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THE ETHICAL AND HUMAN RIGHTS IMPLICATIONS OF PRENATAL TECHNOLOGIES: THE NEED FOR FEDERAL LEADERSHIP AND REGULATION

Preface

In November 1994, DAWN Canada (Disabled Women's Network) and the National Action Committee on the Status of Women (NAC) co-sponsored a conference¹ which focused on reproductive technologies and their implications for women's equality and the recognition of disability rights. The Conference represented a landmark event in the history of the Canadian women's movement in that it was the first official forum to examine reproductive technologies from both a disability rights and feminist perspective.

Women with disabilities were particularly concerned about genetic technologies and their potential to reinforce discriminatory attitudes about life with a disability. Other participants worried that imposing restrictions on the use of genetic technologies could translate into restrictions on a woman's access to abortion services.² One of the major outcomes of the Conference was the recognition by advocates of each perspective that there is a need to construct a critical analysis of genetic technologies which upholds both disability rights and reproductive rights as compatible interests. This is a complex undertaking, and while the dialogue continues, a collaborative strategy has yet to emerge.

The discussions that took place at the DAWN Canada NAC Conference inspired the Research Team* preparing this Paper to find a way to carry on the dialogue between disability rights activists and feminists. Consequently, this Paper was prepared with two objectives in mind. First, to advance the development of a united strategy between feminists and disability rights activists. Second, to offer some initial thoughts on policy options which could be implemented to regulate genetic technologies in a manner that respects and upholds both human rights and women's reproductive autonomy.

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PART I: INTRODUCTION

"Biomedical researchers are currently redefining human geography. These modern explorers are elaborating a new human map, based on genes, that is likely to alter our views of the world - and our place in it - even more profoundly than did the maps generated by Columbus and other fifteenth- and sixteenth-century explorers. More important, this newest expression of territorial expansion and colonization, a process I call geneticization...is likely also to alter our perceptions of self and other, of normality and abnormality, particularly in the area of procreation. This can be seen most clearly in the consideration of the impacts of prenatal genetic testing and screening on women."³

Thanks to the work on the Human Genome Project⁴ and the media reports it has attracted over the past several years, the public has received a steady stream of information on the latest gene to be discovered by science. Such announcements are generally greeted with enthusiasm, and the hope that genetic solutions will save us from our human frailties. But, this hope may be overly optimistic and ambitious. While genetic technologies may offer a few more keys to unlock the genetic puzzle, they have not necessarily produced the solutions required to solve the puzzle.

Despite the imprecision of science and the lack of a clear ethical framework, prenatal technologies are rapidly becoming a routine practice in the care of pregnant women.

For example, although hundreds of human genes have been identified and mapped, in many cases, a corresponding cure or treatment regime has not yet been developed.⁵ Moreover, although many common diseases are suspected of being genetically linked, in most cases, the risk must be augmented by other genetic or environmental factors in order for the disease to occur.⁶ Nor does the detection of a chromosomal disorder, such as Down's Syndrome, predict the severity with which the syndrome will be expressed.⁷

Advocates of new reproductive technologies, particularly prenatal technologies, argue that this technology will expand women's reproductive choice and decrease the incidence of disability in society. This argument is over simplistic at best, and belies the significant social and ethical implications underlying such technologies for women's reproductive autonomy and the equality rights of women and men with disabilities.

It is possible that prenatal diagnostic testing can offer women more control over the occurrence of the birth of a disabled child by providing relevant information about the genetic status of the fetus during pregnancy. However, because there are no therapeutic interventions available for the majority of conditions which prenatal testing detects, the options open to women following a positive diagnosis consist of preparing for a life with a disabled child or terminating the pregnancy.⁸

Negative perceptions about a life with a disability, combined with the difficulties in obtaining adequate social supports may cause a woman to believe that her only real choice is to terminate her pregnancy.

Disability rights activists harshly criticize the intent of prenatal testing and the more often than not, follow-up procedure of aborting disabled fetuses. They are suspicious of the manner in which prenatal testing has been allowed to outpace therapeutic strategies. They argue that gene location is the means for a strategy of eugenics by eliminating defective fetuses.⁹

A. The Shift to Geneticization

Although physical science strives to be objective, like other people in society, medical scientists are influenced by particular social and cultural assumptions about people in general, and people with disabilities in particular.¹⁰ Attitudes can and do play a prominent role in constructing certain physiological or physical conditions as a problem.¹¹ In other words, the construction of a problem is the result of a subjective interpretation of a genetic diagnosis. Relying solely on a genetic lens to assess future quality of life is both misleading and dangerous.¹² It assumes that the complexities of human life can be explained and reduced to an analysis of genetic make-up.

Lippman uses the term 'geneticization' to describe the growing reliance on genetics to reveal and explain health and disease, normality and abnormality.¹³ According to Lippman, "[g]eneticization refers to the ongoing process by which priority is given to searching for variations in DNA sequences that differentiate people from each other and to attributing some hereditary basis to most disorders, behaviors, and physiological variations (including such things as schizophrenia and high blood pressure as well as the ability of children to sit still while watching television and of adults to quit smoking)."¹⁴ The acceptance of geneticization as an assessment model intensifies the need for prenatal technologies as a means of identifying those genetic differences thought to be associated with biomedical abnormalities.¹⁵

B. The Social Construction of Disability

The shift to a geneticized view of life raises two major issues for persons with disabilities. First, it purports an 'ablest' view of disability. Most non-disabled persons cannot imagine life with a disability. This inability to imagine the disability experience often translates into a collective mythology that a person with a disability lives a tragic life, marked by deprivation and suffering, a circumstance that should be resolutely avoided. This perception conflicts sharply with the view of many persons with disabilities who do not see themselves as different or abnormal and who hold society's negative attitudes responsible for disability-based discrimination.¹⁶

Second, it assumes that the barriers encountered by persons with disabilities occur exclusively because a person has a disability. Disability rights advocates reject the notion of disability as a biological condition.

They argue that disability per se is not the problem, but rather society's response to disability which is problematic. Disability is thus a social problem, rather than a biological problem. To put it simply, the difficulties associated with having a disability result from collective societal action rather than personal limitations.¹⁷ The fact that many of society's structures and institutions are designed primarily for able-bodied persons provides a cogent explanation for why persons with disabilities experience limited opportunities to access and participate in community life. For example, it is not a person's wheelchair that prevents participation, but a physical environment that is not designed to include persons who use wheelchairs.

C. The Medicalization of Disability

For persons with disabilities the beliefs underpinning the concept of geneticization are not new. Given the rise of medical influence during the past century, the medical profession has been well-placed to exercise a powerful role over the lives of persons with disabilities. Medical professionals and scientists have historically characterized disability as a defect, deficiency, dysfunction, abnormality, failing or medical 'problem' that is located in an individual.¹⁸ As a result, societal (and medical) attention is directed at fixing or curing the individual or returning the person to 'normality'. Where so-called 'normality' is not achieved, attempts are made to make the person as 'normal' as possible.

The 'medicalization' of disability espouses an ideology of the individual in that it affixes the 'problem' of difference to the body of the disabled individual. Under this ideology, the responsibility for any and all disability-related barriers is placed on the individual, rather than on the social institutions which have excluded persons with disabilities by maintaining barriers to their full participation.

Genetic technologies and the ideology of geneticization threatens to reinforce the traditional view of disability as a medical problem. Language such as defect, abnormality and congenital malformation is sometimes used to describe fetuses in which a disability has been detected.¹⁹ These labels demonstrate that once again, disability is being framed in the context of individual pathology, rather than in a social context.

Prenatal technologies will not eliminate disability from society. The Council of Canadians with Disabilities estimates that only 3% of genetic conditions may be affected by gene therapy.²⁰ Eighty-five percent of adult disability is caused after the age of 13, and more than ninety percent of infant disability is because of social and not genetic causes.²¹ A person is far more likely to become disabled because of situations such as ageing, illness, unsafe working conditions, toxic environments, violence, poverty, lifestyle choices, poor nutrition etc. Consequently, despite the hype offered by the media and the scientific community, it is unlikely that gene identification will significantly reduce the incidence of disability or improve the social status of persons with disabilities.

D. Legislative History in Canada

The Canadian Government has, for the most part, assumed a 'low key' approach with respect to the expanding growth of prenatal technologies in Canada. Since the Royal Commission on New Reproductive Technologies released its final report in 1993, *Proceed with Care*, the Federal government has made three attempts to legislate in the field of reproductive technologies.

The first attempt occurred in June 1996 when the Federal government introduced *Bill C-47*, the *Human Reproductive and Genetic Technologies Act*. The purpose of the *Act* was to prohibit certain of the most problematic aspects of NRGTs, such as cloning of human embryos and sex-selection for non-medical reasons. Prenatal testing, with the exception of sex-selection for non-medical reasons, was not addressed by the *Bill*.

In conjunction with the tabling of *Bill C-47*, the Government of Canada released a Discussion Paper entitled *New Reproductive and Genetic Technologies: Setting Boundaries, Enhancing Health*²² which set out the proposed elements of a regulatory framework for reproductive technologies. The Paper acknowledged the Federal government's role in working with provinces and territories, non-governmental organizations, and the public to develop a policy framework regarding the management of prenatal diagnosis and genetics. However, the Federal government declined to recommend regulating in this area on the grounds that such issues fall largely within the ambit of provincial and territorial jurisdiction.²³ With the call of the 1997 Federal election, final reading of *Bill C-47* did not occur and therefore, did not become law.

In 1999 the Federal Minister of Health once again considered the introduction of comprehensive legislation regulating reproductive technologies. A Discussion Paper that provided details on the proposed regulatory framework also accompanied these proposals.²⁴ The 1999 set of legislative proposals was similar to *Bill C-47* with some minor modifications.

Specifically, the proposals established a statutory framework for regulating human reproductive and genetic technologies through the enforcement of prohibitions (where technologies are unacceptable), and through the regulation of other technologies using mechanisms such as national standards, licensing, information registries, health surveillance, and enforcement and compliance procedures.²⁵ Subject matters proposed by the Discussion Paper for regulation included the use and collection of human reproductive materials in medical research and practice, such as the collection, storage, distribution and use of human eggs, sperm, embryos and fetal tissue. The Discussion Paper also cited "pre-implantation genetic diagnosis" as a matter for regulation, which was the closest the paper came to discussing the regulation of prenatal testing. Thus, while the government's most recent Discussion Paper clearly endorsed a pan-Canadian approach for the regulation of many reproductive technologies, it was noticeably elusive on the matter of prenatal testing.

Canada's second attempt at introducing legislation did not even make it into a Parliamentary Bill before the fall 2000 election was called. Thus, like its first legislative attempt, Canada's second set of legislative proposals died, leaving the regulation of reproductive technologies in limbo once again.

In May 2001, the Federal government mustered a third attempt to legislate in the area of reproductive technologies. Similar to previous proposals, the current proposals seek to prohibit certain activities, such as cloning for the purpose of creating a human being, and controlling through regulation other activities such as reproductive treatments and research.

Rather than introducing these proposals as a Parliamentary Bill, the government has referred them to the Standing Committee on Health for review and consultation. The Committee has also been asked to consider the type of regulatory body that should be established to oversee the implementation of such legislation. The Committee is required to report on the draft legislation by the end of January 2002.

...prenatal/genetic technologies raise a host of issues fundamental to humanity, which require central leadership and management...our intent is that this Paper will encourage further discussion on the need for regulation of prenatal technologies.

According to the Federal Minister of Health, one of the primary objectives of the legislation is to ensure that the health and safety of Canadians is not compromised when using assisted reproduction techniques.²⁶ Why then, we wonder, has the government refused to include the regulation of prenatal technologies in its legislative proposals? Once again, it appears that government has ignored the thoughtful criticisms expressed by organizations representing women²⁷ and disability rights activists.²⁸ In light of the Federal government's current deliberations on reproductive technologies, it is hoped that this Paper will foster further discussion on the need for the regulation of prenatal technologies and the requirement for central leadership and management.

E. Purpose of the Paper

The purpose of this Paper is fourfold. First, we highlight the profound social, ethical and human rights issues raised by prenatal testing for disability rights and feminist values. Second, we analyze prenatal technologies from a human rights and equality rights perspective. Third, we contend that the potential social and human rights consequences of prenatal testing make them an issue of national concern, and a matter that requires regulation by the Federal government. Finally, we offer some recommendations and conclusions about what steps the Federal government should be taking to ensure that genetic technologies as a whole, and prenatal technologies in particular, are implemented for the public good, and not just because science makes them available. However, before turning to these four points, we offer a brief description of prenatal technologies and their use in Canada.

F. Overview of Prenatal Technologies

In this Paper, the term *prenatal technologies* is used broadly to refer to both the current testing procedures that are in use and the plethora of future testing procedures that science advises will soon be available. Our comments are restricted to those technologies designed to assess the genetic make-up of a fetus, and do not include those technologies aimed at embryos and preimplantation diagnosis. The number of conditions that can be diagnosed in utero grows daily. Some of these tests can be used to detect late-onset disorders that can be identified before birth, but which do not manifest themselves until adulthood.²⁹ In addition, prenatal testing can detect susceptibility genes (genes shown to increase an individual's susceptibility to certain conditions that may or may not develop later in life, such as cancer or heart disease).³⁰

Prenatal testing was first introduced into Canadian medical protocols in the 1970's with the emergence of amniocentesis. Since that time advancements in genetic knowledge and technology have resulted in a variety of screening and diagnostic tests being made available. Prenatal screening is conducted on a population-wide basis in an attempt to identify women who are at high risk for carrying a fetus with a disease or disability. It is important to note that screening methods are implemented to define women according to risk factors associated with fetal anomaly, and not to actually determine if the fetus does carry a disability.³¹ As a result, women defined through the screening process as 'high risk' are then offered the option of diagnostic testing. In essence, screening methods can identify possible high risk cases, but diagnostic tests are needed to reach a decisive diagnosis on the actual status of the fetus. Set out below is a discussion of the most common screening and diagnostic techniques currently being utilized in Canada.

G. Prenatal Testing Procedures

1. Ultrasonography

Ultrasound is a routinely used, non-invasive technique for assessing gestational age, tracking fetal growth and detecting major structural abnormalities. Ultrasound functions as both a screening and a diagnostic method.³² The routine use of ultrasound as a standard part of prenatal care illustrates its use as a screening procedure in that it may uncover fetal conditions associated with disability that would place the pregnancy at 'high risk' and thus the woman would be a candidate for diagnostic testing. However, ultrasound can also provide a decisive diagnosis on its own in certain situations, such as when major structural abnormalities are uncovered.³³

2. Maternal Serum Screening

These screening procedures [i.e., Maternal Serum Alpha-fetoprotein (MSAFP) and Triple Marker Tests] analyze the levels of certain proteins and/or hormones found in a pregnant woman's blood serum.

Certain elevated protein or hormonal levels have been found to be associated with open neural tube defects in the fetus, while suppressed levels are suggestive of possible Down's Syndrome.³⁴ The high rate of false-positive and false-negative results associated with these serum tests have led medical researchers to emphasize that these procedures are to be utilized for screening purposes only.³⁵ Specifically, 95% of women with an MSAFP value in the clinical range are carrying a normal child.³⁶ Thus, more precise techniques must be implemented subsequent to an abnormal serum result in order to reach a more conclusive diagnosis.

Recent experimental techniques have been able to isolate fetal cells circulating in the maternal blood stream for the purpose of analysing them for abnormalities.³⁷ Such techniques will result in a non-invasive prenatal diagnostic testing method which poses no risk to the fetus. This is because the serum sample is obtained from the woman's arm. It is also expected that the results of such serum diagnostic procedures would be available sooner and be less expensive to conduct than the current methods of prenatal diagnosis.

3. Amniocentesis

Amniocentesis is a procedure by which a sample of the amniotic fluid surrounding the fetus is withdrawn and analyzed for chromosomal, biochemical and DNA abnormalities. It is usually performed between 14-16 weeks of gestation. Due to its invasive nature, the test carries an estimated risk of fetal loss of between 0.5-1.0%.³⁸ It is important to note that this test is not 100% accurate, and the false-positive and false-negative rates for detecting chromosomal abnormalities via amniocentesis are approximately 0.0007 and 0.004 respectively.³⁹

4. Chorionic Villus Sampling (CVS)

CVS involves obtaining and analyzing a sample of the chorionic sac that surrounds the fetus. Compared to amniocentesis, CVS is accompanied by about a 1.0% higher rate of fetal loss,⁴⁰ a comparable false-negative rate, and an elevated false-positive rate.⁴¹ Its main advantage lies in the fact that it is performed earlier in pregnancy (between 9-12 weeks of gestation) and thus CVS provides women with diagnostic information within the first trimester. A substantial limitation however, is that CVS does not detect neural tube defects.⁴² Thus subsequent screening and/or testing (via ultrasound and amniocentesis) is necessary to provide diagnostic information regarding these conditions.

H. Prevalence of Testing

Prenatal genetic screening has become a routine aspect of prenatal care for most pregnant women in Canada. Physicians monitor the vast majority of pregnancies with at least one ultrasound, and maternal serum screening is fast becoming a component of standard medical prenatal management.

In contrast, diagnostic testing is considered a routine aspect of responsible prenatal care only for women identified as at 'high risk' due to the detection of certain factors which are associated with fetal disability. This includes women with a family history for certain conditions, women from specific ethnic populations with a high prevalence rate for certain conditions, and women 35 years of age and older.⁴³

Hamerton, Evans and Stranc⁴⁴ in their submission to the Royal Commission on New Reproductive Technologies, report that in 1990 approximately 22,000 Canadian women (5% of all pregnant women in Canada) were referred for testing. Thus, it is clear that prenatal testing impacts upon the experience of pregnancy for a substantial number of Canadian women.

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The most common indication for referral to testing is advanced maternal age.⁴⁵ For almost 80% of Canadian women referred to prenatal testing, their age is the sole indication for testing.⁴⁶ It is important to note that the current cut-off for referral at age 35 is more a factor of technological refinement than biology. The minimum age at which women are categorized as high-risk, and thus in need of prenatal testing, has been gradually lowering as technological refinements render the procedures safer in terms of fetal injury and loss.⁴⁷ Therefore, the population of women considered as high-risk will most likely continue to expand as procedures becomes less invasive and thus entail less danger to the fetus.

PART II: A HISTORICAL OVERVIEW OF DISABILITY-BASED DISCRIMINATION - LESSONS LEARNED

"It is an unfortunate truth that the history of disabled persons in Canada is largely one of exclusion and marginalization. Persons with disabilities have too often been excluded from the labour force, denied access to opportunities for social interaction and advancement, subjected to invidious stereotyping and relegated to institutions; This historical disadvantage has to a great extent been shaped and perpetuated by the notion that disability is an abnormality or flaw. As a result, disabled persons have not generally been afforded the 'equal concern, respect and consideration that s. 15(1) of the *Charter* demands. Instead, they have been subjected to paternalistic attitudes of pity and charity, and their entrance into the social mainstream has been conditional upon their emulation of able-bodied norms..."⁴⁸

Many people with disabilities have expressed grave concerns about the intent of prenatal testing and the message it implies about life with a disability.⁴⁹ Some people may find it easy to dismiss or discount these concerns, believing that the views of people with disabilities lack objectivity and are personally motivated. But an appreciation of the historical treatment of persons with disabilities provides an explanation and justification for their concerns.

A. Historical Treatment of Persons with Disabilities

Historically, our society has viewed disability as an individual tragedy. As such, the problems associated with having a disability have been located primarily with the individual. It was assumed that having a disability meant that a person could not or would not participate in the mainstream.

Not only has disability been regarded as the problem of the individual, it has also been characterized as a medical problem requiring a medical solution; that is, the care and intervention of professionals such as doctors, social workers and rehabilitation counsellors. Consequently many people with disabilities have been isolated from society, and forced to live in conditions of dependency and oppression. Framed as an illness or individual defect, disability has been ascribed a negative value.⁵⁰

This part of the Paper provides a brief overview of the historical roots of disability-based discrimination. A historical perspective provides a framework for understanding why people with disabilities are concerned about prenatal testing, and why prenatal testing can be viewed as another manifestation of discrimination. However, the relationship between disability rights and prenatal testing cannot be discussed in a vacuum.

It is women who are subjected to prenatal testing, and the ones who must make sense of, and cope with the results of such testing. Consequently, this part of the Paper argues that a true assessment of prenatal testing requires both a disability rights and a feminist analysis.

It is women who are subjected to prenatal testing, and the ones who must make sense of, and cope with the results of such testing.... a true assessment of prenatal testing requires both a disability rights and a feminist analysis.

During the past 20 years or so, disability activists and scholars alike have challenged the negative characterization of disability. The disability rights movement has offered cogent evidence that the problem does not rest exclusively with the individual, but rather with a society that is organized and structured with only able-bodied persons in mind.⁵¹ This analysis has led to an understanding of disability as a social construct. In other words, the barriers that people with disabilities encounter are more likely to be caused by discriminatory social norms than by a person's particular disability.⁵² For example, a person who uses a wheelchair may feel isolated and depressed because architectural barriers limit her mobility. A barrier-free environment would provide her with the freedom and liberty to travel wherever she pleased.

Disability rights activists argue that the historical medical model of disability distorts reality by emphasizing one aspect, (the medical aspect) while ignoring the crucial influence of social norms and attitudes.⁵³ They argue that our perception of disability, and in particular the limitations associated with disability, are based on myth rather than fact. By describing disability as a social construct, we shift the emphasis from the individual to the society, and the way that it interacts with people with disabilities. This shift in thinking has laid the groundwork for constructing a disability rights approach to address the equality claims of people with disabilities.

Canadians with disabilities have made some progress in securing the legal recognition of their human rights, but such gains are fragile and not well developed. Negative views about disabilities are still very much a part of today's society and are exacerbated by a limited understanding of the capacities and abilities of people with disabilities.⁵⁴ Consequently, in the public mind, the negative value of disability seems to far outweigh any positive qualities of living with a disability.

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People with disabilities are disturbed by prenatal testing because, to them, it represents a return to an individual-based, medical model of disability at a time when they have only just begun to experience the dignity of rights and the hope for a barrier-free society. Their apprehension about prenatal testing arises from a history of eugenic practices that have contributed to the brutal oppression of disadvantaged groups. For example, during the last century, people with disabilities were subjected to non-therapeutic sterilization, institutionalization, and, in Nazi Germany, mass killing.⁵⁵

With this history in mind, people with disabilities are suspicious of the growing trend towards prenatal testing. They worry that such tests will become yet another mechanism for society to express its discomfort and ambivalence about disability. Even more troubling is the knowledge that huge resources are being pumped into scientific research for the singular purpose of identifying defective genes so that disability can eventually be eliminated.⁵⁶ Prenatal testing poses a difficult and perplexing social dilemma; that is, how do we continue to promote the social goal of equality for people with disabilities while concurrently providing support to medical science to find new and improved ways for eradicating disability? In our opinion, the solution to this problem requires government to recognize that morally and ethically, the voices of people with disabilities are critical in this debate, and that government has a significant leadership role to play in this area by developing mechanisms to ensure that prenatal testing is governed by the principles of dignity, respect and equality.

Prenatal testing poses a difficult and perplexing social dilemma; that is, how do we continue to promote the social goal of equality for people with disabilities while concurrently providing support to medical science to find new and improved ways for eradicating disability?

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It can be argued that historically, disability-based discrimination occurred because society was, to a large extent, uninformed and uneducated about the value of human diversity, and in particular, about the potential of people with disabilities. People with disabilities are concerned that genetic technologies and their capacity to be used by science to designate 'good' and 'bad' genes, run the risk of replicating the discriminatory mistakes of our past.⁵⁷

It is conceivable that, in a respectful environment, prenatal technologies could offer positive benefits in the form of new treatments and increased support for reproductive choices. However, to preserve the integrity of our humanity, we must listen to the views of those most affected, and we must use the lessons of the past to guide us into the future.

PART III: A DISABILITY RIGHTS ANALYSIS OF PRENATAL TESTING

"It is clear that while the hype has been about cure, the reality is about termination. Under the wheels of the Biotech Steamroller a climate of intolerance against people with disabilities is being fostered.

And no one is listening to us, the only ones who know the territory which geneticists claim as theirs - the quality of our lives."⁵⁸

A. Framing the Issue

The most frequently given reason for utilizing prenatal testing is an attempt to prevent or ameliorate medical or disabling conditions that are genetically based.⁵⁹ Genetic testing can be used to confirm a clinical diagnosis, detect a genetic predisposition to a disease or give parents the option of terminating a pregnancy.⁶⁰ For many people with disabilities, the most disturbing use of prenatal testing is the latter use and the move to support selective abortion.⁶¹

Like every other sector in society, the views on abortion among disability rights activists range across the spectrum. Some disability rights advocates explicitly condemn abortion.⁶² Other disability activists support a women's right to choose generally, but object specifically to those choices which are based on the elimination of disabled fetuses. For these activists, prenatal diagnosis of any type, if it is aimed at detecting a disability, is regarded as repugnant and discriminatory. Moreover, for some persons with disabilities, the discriminatory nature of prenatal technologies is further underscored by the fact that current legislative proposals prohibit the use of prenatal technologies aimed at sex selection, while remaining silent about those technologies aimed at detecting disabilities.

This Paper argues that the real issue is the subtle but coercive political and social pressures that compel a woman to opt for abortion, be it because of the sex or disability of the fetus.

Regardless of whether the issue is sex selection or disability detection, the notion of criminalizing women's choices in relation to reproductive autonomy is dangerous and inappropriate. This Paper argues that the real issue is the subtle but coercive political and social pressures that compel a woman to opt for abortion, be it because of the sex or disability of the fetus. It also argues that the real issue is the exclusion of a disability rights analysis in the use and development of prenatal technologies.

B. Prenatal Testing Reinforces the Medicalization of Disability

Currently, the implementation of prenatal testing technology is guided to a large degree by medical consensus or norms. Ideologically and historically, the medical model is much more concerned with reducing the incidence of disability in society than in enhancing the reproductive autonomy of women. There is evidence that physicians and geneticists actually perceive prenatal testing more as a means of decreasing the incidence of birth defects than as a way to foster informed, rational family planning. Physicians have been found to strongly encourage the use of the tests,⁶³ present information in a way that increases testing compliance,⁶⁴ and actively attempt to persuade women who have opted not to undergo testing to reconsider their stance.⁶⁵

Although issues of legal liability and instances of wrongful birth litigation may motivate physicians to blur the distinction between informing and persuading,⁶⁶ most likely the primary reason for their professional endorsement of prenatal testing is an adherence to the medical model and its aim of reducing illness and disability. The most blatant support for this hypothesis was provided by the Royal Commission finding that 41% of physicians conducting maternal serum screening do so without the consent, or even awareness, of the woman,⁶⁷ and the fact that a number of Canadian physicians and geneticists refuse to conduct testing unless the woman first agrees to abort in the event of diagnosis of disease or disability.⁶⁸

Deborah Kaplan notes that the abortion of fetuses with disabilities is presented as a means to avoid negative consequences for families, for society and to spare an individual a lifetime of suffering with a disability.⁶⁹ However, she and many other disability group advocates charge that negative attitudes toward people with disabilities served as the actual motivation for the development and advancement of testing.⁷⁰ Disability is currently considered the only legitimate grounds for selective abortion. This suggests that testing, as currently conducted, is primarily concerned with reducing the incidence of disability in society, to the extent that it risks further stigmatizing people with disabilities by labelling their birth as an occurrence to be avoided.⁷¹ The implementation of tests to diagnose specific disorders and the social sanctioning of selective abortion based on the detection of certain disabilities makes a statement about the social worth of people with those disorders.⁷² Thus the use of prenatal testing technology both reflects and reinforces societal attitudes regarding disability.

Disability is currently considered the only legitimate grounds for selective abortion. This suggests that testing, as currently conducted, is primarily concerned with reducing the incidence of disability in society, to the extent that it risks further stigmatizing people with disabilities by labelling their birth as an occurrence to be avoided.

Some critics have noted that if the underlying motivation for prenatal testing is to enhance reproductive autonomy and increase reproductive choices, then selective abortion on the basis of fetal sex would be an option for those who wish to utilize it. That detecting disability is currently considered the only 'legitimate' grounds for using prenatal diagnostic testing raises questions pertaining to the mandate of genetic screening programs.

Specifically this stance suggests that prenatal diagnostic testing as currently conducted is primarily concerned with reducing the incidence of disability, to the extent that it may further stigmatise people with a disability by labelling their birth as an occurrence to be avoided.⁷³ Thornton⁷⁴ advises that the only way to ensure that prenatal testing is not contaminated by eugenic motives to eliminate persons with disabilities is to allow parents complete freedom to individually define for themselves the situations in which abortion is warranted. According to this argument, as long as medical experts hold the power to define disability and to demarcate what are permissible and non-permissible grounds for undertaking prenatal diagnostic testing, there exists the potentiality for systematic discrimination and for pressure being placed on women to make decisions that conform to these definitions.

The possibility that medical definitions of disability are not necessarily shared by all in society is illustrated by the fact that many women of colour and poor women tend to interpret genetic risk differently from medical professionals, and to take a more accepting stance toward disabled children than do women from the dominant culture.⁷⁵ Further, women of colour and poor women oftentimes view prenatal diagnostic techniques within a context of eugenic discrimination and medical exploitation.⁷⁶ Therefore for these women, and for women with disabilities, genetic screening is often perceived more as a discriminatory practice that strives for selective population control rather than as a means of enhancing their reproductive autonomy.

C. Cost Benefit Analysis

Society holds many stereotypes regarding disability. Particularly troubling are the cost benefit analysis notions, and the perception that people with disabilities experience a lesser quality of life than others. These assumptions, though attractive in some circles, must be challenged as to their objectivity and validity.

The cost benefit analysis is a difficult, if not misleading argument for two important reasons. First, there are numerous disabilities, all of which have a unique manifestation and a different impact on an individual's ability to function. In addition, people sharing the same disability may experience the disability quite differently in degree and effect. It is therefore both impractical and impossible to make any substantive judgements about the potential economic impact of carrying a fetus with a disability to term.

Second, a cost benefit analysis raises serious moral and ethical issues. The uniqueness of human nature means that some individuals will need more social supports than others for reasons such as conflict with the law, illness, and lack of resources or sheer misfortune. Generally speaking, life is unpredictable, and there is no real way to determine the contributions and liabilities that a person may bring to bear on society. Why then should we preoccupy ourselves with the cost of disability?

To focus on the economic worth of disability, while other human differences are tolerated, is morally repugnant and highly discriminatory. As noted above, often it is not the disability that is the problem, but an 'ablest' society that excludes people with disabilities. An inclusive society would give people with disabilities the opportunities to be productive, contributing citizens.

D. Quality of Life

The lesser quality of life assumption is associated with the 'disability as tragedy' notion. Our society is obsessed with physical perfection. Specifically, we admire qualities such as strength, beauty and physical fitness. Having a disability challenges our ideal of physical perfection. For this reason, many non-disabled people believe that a person who has a disability (and who, it is believed, has no hope of being perfect) experiences a life filled with suffering and tragedy. It is assumed that if you have a disability you are dependent, incapable and unemployable. Giving birth to a child with a disability or becoming disabled later in life is often regarded as a catastrophic and devastating event.

Obviously, having a disability may cause a person to experience grief and depression over the loss of a particular ability. Time is needed to accept and adjust to the disability and to make required lifestyle changes. This is true for persons who are born with a disability or for persons who become disabled later in life. However, with the right support and assistance, most people can successfully get through this initial adjustment period. The real tragedy is how disability is regarded in our society. A person who becomes disabled is no longer considered to be capable, productive or even desirable.

The assumption underpinning prenatal testing is that "no life is better than a life with a disability". This assumption is premised on the ideal that 'normal' means being strong, beautiful, physically fit and healthy, while the loss of a physical or mental function is seen as 'abnormal' or 'deviant'.

Because able-bodied people tend to associate disability with tragedy and inferiority, they often respond to people with disabilities with feelings of fear, rejection, pity and guilt. Fear because they cannot imagine how they would cope with a disability. Rejection because dealing with someone with a disability makes him or her uncomfortable and aware of their own vulnerability. Pity because they believe the person is living an unhappy and unfulfilled life. And guilt because they have been spared the hardship of disability.

But many people with disabilities would argue that having a disability is not about tragedy and loss. Missing from society's perception of disability is an understanding that there are a variety of ways in which to enjoy, participate in, and benefit from life. Moreover, the potential to live a full and productive life is greatly enhanced by a society that is free of discriminatory attitudes and barriers. So once again we are confronted with the question; what needs fixing - the person with a disability, or a society that discriminates?

As noted previously, prenatal testing has a number of uses. Most people with disabilities do not oppose those applications that are part of an ameliorative therapy or a treatment for illness or genetic conditions. The danger is that such research runs the risk of defining personhood strictly in terms of genetics while ignoring the many diverse natural, social and cultural aspects that define what it is to be human. As Bill Albert, a disability rights activist explains, "What we do oppose is eugenic cleansing carried out in the name of treatment. The price is too high for everyone."⁷⁷

E. The Relationship of Disability Rights and Women's Reproductive Choice

"Discrimination against persons with disabilities is so pervasive and the penalties associated with raising children with disabilities are so grave that refusing to abort a disabled fetus is not a choice that many pregnant women consider is truly available to them. The message from the medical profession is that prenatal testing is available, that eliminating disabilities is desirable, and that if a disability is detected, abortion is the appropriate follow-up procedure.

The message from the larger society in which women are believed to have achieved equality and a high degree of personal autonomy is that a woman who bears a child with a disability, when that disability could have been eliminated through prenatal testing and abortion, is solely responsible for meeting that child's needs, whether or not she is financially equipped to do so.

This societal message is just an extension of the contemporary view that child bearing is a luxury and a personal indulgence, not a necessary and valuable human activity worthy of societal endorsement and support. For the middle class, having children is viewed as an entitlement, but for poor people, having children is viewed as a cause of poverty. People who cannot afford the luxury of children are not supposed to bear them. It follows that nobody is supposed to bear a child with a disability because nobody has the personal financial resources to attend to the special needs associated with disability.

The result is that we are living in a society in which abortion of disabled fetuses is compulsory. There is no law requiring it, but the medical, social and economic pressures compelling it are so powerful that refusing it is not an available choice. Central to any definition of choice is the autonomy to make an uncoerced, informed decision."⁷⁸

Where prenatal testing detects a fetus with a disability, abortion is generally accepted by many physicians as the logical follow-up procedure.⁷⁹ It is this use of abortion that is of particular concern to people with disabilities. Because women have fought hard to secure the right to abortion, some women's groups are reluctant to take a position against this use of abortion for fear of re-igniting the politically-sensitive battle regarding reproductive autonomy. As a result, there are strong differences of opinion between some women's groups and some disability rights advocates.⁸⁰ This difference of opinion has triggered a complex debate about choices and rights.⁸¹

It is a debate that is particularly complicated for advocates who are both feminists and disability rights activists. Consequently, an analysis is needed that goes beyond the choice/rights discourse, and confronts the values and objectives that are driving the proliferation of prenatal technologies.

Adrienne Asch, both a feminist and a disability rights activist, argues that abortion should be supported no matter what the reason. Nevertheless, she challenges those parents who decide to abort wanted pregnancies after learning that the fetus may have a disability.⁸² She says that

"[e]nding the process of becoming a parent because of a future child's likely disability, when one wished to become a parent at the time that the disability was discovered, in the network of relationships and amidst the life plans in which the disability was discovered, is saying that the disability is inimical to the life one wants for oneself, one's family and one's child."⁸³

In other words, Asch does not question a woman's right to choose an abortion, but rather the reasons for ending an otherwise wanted pregnancy. And what factors could sway women toward aborting a wanted pregnancy on the basis of fetal disease or disability? The dominant perceptions of parenting a child with disability are negative, especially with respect to financial expense, time commitment and emotional toll.⁸⁴

...an analysis is needed that goes beyond the choice/rights discourse, and confronts the values and objectives that are driving the proliferation of prenatal technologies.

The costs associated with raising a child with a disability correspond directly to the predominant costs associated with raising children in general,⁸⁵ indicating that the type of costs associated with having children are consistent, but that the costs are viewed as accentuated if the child has a disability. In other words, costs seem to be an inherent and accepted part of parenting children. In contrast, while parenting in general is associated with numerous potential psychological benefits that offset the perceived costs,⁸⁶ it appears that these same rewards are not associated with parenting a child with a disability.⁸⁷ It may be that the perceived absence of psychological rewards or benefits usually associated with parenting contributes to the decisions to abort subsequent to a fetal diagnosis.

However, the perceptions of a large majority of people are based on stereotypes, given that they developed these attitudes without having any personal experience with persons with disabilities.⁸⁸ Targeting education and intervention efforts towards these stereotypes may help to ameliorate the social prejudice experienced by individuals with a disability and reduce the likelihood that prospective parents are basing their desire to use prenatal testing on inaccurate perceptions of what is involved in raising a child with a disability. There are numerous examples of how parenting generally is not well supported in our society. Consequently, in addition to the goal of inclusion, strategies are also needed to support the rearing of all children, including children with disabilities.

F. Social Construction of Choice

This Paper is in no way meant to criticize or second-guess the choices that women feel they must make in relation to the use of prenatal testing, or the termination of a pregnancy. However, to accept the choice argument at face value, without further inquiry, denies the importance of social influences and their impact on the construction of choice.

This Paper argues that the social construction of choice is heavily influenced by factors such as the current social and political status of women, and the growing pressure by the medical profession on women to take advantage of the 'benefits' of prenatal testing. Tom Shakespeare promotes a similar approach, and resists the argument advanced by some disability rights activists who characterize the current practice of prenatal testing as straightforwardly eugenic. Rather, he suggests that it is factors such as the medical profession and the context in which reproductive decisions are made that undermine the capacity for free choice, and promote eugenic outcomes.⁸⁹ In other words, the social context in which a woman must make her choice must be understood; that is, the social, political and economic pressures that may compromise her decision to raise a child with a disability.

For instance, lack of financial resources and lack of personal support may all be factors that influence a woman's decision not to give birth to a child with a disability. As Abby Lippman observes, "[c]ontinuing a pregnancy when the fetus has been found to have Down's Syndrome cannot be considered a real option when society does not truly accept children with disabilities or provide assistance for their nurturance."⁹⁰

From a political perspective, it is assumed that women have attained a certain degree of equality and power to shape their own lives. But, a wealth of evidence suggests that the contrary is more likely to be true.⁹¹ This fact is poignantly illustrated in a report recently prepared by economist Monica Townson. In her report, Townson reveals that despite the rhetoric of equality, women in Canada are steadily getting poorer.⁹²

Thus this Paper argues that for women to exercise reproductive choice in its fullest sense, society must be transformed in a number of ways. For example, disability-based discrimination must be prohibited, meaningful resources and social supports must be provided to families with children, including children with disabilities, and women's equality must become a fact rather than a mythical goal. Equality-seeking advocates continue to struggle to achieve such social transformations. However, the proliferation of prenatal testing in an unchecked environment threatens to undermine the goal of such struggles.

As more and more genetic conditions become amenable to prenatal diagnosis, it is not unreasonable to imagine that society generally, and the medical profession specifically, will place enormous pressure on women to undergo such testing and to follow through with an abortion when the results are positive. This process has the potential to subtly, but effectively, shift the responsibility to ensure healthy babies from society to the private choices of women.

...women who knowingly choose to give birth to a baby with a disability may be accused of weakening or burdening society.

Traditionally, women have assumed the responsibility of caring for the health of the family. Prenatal testing now conveys the message that women are also responsible for protecting the well being of society by aborting fetuses found to be unsatisfactory. In other words, women who knowingly choose to give birth to a baby with a disability may be accused of weakening or burdening society.⁹³ Prenatal testing, therefore, has the power to promote the compulsory abortion of disabled fetuses. Although no government would probably ever dare, at least not in the foreseeable future, to require the systematic abortion of disabled fetuses, the medical, social and economic pressures compelling such a practice are so powerful

that refusing it may not be a realistic choice for women.⁹⁴

In fact, prenatal testing is often cast as a means of meeting a public health need. The economic costs that disabilities place on the social welfare and medical systems are relatively high, and testing and selective abortions are presented as a very cost-efficient way of reducing the incidence of disability on society.⁹⁵ Implicit in this formation is that making use of prenatal testing technology is the act of a responsible citizen and mother-to-be. Women who do not comply with testing, or who decide to continue with a pregnancy after a diagnosis of fetal disease or disability are viewed as socially irresponsible, irrational and selfish.⁹⁶

In fact, a recent investigation concluded that women who chose not to make use of prenatal diagnostic testing, or who did not abort subsequent to a fetal diagnosis were considered by both physicians and community members to be relatively more responsible, more to blame, less deserving of sympathy, and less deserving of social aid subsequent to giving birth to a disabled child than were women to whom prenatal diagnostic testing was not offered.⁹⁷ The process of determining a mother's worthiness of sympathy and social aid to help her care for her disabled child on the basis of her prenatal diagnostic testing use has ramifications for both individuals and society.

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Prior to the implementation of prenatal diagnostic testing, selective reproduction was achievable only through the practice of infanticide, which is officially condemned in all advanced societies. However, the advent of prenatal diagnostic testing has made it possible to control the physical/genetic characteristics of children that are born. Not only does the information gained via prenatal diagnostic testing hold the power to create individual reproductive choice, but the above findings suggest that it also has the power to render the 'chooser' liable in society's mind for the outcomes of the choice which is made. It appears that a woman who is seen as having the means available to her to prevent the birth of a disabled child (i.e. control over the outcome), and who does not act to do so, will be judged as less deserving of sympathy and social aid.

This supports Lippman's assertion that prenatal diagnostic testing technology has the potential to transform the birth of a disabled child from an unfortunate event into a regrettable event that the mother could have, and maybe should have prevented.

This opens the door to women being held responsible and accountable for the birth of disabled children. It is unlikely that women are unaware or unaffected by these attributions and their repercussions. Marteau and Drake (1995)⁹⁸ found that pregnant women assigned more control and blame for the birth of a disabled child to women who chose not to use prenatal diagnostic testing than to women who were not offered prenatal diagnostic testing. One survey of pregnant women revealed that 78% believed that they would not receive any sympathy or social support if they gave birth to a disabled child after either not complying with a testing referral or after choosing to continue with a pregnancy after a defect had been detected.⁹⁹

It is not a forgone conclusion that these opinions will translate into discriminatory action. The potential is there, as demonstrated by insurance companies which do not provide insurance to cover disability-related medical expenses of a child diagnosed in utero,¹⁰⁰ and by those social commentators promoting financial and legal repercussions for women who do not use prenatal diagnostic testing to prevent the birth of a child with a disability.¹⁰¹ Careful observations should be made in order to identify any impact that prenatal diagnostic testing use may have on the availability of, and accessibility to social programs and funding for the care of persons with disabilities.

Paradoxically therefore, it appears that prenatal testing technology can restrict women's reproductive autonomy rather than enhance it, due to the various societal pressures placed on women. It is clear that, under the public health model, the routinized use of testing carries the potential to cast women as the genetic gatekeepers of society, not only responsible, but also accountable for the birth of disabled children.

This Paper does not dispute the overall goal of genetic technologies insofar as it is aimed at identifying new cures and treatments. But, the blunt truth is that there are still very few conditions that can be treated in-utero.¹⁰² This fact seems to confirm that the real purpose of prenatal testing is, first and foremost, to eliminate disabled fetuses. Further evidence of this purpose is derived from research on prenatal testing which is overwhelmingly concentrated on finding ways to diagnose conditions in the first few months of pregnancy, when abortion is a simpler and safer procedure.¹⁰³

Paradoxically therefore, it appears that prenatal testing technology can restrict women's reproductive autonomy rather than enhance it, due to the various societal pressures placed on women. It is clear that, under the public health model, the routinized use of testing carries the potential to cast women as the genetic gatekeepers of society, not only responsible, but also accountable for the birth of disabled children.

Further, the focus on finding and addressing the genetic bases for disability diverts attention from dealing with social or environmental factors.. In reality, the distribution of most disabilities across society is influenced as much, or more, by social factors such as wealth, status, gender and race as it is by genetic make-up.¹⁰⁴ While vast amounts of resources have been directed toward the advancement of the Human Genome Project and the development of diagnostic technologies and clinics, resources targeted towards the development or even maintenance of social programs and specialized health care for the disabled have been dwindling. These conditions create a social and medical context in which it is financially and pragmatically easier for women to selectively abort a fetus with a disability than it is for them to consciously decide to raise a disabled child.

...it can be argued that disability rights, and women's reproductive choice, are not really opposing paradigms. Indeed, they may well become inextricably linked in that both disability rights and women's choice may be casualties of a world obsessed with genetic perfection.

If a woman was assured that she would receive the emotional, social and financial support necessary to ensure the nurturing of her child, and if she was confident that her child would be accepted as a valued member of the community, whatever his or her genetic make-up, more women might choose to forego testing. These avenues of intervention, along with increased acceptance of people with disabilities, provide an alternate route for addressing the social and economic barriers that confront families of children with special needs. These alternative approaches would also address the issues in such a way that the responsibility for 'curing the problems of society' would not rest on the shoulders of childbearing women.

Disability-based discrimination therefore will, in the not-too-distant future, more than likely become an undeniable force in controlling and restricting women's reproductive choice. For this reason, it can be argued that disability rights, and women's reproductive choice, are not really opposing paradigms. Indeed, they may well become inextricably linked in that both disability rights and women's choice may be casualties of a world obsessed with genetic perfection.

G. Reality Check

To capture the real essence of the debate surrounding prenatal testing, it may be necessary to abandon the language of 'rights and 'choice'. Instead, it may be more useful to challenge the motives and reasons for introducing prenatal testing. For example, we should be asking when, why, and how prenatal testing is currently being used, and how it may be used in the future. Given that data on newborns show that people in the general population face about a 4% chance of giving birth to a child with a disability,¹⁰⁵ and that the leading cause of infant morbidity in North America is low birth weight (Rhine, 1993) we must also question why huge resources are being invested into the identification of defective genes rather than into eliminating child poverty, providing better prenatal nutrition for women and reducing the toxins in the environment.

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Women are currently working to reclaim the experience of childbirth and to redefine it as a natural rather than a medical event.¹⁰⁶ Prenatal testing appears to conflict with this move in that it has the power to further an already deeply entrenched, medicalized approach to birth.

The science of prenatal testing will undoubtedly continue to develop. While the development of cures and treatments for serious conditions is important to us all, it is equally important to ensure that such powerful technologies are guided by a system of careful checks and balances.

PART IV: THE CASE FOR CHARACTERIZING PRENATAL TESTING AS A HUMAN RIGHTS ISSUE

Canada holds itself out as a leader in the promotion of human rights - internationally and domestically. We contend that prenatal testing raises many issues that fall squarely within the human rights domain. Thus we focus this part of the Paper on some of the key human rights and equality rights principles adopted by Canada, and their relevance to the regulation of prenatal testing.

A. Role of Human Rights Law

The human rights of Canadians are protected by human rights legislation¹⁰⁷ and the *Canadian Charter of Rights and Freedoms* (hereinafter referred to as the *Charter*) which forms part of Canada's *Constitution*. The existence of both statutory and constitutional recognition of the human rights of Canadians underscores the importance of this issue to Canadian society and its governments.

B. Human Rights Law

The Supreme Court of Canada (SCC) has described human rights legislation as quasi-constitutional, which means that human rights legislation has supremacy over all other legislation.¹⁰⁸ Human rights law covers both public and private activities. Consequently, the activities of all health institutions, be they publicly funded or privately operated institutions, are subject to human rights legislation.

Generally speaking, all human rights statutes prohibit discrimination on grounds such as age, sex, race, colour, nationality, religion, sexual orientation and physical and mental disability. Discrimination is prohibited in areas such as employment, housing, services and facilities etc. Under human rights law, where prenatal testing is offered to the public, it would most likely be considered to be a service. Human rights jurisprudence has defined discrimination to encompass both direct and indirect forms of discrimination.¹⁰⁹ Direct discrimination refers to those acts that blatantly deny or exclude certain groups or individuals from certain activities because of a personal characteristic protected by human rights legislation. For example, a policy that required all women with disabilities to undergo prenatal testing to identify fetuses with disabilities could be regarded as direct disability-based discrimination.

Indirect discrimination refers to policies or practices which appear neutral on their face, but which have an adverse effect on certain groups and individuals protected by human rights legislation. For example, a health facility that can only be entered by climbing steps would be considered to be indirect discrimination against people who use wheelchairs. As a health care service available to the public, it is legitimate to subject the use of prenatal technologies to an anti-discrimination analysis.

According to some disability rights activists the very idea of providing prenatal testing is blatantly discriminatory on the basis of disability. This claim may be difficult to prove where it is based solely on the fact that prenatal technologies are available and being used. However, in certain circumstances, issues such as how the tests are provided, why they are provided, who is eligible for such tests and who has access to test results could raise claims of discrimination. Examples of possible human rights violations may include:

- Policies that deny benefits, such as health care, education or insurance, to children with disabilities whose disability could have been detected prenatally, and whose birth could have been prevented. (For example, life insurance companies in Canada can now demand genetic test results as part of the medical record they require potential customers to provide);¹¹⁰
- Genetic counseling that provides either written or verbal information about disability that is unbalanced and based on negative attitudes and stereotypes about life with a disability;
- Policies that pressure certain populations, such as women with disabilities, or women of a certain age to undergo prenatal testing because it is perceived that they are at risk of passing on a congenital condition;
- Policies that do not ensure equal access to prenatal testing for all women; and
- Policies that deny and/or exclude certain persons from accessing benefits and services, such as disability and life insurance, employment or employer benefit plans based on the results of genetic testing.

Some of these scenarios may seem far-fetched and outrageous. But, looking back, we know that many human rights atrocities have occurred that defy human reasoning and logic. Prenatal testing is therefore not just a health issue. It is, by its very nature, a fundamental human rights issue worthy of serious consideration.

C. The Equality Guarantee of the *Canadian Charter of Rights and Freedoms*

The *Canadian Charter of Rights and Freedoms* forms part of Canada's *Constitution* and thus, as a *Constitutional* document, is regarded as the supreme law of Canada. The *Charter* applies to government action (whether Federal or provincial/territorial) which includes laws, programs, policies and practices. The *Charter* also applies to those situations where a government has delegated some form of government action to an entity which may otherwise be considered to belong to the private sphere.¹¹¹ Where a law, policy or program conflicts with the provisions of the *Charter*, it will be declared by the Court to be of no force or effect unless it can be established that the impugned law, policy or program is reasonably necessary in a free and democratic society.

Section 15 of the *Charter* guarantees equality to all Canadians.

(1) 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.

The *Constitutional* guarantee of equality has played an instrumental role in reshaping our understanding of equality. The Supreme Court of Canada (SCC) has stated that equality does not necessarily mean treating everyone the same.¹¹² Indeed, the Court has recognized that identical treatment can sometimes create inequalities. Consequently, the Court characterizes equality as a dynamic concept whereby the "accommodation of differences...is the essence of true equality."¹¹³ The purpose of s. 15 is therefore twofold; to prevent discrimination, and to ameliorate disadvantages experienced by groups and individuals who have historically been excluded from mainstream society, as has been the case for persons with disabilities.

In assessing an equality claim under s. 15 of the *Charter* the Court looks beyond the actual law being challenged, and considers the social, political and legal position of the claimant in society.¹¹⁴ Clearly, legislatures must have the authority to draw distinctions among people. However, according to the Court's interpretation of the equality guarantee in the *Charter*, such distinctions must not exacerbate or re-enforce the disadvantage of certain groups and individuals in society.¹¹⁵ To be more specific, the Court has stated that the overall purpose of s. 15 is to "...remedy or prevent discrimination against groups subject to stereotyping, historical disadvantage and political and social prejudice in Canadian society."¹¹⁶ Consequently, social context is the key to any equality rights analysis.

According to the Supreme Court of Canada, a discriminatory purpose or intention is not a necessary condition of a s. 15(1) violation. A claim of discrimination under s. 15 can be triggered where the effect or impact of the law denies someone the equal protection or benefit of the law.¹¹⁷ For example, in the *Eldridge* case,¹¹⁸ deaf persons living in British Columbia received the same health care as hearing persons. However, the British Columbia health care system did not provide deaf persons with sign language interpretation services, which seriously affected their ability to communicate effectively with their health care providers. Thus, the Court determined that deaf persons did not benefit to the same extent as hearing persons from the health care system. The Court noted in *Eldridge* that analyzing a claim of discrimination in terms of its effect on a group or individual is particularly important for persons with disabilities. This observation is important because much of disability-based discrimination, if examined out of context, is rendered invisible.¹¹⁹

The purpose of prenatal technologies is to detect fetal anomalies or conditions that may give rise to a disability at birth. Thus, attitudes and perceptions about disability play an important role in the dynamic of why and how prenatal technologies are developed and provided.

As the Court noted in *Eldridge*, historically, people with disabilities have experienced much discrimination and difficulty in being accepted by an able-bodied society. Consequently, the concern expressed by people with disabilities regarding the potential for biased attitudes about disability to infiltrate the use of prenatal technologies has some merit. It is this type of concern which may attract *Charter* scrutiny.

According to the *Eldridge* case, health care institutions that can be characterized as providing services on behalf of a government would likely be subject to the requirements of the *Charter*. The mere fact that a health care institution uses prenatal technologies would not likely trigger a *Charter* inquiry. However, if it could be established that the prenatal technologies offered by the institution directly or indirectly conveyed negative messages about disability, it may be found to be in violation of the equality guarantee of the *Charter*.

It is important to clarify the rights analysis at issue in this scenario. The claim to equality arises specifically from the pregnant woman's experience with prenatal technologies, and not from the disabled fetus she is carrying. The ability of fetuses to claim rights under the *Charter* was clearly rejected by the Supreme Court of Canada in the *G* case.¹²⁰ A woman who is given biased information about raising a child with a disability may feel that her only option is to terminate her pregnancy. The issue is not the woman's right to choose to have an abortion, but rather the institution's failure to provide the woman with balanced information about raising a child with a disability so that she could make a fully informed decision.

The development of a regulatory scheme would enable the government to establish standards on how institutions can provide prenatal technologies in a non-biased, non-discriminatory manner.

Prenatal technologies are more than just neutral medical procedures. They are rapidly becoming a powerful source of information for a pregnant woman about the status of her fetus, and whether or not a disability may be present. In accordance with the Court's analysis in *Eldridge*, the social context in which this information is provided is a critical factor in understanding how prenatal technologies may serve to perpetuate disability-based discrimination. The development of a regulatory scheme would enable the government to establish standards on how institutions can provide prenatal technologies in a non-biased, non-discriminatory manner.

PART V: THE CONSTITUTIONAL AUTHORITY OF THE FEDERAL GOVERNMENT TO REGULATE PRENATAL TESTING

Canada's constitutional powers are prescribed by *The Constitution Act 1867* (hereinafter referred to as the *Constitution*) which divides legislative authority between the Federal government and the provinces. Generally, the provinces control most aspects of the provision of health care services, including the regulation of health care professions.

The Federal government has an overall responsibility to safeguard the health of Canadians, and to regulate those matters that have a national dimension, or that require pan-Canadian standards and co-ordination, such as the use of tobacco and narcotics.¹²¹ Prenatal testing is considered to be a medical procedure and is thus arguably a matter to be regulated by the province. However, there are a number of reasons why the province might not be in the best position to take on the task of regulating prenatal testing.

.....the issues raised by prenatal testing are just as profound in their implications as those technologies which the government proposes to regulate and, that as such, they should be considered as part of the Federal government's regulatory framework.

Currently, many provinces rely on the self-regulation of practitioners to govern the use of prenatal testing. While this approach may be sufficient for those situations where limited prenatal testing is provided, we know that rapid gains are being made in prenatal science, and that such developments will continue to escalate. Groups like the Canadian Medical Association express the concern that problematic variations in standards could result if the regulatory power is handed over to the provinces, or left in the hands of individual practitioners.¹²²

As noted earlier in this Paper, the Federal government proposes to assert its right to regulate certain reproductive technologies, presumably to protect the health and safety of Canadians. Although prenatal testing is mentioned in the government's proposals, it has declined to provide specific proposals on this matter.

In this part of the Paper we argue that the issues raised by prenatal testing are just as profound in their implications as those technologies which the government proposes to regulate and, that as such, they should be considered as part of the Federal government's regulatory framework. Moreover, this Paper argues that the government has the *Constitutional* authority to regulate prenatal testing, particularly in light of the serious social consequences that could result from haphazard management.

A. The Use of the *Peace, Order, and Good Government Doctrine*

The Federal government's most recent package of proposals is based in the criminal law power of the *Constitution Act*. By employing the criminal law power, the government can prohibit certain practices related to reproductive technologies and impose criminal sanctions for breeches of such prohibitions.

...it is about designing a system that can establish controls, while remaining flexible and responsive to changes and new developments in

It is inappropriate and unhelpful to frame prenatal testing as a matter to be governed by the criminal law power. The issue is not about criminalizing prenatal testing. Rather it is about designing a system that can establish controls, while remaining flexible and responsive to changes and new developments in technologies. Moreover, the struggle to decriminalize abortion is still fresh in the minds of many stakeholders and thus, instituting criminal sanctions in a field where abortion may be a consideration would provoke unnecessary conflict. But there are other *Constitutional* powers on which the Federal government could anchor its desire to regulate in the field of prenatal testing.

One of the most promising provisions of the *Constitution* that would support Federal government initiative in the area of prenatal testing is the Federal *Peace, Order, and Good Government (POGG) Power*. The *POGG* power is found in the opening paragraph of s. 91 of the *Constitution*:

"It shall be lawful for the Queen, by and with the Advice and Consent of the Senate and House of Commons, to make laws for the Peace, Order, and Good Government of Canada, in relation to all Matters not coming within the Classes of Subjects by this Act assigned exclusively to the Legislatures of the Provinces."

The Supreme Court has identified two types of situations where the *Peace, Order, and Good Government Doctrine* may be invoked to support Federal legislative action.¹²³ The first situation involves matters of national emergency requiring some form of temporary legislation. The second situation, which is relevant to our discussion, involves matters of national concern, and may be applied to matters that did not exist at the time of Confederation. For a matter to qualify as a matter of national concern, it must have a singleness, distinctiveness and indivisibility that clearly distinguishes it from matters of provincial concern.¹²⁴ In determining whether a matter has the requisite singleness, distinctiveness and indivisibility, the Federal government must demonstrate that national well being outweighs provincial interests.

Martha Jackman, law professor at the University of Ottawa, suggests that reproductive technologies such as prenatal testing constitute matters of significant national concern.¹²⁵ She points to the establishment of the Royal Commission on New Reproductive Technologies and its focus on the social, political and legal aspects of reproductive technologies to support her claim that this is an issue with national dimensions, and an issue that is a serious concern to both legislators and the public.¹²⁶

There are a number of arguments that can be used by the Federal government to support its

decision to regulate prenatal technologies under the *Constitutional* power of the *POGG* clause. First, though some limited form of prenatal testing has been used for several years, it can be argued that the scope and breadth of current and future scientific developments make prenatal testing a new subject matter which is not clearly contemplated by the *Constitutional* division of powers. Second, it can be argued that it is also a matter that goes well beyond local or private concern; that is, it extends beyond the scope of local or provincial health and is more properly characterized as a matter of 'national welfare'.¹²⁷ Finally, it can be argued that there are a number of issues related to prenatal testing that would clearly benefit from a consistent national policy framework. These issues may include:

- The need to ensure that all Canadians have access to consistent prenatal testing services across the country,
- The need to evaluate, approve and monitor the types of prenatal tests offered and why,
- The need to evaluate and approve research projects pertaining to prenatal testing,
- The need to develop national standards for the provision of balanced, client-friendly information on the tests being offered and their possible results,
- The need to develop national standards for ensuring that medical professionals obtain proper consent from patients/clients before they undergo prenatal testing,
- The need to develop national safeguards for protecting the privacy and human rights of women and the children they bear who have been the subject of prenatal testing, and
- The need to develop national standards for the provision of balanced, non-discriminatory genetic counseling, which may include community resources such as seeking input from parents of children with the disability in question or persons who have the disability in question.

From a *Constitutional* point of view, it seems quite clear that the Federal government has the authority it needs to regulate prenatal testing. This is not a new idea. The Royal Commission on New Reproductive Technologies strongly supported this view, and recommended that the government exercise its authority and establish a mechanism for regulating genetic technologies, including prenatal testing.

While the Federal government can make a strong constitutional case for regulating prenatal technologies, it may be prohibited from unilaterally exercising this power. According to the *Framework to Improve the Social Union of Canadians* agreed to by the Federal, provincial and territorial governments in February 1999, where the Government of Canada wishes to introduce new Canada-wide initiatives in health care, it must first obtain agreement from a majority of the provinces.

There is no reason why this requirement should prevent the Federal government from exercising its *Constitutional* powers to develop a pan-Canadian approach to prenatal technologies. Consulting with, and securing the support of provinces could only strengthen the need to ensure that prenatal technologies are provided in an effective, non-discriminatory manner. Given the reasons cited above, it is hoped that the provinces would willingly endorse a Canadian-wide system for regulating prenatal technologies.

PART VI: RECOMMENDATIONS & CONCLUSIONS

For approximately 30 years or so, women living in Canada who have been identified as being at risk of giving birth to a child with a disability have been offered some form of prenatal testing. Generally, these tests have focused on identifying a limited number of genetic disorders. However, with the completion of the Human Genome Project near at hand, the types of genetic characteristics that can be detected through prenatal technologies are sure to accelerate. Some scientists even go as far as to predict with enthusiasm that, with the help of genetic manipulation, parents will be able to assemble their children from genes listed in a catalog.¹²⁸

It is clear that the clock cannot be turned back, and that as genetic science develops, it will be possible to detect more and more genes prior to birth. As a result, it is very likely that prenatal technologies will become more and more of a predominant force in the life of a pregnant woman.

From an individual perspective, it is understandable that some women and their families may find these technologies attractive and beneficial. However, the decision to obtain genetic information about a fetus can be a complex choice, fraught with a variety of human responses. Because prenatal technology has the potential to revolutionize pregnancy and birth, we must broaden our vision and look beyond the realm of private choice, to the social impact that such technologies can have on society as a whole.

In this Paper we have tried to describe the social context underpinning prenatal technologies as it relates to disability rights and feminist values of reproductive choice. Although these two ideologies may conjure up two distinct discourses, in the case of prenatal technologies, there are clearly points of intersection and interdependence.

Prenatal technologies promise to offer women more and more information about the status of their fetus, and more and more opportunities to ensure that they give birth to an acceptably healthy baby. We do not condemn those women who choose to avail themselves of such technologies. Rather, we challenge the attitudes of medical practitioners, the policies of governments, and the conditions of society which coerce a woman to believe that it would be unacceptable or irresponsible to give birth to a child with a disability. In a world where disability discrimination is still very pervasive, encouraging science to develop technologies aimed at the identification and elimination of fetuses with certain disabilities is a blunt reminder of society's reluctance to accept human differences which fall outside the majoritarian notion of physical and mental normalcy.

Perhaps in a world where discrimination is non-existent, and where all persons enjoyed true equality, prenatal technologies may not elicit as great a concern. Regrettably, current trends suggest that we have some distance to go before this goal is achieved.

Set out below are our recommendations and conclusions on some of the steps that Canada can take to begin the process of addressing prenatal technologies and their impact on ethical and human rights concerns. Our goal is to promote dialogue which goes beyond the identification of concerns, and considers possible strategies for action.

A. RECOMMENDATIONS

Recommendation #1

That the Federal government assumes its responsibility for exercising leadership in the field of genetic technologies, including prenatal technologies.

Currently in Canada there are no uniform standards governing the use of prenatal technologies. In many cases standards are set by the health practitioners and facilities which are responsible for administering such technologies. While this system may fulfil certain health requirements, it does not guarantee that ethical and human rights issues will be addressed. For this reason, we believe that prenatal technologies must be subject to some form of governmental regulation, particularly as more and more procedures become available. It is our assessment that the Federal government is the most logical body for initiating such regulation. Moreover, it is our conclusion that the government has the constitutional authority to assume this responsibility.

While this Paper has focused on prenatal technologies, it is important to remember that it represents just one aspect of the overall topic of genetic technologies. A person can undergo genetic testing following birth which may reveal existing conditions or a predisposition to a disease or condition which may or may not manifest itself later in life. Hence, questions such as why such tests are needed, and how information obtained by such tests will be used are important social issues for genetic technology as a whole. While this Paper is advocating for some method of regulating prenatal technologies, it would be reasonable and practical for the Federal government to assume responsibility for the whole field of genetic technologies.

We understand that current political forces such as the trend towards deregulation, and the government's commitment to collaborate more extensively with the provinces on new health initiatives, may pose additional hurdles in introducing a regulatory mechanism. But the government can argue with authority that prenatal technology is a new subject area which is capable of reshaping human make-up and thus, is worthy of national concern and attention. If the Federal government refuses to act, the growth of genetic technologies will either be driven by private commercial interests or be subject to a wide range of provincial controls or lack of controls. In either case, the protection of ethical and human rights interests are uncertain to say the least. It is hoped that out of respect for the rights of Canadians, the Federal government will take its responsibility seriously and opt for leadership over politics.

The role of comprehensive prenatal technologies in the care of pregnant women is still in a formative stage in Canada, though by all accounts, science is making great strides in this area. Therefore, the time is right for the Federal government to establish itself as both a monitor and a standard-setter in the implementation of genetic/prenatal technologies in Canada.

Recommendation #2

That the Federal government establish a regulatory mechanism to address the ethical and human rights issues which may arise in the proliferation of prenatal technologies.

Some critics may argue that it is impractical or futile to regulate in the area of ethics or human rights. However, as human rights legislation and the *Canadian Charter of Rights and Freedoms* demonstrate, in Canada the articulation of commonly held values serves as a persuasive catalyst for developing programs and policies that respect the dignity and worth of all persons. Generally in law the term 'regulation' refers to a power bestowed on a government or governing body through an act of Parliament, or the legislature, to control activities in a specific area. For example, the *Controlled Drugs and Substances Act* controls how narcotics are handled in Canada, and what the penalties are if they are mishandled.

This recommendation does not propose the specific form or substance of a regulatory mechanism. Such an initiative requires careful thought and analysis and extensive consultation with stakeholders. The purpose of this recommendation is to stimulate broad-based thinking about how we might regulate prenatal technologies, and what matters need to be regulated. Possible initiatives may include, but are not limited to the introduction of legislation which addresses subjects such as the process for introducing new prenatal technologies in Canada, the information to be given to women undergoing prenatal screening or testing, the need to obtain clear consent from women undergoing prenatal screening or testing, the requirement for human rights sensitive counseling for women and their families who receive positive test results, the requirement to protect the privacy rights of those who have undergone genetic testing, the development of national standards regarding the use of prenatal/genetic technologies, and the need to engage in public consultation on the use of prenatal technologies in Canada.

Other initiatives may include the development of national standards for health professionals and facilities which offer prenatal technologies, or the development of a licensing system for those technologies which are very new, experimental or controversial. It is worth noting that the concept of establishing a national structure to manage and monitor new reproductive technologies is not a new idea in Canada. In 1993, the Royal Commission on New Reproductive Technologies recommended that the Federal government establish an independent National Reproductive Technologies Commission charged with the primary responsibility of ensuring that new reproductive technologies are developed and applied in the national public interest.¹²⁹ Furthermore, the Royal Commission recommended that such a national structure include a Prenatal Diagnosis and Genetics Sub-Committee.¹³⁰

Recommendation #3

That the Federal government initiates an extensive education campaign to inform and consult with both professionals and consumers on the ethical and human rights issues which may arise in the use of genetic technologies.

A regulatory mechanism can set out the parameters as to how prenatal technologies will be implemented in Canada. However, it may not adequately address the need for public education and debate on the role of genetic technologies in Canadian society. Women specifically need information about prenatal technologies prior to becoming pregnant so that they can make informed choices about the type of maternity care that they wish to receive. The public in general needs information on the pros and cons of utilizing genetic technologies so that they can participate effectively in the development of public policies on such issues. Professionals, while knowledgeable in their field, need information on the legal and ethical dimensions of using genetic technologies.

Recommendation #4

That the Federal government continue to develop, implement and fund social and economic initiatives aimed at enhancing and achieving the equality of persons with disabilities.

Prenatal technologies will not eliminate disability from our society. Their purpose and increasing use however, has the potential to convey the message that, disability is bad and to be avoided. To counteract this perception of disability and the potential for disability-based discrimination to escalate, the government must take the lead in creating a society which is accepting and welcoming of persons with disabilities. The creation of a supportive society will not only enhance the equality of persons with disabilities, it will also enhance the reproductive choices of women by reassuring them that a decision to give birth to a child with a disability will be supported. To cover the cost of removing barriers and providing social supports, the government may find it useful to explore the idea of imposing a disability tax on those manufacturers who wish to market their genetic technologies for use in Canada.

Recommendation #5

That the Federal government develop national standards/policies that ensure that if prenatal technologies are offered, their explicit purpose is to give women genuine choices about the fetus they are carrying and not merely to encourage women to abort disabled fetuses.

In addition to the eugenic potential of prenatal technologies, actions of other countries suggest that prenatal technologies could become an economic device for reducing critical public health costs. For example, the United Kingdom cystic fibrosis (CF) program has been described as 'cost-effective,' since the cost per CF pregnancy detected is 'considerably less' than the cost of treatment.¹³¹ Given the overwhelming demands on Canada's health care budget, it is easy to see how attractive such technologies might be in certain economic circles. To preserve and enhance women's reproductive autonomy, we must ensure that the use of prenatal technologies are governed by clear, non-directive, non-discriminatory policies/standards which do not in purpose or intent coerce a woman to undergo testing or to abort a fetus with a disability.

Recommendation #6

That the Federal government support the Right to Live and be Different Declaration signed by 27 organizations of Disabled Peoples' International (DPI) in Solihull, UK in February 2000 (Appendix).

This *Declaration* was developed by 130 delegates at an international conference designed to address the issue of disability, bioethics and human rights. The first statement of this *Declaration* proclaims "Nothing about us without us." This statement is asserted on the premise that persons with disabilities tend to be excluded from debates on bioethical issues. As a result, such debates have perpetuated prejudices and negative views about the quality of life of a person with a disability.

Because the medical profession and the media tend to be composed of able-bodied persons, the disability perspective is often omitted from an analysis of emerging genetic technologies. The *Declaration* contends that disability contributes to the richness and diversity of human life. It promotes the development of working relationships between persons with disabilities and scientists, the medical professions, ethicists, policy-makers, human rights advocates, the media and the general public.

The *Declaration* also acknowledges the role of the state as a protector of human rights in the implementation of scientific advances and medical practices in relation to genetic technologies. It argues that a disability perspective is essential to understand fully the relationship between genetic technologies and human rights. Therefore, the government must undertake to include the views of persons with disabilities in all of its deliberations or activities including public discussions, policy-making and law reform initiatives, and the development and operation of standard setting or regulatory mechanisms.

B. CONCLUSION

Our society has reached a critical juncture in the evolution of genetic technologies. The media has given us a glimpse of what is currently taking place in the laboratories and what may take place in mainstream society in the very near future. Just as the Federal government has provided public education on the hazards of tobacco smoking, the need for good prenatal nutrition, and the need to take precautions to prevent the spread of AIDS, so to does it need to educate the public on both the promises and the pitfalls of genetic technologies.

Bioethics Declaration
APPENDIX

DISABLED PEOPLES' INTERNATIONAL EUROPE
11 BELGRAVE ROAD, LONDON SW1V 1RB, UK
Tel: +44 207 834 0477 Fax: +44 207 821 9539
E-Mail: dpieurope@compuserve.com

The Right to Live and be Different

On 12/13 February 2000, 130 disabled people and parents, delegates from DPI organisations in twenty-seven countries in Europe, African, Australia and North America, met in Solihull, UK to discuss bioethics and human rights. This was the first occasion of its kind and it is with pride that we make the following declaration. First and foremost we demand:

Nothing about us without us

Up until now most of us have been excluded from debates on bioethical issues. These debates have had prejudiced and negative views of our quality of life. They have denied our right to equality and have therefore denied our human rights.

We demand that we are included in all debates and policy-making regarding bioethical issues.

We must be the people who decide on our quality of life, based on our experiences.

We also call on our organisations to give support, encouragement and reassurance to those of us who are representing our views on bioethical regulatory bodies.

Particular support must be given to empower the voice of mental health survivors, people with learning difficulties, people who cannot advocate for themselves and disabled children, in the debate.

Richness in Diversity

We are full human beings. We believe that a society without disabled people would be a lesser society. Our unique individual and collective experiences are an important contribution to a rich, human society.

We demand an end to the bio-medical elimination of diversity, to gene selection based on market forces and to the setting of norms and standards by non-disabled people.

Biotechnological change must not be an excuse for control or manipulation of the human condition or bio-diversity.

<http://www.johnnypops.demon.co.uk/bioethicsdeclaration/index.html>

3/20/02

We recognise that the only way to ensure universal support for and positive recognition of our particular qualities is through stating our right to diversity clearly, with good arguments, in open

and democratic discussion. We must form alliances with scientists, the medical professions, ethicists, policy-makers, human rights advocates, the media and the general public.

All Human Beings are born free and equal in Dignity and Rights

Human rights are the responsibility of the state as well as the individual. Disabled people, our organisations, families and allies must work to ensure that international, regional and national legal instruments include the implementation of rights throughout all scientific advances and medical practices concerning the human genome, reproduction, assessments of quality of life, therapeutic measures and alleviation of 'pain and suffering'.

Biotechnology presents particular risks for disabled people. The fundamental rights of disabled people, particularly the right to life, must be protected.

In particular we demand:

- An absolute prohibition on compulsory genetic testing and the pressurising of women to eliminate - at any stage in the reproductive process - unborn children who, it is considered, may become disabled.
- The provision of full and accessible (ie. jargon-free, easy to read and in alternate media) information from which people can make informed decisions
- That European governments do not ratify the Convention on Human Rights and Biomedicine as some sections are in contravention of the two documents adopted at the 1999 UNESCO Conference on Sciences.
- That disabled people have assistance to live - not assistance to die.
- That having a disabled child is not a special legal consideration for abortion.
- That no demarcation lines are drawn regarding severity or types of impairment. This creates hierarchies and leads to increased discrimination of disabled people generally.

Disabled people must join together in solidarity to ensure our voices in these life-threatening issues.

STRENGTH IN UNITY!

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<http://www.johnnypops.demon.co.uk/bioethicsdeclaration/index.html>

3/20/02

ENDNOTES

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²⁰ *Supra*, note 17.

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⁷⁸ G. Brodsky, "Making Perfect Babies: From Eugenics to Reproductive Technology" in *Four Discussion Papers on New Reproductive Technologies*, prepared by the Canadian Disability Rights Council and DAWN Canada, Winnipeg, Manitoba (September 1991) at 35-41.

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⁸⁰ Interview with Freya Christiansen, Chairperson of the Health and Reproductive Issues Committee of the National Association of Women and the Law (December 10, 1999).

⁸¹ *Supra* note 62 at 665.

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⁸³ *Ibid.*

⁸⁴ K.L. Lawson, "Contemplating Selective Reproduction: The Subjective Appraisal of Parenting a Child With a Disability" (2001) 19(1) *Journal of Reproductive and Infant Psychology* at 73-82.

⁸⁵ F. Arnold, R. Bulatao, C. Buripakdi, B. Chung, J. Fawcett, T. Iritani, S. Lee & T. Wu, "The Value of Children: Introduction and Comparative Analysis" in *The Value of Children: A Cross National Study* Vol. 1. (Honolulu: East-West Center, 1975); J. Fawcett, "The Value of Children and the Transition to Parenthood" (1988) 12 *Marriage and Family Review* at 11-34.

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⁸⁷ *Supra* note 84.

⁸⁸ *Ibid.*

⁸⁹ *Supra* note 62 at 666.

⁹⁰ *Supra* note 3 at 19.

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⁹⁴ *Supra* note 78.

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⁹⁶ *Supra* note 68.

⁹⁷ K. L. Lawson, "Perceptions of Accountability for the Birth of a Disabled Child as a Function of Prenatal Diagnostic Testing" (in preparation) Accepted for publication in the *Journal of Applied Social Psychology*.

⁹⁸ Marteau & Drake, "Attributions for Disability: The Influence of Genetic Screening" (1995) 40 *Social Social Science & Medicine* at 1127 to 1132.

⁹⁹ E. Gates, "The Impact of Prenatal Genetic Testing on the Quality of Life in Women" 1993 8 (suppl. 1) *Fetal Diagnosis and Therapy* at 236-243.

¹⁰⁰ N. Holtzman & M. Rothstein, "Eugenics and Genetic Discrimination" 1992 50 *Journal of Human Genetics* at 457-459; *supra* note 3; and *supra* note 63.

¹⁰¹ R. Blank, *Mother and Fetus: Changing Notions of Maternal Responsibility* (New York: Greenwood Press, 1992); M. Shaw, "Conditional Prospective Rights of the Fetus" (1986) 5 *Journal of Legal Medicine* at 63-116.

¹⁰² E. Kristol, "Picture Perfect: The Politics of Prenatal Testing" (April 1993) online: <<http://leaderu.com/ftissues/ft9304/kristol.html>> (date last accessed March 19, 2002).

¹⁰³ *Ibid.*

¹⁰⁴ Lippman, 1993.

¹⁰⁵ *Proceed with Care: Final Report of the Royal Commission on New Reproductive Technologies* (Vol. 2) 1993, at 747.

¹⁰⁶ Women across Canada and throughout the world have demanded a return to the use of midwives and the recognition of pregnancy and birth as natural experiences in a woman's life. For example, six provinces have introduced legislation regulating midwifery practice. Four of these provinces have made midwifery a funded service.

¹⁰⁷ Every jurisdiction in Canada has human rights legislation that prohibits discrimination on grounds such as race, sex, religion, disability etc. in areas such as employment, housing and access to services and facilities.

¹⁰⁸ *Ontario (Human Rights Commission) and O'Malley v. Simpson Sear Ltd.*, [1985] 2 S.C.R. 536.

¹⁰⁹ *Canadian National Railway Co. v. Canada (Human Rights Comm.) and Bhinder*, [1985] 2 S.C.R. 561; *Ontario (Human Rights Commission) and O'Malley v. Simpsons-Sears Ltd.*, [1985] 2 S.C.R. 536.

¹¹⁰ S. Gordon, "The Genetic Dilemma" (2001) 10(7) *The Canadian Bar Association- National*.

¹¹¹ *Eldridge v. British Columbia (A.G.)*, [1997] 3 S.C.R. 624.

¹¹² *Andrews v. Law Society of British Columbia*, [1989] 1 S.C.R. 143.

¹¹³ *Ibid.*

¹¹⁴ *R. v. Turpin* [1989] 1 S.C.R. 1296.

¹¹⁵ *Ibid.*

¹¹⁶ *R. v. Swain* [1991] 1 S.C.R. 933.

¹¹⁷ *Supra* note 113.

¹¹⁸ *Ibid.*

¹¹⁹ *Ibid.* at 64.

¹²⁰ *Child & Family Services of Winnipeg (Northwest Area) v. D.F.G.* [1997] S.C.R. 925.

¹²¹ *Supra* note 24.

¹²² Canadian Medical Association, "Regulation of New Reproductive Technologies" (1996) 15 *C.M.A.J.* 92.

¹²³ *R. v. Crown Zellerbach Canada Ltd.*, [1988] 1 S.C.R. 401.

¹²⁴ *Ibid.*

¹²⁵ M. Jackman, "The Constitution and the Regulation of New Reproductive Technologies", Vol. 3. (Ottawa: Royal Commission on New Reproductive Technologies, 1993). at 5.

¹²⁶ *Ibid.*

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¹²⁸ R.Hayes, "The Politics of Genetically Engineered Humans" online: <<http://www.purefood.org/Patent/gehumans.cfm>> (last date accessed March 20, 2002).

¹²⁹ *Proceed with Care: Final Report of the Royal Commission on New Reproductive Technologies*, Recommendation #1. (Ottawa: Royal Commission on New Reproductive Technologies, 1993). at 1023.

¹³⁰ *Ibid.*, Recommendation 230.

¹³¹ A. Lippman, "Is the Expansion of Prenatal Genetic Screening a 'Public Health' Matter/Priority? Some Reflections". (January 2002, unpublished).