a condition that may pose a threat to his or her life.

### 3.6.4 Conclusion

In those cases where the prohibition is backed by offence provisions that include the possibility of jail, section 7 interests are engaged. With respect to the creation of a donor child, the interests and human rights raised by a prohibition on PGD are those affecting the woman and the ill sibling. The sibling may argue that if the state prohibits his mother access to the necessary information to choose an embryo for reproduction that will become a

donor child, his or her s. 7 *Charter* rights to life and security of the person are engaged.

With respect to non-medical sex selection, the courts might consider that this information is not central or is irrelevant to a decision respecting reproduction. On the other hand, the courts might consider information as to the presence of a gene for disease, or genetic compatibility with an existing ill sibling, as central to reproductive decision-making. A state prohibition on accessing the latter type of information for reproductive decision-making could engage a woman's liberty and security of the person interests protected by the *Charter*.

If the courts look to international human rights instruments, such as the CEDAW and the ICCPR, they might be persuaded to broaden reproductive autonomy under s. 7 of the *Charter* to include a right to access certain essential information to make a choice regarding reproduction, free from state interference. The courts could look to U.S. constitutional jurisprudence, as it periodically does when interpreting *Charter* rights, to inform its interpretation of procreational autonomy.

## 3.7 Issue 3: The *In Vitro* Embryo

### 3.7.1 The Right to Life

No Canadian legislation guarantees an embryo or foetus the right to life.<sup>173</sup> In Canada, as in most western countries, the prevailing view of the legal status of the embryo is that it is *sui generis*. The embryo is deserving of respect, but not the legal rights that come with personhood. The embryo or foetus is not viewed as equivalent to that of a child for many reasons, including the lack of developmental individualism and sentience.

The Supreme Court has held that an *in utero* embryo and a foetus are not persons under the law and thus have no legal rights. However, once the foetus is born alive, his or her legal rights crystallize and for certain purposes, such as tort law, the law may recognize that the child existed before birth. Because the *in utero* embryo and foetus have

<sup>172</sup> *Ibid.* at 8

<sup>173</sup> See Chapter 2 for a more detailed discussion.

no legal rights, they are not considered to have a right to life. However, the state's interest in the foetus as a potential human being may increase as it develops within the womb. Once the foetus is viable outside the womb, which may be sometime in the second trimester of the pregnancy, the state may be able to justify legislating to protect it (*Morgentaler, supra*).

Based on the existing jurisprudence, an *in vitro* embryo existing as it does outside a woman's body would likely be assigned the same non-person status as an *in utero* embryo and foetus by the courts, and thus be found to possess no legal rights until after it is born alive. The courts would likely find that an *in vitro* embryo does not have a right to life.<sup>174</sup>

### 3.7.2 The Right to Be Born With a Sound Mind and Body

Does a child have a legal right to be born with a sound mind and body? Do parents have a corresponding ethical or legal obligation to give birth to only genetically healthy children? If there is such a legal right, could it evolve into a human right?

#### 3.7.2.1 International and Regional Instruments

In 1991, Canada ratified the United Nations' *Convention on the Rights of the Child*<sup>175</sup> ("CRC").<sup>176</sup> The CRC sets out a number of important rights and protections for children.

Article 24(1) and (2) of the CRC states:

Article 24

1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.
2. States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:

- a. To diminish infant and child mortality;
- b. To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;
- c. To combat disease and malnutrition, including within the framework of primary health care, through, *inter alia*, the application of readily available technology and through the provisions of adequate nutritious foods and clean drinking-water, taking into consideration the dangers and risks of environmental pollution;
- d. To ensure appropriate pre-natal and post-natal health care for mothers;
- e. To ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents;
- f. To develop preventative health care, guidance for parents and family planning education and services. [emphasis added]

It is of interest to note that the Preamble to the CRC notes that "...the child, by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, before as well as after birth."<sup>177</sup> [emphasis added]

<sup>174</sup> For a detailed discussion on the international approach, and the approach of Canada and other jurisdictions to the right of an *in vitro* embryo to life, see Chapter 2 of the project paper at 40 to 44.

<sup>175</sup> United Nations *Convention on the Rights of the Child*, G.A. res. 44/25, annex, 44 U.N. GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49 (1989), entered into force September 2, 1990.

<sup>176</sup> Catherine Covell and R. Brian Howe, *The Challenge of Children's Rights for Canada* (Waterloo: Wilfrid Laurier University Press, 2001) at 15.

<sup>177</sup> *Supra* note 175 (preamble).

The CRC defines “child” in Article 1 as “every human being below the age of eighteen years unless, under the law applicable to the child, majority is attained earlier.”<sup>178</sup> The *Travaux Préparatoires* to the CRC noted that the original wording of Article 1 was “...a child is every human being from the moment of his birth to the age of 18 years unless, under the law of his state, he has attained his age of majority earlier.”<sup>179</sup>

The *Travaux Préparatoires* also noted that there was “considerable debate” at the third meeting of the Working Group concerning the definition or concept of a “child.” Some delegates argued that such a definition would be contrary to the law of their state which defines childhood as beginning at the moment of conception. Other delegates suggested that, to avoid conflict, any reference to the beginning point of childhood in the Article should be abandoned and instead wording should be chosen that would be compatible with the variety of domestic legislation on the issue.<sup>180</sup>

The current wording of the Article might allow those countries that consider childhood to begin at the moment of conception to interpret the rights in the CRC for domestic purposes to apply from the moment of conception onwards. The *Travaux Préparatoires*<sup>181</sup> noted that Article 24(2)(d) was amended by the representative of the UK to read “ensure appropriate pre- and post-natal health care for mothers and their children.”<sup>182</sup> The Article was further amended by the representative from the U.S. to drop the reference to “their children” so that it read “to ensure appropriate pre- and post-natal care for mothers.”<sup>183</sup> The U.S. amendment was likely prompted by a desire to avoid conflicts between the rights of an embryo/fœtus and those of the pregnant woman.

In the context of genetic testing and therapies, some commentators suggest that the language of both the UDHR and the ICESCR support a view that the right to enjoy the benefits of scientific progress and its applications belong to the embryo rather than the future parents. They argue that the embryo has a right to benefit from genetic testing, such as PGD and germ-line manipulation, because of the emphasis on individual well-being. It presumes a right to be free from the suffering that genetic technology can prevent.<sup>184</sup>

Cook, et al. suggests that, with respect to an individual’s or couple’s access to *in vitro* fertilization and PGD, the most obvious human right implicated would be the right to the benefits of scientific progress.<sup>185</sup> The authors argue that this right serves the goal of other human rights, such as the right to found a family, and the right for both a future child and the parents to have the highest attainable standard of health. With respect to the future child, this would relate primarily to their physical health. However, with respect to the parents, this would include both mental health and social well-being.<sup>186</sup>

### 3.7.2.2 The Law in Other Jurisdictions

In common law jurisdictions, if not barred by statute, a number of different tort actions can be undertaken by children or parents injured prior to birth or during birth, depending on whose interests were affected. Three such tortious causes of action are: preconception torts, the tort of wrongful birth, and the tort of wrongful life. A “preconception tort” occurs when a child, born alive, is harmed prior to or during its birth by the wrongful, preconception conduct of someone other than its parents.<sup>187</sup> Parents may make a claim for “wrongful birth” if the birth of an unplanned child occurs.<sup>188</sup> This is because the parent’s right to control their own reproduction has been denied by the tortious conduct of another person.<sup>189</sup> An action for wrongful life is a claim by a person born with a predictable physical or mental

<sup>178</sup> *Ibid.* at article 1.

<sup>179</sup> Sharon Detrick (Editor), *The United Nations Convention on the Rights of the Child: A Guide to the Travaux Préparatoires* (The Netherlands: Martinus Nijhoff Publishers, 1992) at 115.

<sup>180</sup> *Ibid.* at 115.

<sup>181</sup> *Ibid.* at 343 to 359.

<sup>182</sup> *Ibid.* at 357.

<sup>183</sup> *Ibid.* at 357.

<sup>184</sup> Maha F. Munayyer, “Genetic Testing and Germ-Line Manipulation: Constructing a New Language for International Human Rights” (1997) 12 *Am. U.J. Int’l & Pol’y* 687 at 5 (Lexis Nexis).

<sup>185</sup> Rebecca Cook, Bernard Dickens and Mahmoud F Fathalla, *Reproductive Health and Human Rights: Integrating Medicine, Ethics and Law* (Oxford: Oxford University Press, 2003) at 359.

<sup>186</sup> *Ibid.*

<sup>187</sup> Elizabeth F. Collins “An Overview and Analysis: Prenatal Torts, Preconception Torts, Wrongful Life, Wrongful Death, and Wrongful Birth: Time For a New Framework” (1984) 22 *J. Family Law* 677 at 677-78.

<sup>188</sup> *Ibid.* at 678.

<sup>189</sup> *Ibid.*

disability that, but for the defendant's breach, the person would not have been conceived or born.<sup>190</sup>

This section examines the current status of a cause of action for "wrongful life" and whether there is a right to be born with a sound mind and body.

### The U.S.

On April 1, 2004, President Bush signed into law the *Unborn Victims of Violence Act of 2004*.<sup>191</sup> The Act provides, among other things, that any person who intentionally kills or attempts to kill a child *in utero* (in the mother's womb), shall be punished for intentionally killing or attempting to kill a human being.<sup>192</sup> However, the Act clarifies that the following persons are not subject to prosecution: a person performing an abortion for which the pregnant woman has consented, a person providing medical treatment to the pregnant woman or her unborn child, and the pregnant woman (amendment to article 119a).

Although there is no federal or state law granting a child the right to be born with a sound mind and body, there is a growing body of jurisprudence that recognizes a child's right to sue their parents and third parties for prenatal and preconception torts and, in approximately three states, for the tort of wrongful life. In an action for wrongful life, the plaintiff child typically contends that had the defendant given the mother timely warning of the risk of congenital abnormality, she would have chosen not to conceive the child, or if the negligence is asserted to have occurred after conception, the mother would have chosen to abort the embryo/fœtus. There is no suggestion that the defendant caused the child's disability. Instead, the assertion is that but for the defendant's omission, the child would not have been born and would have been spared a life of physical or mental incapacity, pain and suffering.<sup>193</sup> To date, there are only a handful of states in the U.S. that recognize this cause of action.

The U.S. courts have recognized preconception tort claims on the part of children since the 1970s.<sup>194</sup> In these cases, the courts have essentially recognized a duty of care to future persons.<sup>195</sup> The courts that have refused to recognize such a duty generally take the view that the policy implications that arise from the duty are so momentous that the decision to extend liability in this manner must be left to the elected legislature.<sup>196</sup>

Preconception tort claims have arisen most often in the context of medical malpractice. For example, in *Bergstreser v. Mitchell*,<sup>197</sup> the Circuit Court of Missouri permitted the plaintiff child to recover for injuries caused as a result of a physician's negligence when he performed surgery on the plaintiff's mother before the plaintiff was conceived. The physician's negligent surgery on the mother caused the yet-to-be conceived child's injuries.

Preconception tort claims have also succeeded in the areas of rubella immunization, pharmaceutical products, motor vehicle accidents, and toxic substances. One commentator has suggested that the emergence of AHR technologies, as well as the possibility of preconception gene therapy, makes it likely that the court will face an influx of preconception tort claims arising from these activities.<sup>198</sup>

In addition, there is a growing body of common law recognizing a child's action for damages for wrongful life based on the child's legal right to be born with a sound mind and body. *In the Matter of Baby X*,<sup>199</sup> is a case that involved a tort action by the child against his mother for prenatal neglect because she was addicted to narcotics during the pregnancy. The child suffered postnatal drug withdrawal. The Michigan Court of Appeal noted that:

While there is no wholesale recognition of fetuses as persons...fetuses have been accorded rights under certain limited circumstances...This limited recognition of a child *en ventre sa mere* as a child *in esse* is appropriate when it is for the child's best interest.

<sup>190</sup> Bernard M. Dickens, "Wrongful birth and life, wrongful death before birth, and wrongful law", in Sheila A. M. McLean, ed., *Legal Issues in Human Reproduction* (Aldershot, England: Gower Publishing Company Limited, 1989) at 83.

<sup>191</sup> The *Unborn Victims of Violence Act of 2004*, Chapter 90(a) — Protection of Unborn Children, sec. 1841. Online: <http://news.findlaw.com>.

<sup>192</sup> *Ibid.* at s. 1841(2)(e)

<sup>193</sup> Philip H. Osborne, *The Law of Torts*, 2nd ed. (2003) (D. Human Reproduction) at 2 (QL).

<sup>194</sup> Matthew Browne "Preconception Tort Law in an Era of Assisted Reproduction: Applying a Nexus Test for Duty" (2001) 69 *Fordham L. Rev.* 2555 at 1 (Lexis Nexis).

<sup>195</sup> *Ibid.* at 1 (Lexis Nexis).

<sup>196</sup> *Ibid.* at 4 (Lexis Nexis).

<sup>197</sup> *Bergstreser v. Mitchell*, 577 F.2d 22 (8th Cir. 1978).

<sup>198</sup> Browne, *supra* note 191 at 21 (Lexis Nexis).

<sup>199</sup> *In the Matter of Baby X*, 97 Mich. App. 111; 293 N.W.2d 736 (Mich. Ct. App. 1980) (Lexis Nexis).



*Since a child has a legal right to begin life with a sound body and mind...we believe it is within this best interest to examine all prenatal conduct bearing on that right.*<sup>200</sup> [emphasis added]

The Court held that the mother's prenatal conduct was sufficient cause to allow the probate court to assert jurisdiction and to order a custody hearing. In this case, the Court based its decision on the child's best interest and the child's legal right to be born with a sound mind and body.<sup>201</sup>

In *Turpin v. Sortini*,<sup>202</sup> a child born deaf sued her mother's physicians for not diagnosing her sister's hereditary deafness in time to permit her mother to decide not to conceive her. The child sought damages for being "deprived of the fundamental right of a child to be born as a whole, functional human being without total deafness."<sup>203</sup> Despite the fact that the duty of the physician was originally owed to the plaintiff's sister, the Supreme Court of California allowed the child plaintiff's claim and awarded her extraordinary expenses over her lifetime for specialized teaching, training and hearing equipment, while disallowing the claim for general damages.<sup>204</sup>

The Court noted:

...if medical knowledge were such that a fetus could be treated prior to birth to cure or alleviate the hereditary defect in question. Under those circumstances, Joy [the plaintiff] could properly claim that if defendant had not negligently failed to diagnose the hereditary problem, she could have been treated *in utero* and been born as a healthy or less impaired child. Such an advance in medical science would thus make this case analogous to the prenatal injury decisions....<sup>205</sup>

In *Curlender v. Bio-Science Laboratories*,<sup>206</sup> a child sued a medical testing laboratory and a physician on the basis of wrongful life because the child was born with Tay-Sachs disease (a life-threatening hereditary genetic disease). The parents also sued alleging that the defendant had negligently performed blood tests on them resulting in "incorrect" information as to their status as carriers, and resulting in the birth of a mentally retarded child with serious medical problems and a four-year life expectancy.<sup>207</sup>

The California Court of Appeal awarded the child damages for pain and suffering and any special pecuniary loss resulting from his impaired condition. The Court referred with approval to another wrongful life case in which the court had noted:

...decisional law must keep pace with expanding technological, economic and social change. Inherent in the abolition of the statutory ban on abortion...is a public policy consideration which gives potential parents the right, within certain statutory and case law limitations, not to have a child. This right extends to instances in which it can be determined with reasonable medical certainty that the child would be born deformed. The breach of this right may also be said to be tortious to the *fundamental right of a child to be born as a whole functional human being*.<sup>208</sup> [emphasis added]

In *Grodin v. Grodin*,<sup>209</sup> a child sued both his mother and her physician. He sued his mother for her negligent failure to seek proper prenatal care. She failed to request a pregnancy test from her physician and failed to inform him that she was taking the drug tetracycline, which caused the child's teeth to be discoloured. The Michigan Court of Appeal recognized the child's legal right to "begin life with a sound mind and body," and ruled that the mother could be liable for such failures if they were found to be unreasonable with respect to the magnitude of the risk.<sup>210</sup>

<sup>200</sup> *Ibid.* at 2 (Lexis Nexis).

<sup>201</sup> *Ibid.* at 3 (Lexis Nexis).

<sup>202</sup> *Turpin v. Sortini*, 31 Cal.3d 220; 643 D.2d 954 (Supreme Court of Cal. 1982) (Lexis Nexis).

<sup>203</sup> *Ibid.* at 8.

<sup>204</sup> Penelope Watson "Edwards v. Blomely; Harriton v. Stephens; Waller v. James: Wrongful Life Actions in Australia" (2002) 26 Melbourne U. L.R. 736 at 7 (Lexis Nexis).

<sup>205</sup> *Turpin*, *supra* note 199 at 8.

<sup>206</sup> *Curlender v. Bio-Science Laboratories*, 106 Cal.App.3d 811; 165 Cal. Rptr. 477 (Cal. Ct. App. 1980) (Lexis Nexis).

<sup>207</sup> *Ibid.* at 3.

<sup>208</sup> *Ibid.* at 7, referring to *Park v. Chessin* (1977) 60 App. Div.2d 80 [400 N.Y.S. 2d 110].

<sup>209</sup> *Grodin v. Grodin*, 301 N.W.2d 869 (Mich. Ct. App. 1980) (Lexis Nexis).

<sup>210</sup> *Ibid.* at 870 and 871.

## Germany

In Germany, both the *in vitro* and *in utero* embryo are assigned rights from the moment of conception. The *Embryo Protection Law* permits only those activities on the embryo that are for its preservation and protection. Abortion, although illegal in Germany, has been permitted by the Constitutional Court to be performed until fourteen weeks gestation but only after the woman has undergone counselling.<sup>211</sup>

Despite Germany's legislative scheme giving protection and assigning rights to the *in vitro* embryo, it is unlikely that Germany would condone PGD and genetic therapies to improve the life chances or the health of an *in vitro* embryo. Germany's position may be seen as contradictory by some. It is understandable, however, given the concern that allowing PGD, genetic manipulation, and alteration would result in a eugenics movement reminiscent of what occurred in Germany before and during World War II.

## The U.K.

In 1976, the U.K. passed the *Congenital Disabilities (Civil Liability) Act* which imposed certain limits on the rights of a child born disabled to sue in negligence for injuries that occurred prenatally. The *Act* exempts a mother from tort liability for prenatal negligence to her children who are born alive. However, the exemption does not apply to prenatal negligence that occurs when the pregnant woman is in breach of her general duty of care while driving a motor vehicle.

*McKay et al. v. Essex Area Health Authority et al.*<sup>212</sup> ("McKay") was the first "wrongful life" claim brought in the U.K. and in the British Commonwealth. In this case, the infant plaintiff was born severely disabled because her mother contracted rubella during the early stages of pregnancy. The child brought a claim for "wrongful life" against the physician and the Essex Authority.

The Court concluded, relying in part on a report by the U.K. Law Commission, that the *Congenital Disabilities Act 1976* deprived any child born after its passing of a cause of action for "wrongful life."<sup>213</sup> Since this was the first case in which a court in the UK or the Commonwealth had to consider this cause of action, it gave further reasons for striking out the claim.

While the three judges of the Court were unanimous as to the disposition of the case, they each gave separate reasons. The most oft-quoted reasons are those of Stephenson L.J. He noted that the physician was under a duty to advise the mother of her right to have an abortion after contracting rubella. However, the physician owed no such duty to the child. In his view, imposing such a duty would make a "further inroad on the sanctity of human life which would be contrary to public policy. It would mean regarding the life of a handicapped child as not only less valuable than the life of a normal child, but so much less valuable that it was not worth preserving."<sup>214</sup>

Furthermore, Stephenson L.J. found it impossible in a case for wrongful life to make an award of damages. He noted:

To measure loss of expectation of death would require a value judgment where a crucial factor lies altogether outside the range of human knowledge and could only be achieved, if at all, by resorting to the personal beliefs of the judge who has the misfortune to attempt the task. If difficulty in assessing damages is a bad reason for refusing the task, impossibility of assessing them is a good one...I would regard it on principle as disclosing no cause of action.<sup>215</sup>

*McKay* is considered by many courts in common law jurisdictions as the leading case on wrongful life.

In 1990, the U.K. passed the *HFE Act*. Section 44 of the *HFE Act* amended the *Congenital Disabilities (Civil Liability) Act, 1976*, by extending liability to cover AHR procedures. Section 44 amended the *Congenital Disabilities Act* with the following addition in section 1:

<sup>211</sup> Questions and Answers about Germany, "Health Care, Health Issues and Social Welfare" (2001) at 1 Online: [http://www.germany-info.org/relauncy/info/facts/facts/questions\\_en/he.../healthissues3.htm](http://www.germany-info.org/relauncy/info/facts/facts/questions_en/he.../healthissues3.htm)

<sup>212</sup> *McKay et al. v. Essex Area Health Authority et al.* [1982] Q B 1166 (Court of Appeal) (Lexis Nexis).

<sup>213</sup> *Ibid.* at 3 and 8.

<sup>214</sup> *Ibid.* at 10.

<sup>215</sup> *Ibid.* at 11.



- 1A. (1) In any case where —
- a. a child carried by a woman as the result of the placing in her of an embryo or of sperm and eggs or her artificial insemination is born disabled,
  - b. the disability results from an act or omission in the course of the selection, or the keeping or use outside the body, of the embryo carried by her or of the gametes used to bring about the creation of the embryo, and
  - c. a person is under this section answerable to the child in respect of the act or omission,

the child's disabilities are to be regarded as damage resulting from the wrongful act of that person and actionable accordingly at the suit of the child.

Some Commentators suggest that, with the passage of this amendment, the U.K. Parliament has opened the door to wrongful life claims by children born with a preventable disability or disorder. It permits an "action by the child for the negligent selection of an embryo and thus for claims of 'wrongful life'."<sup>216</sup> It would allow a child, created through AHR and born with a disability, to sue the person responsible for damages where the disability resulted from an act or omission in the selection, storage or use of the *in vitro* embryo. This might include a failure to undertake PGD and a failure to select for transfer only those *in vitro* embryos that were free of a particular genetic disease. This would be especially so where one or both of the biological parents had a family history of the disease.

To date, only one action has been brought under the amended provisions of the *Congenital Disabilities Act* and it was settled. In *Heath v. Bromley Health Authority*,<sup>217</sup> the parents of children born with disabilities sued the Bromley Authority on behalf of their children for the harms suffered as a result of being born premature. The parents alleged that the Authority's negligent pre-conception treatment and monitoring of the mother during fertility treatments in 1992 resulted in the premature births. Although the Authority knew that the mother was carrying multiple fetuses, information respecting warnings and risks

associated with multiple pregnancy were not disclosed to the parents.

The case was settled out of court. Mr. Justice Leveson approved the settlement of all the claims of liability. The Bromley Authority admitted breach of its duty to the parents in relation to their wrongful conception claim. Although the Authority agreed to the settlement of the children's claims, it did not admit to liability.

### 3.7.2.3 Academic Literature and Commentary

The following discussion primarily refers to American literature and commentary. The case law in the U.S. is the most evolved with respect to prenatal and preconception torts. Furthermore, unlike other common law jurisdictions, claims for wrongful life have been allowed in a number of U.S. states. These judicial developments have spurred controversy and an abundance of commentary.

Some American academics have suggested that children may have an emerging right to be born free of genetic disabilities. They have suggested that this emerging "right" may become more prominent given the limited resources for health care and a growing public view that individuals have a social responsibility to take the necessary preventative steps in their private lives so as not to unduly burden public budgets.<sup>218</sup>

Other commentators have argued that women may have an obligation to undergo prenatal screening when there is a known risk of passing a genetic disease to the child. Once such testing and screening becomes less risky and invasive (as it most likely will) and widely available, mandatory testing for serious genetic anomalies may be a practice the government would consider adopting. In the view of at least one American commentator, it would likely withstand a challenge under the *U.S. Constitution*.<sup>219</sup>

<sup>216</sup> Shaun D. Pattison, "Wrongful Life Action as a Means of Regulating Use of Genetic and Reproductive Technologies" (1999) 7 Health L.J. 19-32 at 11 (Lexis Nexis); I. Kennedy & Grubb, *Medical Law: Text with Materials*, 2d. ed. (London: Butterworths, 1994) at 977.

<sup>217</sup> *Heath v. Bromley Health Authority* (unreported, High Court (2001)).

<sup>218</sup> Lois Shepherd "Protecting Parents' Freedom to Have Children with Genetic Differences" 1995 U. ILL. L. Rev. 761 at 3 (Lexis Nexis).

<sup>219</sup> *Ibid.* at 8 citing John A. Robertson "Procreative Liberty and the Control of Conception, Pregnancy and Childbirth" (1983) 69 VA. L. REV. 405 at 425.

To override constitutionally guaranteed rights of liberty and privacy, the state interest would have to be found to be compelling. It has been suggested that such an interest would be found where it provided women with the “necessary” information to decide whether to abort an affected foetus, or to prepare for the birth of a child in order to maximize the child’s well-being.<sup>220</sup>

Furthermore, it has been suggested that perhaps there is a “conditional prospective foetal right.” This right would belong to and would protect only those foetuses whose mother or parents intend to bring them to term. Some U.S. courts have labelled this legal right as the right to be born “with a sound mind and body” or “free from defects.”

U.S. commentators have argued that when this right is combined with society’s increased willingness to scrutinize prenatal conduct, the medical profession’s growing view of the foetus as a patient, independent from the mother and with a developing standard of care that promotes prenatal testing, the right can be seen as expanding to cover parental and physician decision-making in the context of genetics.<sup>221</sup> Others have suggested that the emergence of the right to a sound mind and body may be driven by a desire to prevent human suffering. From the perspective of some proponents of such a right, it would operate to ensure that children do not suffer needlessly with a severe disability or with a life-threatening genetic disease.<sup>222</sup>

However, there are other commentators who have expressed deep concerns with the emerging right to be born with a sound mind and body. Widespread acceptance of such a right for the embryo or foetus would undoubtedly violate or infringe upon the woman’s right to liberty and privacy, especially if the state attempted to impose mandatory genetic screening.

Both prenatal testing and PGD<sup>223</sup> require invasive surgical procedures into the woman’s body; such mandatory screening would thus constitute state interference with the woman’s liberty and bodily integrity. Furthermore, because the testing would be mandatory, it would remove the requirement for a woman’s freely given consent, an essential requirement for medical treatment of any kind.

Many of the opponents of a right to be born with a sound mind and body can be found in the U.S. pro-life movement.<sup>224</sup> The legal right to be born with a sound mind and body is most often claimed by a child plaintiff in a tort action for wrongful life. Actions for wrongful life are viewed by pro-life groups as violating the sanctity of human life and encouraging physicians to perform abortions.<sup>225</sup>

One Canadian academic, Bernard Dickens, noted that the judicial treatment of wrongful life cases is surprisingly similar to that initially given to wrongful birth cases. He observed that the courts were initially reticent to recognize wrongful birth cases, using the same arguments that are used today by the judiciary to dismiss wrongful life cases. However, he noted that today courts are increasingly unwilling to say as a matter of law that life, even with the most severe and debilitating of impairments, is always preferable to non-existence.<sup>226</sup>

In his view, rhetoric about the sanctity of life and the symbolic or public policy goal the law must serve in the celebration of life ignores the harsh reality of life for many severely disabled persons. He suggested that this is especially true in the U.S. where meagre public health services fail to provide adequately for all of its citizens. He noted that, even in Canada, provincial health insurance plans operate on subrogation and the provinces are often anxious to recover additional care costs through plaintiff court actions.<sup>227</sup>

Furthermore, he observed that judicial resistance to claims for wrongful life reveal a “reactionary insistence” that human birth is always beneficial. In his view, the law could retain its integrity and potential to achieve social justice by recognizing claims for pain, suffering and financial costs that can be attributed to others’ negligent acts.<sup>228</sup>

<sup>220</sup> Shepherd, *supra* note 215 at 8.

<sup>221</sup> *Ibid.* at 4.

<sup>222</sup> *Ibid.* at 9.

<sup>223</sup> In order for PGD to be carried out the embryos must exist outside the woman’s body, i.e., *in vitro*. In order to fertilize the woman’s eggs outside her body, they must be removed via an invasive procedure into her body.

<sup>224</sup> Dickens, *supra* note 187 at 80.

<sup>225</sup> *Ibid.* at 81.

<sup>226</sup> *Ibid.* at 92-3.

<sup>227</sup> *Ibid.* at 95.

<sup>228</sup> *Ibid.* at 107.

One way to do this would be to allow the child born with a preventable genetic disease to ground an action in tort for wrongful life.

Some U.S. academics have argued, however, that an individual foetus has the right to be free from any genetic manipulation: a foetus has the right to enter the world unaffected by their predecessors' genetic priorities and wishes.<sup>229</sup> They suggest that this right would flow from the right to security of the person guaranteed in international instruments, such as the UDHR and the ICCPR.<sup>230</sup>

The discourse of rights presumes that one has the ability to demand, exercise and enforce their rights. This is difficult if one is not yet a member of human society.<sup>231</sup> However, the issue of non-existence has not hampered the increase in preconception tort claims in the U.S. for injuries sustained prior to the child's conception and birth.

It has been suggested that because *in vitro* fertilization separates the embryo from the woman's womb, the *in vitro* embryo could be viewed as a separate and physically discrete unit possessing rights independent of the mother.<sup>232</sup> If that were the case, could one argue that the *in vitro* embryo possesses a human right to be born with a sound mind and body? Such a right might oblige others to conduct PGD and to select only those embryos for transfer that appear free of life-threatening or debilitating disease or to provide the embryo with genetic or other therapies to ensure its development into a healthy human being.

Presumably, such a right would not conflict with the mother's right since the *in vitro* embryo is outside her body. Legal counsel could always be assigned to represent the *in vitro* embryo's interests, as is the case today with children who sue for prenatal or preconception injuries, or for wrongful life.

#### 3.7.2.4 The Law in Canada

The law in Canada has not recognized the rights of a foetus or embryo until they are born alive, although recent cases, such as *Petkovic (Litigation Guardian of) v. Olupona*<sup>233</sup> and *McDonald-Wright (Litigation Guardian of) v. O'Herlihy*,<sup>234</sup> indicate that this approach may be changing. In *Winnipeg, supra*, the court referred to the general principle that in Canadian law a foetus is not recognized as a legal person

capable of possessing rights. However, once the child is born alive, the law may acknowledge that the child existed prior to its birth for limited purposes, i.e., the court may look back and acknowledge prenatal existence.<sup>235</sup>

In 1972, the High Court of Ontario, in *Duval et al. v. Seguin et al.*<sup>236</sup> ("*Duval*"), recognized that a driver of a motor vehicle owed a duty of care to a foetus which was actionable by the child as soon as it was born alive. In its decision, the Court traced the history of foetal legal rights, noting that for some purposes, such as property rights, the foetus has long been recognized as having rights.<sup>237</sup>

The Court examined American case law and noted that until 25 years ago the weight of authority was against recovery for damages by the child for prenatal injuries. According to the Court, the most oft-cited reasons for denying the child such a right of recovery was the difficulty establishing causation, the likelihood of extravagant testimony and fraud, and the fear that it would open the litigation floodgates to speculation and abuse.<sup>238</sup> However, the Court noted that today the position is reversed.<sup>239</sup> For example, in *Sinkler v. Kneale*,<sup>240</sup> the Supreme Court of Pennsylvania held that a child could maintain an action for an injury received when it was a one-month-old foetus.

In addition, the Ontario Court referred to *Montreal Tramways Co. v. Leveille*<sup>241</sup> ("*Montreal*"), a case decided in

<sup>229</sup> Munayyer, *supra* note 1 at 10 (Lexis Nexis); Hendricks & Nowak "Western European Case Study: The Impact of Technology on Human Rights, Global Case Studies 243 (C.G. Weeramantry ed., 1993) at 272; Recommendation 934 of the Council of Europe on Genetic Engineering, Eur. Parl. Ass., 22nd Sess., Doc. Nos. 4832-33 (1982) (acknowledging the right to inherit a genetic pattern that has not been artificially altered), reprinted in Rogers & de Bousingen *Bioethics in Europe* (1995) at 303.

<sup>230</sup> *Ibid.* (Munayyer) at 10.

<sup>231</sup> *Ibid.* at 11.

<sup>232</sup> Roberts, *supra* note 12 at 10 (Lexis Nexis).

<sup>233</sup> *Petkovic (Litigation Guardian of) v. Olupona*, [2002] O.J. No. 1269 (Ont. Superior Court of Justice) (QL).

<sup>234</sup> *McDonald-Wright (Litigation Guardian of) v. O'Herlihy*, [2005] O.J. No. 135 (Ont. Superior Court of Justice) (QL).

<sup>235</sup> See more discussion re *Winnipeg supra* note 92 at 19 and in Chapter 2 at 48.

<sup>236</sup> *Duval et al. v. Seguin et al.* [1972] 2 O.R. 686-703 (Ont. Court of Justice) (Lexis Nexis); *affm'd* (1974), 1 O.R. (2d) 482 (Ont. Court of Appeal).

<sup>237</sup> *Ibid.* at 7.

<sup>238</sup> *Ibid.* at 7-9.

<sup>239</sup> *Ibid.* at 8.

<sup>240</sup> *Sinkler v. Kneale* (1960), 164 A. 2d 93.

<sup>241</sup> *Montreal Tramways Co. v. Leveille*, [1933] S.C.R. 456.

1933 by the Supreme Court under the civil law of Quebec. In *Montreal*, the Court held the defendant liable for injuries received by the child *en ventre sa mere* or *in utero*.<sup>242</sup> Under the civil law, a foetus was considered alive when to do so was for its benefit.<sup>243</sup>

Lamont J., speaking for a majority of the Ontario Court in *Duval*, noted that:

...no decided case (or at most only one) has been found in which the child's right of action for pre-natal injuries has been maintained. The paucity of decided cases is far from conclusive, and may be largely accounted for by the inevitable difficulty or impossibility of establishing the existence of a causal relation between the fault complained of and the injury to the child. With the advance in medical science, however, that which may have been an insuperable difficulty in the past may now be found susceptible of legal proof.<sup>244</sup>

It has been noted that *Duval* brought attention to the issue of liability and the unborn, and the expansionary trends of negligence law.<sup>245</sup> The courts have been resistant to claims for wrongful birth in which the mother claims damages for the unwanted birth of a healthy child.<sup>246</sup> When a child has been born with disabilities, the courts response has been mixed.<sup>247</sup>

The case of *Dobson (Litigation Guardian of) v. Dobson*<sup>248</sup> ("Dobson") established that a duty of care is not owed by a mother to her unborn child. A majority of the Supreme Court expressed concern that if such a duty was found in the case, it might be expanded beyond the operation of motor vehicles and lead to judicial scrutiny and assessment of all maternal activities that might pose a risk to the foetus, such as continuing in the work force and careless performance of household activities.<sup>249</sup> The minority in *Dobson* would have recognized a duty in the present case, i.e., a duty to drive safely, because such a duty is already owed to third parties.<sup>250</sup>

The Canadian courts have traditionally resisted recognizing a cause of action for wrongful life. For example, in *Lacroix (Guardian of) v. Dominique*<sup>251</sup> ("Lacroix"), the Manitoba Court of Appeal was asked to decide whether

the trial judge had correctly dismissed the child's claim for wrongful life. The Court followed the reasons in *McKay, supra*, and held that such a cause of action could not be maintained in Canada.<sup>252</sup> In 2001, the Supreme Court denied leave to appeal.

*Petkovic (Litigation guardian of) v. Olupona*<sup>253</sup> ("Petkovic") suggests a slight crack in the courts resistance. The Ontario Superior Court of Justice was asked to strike out a claim for wrongful life by a minor plaintiff on the ground that it did not disclose a reasonable cause of action. The defendants relied in part on the fact that the Supreme Court denied leave to appeal in *Lacroix*, arguing that it must now be considered settled law in Canada that an action for wrongful life cannot be maintained.<sup>254</sup>

The Court responded by stating:

The fact that the Supreme Court refused leave in *Lacroix* is not, in my respectful opinion, dispositive of the issue on a national basis even though subsumed in the application is an issue of great and universal concern. It does not follow that the court accepted the decision of the Manitoba Court of Appeal without question...a denial of leave can occur for any number of reasons...[T]he decision of the Manitoba Court of Appeal in rejecting the wrongful life claim is rooted, without analysis, in the decision of the English Court of Appeal in *McKay v. Essex Area Health Authority*... Arguably, when that decision is subjected to careful scrutiny, it in turn appears to be reflective of the then-English public policy and the prevailing statutory regime in respect of the protection of viable foetii.

<sup>242</sup> *Duval, supra* note 233 at 7 (Lexis Nexis).

<sup>243</sup> *Ibid.* at 7.

<sup>244</sup> *Ibid.* at 9.

<sup>245</sup> Osborne, *supra* note 190 at 1 (QL).

<sup>246</sup> Jocelyn Downie, Timothy Caulfield and Colleen Flood, *Canadian Health Law and Policy* (Markham, Ontario: Butterworths, 2002) at 361.

<sup>247</sup> *Ibid.*

<sup>248</sup> *Dobson (Litigation Guardian of) v. Dobson*, [1999] 2 S.C.R. at 753. Online: <http://www.lexum.umontreal.ca>.

<sup>249</sup> *Ibid.* at 13.

<sup>250</sup> *Ibid.* at 25.

<sup>251</sup> *Lacroix (Guardian of) v. Dominique*, 2001, Man. Court of Appeal. Online: <http://www.Canlii.org/mb/cas/mbca/2001mbca122.html>; leave to appeal to the Supreme Court of Canada denied [2001] S.C.C.A. No. 477.

<sup>252</sup> *Ibid.* at 7.

<sup>253</sup> *Petkovic, supra*, note 230 (QL).

<sup>254</sup> *Ibid.* at 2.

[...]

Furthermore, I am not persuaded that the “sanctity of life” notion that appears to underpin in part the decision of at least one of the members of the court in *McKay*, remains as sacrosanct today as apparently it was at the time of that decision...In my opinion, the issue of the existence of a cause of action for wrongful life is not clear, obvious and beyond doubt, particularly as it is presently pled.<sup>255</sup>

The court dismissed the defendants’ motion to strike the plaintiff child’s claim and allowed it to go forward.<sup>256</sup> On appeal, the Divisional Court of Ontario<sup>257</sup> referred to the decision of Sharpe J. in two unreported 1997 wrongful life cases, where he stated:

In my view, the appropriate order...is to permit the ‘wrongful life’ claim to proceed to trial. This is an evolving area of law. The issue has not been considered in depth by Canadian courts. It is only recently that the parents ‘wrongful birth’ claim was [sic] been recognized by a Canadian court...More generally, the legal regime relating to abortion has undergone significant change resulting in an expanded scope for parental choice.<sup>258</sup>

The Divisional Court held that the lower court had correctly decided the issue by allowing the action to proceed to trial. Epstein J. noted:

It [should] be for the trial judge, in the context of a complete record, to determine whether the plaintiff should have a remedy. This is how the progress of the common law is marked in cases of first impression, where the court has created a new cause of action where none had been recognized before.

A few years ago wrongful life was not considered to be a cause of action and now it is. Plaintiffs’ counsel argues that the law in this area is clearly in a state of flux...I am of the view that in this complex area, a trial record may be of assistance to the appellate court.<sup>259</sup>

The Court dismissed the defendants’ motion for leave to appeal the lower court’s decision and allowed the child’s

claim to go forward. In doing so, the Court stated “...there is no reason to doubt the correctness of the principles used by the learned motions judge in the exercise of his discretion.”<sup>260</sup>

In 2005, the Ontario courts are once again facing a claim by a child for wrongful life. *McDonald-Wright (Litigation Guardian of) v. O’Herlihy*<sup>261</sup> is in many respects similar to *Petkovic, supra*. The Ontario Superior Court of Justice was asked to rule on a motion striking a claim by the injured child, Beau McDonald-Wright, against the defendants for wrongful life.<sup>262</sup> Justice Lax stated that a tort claim for wrongful life is a matter of law that has not been fully settled in either Ontario or Canada, and thus she held that “[i]t should proceed to trial.”<sup>263</sup> In reaching her decision, she relied in part on Justice Wilson’s comments in *Hunt v. Carey*:

The fact that a pleading reveals “an arguable, difficult or important point of law” cannot justify striking out part of the statement of claim. Indeed, I would go so far as to suggest that where a statement of claim reveals a difficult and important point of law, it may well be critical that the action be allowed to proceed. Only in this way can we ever be sure that the common law in general, and the law of torts in particular, will continue to evolve to meet the legal challenges that arise in our modern industrial society.<sup>264</sup>

The significance of allowing a cause of action for wrongful life in Canada would lie in the fact that, as was the case in the U.S., at some point the courts might have to struggle with the question of whether a child has a legal right to be born with a sound mind and body.

<sup>255</sup> *Ibid.*

<sup>256</sup> *Ibid.* at 3.

<sup>257</sup> *Petkovic v. Olupona*, [2002] O.J. No. 3411 (Ont. Ct. of Justice, Divisional Court) (QL).

<sup>258</sup> *Ibid.* at 2.

<sup>259</sup> *Ibid.* at 4.

<sup>260</sup> *Ibid.* at 4. There are no further reports of *Petkovic*. It may be that the case was settled out of court and is unreported.

<sup>261</sup> *McDonald-Wright, supra* note 231(QL).

<sup>262</sup> *Ibid.* at para. 1.

<sup>263</sup> *Ibid.* at para. 16.

<sup>264</sup> *Hunt v. Carey Canada Inc.*, [1990] 2 S.C.R. 599 at para. 49.



### 3.7.2.5 Discussion

The following discussion addresses a controversial area and it is restricted to the evolving situation in the U.S. It examines whether the emerging legal right to be born with a sound mind and body, currently grounded in tort law, could evolve into a human right.

In the past, there were no scientific or medical procedures available to diagnose a genetic disease in an *in utero* embryo, foetus or an *in vitro* embryo. Today, if physicians or clinics fail to advise parents at risk about genetic testing, such as PGD or amniocentesis, children born with a life-threatening genetic disease may claim damages in certain U.S. states based on wrongful life and a legal right to be born with a sound mind and body. In other states, the child's claim for wrongful life would be dismissed. However, the parents would likely still be able to sue the physician for a prenatal tort for damages occurring before or after birth, but after the child's conception,<sup>265</sup> depending on the facts of the case.

It is possible to foresee that as rapid advances in biotechnology occur, society and the courts may have cause to rethink more traditional human rights concepts and perhaps create new ones.

One solution might be to broaden the child's right to be born with a sound mind and body to apply outside the civil tort law context. Could such a right be grounded in constitutionally protected guarantees to liberty or security of the person? Could the right be narrowed so that it applied to only those *in vitro* embryos selected for reproduction purposes? The right would only exist during the time between the creation of the *in vitro* embryo and the embryo's transfer into the woman. Once the *in vitro* embryo is transferred, the rights of the woman and the *in utero* embryo would have to be balanced (this approach would be similar to that adopted by Louisiana, under its *Code*, where the *in vitro* embryo only has legal rights prior to transfer).

The recent right to procreational autonomy was derived from the constitutional guarantees to liberty and privacy, which originated in the First, Fourth and Fifth Amendments to the *U.S. Constitution*. Any rights secured under the guarantee to privacy are considered fundamental by the courts because they are located within areas

of a personal nature where unwarranted governmental intrusion is deemed improper. Fundamental rights are granted the highest protection under the law.

The U.S. has signed but not ratified the U.N. *Convention on the Rights of the Child* ("CRC"). The rights provided in the CRC could be referred to the courts for their interpretive value with respect to the *U.S. Constitution* and domestic legislation. Article 24(1) provides that State Parties recognize the right of the child to the enjoyment of the highest attainable standard of health. It could be relied on to support an argument that children have a right to be born in the best possible state of health. This right could include and protect parental access to genetic testing, such as PGD, without state interference, to ensure as far as possible that the child would be born without a particular genetic disease. It could be argued that the state should not deny access to readily available technology to assist the future child in the enjoyment and attainment of the highest standard of health. However, since these international instruments speak only of children, it is questionable whether they would be interpreted to apply to a future child existing as an *in vitro* embryo.

Such a right would be a negative right vis-à-vis the state. The right would impose a duty on the state not to interfere with the parent's access to PGD to ensure that the *in vitro* embryo selected would, as a child, have the potential to enjoy the highest possible standard of health.

Although the state duty would be to a future person, this approach accords with that already taken by the court in preconception tort claims, where the physician has a duty of care, when treating the woman, to any future children as well. The state's duty would be to the future child, existing as an *in vitro* embryo, while the child's right would only crystallize once it is born alive. This approach would also be similar to that taken by the court in prenatal tort claims. The court recognizes the child's existence prior to its birth for the specific and limited purpose of allowing tort actions for damages. In addition, the courts generally inquire whether such an approach is in the child's best interest.

<sup>265</sup> Collins, *supra* note 184.

Once the child is born alive, the courts could be asked to look back to the time when the child was an *in vitro* embryo for the limited purpose of asserting a claim against the state for depriving his or her parents of access to information necessary to allow optimum health. This approach would accord with the long-standing common law rule of only granting rights to an foetus once born alive. The child's right would be a negative right, meaning that the child has a right to be born of sound mind and body, free from state interference.

Assuming the right to be born with a sound mind and body was grounded in one or more of the Amendments to the *U.S. Constitution*, the state could still limit the right. It could infringe on the right, but only where the state has what the American courts consider a "compelling reason."

### 3.7.2.6 Conclusion

Despite evidence from the U.S. that the right to be born with a sound mind and body is an emerging legal right, it has only been recognized in three U.S. states and only in the context of a civil action for wrongful life. To date, the courts in Canada have been unwilling to recognize actions for wrongful life, although there is some evidence in lower court decisions that this may change. In addition, the courts in Canada have not yet been asked to decide on the existence of a legal right to be born of sound mind and body.

In the UK, recent legislative amendments appear to have opened the door to claims for wrongful life, at least in the context of AHR procedures. As technology advances and testing for genetic anomalies becomes more accessible and less intrusive, the courts might begin to recognize claims based on a right to be born with a sound mind and body. Over time, such a right might evolve into a fundamental right or norm. It would become more difficult for the state to prohibit access to tests, such as PGD, as well as gene therapies developed to eradicate genetic disease in the *in vitro* embryo. As a negative right, the child would be able to challenge the state prohibition as violating a fundamental right to be born in optimal health – of a sound mind and body – to enjoy the highest attainable standard of health.

Whether such a right would evolve into a *Charter*-protected right in Canada, is highly speculative. It remains extremely difficult to attain a consensus viewpoint within society about the moral and legal status of an *in vitro* embryo. The same difficulty exists at the international level and would likely hamper any attempt to fashion such an international norm or right for the *in vitro* embryo.

In addition, any explicit right to screen for genetic disease would have to be balanced against the reproductive autonomy rights of the woman. For now, the issue is largely confined to the U.S. and unlikely to arise in other parts of the world unless and until access to AHR technologies, including PGD and genetic therapy, becomes relatively easy, somewhat affordable and viewed as a culturally acceptable intervention.

## 3.8 Conclusion

Although foetal rights have been dealt with by the courts in the context of civil litigation and to some extent in jurisprudence regarding abortion, the legal rights of an *in vitro* embryo, existing as it does outside the body of a woman, have not been decided by the courts. Advances in AHR technology, especially pre-conception and *in vitro* genetic diagnosis, may force the court to examine this issue sometime soon. The current lack of jurisprudence represents a gap in the existing human rights framework.

A right to reproductive autonomy, although not particularly clear or settled in the international arena, has been addressed to some extent by the courts in Canada. The right to liberty, enshrined in section 7 of the *Charter*, contains a right to make fundamental personal decisions without interference from the state (unless the interference is found to be in accordance with the principles of fundamental justice).

The courts have held that women in Canada have a degree of autonomy flowing from the liberty interest in section 7 to make personal decisions regarding reproduction. In particular, women have an unrestricted right to abort in the early stages of the pregnancy. This right to reproductive autonomy would most likely be found to protect a woman's decision to use AHR technologies. Furthermore, the woman's right to reproductive

autonomy would arguably include the right not to be deprived of “necessary” medical information, about her *in vitro* embryos in order to make a decision regarding reproduction.

Now that certain provisions of the AHR Act have been proclaimed in force, the *Charter* will apply to some of the activities discussed in this chapter. It is likely that disputes will arise between individuals and the state with respect to some of the prohibited activities. The courts in Canada will, for the first time, be faced with deciding

these issues and will no doubt be referred to rights and principles set out in international instruments. The challenge for the courts will be to decide these issues in a forward-looking manner, taking into account broader societal interests, as well as individual rights. The pluralistic nature of Canada, in which communities and individuals hold differing moral and ethical views, as well as the unknown and uncharted path represented by these new technologies, will combine to make this task extremely challenging.