

**MANUFACTURING EUGENICS:
The role of scientific norms and liberal values in the debate over prenatal genetic
technologies**

by

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ABSTRACT

This thesis examines the dominant and influential role of scientific norms and liberal values in the legitimization of access to prenatal testing. In providing mothers with genetic information regarding the health of their foetus, the use of reproductive genetic technologies (RGT) coupled with access to abortion, results in a devaluation of the lives of persons with disabilities. Yet, the individual has complete autonomy of choice in this matter; accordingly, these discrete decisions, when taken in aggregate, have profound social implications. A person has the right to exact this individual agency without regard to the externalities that develop in consequence, namely, a new way to socially select for 'good genes'—a process known as 'liberal eugenics'. This paper asks the question: Why has access to RGT not been curtailed, given the negative externalities of use thereof? Two prevailing social norms emerge as the forces that drive and legitimize liberal eugenics. Liberal societies (1) embrace science as good and (2) view the rights bearing individual as primary. This paper argues, first, that these two social norms transform genetic tests into an instrument of eugenics, and second, that society's belief in the importance of individual choice has roots in the history of liberal political theory. I show how Locke's theory of the body as self-owned property acquires new meaning in this era of genetic progress and, in turn, strengthens the influence of J.S. Mill's theory of the free-choosing individual. In doing so, I set up my ultimate argument: that the successes of the principles of 'the body as self-owned property' and 'the free-choosing individual' in ensuring individual autonomy have resulted in their societal 'normalization', validating and legitimizing individual rights, while simultaneously and ironically engendering a liberal eugenics by permitting access to prenatal reproductive technologies.

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Reproduction is one of humankind's most primordial of functions. It has represented both the most natural and the most awe-inspiring of processes. Many cultures embrace it as a mystical experience; while for others, however, answers to the reproductive mysteries lay within physiological science. Alongside the progression of reproductive science, there has been a simultaneous and inevitable evolution of the views on pregnancy and childbirth. A process historically imbued with chance and risk, reproduction has now become, through the development of new technologies, an increasingly more controlled undertaking. The technologies themselves have evolved from implements that aid in delivery and practices that increase the mother's comfort, to equipment that monitors the foetus's health before and during delivery.

The 21st Century, through the mapping of the human genome, has ushered in a genetic revolution that has, once again, transfigured medical reproductive practices. The newest forms of reproductive technologies seek to identify 'abnormal' genes before the birth of a child so that parents may have the opportunity to make decisions regarding the fate of the pregnancy. Many people find that these prenatal tests provide numerous benefits, including peace of mind and a greater sense of control over their pregnancy; consequently, these procedures have become routine in Canada and throughout most liberal democracies. What is not yet routine in these same societies, is an examination of the greater social implications of prenatal genetic tests. The consequences of these tests for those individuals living with disabilities are critical and yet to date, the consideration of these effects within regulation has not led to any curtailment of the individual right to access prenatal tests.

In this paper, I argue that, because of socially embedded scientific and liberal norms, access to and the existence of prenatal genetic technologies engenders the nascent practice of

liberal eugenics. In Chapter II, I begin by providing an explanation of reproductive genetic technologies (RGT), the science behind them and their accessibility to patients. In Chapter III, I argue that through liberal society's tendency to view science as *good* and the rights-bearing individual as primary, prenatal genetic tests have become a vehicle for the legitimization of liberal eugenics. In Chapter IV, I look to liberal political theory for an explanation for the primacy of individual choice in modern liberal society. I argue that the impassioned debate over the existence and use of reproductive genetic technologies is fuelled by liberal society's adherence to *certain* aspects of liberal theory—those notions that have granted the individual complete right to choice in all personal medical decisions. Society's failure to account for the negative externalities of the sum of individual choices results in discrimination of disabled persons.

CHAPTER II

REPRODUCTIVE GENETIC TECHNOLOGIES—WHAT ARE THEY?

2.1 Introduction

A discussion of the ethics behind any scientific or medical technology is incomplete and inaccessible without a basic understanding of the underlying science and physiology.

Reproductive genetic technologies (RGT) are no exception. In effect, and if for no other reason than to dissolve the overabundance of common misapprehensions regarding anything genetic, such technologies require elucidation from a technical, but intelligible, perspective.

Accordingly, this opening chapter offers a brief account, of human genetics and, more specifically reproductive genetic technologies. In so doing, it lays the technical groundwork for the forthcoming conceptual discussion.

The crux of the argument of this thesis, that scientific and liberal norms transform prenatal testing into a vehicle of liberal eugenics, cannot be fully appreciated unless one is aware of the medical procedures, their benefits and drawbacks, and their physical and psychological risks. Drawing on the quiddities of this technology, I will show how both its positive and negative attributes contribute to the growing conflict between the struggle for autonomy and the preservation of group rights in the debate over prenatal genetic technologies.

The last decade has seen public awareness of genetics and genomics mushroom as a consequence of the rapid evolution of biotechnologies within these research fields. Mass media has made a point of disseminating biotech information in response to the major scientific breakthroughs (not lacking in sensationalist character), such as the mapping of the human genome, the cloning of Dolly the sheep and the proliferation of stem cell research. Although the development of these technologies is of paramount significance for the progression of human genetic science, its ensuing applications are fraught with frightening potential that harkens back to a dystopia of Huxleyan proportions. On the one hand, humanity's eternal desire for answers

to both physical and metaphysical mysteries motivates scientists to pursue genetic and genomic research in search of a more complete understanding of disease, evolution, life and death. On the other hand, human morality, our intrinsic sense of right and wrong, causes society, or sections thereof, to question the objectives, not to mention the ethics, of said research. This ensuing tug of war between a desire for unfettered scientific research and a need for regulatory ethical restraint has yielded an immensely contentious debate within legislatures, universities, hospitals, households and the media. It is also fair to suggest, however, that the controversy stems from the worrisome term *genetic*, or rather, from the erroneous associations that have been bestowed upon it.

In an effort to dispel some of the myths associated with genetic and genomic technologies, this chapter will begin with a basic description of human genetics and the most recent scientific developments in this area of research. It will subsequently discuss RGT, their uses, their benefits, their drawbacks, their evolution within the social/medical institutions and public access thereto.

2.2 Genetics, Genomics and DNA: What does it all mean? Where are the ties?

To define genetics is a complex task. "Some define it as the study of heredity," but this would be an inaccurate definition as phenomena of heredity have been under examination for millennia, dating back to breeding practices of ancient people who sought the improvement of plant crops and domesticated animals through the selection of desirable individuals for breeding.¹ These efforts, however, could hardly have been considered genetics because there was no knowledge of the gene. "Genetics as a set of principles and analytic procedures" did not begin until the 1860s when Gregor Mendel's experiments postulated the existence of genes.² A

¹ Anthony J. F. Griffiths et al., *An Introduction to Genetic Analysis*, Sixth ed. (New York: W. H. Freeman and Company, 1996), 2.

² Ibid.

widely accepted definition of genetics is 'the study of genes', irrespective of the level of analysis—molecular, cellular, organismal, family, population or evolutionary. As long as the gene is central to the analysis, a scientist is engaging in genetics. The goal of genetics is to "understand the structure, function and evolution of genomes", hence the Human Genome Project (HGP).³ 'Genome', although a term in widespread circulation, is largely misunderstood. In order to fully comprehend the scientific potential of mapping the human genome, a basic understanding of structure and function of genetic material is essential.

A small, reminiscent trip back to high school science reminds us that our bodies are comprised of cells that together make up tissues which, in turn, comprise our organs. Inside every one of these cells is a complete copy of our DNA, deoxyribonucleic acid, "the hereditary material that passes from one generation to the next and dictates the inherent properties of a species."⁴ This molecule is a double stranded helix composed of subunits called nucleotides.⁵ Each triplet of nucleotides, called a codon, can be translated into an amino acid through a process called protein synthesis.⁶ Since amino acids are the building blocks of proteins, specific sequences of codons on the DNA molecule, called coding regions, will be translated into entire proteins. These functionally active regions are called genes. So a gene is simply a section of DNA that codes for a specific protein.⁷

It follows that the human genome is "the complete set of [approximately 30,000] human genes."⁸ This complete set of DNA is in the form of a "loose complex of protein and DNA"

³ Ibid., 520.

⁴ Ibid., 2.

⁵ A nucleotide is made up of a phosphate, a sugar and one of four nitrogen bases—Adenine (A), Guanine (G), Cytosine (C) or Thymine (T). Each base on one of the two complement strands has an affinity for its complementary base on the other strand. A binds with T; G binds with C. The complementary bases bound together are known as base pairs. There are up to 3 billion base pairs

⁶ There are also non-coding sequences within DNA that serve to regulate gene expression, turning genes on or off and adjusting the rate of transcription.

⁷ Sometimes genes also code for RNA molecules.

⁸ R. David Cole, "The Genome and the Human Genome Project," in *Genetics: Issues of Social Justice*, ed. Ted Peters (Cleveland: The Pilgrim Press, 1998), 52. In Cole, the actual number of genes quoted is 50,000 to 100,000,

most of the time. However, during the process of cell replication, in which a cell divides into two progeny cells, the genome becomes packaged into 46 bundles known as chromosomes.⁹ These 46 particles are arranged in 22 pairs of homologous chromosomes (autosomes) and 1 pair of sex chromosomes—either XX for females or XY for males. One member of each pair originated with/in the father of the individual and the other from the mother. Although the two members of the homologous pairs are almost identical in that they each contain the same genes, small variances may occur between them since the genetic heritage of the mother and father are different. For example, if the mother has a familial history of Alzheimer's disease and the father does not, the gene S182 on chromosome 14 that is responsible for the coding of a membrane protein will differ slightly in its base pair sequence.¹⁰ "Each version, or variant, of a particular gene is called an allele"; moreover, an individual with two identical alleles is said to be homozygous and one with two different copies is heterozygous. Just before cell division, the DNA is replicated, making another 23 pairs of chromosomes identical to the original 23. Through complex molecular process, one set of 23 is pulled to one end of the cell while the other is pulled to the other pole. The cell divides in the middle yielding two progeny cells with a genome identical to the parental one.

It follows that genomics is the "subdiscipline of genetics concerned with the cloning and molecular characterization of whole genomes" and merits special attention because of the "distinctive experimental techniques that have been devised to carry out the difficult task of manipulating whole genomes, which contain huge amount of DNA."¹¹ Why is it that enormous amounts of funding have been and continue to be pumped into this area of research?

but this was the number hypothesized by genome scientists before the completion of the HGP whose results showed that there are only approximately 30,000 genes in the human genome.

⁹ Ibid., 53.

¹⁰ Griffiths et al., *An Introduction to Genetic Analysis*, 5.

¹¹ Ibid., 520.

The DNA of a genome contains the code necessary to build a living cell, to build a living organism. Within this *blueprint*, within the sequence of nucleotides, lies information regarding organism-specific data. Why is an organism the way it is and different from other organisms? How do different genotypes yield different phenotypes? Which genes perform which functions? Does a gene's position on a chromosome affect the proper functioning of an organism? Although these questions may still seem abstract or very technical, the motive for posing them stems from the quest to alleviate human suffering, to improve life for humanity and to better understand the origins of our existence. These are some large questions to be asking of a mere molecule, are they not? Notwithstanding the rapid evolution of this genomic science, much more needs to be understood about DNA and its function before we can assume that all these answers lie within.

Genetic science took an enormous leap forward on March 18th, 1953 when James Watson and Francis Crick published the first account of the helical structure of DNA. This discovery "ushered in a revolution in biology by revealing the mechanism of heredity."¹² Genomic science and genetic engineering have since made it possible to determine the correlation between genes and many medical conditions. There are three major types of genetic 'ill health'.

The first type comprises "inherited genetic diseases, caused by abnormal forms of genes that are passed on from one generation to the next."¹³ An abnormal form of a single gene causes many of these diseases, such as cystic fibrosis, phenylketonuria, muscular dystrophy and familial breast cancer. Since the completion of the HGP, scientists have realized that many disorders may be the result of the complex interaction between certain forms of many genes.

¹² Aliza Kolker and B. Meredith Burke, *Prenatal Testing: A Sociological Perspective* (Westport: Bergin & Garvey, 1994), 2.

¹³ Griffiths et al., *An Introduction to Genetic Analysis*, 4. Note that the use of the term 'abnormal' here is as quoted in the reference and is not reflective of my word choice. I understand 'abnormal' not as aberrant, but as less-common in occurrence.

Some of the traits that fall into this category are heart disease, hypertension, diabetes, various forms of cancer and infections.¹⁴ The second type of genetic ill health is "somatic genetic disease, which is caused by the sudden appearance of an abnormal form of a gene in one part of the body."¹⁵ The most prevalent form of the somatic genetic disease is cancer, in which spontaneous mutations occur in the DNA sequence. These changes are not passed on to the next generation; however, predispositions to cancer are inherited as atypical genes. The third type is a result of "chromosomal aberrations, such as Down's Syndrome and cri du chat syndrome."¹⁶ In individuals with these disorders, abnormalities occur within the chromosomal structure or number. Down's, for example, is caused by the presence of a third chromosome 21 in the cells.

Until Watson and Crick's discovery, prenatal diagnosis was limited to advising parents with one disabled child about the probability of having a second child affected with the same condition. Prior to the 1970s, methods to diagnose inherited diseases were scarce. They included "(1) studying inheritance patterns by observing affected family members, (2) taking blood samples to diagnose conditions with biochemical (mostly protein) tests, and (3) looking under a microscope for structural abnormalities of the cells and chromosomes."¹⁷ At the dawn of prenatal technologies, tests were "designated for pregnancies judged by medical norms to be at high risk of foetal abnormality, whether because of a family history of hereditary disorders or because of maternal age."¹⁸ The practice of prenatal diagnosis has now, however, become much more commonplace, as many woman have begun to request or have been persuaded to undergo screening. There are several prenatal diagnostic procedures to which women have access today. The following section outlines the procedures, their uses and their consequences.

¹⁴ Ibid., 6.

¹⁵ Ibid.

¹⁶ Ibid.

¹⁷ Patricia Spallone, "Genetic Diagnosis," in *Encyclopaedia of Reproductive Technologies*, ed. Annette Burfoot (Boulder: Westview Press, 1999), 31.

¹⁸ Kolker and Burke, *Prenatal Testing: A Sociological Perspective*, 2.

2.3 Amniocentesis

Amniocentesis was first employed in prenatal diagnosis in 1968, but the procedure dates back to 1882 when it was used to remove excess amniotic fluid.¹⁹ It has long been “performed in late pregnancy to assess anaemia in babies with Rh disease and to find out if foetal lungs are mature enough for the baby to be delivered.”²⁰ Today, amniocentesis is performed in the second trimester, usually between the fourteenth and eighteenth week of pregnancy, to diagnose or to rule out certain birth defects.²¹

The procedure involves the insertion of a thin, hollow needle through the abdomen and uterus of the woman and into the amniotic sac. Several teaspoonfuls of amniotic fluid are withdrawn. There are living cells from the foetus that reside with this fluid, which are subsequently grown in a laboratory and analyzed for chromosomal abnormalities, genetic birth defects and neural tube defects. The results usually take approximately two weeks to be reported to the woman. Among other disorders, amniocentesis can diagnose Down’s Syndrome (occurs as a consequence of the presence of a third chromosome 21), Spina Bifida (characterized as an opening of the spine) and Tay-Sachs disease (a fatal disease of the central nervous system).

A risk of miscarriage is inherent in this procedure. Studies have shown that the risk factor is 2.6% after a first-trimester amniocentesis and decreases to 0.8% after a second-trimester amniocentesis.²² Another factor for women to consider prior to the procedure is that, although amniocenteses are relatively accurate in predicting or ruling out the occurrence of disorders, there is always a chance of a false positive or false negative. The procedure has

¹⁹ *Medical References: Amniocentesis* [Web Site] (March of Dimes Birth Defect Foundation, 2003 [cited October 13, 2003]); available from http://www.marchofdimes.com/professionals/681_1164.asp.

²⁰ *Ibid.*

²¹ Kolker and Burke, *Prenatal Testing: A Sociological Perspective*, 16. In some instances, amniocentesis is done in the first trimester, but this procedure is still considered experimental and is riskier than those in the second trimester.

²² *Medical References: Amniocentesis*.

proven to be accurate between 99.4 and 100% of the time in diagnosing chromosomal abnormalities.²³ This means that there is a small chance that the test will incorrectly predict that the foetus has an abnormality when, in reality, it does not, and vice versa.

2.4 Chorionic Villus Sampling (CVS)

CVS is a prenatal test that involves “obtaining cells from the hair-like projections (villi) of the chorion, the outer tissue of the sac that surrounds the embryo early in the pregnancy and later develops into the placenta.”²⁴ This procedure, usually performed between the tenth and twelfth week of pregnancy, entails the insertion of a catheter through the woman’s vagina and cervix to the villi, which usually have the same biochemical and genetic makeup as the foetus.²⁵ This procedure may be used as an earlier alternative to amniocentesis to rule out certain chromosomal abnormalities and specific genetic problems; however, CVS is slightly more likely to give inconclusive results. In opposition to amniocentesis, CVS cannot detect neural tube defects.

The risk factors in CVS may be slightly higher than in amniocentesis. Studies suggest that there is a 0.5% to a 1% chance of miscarriage after the procedure, but rises to 5% in certain women who have a retroverted cervix.²⁶ Some reports have indicated that there are other potential complications for the foetus following CVS, including the possibility of being born with missing or shortened fingers or toes; however, follow-up studies have suggested that the incidence of these complications is statistically insignificant.²⁷

²³ Ibid.

²⁴ *Medical References: Chorionic Villus Sampling* [Web Site] (March of Dimes Birth Defects Foundation, 2003 [cited October 13, 2003]); available from http://www.marchofdimes.com/professionals/681_1165.asp.

²⁵ Ibid.

²⁶ In these cases, women are offered a transabdominal CVS instead of a transcervical procedure.

²⁷ Kolker and Burke, *Prenatal Testing: A Sociological Perspective*, 21.

2.5 Maternal Blood Screening—Triple Screen

The Maternal Blood Screening procedure is not a diagnostic test in that it cannot determine whether a baby will have a disorder. The triple screen can only “identify pregnancies at higher-than-average risk of certain serious birth defects, including spina bifida and Down’s Syndrome.”²⁸ In the early 1980s when the procedure was still in its nascent phase, the blood test could only measure the levels of alpha-fetoprotein (AFP). Today, the blood test not only measures levels of AFP, but it also evaluates the quantity of estriol and human chorionic gonadotropin (hCG), two pregnancy hormones. This is why it is called the triple screen. The test is typically offered between the sixteenth and eighteenth weeks, and results are available within a week.

Although routine and relatively inexpensive, the triple screen has a high rate of inaccuracy. For every 1000 women whose blood is tested, up to 100 will have an abnormal test result; however, only 2 or 3 of those women will have a foetus with a birth defect.²⁹ A false positive result causes extreme anxiety in many women. Researchers have found that “receiving an abnormal AFP result on a routine screening test is associated with extremely high levels of maternal anxiety, as high as patients with a diagnosis of generalized anxiety disorder.”³⁰ Following an abnormal triple screen, an ultrasound is recommended. If the ultrasound does not provide an explanation for the irregularity in the initial test, the health care provider will offer the woman an amniocentesis. Women who proceed with an amniocentesis to verify the triple screen results see their pregnancies as substantially more vulnerable. Even after the majority of

²⁸ *Medical References: Maternal Blood Screening for Down Syndrome and Neural Tube Defects* [Web Site] (March of Dimes Birth Defects Foundation, 2003 [cited October 13, 2003]); available from http://www.marchofdimes.com/professionals/681_1166.asp.

²⁹ *Ibid.*

³⁰ Kolker and Burke, *Prenatal Testing: A Sociological Perspective*, 23.

women (98% or higher) subsequently receive good news, their fears persist because "the pregnant woman believes that the initial bad results had to indicate some underlying problem."³¹

2.6 Ultrasound

Ultrasound is a procedure that uses sound waves to produce a picture of the foetus in the womb. A computer produces an image of the foetus on a monitor by registering the echoes of sound waves that bounce off the developing foetus.³² This practice is used to determine the gestational age and location of the foetus, to guide the instruments involved in amniocentesis and CVS, to diagnose certain conditions of the foetus and the placenta and to determine the number of foetuses.³³ New ultrasound equipment has led to an evolution in ultrasound technology, yielding three-dimensional images of the foetus with resolution comparable to that of a photograph.

Health care providers have been using ultrasound for more than thirty years and have identified no physiological risk. Notwithstanding the medical safety of the procedure, there is a certain immediacy involved in seeing one's foetus on a screen that, in instances of abnormal diagnosis, may be much more traumatic for expecting parents. Seeing one's foetus on a screen may provide a certain closeness to the unborn child, blurring the distinction between born and unborn. The enjoyment of seeing one's baby on a monitor "may turn into an immediate tragedy."³⁴

³¹ Ibid.

³² *Medical References: Ultrasound* (March of Dimes Birth Defects Foundation, 2003 [cited October 13, 2003]); available from http://www.marchofdimes.com/professionals/681_1167.asp.

³³ Kolker and Burke, *Prenatal Testing: A Sociological Perspective*, 25.

³⁴ Ibid., 26.

2.7 Preimplantation Genetic Diagnosis (PGD)

PGD is a procedure in which the woman's egg is fertilized *in vitro*. Once the embryo is at the four to eight cell stage, a single cell is removed and analysed for genetic conditions such as Tay-Sachs or cystic fibrosis. The sex of the embryo can also be read in order to "transfer only female embryos to women at risk for passing a sex-linked genetic disease."³⁵ The embryo is transferred to the uterus for pregnancy only after existence of the disorder in question has been ruled out.

PGD is regarded as "significantly different from prenatal testing because it prepares for the correction of disease-linked genes in embryos."³⁶ Some view this as a more ethical option. Many people who would not abort based on an abnormal prenatal diagnosis but who are at high risk for passing on a genetic disorder may choose IVF and PGD to ensure that the embryo implanted is free of the genetic condition in question. In soliciting this process, people are not faced with the decision of terminating a pregnancy that is already underway. Perhaps an embryo that is fertilized inside a test tube seems less human than one fertilized inside the body. Perhaps there is less of an emotional attachment to an embryo that looks like chemicals in a lab as opposed to the idea of an egg and sperm combining within the interstices of a woman's reproductive organs. Either way, many women find it emotionally and objectively easier to proceed in this fashion of PGD.

Still, although PGD "improves genetic testing by allowing diagnosis at the earliest stages of the reproductive process, it is a gateway to controversial applications."³⁷ The uses of PGD may not entail only detection of anomalies, but may, with further scientific advances, eventually lead to their 'correction'. In theory, these 'corrections' will be permanently encoded in the reproductive line of descendants. This prospective process is known as germline genetic

³⁵ Andrea Bonnickson, "Preimplantation Genetic Diagnosis," in *Encyclopaedia of Reproductive Genetic Technologies*, ed. Annette Burfoot (Boulder: Westview Press, 1999), 361.

³⁶ *Ibid.*, 362.

³⁷ *Ibid.*

engineering and is highly contentious because it “gives a new degree of power to humans, it raises the prospect of unexpected side effects and it creates the temptation to correct an array of nonmedical traits.”³⁸

2.8 Conclusion

With this basic understanding of the science behind the genetic technologies in question and awareness of their practical applications, we are better equipped, epistemologically, to envision the entire portrait of a society influenced by genetic technologies. Science and its ensuing technologies are not value-free, and to deem them so is to spuriously negate the stark ethical consequences their societal applications will engender.

In the following chapter, I will discuss the implications of use of this technology for the disabled communities. The legitimization of RGT places negative value on the lives of people living with disabilities. The widespread access to prenatal tests results now, and will result in more social discrimination against the disabled through the practice of a new brand of eugenics, one that is decentralized in nature. The next chapter argues that socially embedded views of science as *good* and the individual as primary validate these new eugenic practices and, in turn, affect individuals with disabilities.

³⁸ Ibid., 363.

3.1 Introduction

In the previous chapter, I gave an account of the tests available to women who choose to seek out genetic information about their foetuses, the results of which will provide mothers (and their partners) with genetic facts (or in some cases, probabilities). Doctors or technicians read these facts directly off strands of DNA, which are structural realities; sequences of nitrogen bases—mere chemicals. Yet, there is so much value attached to the messages contained in that double helix; there is so much worth given to knowing those molecular details. Information of this nature cannot be treated dismissively, for it could provide a glimpse into the future health of one's child. At first thought, it seems almost unconscionable that a woman would reject the opportunity to acquire this information. Could the negatives ever truly outweigh the positives of discovering aspects of the genetic makeup of one's child-to-be? This sentiment encompasses the prevalent social belief in the *goodness* of knowledge acquisition. There is, however, more to knowledge than simply amassing fact. There are implications and consequences associated with awareness.

In the case of prenatal genetic tests, upon selecting to receive genetic information, a woman (and her partner) must inevitably face decisions that may otherwise not have been in question had the option to test not been available. A person has the right to exact this individual agency without regard to the externalities that develop in consequence, namely, a new way to socially select for 'good genes'. This process has acquired the label, 'liberal eugenics'. Two prevailing social norms emerge as the forces that drive and legitimize liberal eugenics. Liberal societies (1) view the rights bearing individual as primary and (2) embrace science as good. Let us consider each in turn.

First, present policy regarding access to this technology highlights the primacy of the individual as the rights bearing entity. She is fully empowered to do with this technology whatever she so desires and then to follow through with whichever course of action she chooses. Second, most women select to undergo prenatal testing on their foetus, rather than to forego receipt of this information. This predominant choice points to the widespread belief that science is good and that the acquisition of genetic data will assist in making the most informed decision.

Given these two factors, limiting access to genetic testing appears to be an infringement upon liberal rights, and thus is scarcely considered. Nevertheless, individuals living with disabilities find themselves having to endure an increase in social stigma through this practice of liberal eugenics. The irony of this practice is that the *liberal* framework that guarantees our rights and freedoms as citizens of liberal states is the same agenda that now puts in peril the rights of the disabled through providing unlimited access to prenatal genetic technologies. Disability communities fear not only the use of, but also the sheer existence of the tests, because they result in discriminatory practices and a devaluation of self-worth.

In this chapter, I argue that, the combination of socially embedded scientific and liberal norms, and access to and existence of prenatal genetic technologies has created *liberal eugenics*. My argument begins with an explanation for how liberal societies came to adopt views of the individual as primary and science as good by looking to the Enlightenment and the rise of liberalism. In accounting for the evolution of fact, I discuss how a particular kind of 'truth' has come to be so highly valued and how science has gained such ubiquitous legitimacy, such that it has authority and power within the legislative and societal arenas. In the second section, I will examine earlier eugenic practices in order to both distinguish them from and provide insights into the new form of liberal eugenics. The third section, using Aristotle's distinction between *techne* and *phronesis*, explores the question of how a society should move from acquiring scientific information to regulating the use of that knowledge. What difficulties arise with

respect to the meaning of science when working within a modern liberal framework that paradoxically prohibits discrimination while legitimizing liberal eugenics? The last section discusses how the societal norms of science and liberal norms of individualism convert prenatal tests into a channel of liberal eugenics.

3.2 Evolution of Fact through the Enlightenment

Genes exist, or so it would seem. DNA arose, presumably, shortly after the Big Bang. That a dinosaur took on its shape and its characteristics consequent to its genetic make up is neither good nor bad. It just is. That a bird flies or a fish swims is but a value-neutral state of affairs, which existed *prior* to man's discovery or comprehension thereof. In the same way, the gene for cystic fibrosis existed before its discovery by humans. The existence of this fact is also value-neutral. Therefore, a fact can exist outside of the realm of human cognition; however, a fact, although universal and invariable, has been identified and classified as such only subsequent to its discovery by and incorporation into the human mind. So, although a factual entity has a function and an identity unto itself prior to its discovery by humanity, for the human, a fact is effectively non-existent before its discovery. It follows that, despite the neutrality of fact as an absolute and independent entity, we can only know and comprehend fact through the filter of our human minds, the consequence of which is the attribution of value. This means that for us, fact and our knowledge thereof are inseparable because, by definition, a fact does not exist without proof of its existence, and a proof cannot exist without our awareness of the fact it seeks to validate

Accordingly, for a fact to exist for a human, it becomes inextricably interwoven with cognition. In seeking out fact, modern attempts to arrive at 'truth' through scientific reason, gained popularity and legitimacy during the 18th Century, with the intellectual movement known as the Enlightenment. The pervasive appeal, as expressed by Voltaire, was the autonomy of

reason, confidence in the ability to discover causality, perfectibility and progress, and the new sort of methodological certainty called 'scientific'. It became popular belief that "the good scientist is the one willing to test all assumptions, to challenge all traditional opinion and to get closer to the truth."³⁹

Simultaneously, the more liberal notions of human rights, self-rule, natural law, inherent freedoms and self-determination also grew out of the Enlightenment with thinkers such as Jefferson, Rousseau, Locke and de Montaigne. Interestingly, the same language used in writings of liberalism are the basis upon which our modern liberal states were built.

The tandem rise of liberalism and the Enlightenment revolutionized society's conception of two ideas—the individual and science. Liberal societies began to view the individual as the primary locus of rights. He/she became an agent entitled to think, to act and to choose in all personal and civic affairs. This new individual could use science as a tool, which would lead him/her to truth. Logic emerged as a powerful avenue to truth; the scientific method concretized *logic* into an impressive truth-exposing machine. Thus, the individual and liberal societies embraced science as *good*. Science and liberalism in other words were united in a shared normative effort to challenge traditional sources of authority that could not withstand the power of reason: "In a sense, the strength of science at its best is that it is always aware of its limits, aware that knowledge is always growing, always subject to change, never absolute. Because knowledge depends on evidence and reason, arbitrary authority can only be its enemy."⁴⁰ These beliefs have survived the test of time; consequently, embedded within our modern liberal societies are notions of the primacy of the individual as the central bearer of rights and of the legitimacy of science as the generator or the elucidator of fact. Indeed, science has gained so much legitimacy that we allow it to *lead* our societal choices, at times with

³⁹ Paul Brians, *The Enlightenment* [Website] (Paul Brians, May 18, 2000 1998 [cited February 26 2004]); available from <http://mars.wnec.edu/~grempel/courses/wc2/lectures/enlightenment.html>.

⁴⁰ Ibid.

seemingly little regard to the potentially devastating consequences of its application. As I shall argue, the combination of liberalism and science can lead to the practice of eugenics both in the past and present.

Thus, while the notion of *liberal* eugenics is new, eugenics, per se, has a history dating back to the 19th century. In previous incarnations, eugenics has represented the liberal belief in 'progress' on the one hand, combined with the handing over of social policy to the dictates of science, with little ethical or sociological consideration. At the end of the 19th century, the biological determinism that grew out of Charles Darwin's work gained enormous legitimacy and was central to the creation of eugenics policies in liberal states, such as Britain and the United States. The following section outlines the origins of eugenics and its progression throughout history, with the intent, first, to establish an image of the historical context of the practice and, second, to juxtapose earlier forms of eugenics with the modern brand.

3.3 History of Eugenics

Although it could be argued that societies in ancient times and in the middle ages valued the 'strong' or the 'intelligent' more highly than their more 'vulnerable' counterparts⁴¹, the advent of 'scientific' eugenics lies within Victorian England. Notions of survival of the fittest were first popularized by and absorbed within mass consciousness as a result of the work of naturalist and evolutionary biologist, Charles Darwin. In his book *On the Origin of Species*, Darwin explains his discovery of the evolution of species by *natural selection*:

As many more individuals of each species are born than can possibly survive; and as, consequently, there is a frequently recurring struggle for existence, it follows that any being, if it vary however slightly in any manner profitable to itself, under the complex

⁴¹ Roger Gosden notes, "Historical precedents seemed to point to the selection of the fittest as a formula for a successful society." He discusses the common Spartan practices of throwing boys of a certain age into a pit of water to "let nature decide who was fit enough to become a citizen of that supposedly virtuous state." Roger Gosden, *Designing Babies: The Brave New World of Reproductive Technologies* (New York: W.H. Freeman and Company, 1999), 62.

and sometimes varying condition of life, will have a better chance of surviving, and thus be *naturally selected*.⁴²

The *Origin* sold 3,800 copies in its first year alone and 27,000 copies within the British market in Darwin's lifetime. Throughout both British and American society, there was sudden dissemination of the idea that the 'fittest' in society would outlive their weaker counterparts as a result of a *natural*, evolutionary process.

Although Darwin kept, for the most part, his views regarding the injustice of propagating the weak members of society to himself, his cousin, Sir Francis Galton, was an outspoken proponent of "the hindrance of marriages and the production of offspring by the exceptionally unfit."⁴³ It was he who subsequently coined the term *eugenic* and defined it as 'the science of improvement of the human germ plasm through better breeding', in other words, 'genetic improvement'.⁴⁴ He regarded eugenics as "a corollary to evolutionary theory, for 'natural selection rests upon excessive production and wholesale destruction; eugenics [rests] on bringing no more individuals into the world than can properly be cared for, *and those only of the best stock*'."⁴⁵ Galton's subsequent binary classification of eugenics included "'positive eugenics', which focused on encouraging so-called good stock to breed, and 'negative eugenics', which focused on discouraging the mentally and morally unfit from breeding."⁴⁶ Seen as rooted in evolutionary theory, eugenics sounded "intellectually respectable" and "socially responsible."⁴⁷ Despite its biological origins, eugenics morphed not only into ideology, but also into widespread public policy.

⁴² Philip Appleman, ed., *Darwin*, Third Edition ed., *A Norton Critical Edition* (New York: W.W. Norton and Company, 2001), 97.

⁴³ From: Francis Galton, *Hereditary Genius: An Inquiry into Its Laws and Consequences* (London: J. Friedman (originally published in 1869), 1979), quoted in: Gosden, *Designing Babies: The Brave New World of Reproductive Technologies*, 61.

⁴⁴ Anne Kerr and Tom Shakespeare, *Genetic Politics* (Cheltenham: New Clarion Press, 2002), 4.

⁴⁵ Gosden, *Designing Babies: The Brave New World of Reproductive Technologies*, 60.

⁴⁶ Kerr and Shakespeare, *Genetic Politics*, 8.

⁴⁷ Gosden, *Designing Babies: The Brave New World of Reproductive Technologies*, 60.

By the turn of the 20th Century, a period of considerable social turmoil, concerns began to mount not only in Britain, but also throughout continental Europe and America, about the propagation of inferior stock. Mass immigration to the US from southern European countries led to the fear that the 'original' American stock would be tainted—a public prejudice that led to a 1924 legislation restricting the number of entering immigrants.⁴⁸ In Britain, following “concerns about the declining birth rate amongst the middle classes and the unrestrained reproduction of the ‘unfit’ amongst the lower classes,” the Metropolitan Poor Act (1867) and the Idiots Act (1886) were spawned to ‘deal with’ the growing ‘social problem’ of the mentally deficient in society. The legislative solution lay in the “wide-scale institutionalization of people considered socially and mentally inadequate.”⁴⁹

One of the major reasons for the legitimation of eugenics within society was its accession to an ‘objective’ sub-discipline of science. It was during this period that biologists and geneticists began to professionalize and gain ‘hard scientist’ status alongside physicist colleagues. These new norms all contributed to the institutionalization of science and, consequently, the adoption of eugenics as a teachable university subject.⁵⁰ Beginning with Galton’s creation, the Eugenics Laboratory at the University of London in 1907, colleges and universities across Britain and the US began offering courses in eugenics.⁵¹

Until WWII, the sterilization and institutionalization of individuals believed to be ‘unfit’ in various ways (including mentally ill, mentally disabled, epileptics, deaf and blind people) was commonplace in both Britain and the United States. Countless eugenics movements amassed widespread popular support from groups and individuals representing the social and political spectrum. In Britain, beginning in 1907, the Eugenics Education Society drew membership

⁴⁸ Ibid., 62.

⁴⁹ Kerr and Shakespeare, *Genetic Politics*, 9.

⁵⁰ Kerr and Shakespeare provide a comprehensive account of the evolution of eugenics as a science during the early 1900s. See: Ibid., 10-13.

⁵¹ By 1928, 376 schools in the US offered courses in eugenics. Ibid., 11.

from psychiatrists, physicians and academics, half of which were women. The Sociological Society became interested in eugenics and included individual supporters such as George Bernard Shaw and H. G. Wells, groups such as Marxists and feminists, and politicians such as A. J. Balfour and Neville Chamberlain.⁵² The United States saw the creation of the American Eugenics Society in 1923, which was the beneficiary of donations from the likes of John D. Rockefeller, among other professionals and luminaries.

Eugenics legislation successes were also seen in both countries during the pre and interwar period. In 1913, the British Mental Deficiency Act was passed, which legislated the segregation of the so-called feeble-minded. In the USA, "eugenicists instituted a widespread sterilization programme of inmates of prisons and mental institutions."⁵³ By the 1960s, 60,000 people had been victimized by sterilization laws present in 30 states.⁵⁴

No country's ensemble of eugenics policies surpassed the terror and the brutality of that in Nazi Germany. Eugenics policies during this period in Germany manifested themselves in sterilization, euthanasia and genocide.⁵⁵ People with disabilities were the objects of much hatred and cruelty; consequently, through state sanctioned programs, those with disabilities (as classified by the Nazi regime) were sterilized and murdered.⁵⁶

After revelations about the Nazis' eugenics policies, the eugenics movement in the United States was effectively terminated, followed by a complete inoculation against any revival

⁵² Ibid., 13.

⁵³ Ibid., 15.

⁵⁴ I should note here that Canada also practiced eugenics throughout most of the 20th Century.

⁵⁵ As explained in Kerr and Shakespeare, *Genetic Politics*, 22.

⁵⁶ The sterilization list included the following: Congenital feeble-mindedness, schizophrenia, manic-depressive psychosis, hereditary epilepsy, hereditary St Vitus Dance (Huntington's), hereditary blindness, hereditary deafness, severe hereditary physical deformity, severe alcoholism on a discretionary basis. This was legislated under the Law for the Prevention of Genetically Impaired Progeny (July 14, 1933). From 1933 to 1939, the Nazis sterilized 375,000 people on the grounds of heritable conditions. Similarly, under the guise of 'euthanasia', hundreds of thousands of patients (adults and children) who had been institutionalized for having a psychological condition were brutally murdered—shot, starved, killed by lethal injection, asphyxiated in gas chambers, poisoned by drug overdose, blown up with dynamite. For a comprehensive account of the Nazi crimes toward the disabled, please see Ibid., 22-45.

of eugenics in continental Europe.⁵⁷ Despite this reaction against eugenics post WWII, several states, including the social democratic Scandinavian countries, maintained their eugenics laws well into the 1960s and '70s.

The common thread that runs through all eugenics movements of the past is that they were all state-sponsored and coercive. In the US, the fatuous belief that a wide variety of behaviours, such as criminality, alcoholism and feeble-mindedness, were inherited provided the state and the courts the right to order that people be involuntarily sterilized. The Nazi administration, of course, sanctioned these practices but to horrendous extremes. Today, virtually all Western states have rejected views that their administrations should be involved in the 'purification' of their national gene pools, and the term *eugenics* has become all but taboo in legislative arenas, given its 'ableist' and elitist connotations, just as the words 'genetic' and 'reproductive genetic technologies' have gained both currency and respectability.

3.4 What makes eugenics 'liberal'?

Despite the human rights frameworks in place in developed countries that explicitly protect individuals from state-imposed attempts to annihilate sections of the population, access to prenatal genetic technologies presents the possibility of a new form of eugenics—a decentralized, liberal eugenics driven not by a coercive state but by the aggregate decision making of individual parents, supplemented and guided by contemporary medical practice. There is evidence that not only a highly valued science, but also the primacy of the individual have informed policymaking in the area of genetic technology. Whereas past eugenics movements suppressed certain *groups* of people through legislation informed by evolutionary biology, the new eugenics takes form because the *individual* has sovereignty over reproductive

⁵⁷ Francis Fukuyama, *Our Posthuman Future: Consequences of the Biotechnology Revolution* (New York: Farrar, Straus and Giroux, 2002), 85.

choice and the discrete decisions, *in aggregate*, result in discrimination against the disabled. The individual has complete autonomy to choose or reject testing and to abort or keep the foetus. Implicit in the availability of the tests are socially embedded assumptions of science as both the creator of and answer to humanity's most burning of questions. These prenatal tests will supply individuals with genetic information about their unborn foetus—probabilities of its predisposition to certain conditions. The *individual* has the unrestrained right to decide the fate of the foetus based on this genetic data derived from the process of *science*. Society's valuation both of science and of the individual has implications for the persons who are embedded within that culture, within that mindset.

If we value science as good, we could also infer that the products of science are good, and thus could or, more demandingly, *should* be put to good use. Inevitably, in attributing positive qualities to science, there are both accompanying social pressures compelling individuals to use the *highly valued* genetic technologies, and potential societal punishments in rejecting their use. Because of these pressures and punishments that breed within this social context of scientific norms and structures, the option of abortion after receiving a positive test result may seem more acceptable than having a disabled child, or at least a wholly legitimate choice. In this section, I argue that these scientific technologies, and their social meaning, in conjunction with the paramouncy of the 'individual' in liberalism are the vehicles through which a new brand of eugenics has arisen, with profound implications for the community of persons with disabilities. The discussion begins with Aristotle, and his views regarding the different forms of knowledge, who brings needed insights into the nature of 'science'. It then turns back to prenatal technologies and how modern norms of knowledge and individualism have transformed genetic tests into an instrument of eugenics.

3.5 The Phronetic Plight—how to navigate through liberal values

According to Aristotle, the “desire for knowledge” is the very definition of man, and the pursuit of truth through reason quenches the thirst of human inquiry and curiosity.⁵⁸ Prenatal genetic tests give expecting parents this desired knowledge of the genetic health of their foetus. Clearly, the end of soliciting this test is not only the quenching of one’s curiosity; on the contrary, the end may be one of several options, including termination of the pregnancy, preparing for the birth of a child with a given condition, and easing one’s mind. It follows that knowledge acquisition and the process of science are never ends in themselves, but means to other ends. Miller explains this relationship between the scientific process and its outcome:

The locus of the origin of ends is the minds of men. This implies roughly that no basic knowledge (or neutral knowledge) takes on the character of means unless it is first considered in relation to an end. But the end, the *there-then*, which is a possible stimulus because of the temporal dimension of human minds, is logically prior to a means of attaining it.⁵⁹

Since the end of science or the application of the derived knowledge exists conceptually before the existence of the knowledge, any neutrality that we attempt to attribute to fact is rationally inconsistent. It is impossible to detach knowledge from the reasons for which science (and thus humans) sought it out—most likely for an end deemed valuable or *good*. Accordingly, questions of application of knowledge beg questions of ethics that must also be addressed.

Aristotle asks the question “what is the right principle that should regulate conduct?”⁶⁰ He discusses five types of knowledge; each is a “way in which the soul arrives at truth by affirmation or denial.”⁶¹ The first is Episteme, science or scientific knowledge.⁶² Aristotle explains Episteme as follows:

⁵⁸ Jean-Jaques Salomon, “Science, Technology and Democracy,” *Minerva* 38 (2000).

⁵⁹ David L. Miller, “Science, Technology, and Value Judgements,” *Ethics* 58, no. 1 (1947): 67.

⁶⁰ Aristotle, *The Ethics of Aristotle*, ed. Hugh Tredennick, trans. J.A.K. Thomson (London: Penguin Classics, 1976), 203.

⁶¹ *Ibid.*, 206.

⁶² The Penguin translation of *Ethics* uses the translated English names when referring to the different types of knowledge. In my text, I use the Greek terms (i.e. episteme, phronesis, techne, nous and sophia).

The object of scientific knowledge is of necessity. Therefore, it is eternal, because everything that *is of necessity* in the unqualified sense is eternal; and what is eternal cannot come into being or cease to be. Again, all scientific knowledge is supposed to be teachable, and its object to be capable of being learnt.... Thus, scientific knowledge is a demonstrative state (i.e. a state of mind capable of demonstrating what it knows).... A person has scientific knowledge when his belief is conditioned in a certain way, and the first principles are known to him; because if they are not better known to him than the conclusion drawn from them he will have knowledge only incidentally (i.e. his knowledge will not be scientific because he cannot demonstrate its truth).⁶³

The second knowledge is *Techne*, art or technical skill:

Art is a productive skill that is truly reasoned, while its contrary non-art is a productive state that is falsely reasoned; both operate in the sphere of the variable.... Every art is concerned with bringing something into being, and the practice of an art is the study of how to bring into being something that is in the producer and not in the product. For it is not with things that are or come to be *of necessity* that art is concerned, nor with natural objects (because these have their origin in themselves). And since production is not the same as action, art must be concerned with production, not with action.⁶⁴

The third is *Phronesis*, prudence or practical wisdom. Aristotle explains prudence as follows:

It is thought to be the mark of a prudent man to be able to deliberate rightly about what is good and advantageous for himself; not in particular respects e.g. what is good for health or physical strength, but what is conducive to the good life generally.... The man who is capable of deliberation is prudent. But nobody deliberates about things that are invariable or about things that he cannot do himself. Prudence is a virtue not an art.... What remains, then, is that it is a true state, reasoned, and capable of action with regard to things that are good or bad for man.⁶⁵

The fourth is *Nous*, intelligence or intuition, which is a "state of mind that apprehends first principles."⁶⁶ Finally, the fifth type of knowledge is *Sophia*, or wisdom, which "must be intuition *and* scientific knowledge: knowledge 'complete with head' (as it were) of the most precious truths."⁶⁷

With this separation of knowledge, Aristotle clearly indicates that *episteme* and *techne*, although essential aspects of knowledge, do not outline 'what ought to be done', but 'what is' and 'how to do/make things' respectively. For Aristotle, morality is a form of knowledge that he calls *Phronesis* or prudence; which "apprehends the ultimate particular, which cannot be

⁶³ Aristotle, *The Ethics of Aristotle*, 207.

⁶⁴ Ibid., 208.

⁶⁵ Ibid., 209-10.

⁶⁶ Ibid., 211.

⁶⁷ Ibid., 212.

apprehended by scientific knowledge, but only by perception.... Thus it is opposite to intuition; for intuition apprehends the definition, which cannot be logically demonstrated.”⁶⁸ He then goes on to say:

Political science and prudence are the same state of mind.... Politics is the fullest realization of prudence.... Prudence concerning the state has two aspects: one, which is controlling and directive, is legislative science; the other, which deals with particular circumstances, bears the name that properly belongs to both, viz. political science. This latter is practical and deliberative; for an enactment is a thing that can be done, and the last step <in a deliberative process>.⁶⁹

Aristotle’s account of knowledge helps in answering the ethical dilemma concerning societal and individual acquisition of scientific knowledge (episteme) through technical procedures (techne). These two forms of knowledge cannot stand alone or be allowed to command policy decisions, consequently undermining phronesis, which should be at the helm of scientific progress.

Habermas warns, “the authority of the sciences holds the societal monopoly of secular knowledge.”⁷⁰ Modern science in Habermasian terms, has come to mean, techne and episteme and has set phronesis aside. Having embraced science—both the process of discovery and the *truth* it produces—as *good*, society has elevated it to a position of authority. Much scientific research is unravelling wildly, unrestrained by any legislation. Although phronesis, through political deliberation and moral concern, could provide guidance with respect to the application of episteme (scientific knowledge), could it also provide guidance in the regulation of those principles or those facts that exist but are yet undiscovered by or unbeknownst to the human mind?

There is a logical difference between using prudence in deciding what should be done with scientific knowledge and/or technology and using prudence to restrict the discovery of truth (such as a human’s genetic makeup). Aristotle clearly states that phronesis can and should rule

⁶⁸ Ibid., 215.

⁶⁹ Ibid., 213-14.

⁷⁰ Jurgen Habermas, *The Future of Human Nature* (Cambridge: Polity Press, 2003), 104.

over *techne* because it is variable (i.e. it can be otherwise) and thus, can be deliberated upon.

However, *phronesis* cannot guide *episteme* because it

...consists in forming judgements about things that are universal and necessary; and demonstrable truths, and every kind of scientific knowledge (because this involves reasoning), depend upon first principles, ...[which] cannot be grasped either by science (*episteme*) or by art (*techne*) or by prudence (*phronesis*).... What remains is that the state of mind that apprehends first principles is intuition (*nous*).⁷¹

Aristotle makes the point that since *episteme* is invariable (i.e. “is of necessity”), it “cannot come into being or cease to be,”⁷² and therefore is not subject to deliberation. But if we were to apply this to the case of biotechnology, would it hold?

The discovery of genes has changed human self-understanding. To take this information and file it away in some library of truths would be preposterous. The meaning of this discovery for humanity is unparalleled and deliberation on the topic is essential in order to discuss the implications of these findings. *Phronesis* is unquestionably necessary in regulating access to the information contained within our DNA, for it is a powerful and dangerous tool. It is, however, difficult to rally support for regulation of the acquisition of knowledge—especially scientific—because we cannot, with certainty, foresee the consequences (good or bad) of the application of that knowledge. It is also a logical anomaly to ban attempts to discover something that we do not know exists. Until the moment of discovery, neither *phronesis* nor *sophia* can logically regulate scientific findings.

The tension therefore arises between what *should* be done with the knowledge, and what *could* be done with the knowledge—between *phronesis* and *techne*, respectively. Once the facts have been discovered, politics and ethics try to place guidelines and restrictions on their use, while technology tries to maximize their social/medical/technological utility. What results is a regulatory stalemate between *phronesis* and *techne*. On one hand, we would not want *phronesis* to overregulate the expansion of societal knowledge for fear of missing a potential

⁷¹ Aristotle, *The Ethics of Aristotle*, 210-11.

⁷² *Ibid.*, 207.

breakthrough; on the other hand, we would not want techne to run amuck and unleash products that may empower evil people to use the knowledge for evil ends. Despite its possible dreadful outcomes, techne could also yield beneficial products. Since we cannot predict the output of science, society leans toward giving it ample playing room. Nevertheless, we must not dismiss the power that is associated with knowledge, and that power in the wrong hands can very quickly morph into a villainous tool. Eugenic agendas in history are a testament to how mass injustice can result from a misuse of knowledge and power—end products of techne.

In the case of prenatal testing and the resultant liberal eugenics, the issue is not so much that techne has run wild and that evildoers are abusing the acquired genetic knowledge. The issue is that individuals and society *believe* that techne (i.e. prenatal genetic tests) and the information it provides are *good*, and that providing people with a genetic reading of their foetuses is *good*. There is no evil in the desire to know whether one's child will have a genetic condition. Even a decision to abort is not laced with evil but with a personal belief in what is right and good. Yet, the external consequences for the disabled are caustic and devastating. Any deliberation or moral guidance that phronesis offers on the matter is constrained by the two pervasive liberal, enlightened trends—the primacy of the individual and the belief that science is good. Testing leads an individual closer to *truth*, which increases her autonomy and allows her to make decisions that are more informed. To take away that ability is to encroach upon the political rights of the individual—one of the cornerstones of our modern liberal states. There is little less authoritarian than limiting access to information about one's body, and to argue against the inherent *goodness* in the right to have control over one's body is to argue for a return to tyranny. Success in swaying individuals to forego their right to foetal genetic information would involve complete exhumation of the socially embedded norms of individualism and science. These liberal values place manifest constraints on phronesis, impeding its duty to help guide techne toward equitable, virtuous ends.

3.6 The causal link—from social norms to individual pressures to liberal eugenics

Remembering that *eugenics* means ‘good genes’ and that eugenic policies were established to ensure the propagation of a ‘healthy’ gene pool and to eradicate ‘defective’ genes, a new kind of eugenics, not compelled by the state, but guided by medical science and practice through the aggregation of individual choice, has been quietly emerging in liberal states—unchecked because its terms are grounded in the sacred idea of liberal autonomy. For example, in Canada, women have the right to access any and all of the genetic technologies discussed above. Provincial health care policy in Canada is to offer all these tests to all pregnant women during the gestation period in which the tests are safest. At this point, women are free to choose to either accept or reject use of any or all of these technologies. Why, then, does the majority choose to undergo testing?

Out of the genetic revolution that blossomed with Watson and Crick’s discovery of DNA, humanity has acquired access to the very biological essence of heredity. The recent completion of the Human Genome Project has further increased our understanding of the structure and function of genes. Consequently, these scientific developments have broadened the scope of prenatal tests, rendering them diagnostically capable in many cases and allowing them to answer many questions for expecting parents.

All too often, upon asking a pregnant woman if she would prefer a boy or a girl, the answer is often: “It doesn’t matter as long as the child is healthy.” Prenatal diagnostic tests and reproductive genetic technologies can now provide expecting mothers more assurance than ever before, albeit not without limitation or ethical questions. Undeniably, these tests provide numerous benefits for expectant parents. They offer “improved chances of having healthy offspring, [provide] some reassurance of foetal health during pregnancy, and [increase]

women's bonding with the 'child-in-the-making'."⁷³ Achieving a healthy baby is what most parents-to-be long for. It seems rather silly to think that any expectant parent should hope for a child who will lead a life of suffering due to some genetic condition.

Reproductive science has progressed to a stage wherein it can now provide pregnant couples with *information* regarding the prospective health of the foetus. The limited scope of the testing leaves parents with very few decisions in the face of the acquired knowledge. Prenatal testing is strictly diagnostic. At this moment in time, any attempts at 'fixing' a genetic abnormality before birth are still experimental, but also raise another set of distinct ethical problems. In any case, the existence of prenatal genetic tests has placed not only expecting parents, but also society as a whole, in an ethical bind.

In addition, pregnancy, in general, entails risk-taking. Prenatal tests do not remove risk from pregnancy. On the contrary, they impose both physical and psychological costs upon the parent(s) and/or the foetus. Once pregnancy is confirmed, a woman (and her partner) must choose whether or not to undergo testing, and if so, which type. She is informed (or should be) of all options and the respective risks during the first medical visit. The consequences of testing are numerous and varied depending on the types of tests chosen, the number of tests undertaken and the results of those examinations. The risk of miscarriage increases with many of the procedures. Should parents choose to accept this risk and not lose the pregnancy, upon receiving positive or negative diagnoses, they must decide upon the fate of the foetus. Should they receive a negative test result (i.e. foetus is not found to have a genetic abnormality) and feel reassured by and confident with the result, they will most likely decide to continue the pregnancy, recognizing the small potentiality of having received a false negative, at which point they may or may not be prepared to deal with the birth of an affected child. Should they receive a positive test result (i.e. foetus has a greater risk of having a genetic abnormality) after one or

⁷³ Kolker and Burke, *Prenatal Testing: A Sociological Perspective*, 163.

more tests; they have the option of aborting the foetus or proceeding with the pregnancy and bearing a child with some degree of impairment, pending the accuracy of the test.

The psychological costs may not be as clear. Palpable and profound psychological torment is likely to be felt by parents who must decide whether or not to abort based on positive test results. The burden of decision, however, manifests itself long before this final decision need be made. The sheer existence of these procedures imposes this burden upon parents perhaps even before conception.

Prior to the existence of such diagnostic tests, people could decide to have a child, and in doing so, assume the natural risks involved, including the possibility of bearing a child with a genetic defect. Aside from assessing the pattern of occurrence of a disorder based on phenotypic consideration of previous generations and Mendelian statistical analysis, there was no way of knowing the foetus's probability of inheriting a genetic abnormality. Whereas the Mendelian analysis could be quite accurate in the case of dominant traits, detecting recessive traits through this method would prove much more challenging. Mendelian statistics aside, the average parents did not enlist the services of a genetic counsellor unless there was a high familial incidence of a given genetic abnormality. The risks associated with childbearing and a lack of control were inherent, unavoidable dimensions of pregnancy for all.

The new era of foetal genetic tests has changed and continues to challenge society's perception of pregnancy and parents' perceived sense of control. The intended purpose of prenatal testing is "the detection of major abnormalities in utero.... The only alternative to bearing a sick, untreatable child is to terminate the pregnancy."⁷⁴ Knowledge of the existence of prenatal diagnostic testing carries a heavy burden with it for a pregnant woman. Even before someone chooses to either undergo or reject the test, the knowledge of its existence could result

⁷⁴ Ibid.

in harmful emotion, including a sense of obligation to acquire genetic information and a need to place hierarchical values on different disorders.

Reflecting his pro-science sensibilities, Auguste Comte (1798-1857) stated: "To know is to predict; to predict is to control."⁷⁵ It is true that prenatal tests provide knowledge and predict (within a margin of error) if a child will be born with a genetic defect. But where is the control? A parent cannot ask the doctor to 'fix' that foetus. Genetic tests "can never banish the spectres of undetected defects in the foetus or of birth trauma, and ordinarily it cannot turn an affected foetus into a healthy baby."⁷⁶ Parents are forced to choose between the lesser of two evils now that they know that they can acquire genetic information on their foetus. To test or not to test? To risk or not to risk? To abort or not to abort?

This knowledge, which is meant to benefit, to empower, may, in actuality, bewilder and distress. Perhaps, in this interim period between not having any access to genetic information and having foetal genetic therapies, we are trapped within this confounding reality of being given too much information while not having enough constructive options with which to deal with it.⁷⁷ Although a woman has the right to reject any prenatal test, will knowledge of the existence of the technology cause her to feel a certain sense of responsibility to herself, her future family, her foetus and to society to seek out as much genetic knowledge as possible? Is there a certain sense of obligation that the availability of this technology instils within her? Could her choice to reject prenatal testing be spun in such a manner as to label her irresponsible and negligent? Through a series of changing medical norms and practices, a woman's choice to reject testing is undermined and even rendered neglectful.

⁷⁵ Auguste Comte, *The Positive Philosophy of Auguste Comte, Translated and Condensed by Harriet Martineau* (London: Bell Publishers, 1896), 20-21.

⁷⁶ Kolker and Burke, *Prenatal Testing: A Sociological Perspective*, 164.

⁷⁷ It must also be noted that although they would provide individuals with more options post testing, foetal genetic therapies, would also pose different ethical dilemmas, but dilemmas nonetheless.

By way of these tests, science and society are conveying that: If technology can provide you, the consumer, with this information, you have the *responsibility* to absorb the knowledge and act upon it. Although parents are not overtly forced by their physicians/genetic counsellors (or at least should not be) into testing their foetus for the battery of genetic abnormalities, they are subjected not only to an enormous amount of social pressure but also to an inescapable normalization of the notion that medical science and practice are good and ubiquitously legitimate. Now, we begin to see the link between the social forms of coercion that grow out of scientific norms and the discrete choices made by the liberal individual embedded within this social context. A woman, although compelled by internal pressures, is a member of a society that offers such technology, and thus feels pressured by her social context to test and not to produce a disabled person. She is an individual empowered with autonomous choice, but she does so as an *organ* of a greater whole—a society with norms that valorize science and ‘normality’ and devalue ‘disabled’ life.

The information age (with a little help from post-enlightenment, socially embedded science) has normalized the belief that access to more information (techne) will lead to a greater level of understanding (phronesis). It has also helped to legitimize science as the herald of fact and knowledge; therefore, the genetic revolution has had unparalleled success in captivating the masses with both its sensationalist developments and its more functional discoveries. The consequence is the occurrence of a tendency to ‘medicalize’ all deviant behaviours and all abnormal conditions, leading to the belief that genetic science will be capable of finding a ‘cure’ or ‘treatment’. In doing so, the ‘what is the gene for’ language is spuriously adopted by many who have become prey to the ‘one gene one disease’ hypothesis’, which has limited scientific validity.

Kerr and Shakespeare caution against espousing this discourse of genetic determinism. They reiterate the important point made by biologists Bateson and Martin: “No simple

correspondence is found between individual genes and particular behaviour patterns or psychological characteristics.... [Genes] do not code for parts of the nervous system and they certainly do not code for particular behaviours.”⁷⁸ Polygeny, the process by which many genes contribute to one variation, is seen as a more plausible argument in the explanation of the link between genotype and phenotype. Moreover, to disregard the impact of the environment on phenotype is also a faulty assumption, but one that is still, all too often, being made.

Wholly legitimate science heralds the study of genes “as a way of understanding the environmental aspects of disease and behaviour with too little attention being paid to the variability and uncertainties in knowledge about diseases and behaviours.”⁷⁹ Because of this, many mothers who decide to utilize prenatal testing fall victim to the faulty notion that these procedures will rule out all ailments, when in reality they provide information based only on uncertain and incomplete conclusions about the genetic makeup of a foetus. Many things can go wrong in the birthing process that may develop extraneous to all prenatal testing. Yet, the potential acquisition of this genetic information can provide the mother with a greater sense of control, and the feeling that she is not snubbing her *perceived, socially embedded* duty to make a genetically informed decision. The value placed on knowledge acquisition in this culture driven by techne and not phronesis, can override the catch-22 in which a mother may find herself post-testing. It may very well be that a woman, having prioritized the acquisition of scientific information over her right ‘not to know’, may undergo the procedures without fully considering how she would react to the spectrum of potential outcomes, at which point she is forced to make a decision in haste, or at least constrained (or empowered, depending on how you look at it) by knowledge.

⁷⁸ Kerr and Shakespeare, *Genetic Politics*, 110.

⁷⁹ *Ibid.*, 111.

The practice of aborting a foetus based on prenatal knowledge of its genetic future can be categorized as selective breeding, isolating for 'good genes'.⁸⁰ Once executed through forced sterilization and inhumane euthanasia, eugenics now occurs through abortion. The subjects of such practices have been reimagined: once the socially deviant, they are now the genetically disabled; once living people, they are now unborn. And yet, the consequences for the disability community are potentially equally dire.

Though parents now have the ability to decide whether they want to proceed with the birth of a baby with a genetic difference, society will be left to contend with the sum total of the discrete decisions. Whereas state-sponsored eugenics policies violated individual human and political rights, this new eugenics, grounded in principles of individual choice, can be seen to violate the collective rights of the disabled to live a life free of discrimination. How so? Distressing messages underlie the existence of prenatal tests which foster a hierarchical value system based on genetic makeup. Consider the following.

Does not the sheer existence of a prenatal test that seeks out a third copy of chromosome 21 automatically remove value from the life of individuals who live with Downs' Syndrome? If parents are given information regarding the existence of some genetic factor that will contribute or ultimately lead to certain genetic abnormalities, does this not suggest that these abnormalities would be better left out of the human gene pool? The existence of these prenatal technologies contributes to a societal perception that individuals with disabilities have less intrinsic value than those without. Present testing does not provide parents with information about eye colour or hair colour, and health care professionals withhold the sex of the foetus until after abortions are legally allowed because, within our liberal society, there is less tolerance for termination based on these qualities. But, when a genetic abnormality is in question, there are no legal

⁸⁰ It is important to note that the spectrum of chromosomes for which these procedures test includes both genes whose influence may lead to the death of the foetus or child and those whose influence may result in the birth of a child with non-life threatening impairments. Below, I discuss how the latter fit into the eugenics category, whereas the former do not, necessarily.

restrictions in place to stop a woman from terminating the pregnancy, nor are there limitations placed on which genetic abnormalities are divulged to the parents.⁸¹

It is important to note that existing procedures test for a spectrum of genetic conditions, varying from a disability as serious as Trisomy 18 to something as benign and non-debilitating as cleft lip.⁸² It is one thing to legitimate prenatal testing by appealing to parents' efforts to minimize the suffering of yet-to-be-born children, and quite another to provide information about disabilities that will not cause suffering at all. Kerr and Shakespeare explain, "People with sensory impairments or learning difficulties may be different, and may experience limitation, but they do not necessarily suffer as a result of their disability."⁸³ Despite this, information regarding these non-debilitating disabilities is still being provided to parents—information upon which they can and do base their decisions to abort.

Suddenly the purpose of these tests seems somewhat larger than the avoidance of suffering. Perhaps the purpose lies in the elimination of genetic difference. Perhaps the purpose lies in striving for a child who fits society's image of 'perfection' and/or 'beauty'.⁸⁴ Perhaps the purpose is simply to provide parents with the greatest amount of reproductive autonomy—an individual choice that transfers the burden of decision to them. In any case, there is still a prevalent sense of tragedy that is associated with the birth of a child who has a disability, almost as though that baby were tainted. Living in a society in which this attitude is fostered through

⁸¹ This remark is not meant to imply that I am in favour of curtailing a woman's right to choose. On the contrary, I am pro-choice. The purpose of the remark is to demonstrate that prenatal testing and access thereto has developed and evolved without the implementation of legislative restrictions and devoid of legislative consideration for the underlying messages of relative human value these technologies propagate.

⁸² Trisomy 18 is a genetic disorder with onset before birth characterized by severe heart defects, joint contractures, spina bifida, eye abnormalities, hearing loss, kidney defects, seizures, scoliosis, etc. 20-30% die within the first month of life, 90% die by age one. John Carey, *Trisomy 18 Facts* [Web Site] (Support Organization for Trisomy 18, 13 and Related Disorders, 2003 [cited November 17 2003]); available from http://www.trisomy.org/html/trisomy_18_facts.htm.

⁸³ Kerr and Shakespeare, *Genetic Politics*, 144.

⁸⁴ I suggest *beauty* here because cleft lip will leave a small scar on the lip of individual forever. This may be seen as an undesirable physical characteristic that may affect the child's beauty. I should also add here that many chromosomal abnormalities are also accompanied by higher incidences of other medical complications. For example, a child with Down's Syndrome has a higher risk of heart disease, cancer and diabetes. Parents are also grappling with these issues.

ignorance, misunderstanding or lack of exposure, may make it quite difficult for a mother (or father) to come to terms with bearing a child with a disability. And although the option of abortion is also psychologically and physically arduous, it may seem more palatable than that of raising an individual with some type of physical or mental impairment, regardless of what it may entail.

The prospect of a costly disorder may also provide impetus to opt for testing and then to abort if results are positive. Depending on the severity of a disability and the extent of one's health insurance coverage, a child with a disability may incur more costs to the parents than one without. In countries with universal health care, like Canada, this is less of a concern, unless of course a parent should choose to place her child in a private care facility. In the US, however, this consideration could potentially be the deciding factor in accepting prenatal testing, given the following case: "A health maintenance organization (HMO) denied coverage to a child born with cystic fibrosis. The condition had been diagnosed before birth, and the parents had chosen to have the child. The HMO eventually backed down."⁸⁵ Once again, in this case we can see how, depending on one's financial situation and one's willingness to contend with unscrupulous insurance companies, abortion may seem like the only possible financial option.

Thus, the link has been drawn. Socially embedded norms of science as good translate into real pressures that may urge a mother to select genetic testing and to abort the foetus. Since all liberal individuals who live as part of this context are subject to the same norms, the effects of their discrete choices, in aggregate, are felt en masse. The result is a liberal eugenics, harming those who live with disabilities.

⁸⁵ Kolker and Burke, *Prenatal Testing: A Sociological Perspective*, 175.

3.7 Conclusion

In this chapter, I have given a brief history of eugenic practices of the past, and a more detailed account of what I have called present-day 'liberal eugenics'. I have shown that social norms of science as good and the individual as primary have led to the legitimization of these new eugenic practices. Although the state has removed itself from coercively guiding eugenics, new reproductive practices and current medical practice, enabled by state choices, are contributing to a similar kind of threat to the disabled communities by allowing parents, through their medical practitioners, to select for 'good genes' prior to birth. As I have discussed and as Kerr and Shakespeare note: "The consequences of genetic testing and screening [include] the pressure to eliminate disabled fetuses, and the potential for intensification of discrimination and stigma against disabled people."⁸⁶ Different from the eugenics of the past, these aspects of genomics render "coercion less explicit and discrimination more covert."⁸⁷ That there is no formal dictate impelling citizens to be tested and to abort disabled fetuses should not be an indication that there is nothing amiss.

If this matter of liberal eugenics is not addressed by legislators and placed under some type of regulatory regime, society may find itself faced with intensifying eugenic practices, whereby discriminatory practices against persons with disabilities become deeply institutionally entrenched because of the belief that people with genetic conditions could have been terminated at the foetal stage. Aristotle provided much insight into how knowledge acquisition has gained such authority at the expense of ethical restraint. There is evidence that appeals to phronesis would assist in guiding developments in techne; however, liberal ideals seem to come into conflict with this type of political prudence. The regulation of prenatal testing, therefore, raises some difficult challenges for liberalism. In the next chapter I discuss why notions of individual

⁸⁶ Ibid., 159.

⁸⁷ Ibid.

autonomy, derived from liberal political theory, still retain primacy in access to prenatal tests despite the implications for liberal eugenics.

4.1 Introduction

Having discussed the potentially devastating effects of reproductive genetic technologies on disability communities, the next logical question to pose is: how do we prevent this from happening? Do we simply outlaw prenatal testing? Alternatively, perhaps we could limit the amount or type of information we give to the parents. Unfortunately, as with most regulation respecting reproduction, the solution to this conundrum is not simple.

The previous chapter explored how embedded social norms pressure individuals to choose genetic testing over rejecting it based on the belief that science is good. I discussed how the Enlightenment contributed to the legitimation of science as an authority, and how, in turn, that notion still informs biotechnology policymaking today. I also touched on the norm in liberal societies that sees the individual as primary. This valuation of the individual empowers her with the *right* to think, to act and to choose, as she so desires, irrespective of reasoning and/or obligation, and at the expense of fundamental group rights in the case of prenatal testing. In this chapter, I take up two central questions. (1) How did individual choice, growing out of liberal theory, become paramount in society, given the implications for liberal eugenics? (2) Are there *other aspects* of liberal theory (beyond free choice) that could be employed to help guide reproductive genetic technologies toward more equitable social policies?

To address the first question, belief in the legitimacy of certain rights prescribed by liberal individualism has led to the practice of liberal eugenics. Liberal society's tendency to embrace individual choice as the ultimate good has grown out of a progression of liberal thought. We see emerging traces of the autonomous individual-as-chooser in Locke's rights bearer and in Mill's free chooser. There is evidence that the right to access prenatal technologies is based on the triumphant notion of the individual as the primary decision-maker.

This case of genetic technologies is unique in that individuals feel a sense of managerial entitlement because their self-owned bodies are both the receptacles and purveyors of genetic information. Locke proposes the notion of the body as self-owned property, while Mill, although not a radical individualist like his earlier liberal counterpart, builds on Locke and constructs a theory of individuality in an effort to ensure a just and free society. In the following pages, I argue that the impassioned debate over the existence and use of reproductive genetic technologies is fuelled by liberal society's adherence to *certain* aspects of liberal theory—those notions that have granted the individual complete right to choice in all personal medical decisions. Ironically, these liberal principles, foundations of modern human and political rights frameworks, protect a citizen's right to autonomy of choice, but accordingly, promote liberal eugenics. The ensuing political implications are enormous for disability rights, women's rights, liberal democracy and human biodiversity. The double-edged nature of the technology is such that while for some it empowers and informs, for others it simultaneously victimizes and devalues.

In response to the second question, liberalism is not an absolute culprit in the creation of liberal eugenics—at least not in its pure theoretical form. The aggregate manifestation of individual rights has led to this unfortunate devaluation of selected types of human life, but it is important to note that liberal political theory also holds a wealth of constructive solutions to this conundrum. And although the translation from theory to practice may provide some difficulty, an acknowledgement and discussion of the theoretical resolutions may, in the interim, provide fodder for an initial attempt at genetic equity. In reply to this question, I will consider Mill's harm principle and Kant's Categorical Imperative. Moreover, I will show how the disabled community has used liberal ideas to construct an innovative model of disability that may assist in the dissolution of the prevailing social norms and values that have generated the stigmas associated with 'disability'.

In this chapter, I will first provide an overview of Locke's, Mill's and Kant's respective views of the liberal individual. Second, I will show how liberal notions of the body as property and the supremacy of individual choice have been ubiquitously adopted within liberal society despite the implications for liberal eugenics. Third, I will discuss other aspects of liberal theory that may assist policymakers in arriving at more equitable genetic policies.

4.2 Liberal Individualism

When we look at the international human rights framework or at the Canadian Charter of Rights and Freedoms, for example, we notice that the laws are entrenched to protect, primarily, the rights of the *individual* living within a given society. Granted, there have been amendments made to the charter to protect the rights of certain minority groups; but, overall, the objective of rights frameworks is to shield the individual from encroachments of state power, tyranny of the majority and assaults from other individuals/groups. Societies that view the individual as the primary holder of rights are built on a brand of liberalism known as 'liberal individualism'. As Jonathan Wolff explains, "A good example of a liberal individualist position is Locke's assumption that human beings are naturally free, equal, and independent."⁸⁸ Most liberalists who followed Locke picked up and rewove certain strands of the individualist fabric that he laid. In this section, I discuss the liberal theoretical foundations, found in Locke, Mill and Kant, which have contributed to society's valuation of the individual as primary. In doing so, I set up my ultimate argument: that the successes of the principles of 'the body as self-owned property' and 'the free-choosing individual' in ensuring individual autonomy have resulted in their societal 'normalization', validating and legitimizing individual rights, while simultaneously and ironically engendering a liberal eugenics through permitting access to prenatal reproductive technologies.

⁸⁸ Jonathan Wolff, *An Introduction to Political Philosophy* (Oxford: Oxford University Press, 1996), 197.

4.2a John Locke and the rights-bearing individual

The discussion begins with John Locke (1632-1704), the quintessential radical individualist. In the *Second Treatise of Civil Government*, Locke outlines his prescriptions for the organization of civil society. The book begins with account of the state of nature, “a condition in which men are free and equal.”⁸⁹ Locke describes this condition:

The state of nature has a law of nature to govern it, which obliges every one; and reason, which is that law, teaches all mankind...that, being all equal and independent, no one ought to harm another in his life, health, liberty, or possessions.... In transgressing the law of nature, the offender declares himself to live by another rule than that of common reason and equity...and so he becomes dangerous to mankind.⁹⁰

Locke compares the state of nature with ‘civil society’. While in the former, “every one has the executive power of the law of nature,”⁹¹ in his own hands and, thus, disorder might follow, in the latter, “the establishment of a government, but not of an absolute government, is the proper remedy for this.”⁹² It follows that “a political society exists only where men have agreed to give up their natural powers, and to erect a common authority to decide disputes and punish offenders.”⁹³ Although man lives under this common authority, Locke is explicit in his call for individual freedom.

The natural liberty of man is to be free from any superior power on earth, and not to be under the will or legislative authority of man, but to have only the law of nature for his rule. The liberty of man in society is to be under no other legislative power but that established by consent in the commonwealth; nor under the dominion of any will or restraint of any law, but what that legislative shall enact according to the trust put in it.... But freedom of men under government is to have a standing rule to live by, common to every one of that society, and made by the legislative power erected in it; a liberty to follow my own will in all things, where that rule prescribes not; and not to be subject to the inconstant, uncertain, unknown, arbitrary will of another man: as freedom of nature is to be under no other restraint but the law of nature.⁹⁴

⁸⁹ J.W. Gough, "Introduction," in *The Second Treatise of Civil Government*, ed. J.W. Gough (Oxford: Basil Blackwell, 1948), xii.

⁹⁰ John Locke, *The Second Treatise of Civil Government and a Letter Concerning Toleration*, ed. J.W. Gough (Oxford: Basil Blackwell, 1948), 5-6.

⁹¹ *Ibid.*, 8.

⁹² Gough, "Introduction," xiii.

⁹³ *Ibid.*, xiv.

⁹⁴ Locke, *The Second Treatise of Civil Government and a Letter Concerning Toleration*, 13.

Accordingly, Locke suggests that the state has the duty to safeguard the rights of the individual, among which he includes the right to property:

Though the earth and all inferior creatures be common to all men, yet every man has a property in his own person; this nobody has any right to but himself. The labour of his body and the work of his hands we may say are properly his. Whatsoever, then, he removes out of the state that nature hath provided and left it in, he hath mixed his labour with, and joined to it something that is his own, and thereby makes it his property.⁹⁵

This is an interesting and important point. For Locke, property naturally exists within the person of every individual. This personal property can be translated into material property through the use of one's labour.

He that is nourished by the acorns he picked up under an oak, or the apples he gathered from the trees in the wood, has certainly appropriated them to himself. Nobody can deny but the nourishment is his. I ask, then, When did they begin to be his? When he digested? or when he ate? or when he boiled? or when he brought them home? or when he picked them up? And 'tis plain, if the first gathering made them not his, nothing else could. That labour put a distinction between them and common; that added something to them more than nature, the common mother of all, had done, and so they became his private right.... And the taking of this or that part does not depend on the express consent of all the commoners. Thus the grass my horse has bit, the turfs my servant has cut, and the ore I have dug in any place where I have a right to them in common with others, become my property without the assignation or consent of anybody. The labour that was mine removing them out of that common state they were in, hath fixed my property in them.⁹⁶

Therefore, labour creates property and it is "labour indeed that puts the difference of value on everything."⁹⁷ The protection of both an individual's person and his material property fall under the duties of state laws, even though Locke believes it is a *natural* right along with life and liberty.

From all which it is evident that, though the things of nature are given in common, yet man, by being master of himself and proprietor of his own person and the actions or labour of it, had still in himself the great foundation of property; and that which made up the great part of what he applied to the support or comfort of his being, when invention and arts had improved the conveniences of life, was perfectly his own, and did not belong in common to others.⁹⁸

⁹⁵ Ibid., 15.

⁹⁶ Ibid., 15-16.

⁹⁷ Ibid., 22.

⁹⁸ Ibid., 23.

As a member of the social contract, the individual must divest himself of certain liberties available to him in the state of nature—heinous and senseless freedoms like brute violence, for example—so that he may enjoy the legal protection of his natural rights.

Men being born, as has been proved, with a title to perfect freedom, and an uncontrolled enjoyment of all the rights and privileges of the law of nature, equally with any other man or number of men in the world, hath by nature a power not only to preserve his property—that is, his life, liberty, and estate—against the injuries and attempts of other men, but to judge of and punish the breaches of that law in others as he is persuaded the offence deserves, even with death itself, in crimes where the heinousness of the fact in his opinion requires it.⁹⁹

Locke paints a rather clear picture of the position of the individual in society.

Adherence to the social contract is based, in theory, on the individual's *voluntaristic obligation*; that is, "the existence of the state can be explained in voluntaristic terms...—that every last individual (or at least every mentally competent adult) has given the state its authority over them."¹⁰⁰ Although there are obvious practical problems with social contract theory, analyzing it is beyond the scope of this thesis. What I wish to draw out from Locke's theory is the implied agency of the individual within society. He has the freedom to seek membership; he is naturally endowed with property and is socially empowered with the choice to acquire material property through physical labour. He is a bearer of rights, with entitlement to life, liberty and the protection of property. The sole end of the state is to ensure protection of these individual freedoms and "the great and chief end...of men's uniting into commonwealths, and putting themselves under government, is the preservation of their property."¹⁰¹

4.2b John Stuart Mill and the free choosing individual

John Stuart Mill (1806-1873) is known for his writings on liberalism and individuality.

On Liberty (1859) discusses individual freedom and has three main themes:

⁹⁹ Ibid., 42-43.

¹⁰⁰ Wolff, *An Introduction to Political Philosophy*, 43.

¹⁰¹ Locke, *The Second Treatise of Civil Government and a Letter Concerning Toleration*, 62.

It is a plea for the widest possible scope for freedom of speech; it is a defence of individuality; and it seeks to provide a criterion for distinguishing between those actions which should be left for the individual to treat as his own concern and those in which 'society' or the State is justified in interfering.¹⁰²

In *On Liberty*, and specifically in its third chapter entitled *Of Individuality*, Mill presents his theory on the liberty of the human being to assert individual agency. A mistaken reading of Mill would suggest that his liberal individual is a rational utility maximizer, who pursues his own interests, and who seeks pleasure and avoids pain. Such an interpretation fails to see the nuances within Mill's view of the liberal self. He is primarily concerned with "get[ting] support for individual liberty in a society where it is not generally prized,"¹⁰³ and protecting the individual from any unwarranted interference by the state.

Mill recognizes that men may pursue higher ends than pleasure...and he even recognizes the possibility of altruistic or other-regarding feelings of sympathy and compassion. Nevertheless, society continues to be viewed as a system of independent centres of consciousness, each pursuing its own gratification and confronting the others as beings standing-over-against the self, which is to say, as objects.¹⁰⁴

Whereas Bentham's view of the utility maximizing individual is considerably more stark than Mill's, failing to account for the possibility that the good of society may (or should) trump the good of the individual, Mill makes an allowance, albeit small, for the exertion of state power over autonomy of individual agency. Freedom of speech and thought, according to Mill, should never be curtailed; however, he recognizes that liberty of action, although of utmost importance for individual freedom, can be justifiably controlled in some instances.

The sole end for which mankind are warranted, individually or collectively, in interfering with the liberty of action of any of their number, is self-protection. That the only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant.¹⁰⁵

¹⁰² H.B. Acton, ed., *Introduction, Utilitarianism, Liberty, Representative Government* (London: J.M. Dent & Sons Ltd., 1972), xx.

¹⁰³ *Ibid.*, xxiii.

¹⁰⁴ Robert Paul Wolff, *The Poverty of Liberalism* (Boston: Beacon Press, 1968), 142.

¹⁰⁵ John Stuart Mill, "On Liberty," in *Utilitarianism, Liberty, Representative Government*, ed. H.B. Acton (London: J.M. Dent & Sons Ltd., 1972), 73.

This implies, therefore, that the individual is accountable to society when his actions impinge upon the interests of others. So the Millian liberal individual is free in thought, speech and action, but always with a concern for justice: "To individuality should belong the part of life in which it is chiefly the individual that is interested; to society, the part which chiefly interests society."¹⁰⁶ The theory seems simple enough if it sees every man for himself; however, Mill's accounting for the wellbeing of others complicates the workings of his theory; some have argued that it renders it inconsistent. How does Mill reconcile this autonomous, rational individual with the society?

Mill recognizes that the individual and society are inextricably interwoven:

...Each [individual] should be bound to observe a certain line of conduct towards the rest. This conduct consists, first, in not injuring the interests of one another; or rather certain interests, which, either by express legal provision or by tacit understanding, ought to be considered as rights; and secondly, in each person's bearing his share (to be fixed on some equitable principle) of the labours and sacrifices incurred for defending the society or its members from injury and molestation.... The acts of an individual may be hurtful to others, or wanting in due consideration for their welfare, without going to the length of violating any of their constituted rights. The offender may then be justly punished by opinion, though not by law. As soon as any part of a person's conduct affects prejudicially the interests of others, society has jurisdiction over it, and the question whether the general welfare will or will not be promoted by interfering with it, becomes open to discussion. But there is no room for entertaining any such question when a person's conduct affects the interests of no persons besides himself, or needs not affect them unless they like (all the persons concerned being of full age, and the ordinary amount of understanding). In all such cases there should be perfect freedom, legal and social, to do the action and stand the consequences.¹⁰⁷

This passage points to the complexity of Mill's theory of individual liberty. He acknowledges that not even the legal system is thorough enough to protect the entire gamut of societal and individual interests; therefore, an individual who *legally* engages in autonomous action may concurrently be violating the rights of another. In these cases he advocates for open social discussion, a forum in which the opinions of the delegates will carry the decree. Mill attempts to distance the autonomous individual from being forced to act in accordance with the wishes of

¹⁰⁶ John Stuart Mill, "On Liberty," in *Three Essays* (Oxford: Oxford University Press, 1975), 92.

¹⁰⁷ *Ibid.*, 92-93.

others, while at the same time protecting the rights of others from being infringed upon by actions of the autonomous individual.

Despite the implied interconnectedness of society and the individual, a caveat exists to admonish the individual from blindly complying with social convention. Mill cautions against mindless acceptance of the torpid custom that swathes society. The individual has a series of capacities that are socially shaped and educated. Through the proper socialization, the individual makes reflective choices, fulfilling his moral obligations to others. As Donner explains, "Mill's competent judges are rational and benevolent agents who have been provided with an initial set of social standards and then asked to evaluate and choose those pleasures and projects worth pursuing both individually in the private sphere and socially in the realm of public choice. He thus specifies the sort of agents who make these choices, explaining how they are to be educated for the task."¹⁰⁸ Mill emphasizes that:

...to conform to custom, merely as custom, does not educate or develop in him any of the qualities which are the distinctive endowment of a human being.... The human faculties of perception, judgement, discriminative feeling, mental activity, and even moral reference, are exercised only in making a choice. He who does anything because it is the custom, makes no choice. He gains no practice either in discerning or in desiring what is best. The mental and moral...powers are improved only by being used.... He who lets the world...choose his plan of life for him, has no need of any other faculty than the ape-like one of imitation. He who chooses his plan for himself, employs all his faculties.¹⁰⁹

Thus, Mill's competent agents are prepared not only through experience, but also through education to judge the value of pleasures and subsequently make their choices. Reason, rational thought and education all contribute to the fulfillment of one's capacities to be a free-choosing agent. The opportunity to make individual choice is essential in the development of a human because choice, in itself, is educative.

¹⁰⁸ Wendy Donner, *The Liberal Self: John Stuart Mill's Moral and Political Philosophy* (Ithaca: Cornell University Press, 1991), 143.

¹⁰⁹ Mill, "On Liberty," 72-73.

Moving from Locke to Mill, we see the thread of liberal individuality lace its way through both of their theories, in very distinct and influential ways. In each, we see evidence of the individual endowed with agency—in the first as property owner, and in the second as free-chooser. These aspects of liberal individualism have informed the structures of our modern liberal states, and are therefore, still widely accepted and wholly legitimate when applied to the legal system.

4.2c Immanuel Kant and the individual as a being

Immanuel Kant (1724-1804), also a liberal philosopher concerned with individuality, sees the human being as capable of rationally-motivated agency; however, his theory diverges from those previously discussed in his views of life as an end in itself:

Man and generally any rational being *exists* as an end in himself, *not merely as a means* to be arbitrarily used by this or that will, but in all his actions, whether they concern himself or other rational beings, must be always regarded at the same time as an end.... Rational beings...are called *persons*, because their very nature points them out as ends in themselves, that is, as something which must not be used merely as means, and so far therefore restricts freedom of action (and is an object of respect).¹¹⁰

This, Kant's view of human life as an end in itself, is the cornerstone of his moral theory. For Kant, the heart of morality is the struggle between duty and inclination, between reason and desire; nevertheless, the two are inextricably intertwined with respect to the will. Wolff summarizes Kant's view of the relationship between the two: "Reason without desire is impotent; desire without reason is blind."¹¹¹ Desire is a weakness in humankind, a temptation to which the will is exposed, and to have a will is to be capable of being moved by reason. Kant expresses the interrelation between reason, desire and the will:

But if reason solely by itself is not sufficient to determine the will; if the will is exposed also to subjective conditions (certain impulsions) which do not always harmonize with the objective ones if... the will is not *in itself* completely in accord with reason (as actually happens in the case of men); then actions which are recognized to be

¹¹⁰ Immanuel Kant, "The Categorical Imperative," in *Contemporary Moral Issues*, ed. Wesley Cragg and Christine M. Koggel (Toronto: McGraw-Hill Ryerson Limited, 1997), 543.

¹¹¹ Robert Paul Wolff, *The Autonomy of Reason: A Commentary on Kant's Groundwork of the Metaphysics of Morals* (New York: Harper & Row Publishers, 1973), 119.

objectively necessary are subjectively contingent, and the determining of such a will in accordance with objective laws is *necessitation*.¹¹²

So, it seems as though Kant believes that agency should be rationally motivated; however, given that man is fallible, although he may rationally know what is right, he may succumb to desire, yielding a blameworthy act. But given that Kant's is a deontological theory, moral viability or iniquity of an act cannot be based on the consequence of that act but only on the motive for it.

Kant's *Imperative* provides further insights into how a rational, moral individual is motivated to act.

The conception of an objective principle, so far as it constrains a will, is a command (of reason), and the formula of this command is called an *Imperative*.... So imperatives are only formulae for expressing the relation of objective laws of willing to the subjective imperfection of the will of this or that rational being—for example, of the human will.¹¹³

Moral laws are not commands, but “principles of practical reason which are *experienced* as commands only by creatures who might be inclined to violate them.”¹¹⁴ Kant's Categorical Imperative states: “Act only on that maxim through which you can at the same time will that it should become a universal law.”¹¹⁵ This imperative is predicated upon the hypothetical proposition, “If man is capable of rational agency (if man can be moved by reason), then he stands under the Categorical Imperative.”¹¹⁶

Kant then goes on to discuss the value of ends and concludes that “products of our will, states of affairs, and things which we employ for our several purposes are clearly only of relative value. That is, their value is relative to the purposes for which they are employed or the desire which they satisfy.”¹¹⁷ The only thing, therefore, that serves as an end in itself, is a human. The Categorical Imperative, henceforth, stipulates:

¹¹² Immanuel Kant, *Groundwork of the Metaphysics of Morals*, ed. Paul Menzer, trans. H.J. Patton (New York: Harper & Row, Publishers, Harper Torch Books, 1964), 412-13.

¹¹³ *Ibid.*, 413-14.

¹¹⁴ Wolff, *The Autonomy of Reason: A Commentary on Kant's Groundwork of the Metaphysics of Morals*, 124.

¹¹⁵ Kant, *Groundwork of the Metaphysics of Morals*, 421.

¹¹⁶ *Ibid.*

¹¹⁷ Wolff, *The Autonomy of Reason: A Commentary on Kant's Groundwork of the Metaphysics of Morals*, 175.

Act in such a way that you always treat humanity, whether in your own person or in the person of any other, never simply as a means, but always at the same time as an end.¹¹⁸

The notion of autonomy runs implicitly through this discussion of the rational, moral agent and the Categorical Imperative. Kant addresses it in the following way. In acting on laws that one has given to oneself and being bound to them by virtue of having so given them, would this not lead to a crisis of ethics? How could the law I make and wish to act upon be universally acceptable and demand that all be accountable to it? Kant's solution to this problem is that "all who legislate, must do so disinterestedly, that is to say, legislating independently of or in abstraction from the particular interests of the agent."¹¹⁹ Thus for anyone to create a law that binds universally, she must abstract from any interest she may have *and also* from any interest that any other agent may have. Then autonomy lies in the rules governing how the imperative binds the individual: "a categorical imperative can only move me insofar as I will it myself...." Needless to say, it remains open whether there can be a valid categorical imperative, but if there can be—if pure reason is to be practical at all—then it (pure reason) must be autonomous.¹²⁰

To summarize, the liberal conception of the self that Kant sets forth is: a rational, moral individual who, through his possession of freedom to act in accordance with his conception of laws (i.e. his will), attempts to act according to self-legislated universally-binding imperatives that he has created in abstraction from interest. He does all this while ensuring that he never instrumentalizes a human being because humanity is endowed with the intrinsic attribute of dignity. In the same way that we can see traces of Locke and Mill in our legal system today, Kant's notion of human life as an end in itself is also implicit in many laws.

Undeniably, there is worth in each of these philosophers' theories. Their merits extend far beyond the theoretical realm and well into the practical, as these theories represent the foundations of our modern liberal states, replete with our highly coveted rights and freedoms.

¹¹⁸ Kant, *Groundwork of the Metaphysics of Morals*, 429.

¹¹⁹ Wolff, *The Autonomy of Reason: A Commentary on Kant's Groundwork of the Metaphysics of Morals*, 179.

¹²⁰ *Ibid.*, 180.

Conversely, these rights to property, autonomy and choice are factors that directly contribute to the discrimination of the disabled in the face of the genetic revolution.

4.3 Question #1: How has individual choice become paramount in the question of reproductive genetic technologies?

Each of the conceptions of the liberal individual as set forth by Locke, Mill and Kant was proposed as a way to increase individual liberty and to stimulate the attainment of the 'good life'. Today, we can clearly see evidence of their influences within the liberal and human rights frameworks established within liberal democracies and on the international level. Entrenched within charters and constitutions are the political manifestations of the characteristics embodied by the various conceptions of the liberal selves. Autonomy of choice and action, self-determination, justice, freedom of speech and non-discrimination are all hallmarks of liberal democracies; they are also all derivatives of the above-mentioned theories. The practice of prenatal diagnostic testing provides a very interesting case through which we may assess the dominance of individual decision-making within the modern medical system. Whereas allowing unfettered access to the technology and leaving all aspects of the decision to individual choice supports the liberal value of autonomy with respect to the body as self-owned property, it simultaneously contributes to the occurrence of liberal eugenics, thus impinging on the right to non-discrimination, and even life, of the disabled. A rights paradox surfaces from this irreconcilable tension: complete individual autonomy over one's body results in the instrumentalization of the human life of another. This tension, however, is not easily resolved through regulation (if resolvable at all), since to renege on a woman's right to choose is to commit a grave injustice. Then again, to remain unaware of the contraventions against human dignity, which develop as a result of prenatal diagnostic tests, is an equally faulty legislative

stance. Given this contravention of human rights, how has individual choice become paramount in the question of reproductive genetic technologies?

4.3a To protect one's body

Access to prenatal genetic technologies has revolutionized human reproduction, offering a lens into the sacred and unspoiled environment of the human womb—a milieu whose workings were inaccessible to humans for centuries. Developments in genetics give parents the sense that they have the ability to glimpse into the future of their unborn child. A process that has historically involved a considerable amount of risk and uncertainty has now been rendered more transparent, or so it seems. Although prenatal diagnoses can only provide a probability of contingency concerning certain genetic conditions, parents now have access to information that was virtually unobtainable just two decades ago. What does this mean for the reproductive ‘enterprise’? It has been argued that prenatal knowledge of the foetus’s genotype increases a woman’s autonomy over her own body since any decision she and her partner decide to make with respect to the pregnancy will be more informed by medical science and statistics. To seek greater control over one’s body and its functions appears to be an instinctive desire. Its political roots can, however, be traced back to Locke’s notion of the body as self-owned property. Genetic technologies, more than ever, provide individuals with information that increases their perceived sense of bodily control. Since liberal rights schemas have entrenched the sanctity of the body as a central value, the individual right to access prenatal diagnostic tests appears to be not only a wholly legitimate option but in many cases an imperative. In this section, I will show how Locke’s model of the body as property contributes to the legitimation of individual hyper-autonomy when accessing prenatal tests, resulting in the application of the free-choosing aspect of Mill’s theory with a social disregard for the negative externalities.

It is not difficult to understand why most people feel a special attachment to their bodies. It is not difficult to understand why most people desire administrative rights over their bodies. For John Locke, protection of one's body is a natural right. As we saw in section 4.2a, bodily labour is the vehicle through which a person may legitimately attain other property, which then is also subject to legal protection. Therefore, Locke makes the case that not only is the body an entity with intrinsic rights to protection, but our use thereof is crucial to the acquisition of all other property.¹²¹ He says: "no one ought to harm another in his life, health, liberty, or possessions."¹²² These four natural rights are contingent upon protection of the body, which must be guaranteed both by the laws of nature and civil society. Life and health depend upon the physical well being of the body, and liberty is based on "being master of himself and proprietor of his own person and the actions or labour of it."¹²³ Therefore, an individual, as 'master of his own person', must have complete entitlement to any and all decisions regarding his body. When we apply these ideas to the medical context, there is evidence that Locke has made an impact. A patient has the right to make all medical decisions that concern her body. She always has the right to accept or reject any medical treatment. She has the right to sign a 'do not resuscitate' form in the case that she should be close to death and want to refuse medical intervention that may prolong her life. Common medical practice in liberal democracies is to give complete autonomy of choice over one's body to its proprietor, in line with Locke's beliefs.

In the case of reproduction, the issues have not always been as clear-cut. Women have fought many difficult battles in pursuit of reproductive freedom. With the introduction of prenatal diagnostic technologies, women, who have battled so ardently for and, justly, acquired abortion rights, have reached another level in the fight for reproductive autonomy. The result

¹²¹ See footnote 96.

¹²² Locke, *The Second Treatise of Civil Government and a Letter Concerning Toleration*, 5-6.

¹²³ *Ibid.*, 23.

has been the primacy of individual choice in matters of reproduction.¹²⁴ What exactly does this right entail and how is it exercised in the realm of reproductive technologies? The term "autonomy" literally means self-rule and is frequently translated as self-determination.¹²⁵

Respect for individual autonomy is a touchstone of modern liberal states and is often expressed in the language of human rights. Juxtaposed to the language of paternalism, the concept of autonomy "is a commitment to recognizing the right of the individuals to make certain sorts of decisions for themselves, free from coercion, manipulation, deceit or interference".¹²⁶

This view was of special significance to the reproductive and sexual health stage of the women's rights movement. We can come to understand the importance of autonomy over one's body when we consider the battle women fought in the 1960s and 1970s to secure their legal right to choose abortion. Prior to the legalization of abortion (or its removal from the penal code, as in Canada), women were forced to undergo clandestine abortions in the event of an unwanted pregnancy. The morbidity rate and risk of death in these under-the-radar procedures was frighteningly high. Moreover, "the punitive behaviour of others towards women having an abortion [was] one of the most harmful aspects."¹²⁷ Although the decriminalization of abortion has not dissolved the castigatory attacks on women who seek this option, it has helped in the legitimization of the practice. Worldwide legalization of abortion is indisputably necessary if we hope to render the practice safe and accessible to all women. This legal breakthrough was of significant importance in advancing individual autonomy and in liberating women from the shackles in place to limit their reproductive choices. The struggle for the right to choose

¹²⁴ Although, recent legislation in the U.S. banning partial birth abortions indicates that the public (not to mention the present administration) still struggles with issues regarding reproductive rights.

¹²⁵ Susan Sherwin, "Toward an Adequate Ethical Framework for Setting Biotechnology Policy," (Ottawa: Canadian Biotechnology Advisory Committee, 2001), 20.

¹²⁶ Ibid., 21.

¹²⁷ Marge Berer, "Making Abortion a Woman's Right Worldwide," *Reproductive Health Matters* 10, no. 19 (2002): 3.

abortion is also a testament to the dominance of the Lockean notion of individual property rights, wherein the body *is* the property.

4.3b The legitimacy of individual autonomy

Equally noteworthy is the effect of the genetic revolution on the reproductive autonomy of both men and women. Not only has it brought new meaning to the uniqueness and inviolability of the body (as proposed by Locke), but it has also thrust the idea of individual choice to the vanguard of individual rights. The technologies that are now available and the knowledge that is now accessible have given new momentum to the idea of autonomy over one's body. Society's ability to acquire information that was historically beyond reach inevitably increases humanity's desire to access genetic knowledge because, in doing so, the individual will presumably make more informed decisions. Mill expounds the idea that seeking out information pertinent to decisions enriches autonomy and human individuality:

[The individual] must use observation to see, reasoning and judgement to foresee, activity to gather materials for decision, discrimination to decide, and when he has decided, firmness and self-control to hold to his deliberate decision. And these qualities he requires and exercises exactly in proportion as the part of his own conduct which he determines according to his own judgement and feelings is a large one.¹²⁸

It is evident that Mill's individual must make *reflective* choices—an activity that involves gathering information, making observations, and employing reason and discrimination—in order to better assert his/her individual autonomy.

How, then, does access to prenatal genetic technologies increase reproductive autonomy through informed choice? It could be argued that recent developments in genetic science can now provide individuals and society with greater understanding of human biology and the causes of disease. In theory, having more knowledge leads to a greater level of understanding, which allows a more informed decision to be made, thus increasing autonomy. A mother who

¹²⁸ Mill, "On Liberty," 73.

seeks out prenatal testing to find out the genetic condition of her foetus actively “gather[s] materials for [her] decision.”¹²⁹ Access to this technology contributes to her ability to make a reflective choice, as prescribed by Mill. As explained in Chapter II, prenatal diagnosis of genetic conditions provides expecting parents with a probabilistic indication of the potentiality of having a child with any of the identifiable genetic disabilities. With this extra, albeit imperfect, knowledge, parents can make certain decisions—not only regarding the fate of their pregnancy, but also concerning the planning involved in having a child with a given genetic condition—based on empirical statistical and genetic information.¹³⁰

This knowledge may also affect the way in which women view abortion. As Berer explains, “women have abortions for only one reason—because they cannot cope with a particular pregnancy at a particular time.”¹³¹ Whereas before the existence of prenatal diagnosis, this inauspicious condition was most likely social in character—or if medical, then in regards to the parents’ health—now, a ‘particular pregnancy’ may indicate a foetus with a genetic abnormality. This type of information could be of crucial importance to a young, unemployed woman who does not have the personal financial means to care for a child with a disability, nor an adequate medical insurance plan. Perhaps she would consider having the child if the probability of its being genetically healthy outweighed that of its having an abnormality; however, the irregular prediction renders carrying the pregnancy to term a financial impossibility. This medical knowledge can add a new dimension to the right to choose abortion.

Granted, there has always been a sense of self-protection associated with the notion of body; however, the genetic revolution has almost concretized the essence of ‘humanness’. With the mapping of the human genome, people now have a way to access ‘empirical causal evidence’ in the prediction of certain disabilities. ‘Not only is my body physically mine, but

¹²⁹ Ibid.

¹³⁰ I will discuss, below, the dangers of placing too much credence in this ‘empirical’ information and why our liberal societies have given so much legitimacy to all data and procedures derived from science and technology.

¹³¹ Berer, “Making Abortion a Woman’s Right Worldwide,” 3.

now I can draw the causal link between my genes and my traits. I can tell you that gene X on chromosome Z made my eyes blue.’ Locke’s view of the body as self-owned property is further legitimated through the prevalent (and skewed) societal belief in genetic determinism. Perhaps there is a new sense of entitlement when making decisions based on ‘genetic evidence’? ‘I have a greater right to abort because now I *‘know’* that my child will have X disorder.’ There is a growing sense that now we have *more* than just our bodies to protect, we now have our sacred genetic code to protect and keep private. Belief in the authority of genetic science to discover molecular ‘evidence’ for disease increases our sense of entitlement to all decision-making regarding our own bodies. Therefore, we can see how Mill’s reflective, autonomous individual becomes the primary holder of rights, and how individual choice becomes paramount in policies regarding access to reproductive genetic technologies.

4.4 Question #2: Are there *other aspects* of liberal theory (beyond free choice) that could be employed to help guide reproductive genetic technologies toward more equitable social policies?

The consequences of the sum of individual choices, however, beg questions of social implication. Given the primacy of individual reproductive choice, how do we safeguard against liberal eugenics? Liberal theorists like Locke and Mill developed theories on individuality and liberalism in an effort to ensure social justice, to increase liberty, to protect individual and minority rights and to shield against state and social tyranny. It seems as though biotechnology policy documents include clauses that warrant state intervention should individual choices impinge upon the interests of others. Sherwin explains that in the Canadian Biotechnology

Strategy Consultation documents, autonomy is defined as "recognition of each individual's right to make informed decisions about his or her use of biotechnology".¹³² She goes on to say:

Interpreting autonomy as informed personal choice reflects a popular understanding of the concept as it is frequently invoked in political contexts. This usage captures deeply held views about citizens' relationship to the state. It speaks specifically to the need to restrict the state from undue interference in individuals' pursuit of their personal preferences. One of the common assumptions of the modern democratic state is that there must be a sphere of individual privacy outside of the reach of state intrusion. Thus, there is virtual consensus within Canada on the view that the state should refrain from interfering in matters of personal freedom unless there is a very clear risk of harm to specific others. Many proponents of the decriminalization of abortion have embraced this notion of autonomy, framing their position as one of being "pro-choice" in support of women's right to make their own decisions regarding pregnancy continuation or termination. Autonomy language is often used to assert individual rights against state interference with matters of personal morality and action.¹³³

This analysis of the significance of informed choice is astoundingly consistent with Mill's views on individual autonomy and reflective decision-making; in fact, it is almost verbatim from *On Liberty*.¹³⁴ This passage from the consultation document also demonstrates a practical application of Mill's harm principle: "the only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others.... The only part of the conduct of any one, for which he is amenable to society, is that which concerns others."¹³⁵ There is, thus, textual evidence, both in Millian political theory and in the Canadian Biotechnology Strategy Consultation document, that, in the instance of harm to others, individual choice should be regulated and/or curtailed. Why, then, do individual rights still prevail when people with disabilities suffer discrimination, or harm, as a result? How can liberal political theory help us understand why policymakers have not seen "the very clear risk" that prenatal testing poses for the disabled?

¹³² Sherwin, "Toward an Adequate Ethical Framework for Setting Biotechnology Policy," 21.

¹³³ Ibid.

¹³⁴ See quote that corresponds with footnote #105 above.

¹³⁵ Mill, "On Liberty," 15.

4.4a The weight of social tyranny

I have discussed how the genetic revolution has contributed to the individual's sense of entitlement over her own body and, in turn, how this notion renders individual choice paramount. Another contributing factor is the influence of society over the individual. Certainly, a mother in a doctor's office will feel entitled to make an autonomous decision, but it is important to note that she is *one* agent acting within a very complex environment, replete with other agents, hidden pressures and social norms. That women are opting for the testing more often than not is an indication that there is a sense of perceived utility within these tests. People who choose to undergo prenatal diagnostic testing do so in hopes that the resulting information will either provide peace of mind should all the tests come out negative, or will equip them with the data necessary to make a decision which they believe will lead to an end that most closely approximates their sense of what is right for them. What is probably less obvious to them is that their perceived sense of right or personal utility is a product of their education, socialization and experience. Social opinion and embedded norms influence individual perception in all domains of life, but especially within the sphere of genetics and disability. Mill helps to illuminate the dangers of social tyranny:

...When society itself is the tyrant—society collectively, over the separate individuals who compose it—its means of tyrannizing are not restricted to the acts which it may do by the hands of its political functionaries. Society can and does execute its own mandates: and if it issues wrong mandates instead of right, or any mandates at all in things with which it ought not to meddle, it practises a social tyranny more formidable than many kinds of political oppression, since, though not usually upheld by such extreme penalties, it leaves fewer means of escape, penetrating much more deeply into the details of life, and enslaving the soul itself. ...There needs [to be] protection...against the tyranny of the prevailing opinion and feeling; against the tendency of society to impose, by other means than civil penalties, its own ideas and practices as rules of conduct on those who dissent from them; to fetter the development, and, if possible, prevent the formation, of any individuality not in harmony with its ways, and compel all characters to fashion themselves upon the model of its own.¹³⁶

To understand the role of social tyranny in individual prenatal decision-making, let us consider the following case. A pregnant woman, Tanya, and her partner, Nick, have been

¹³⁶ Ibid., 9.

informed of their prenatal diagnostic options by their medical professional. Tanya's pregnancy is not at high risk for any genetic abnormality (i.e. there is no family history nor is she over 40). The doctor provides them with the list of examinations that are available and the risk involved with each. She also tells them the disabilities for which the technology tests. Neither Tanya nor Nick knows any individuals who have any of the disabilities the doctor mentions; however, they are familiar with several of the genetic conditions through media exposure. After conferring with each other, and weighing all the costs and benefits, the couple decides that they would rather give up the pregnancy than have a child with a genetic abnormality that could have been detected prior to birth; therefore, they opt for the testing with the intention of aborting should they receive positive test results for any abnormality. They base their decision on the belief that, for them, a disabled child would represent too much of an emotional burden. They could not endure the thought of bringing a child into this world who would suffer as a result of a genetic makeup they could have foreseen. By choosing to take advantage of the technologies, Tanya and Nick wield their reproductive freedoms through informed choice since science provides them with knowledge otherwise unattainable.

Let us consider for a moment upon what *type* of information Tanya and Nick have based their choice to abort. The prenatal test reveals that their foetus has a probability of being born with cystic fibrosis. The couple has never had a child, able-bodied or disabled. The couple knows nothing about cystic fibrosis, other than the information they receive from the doctor. How *truly* informed is their decision? If their perceptions of life with a disabled child have been primarily informed by the media, perhaps Tanya and Nick are not competent judges of the pleasure or pain derived from that circumstance. Moreover, if their education has not included modules on reproductive science or on the sociology of disability, this might also preclude them from acting in accordance with their own personal beliefs, because they are basing their

decisions not on experience or education, but on a socially constructed view of disability, which has also consumed their viewpoint.

Scientific hyper-legitimacy, a socially embedded norm rooted in society's desire for progress, is a social tyrant that constrains women's reflective choices. The National Academy of Sciences states: "Autonomy is also the right of the individual to control his or her destiny, with or without reliance on genetic information, and to avoid interference by others with important life decisions, whether these are based on genetic information or other factors."¹³⁷ So, on the one hand, and in line with Mill's free-chooser, parents have the autonomy to opt for prenatal diagnosis and, based on their feelings regarding the outcome of the tests, decide to keep or abort the foetus. This is their prerogative as autonomous free individuals. On the other hand, the right to opt *against* testing is also within the realm of Millian rights of as autonomous individuals. This autonomous right would therefore sanction an individual's entitlement to genetic ignorance. Yet, this right is fraught with many an ethical impasse.

As a citizen of a liberal state, I am afforded the right to reject any medical procedure; however, if the objective of the procedure is to provide genetic information which will lead to a greater understanding of the future health of my foetus, would not a decision made subsequent to the acquisition of this information be more informed and thus more autonomous? If I choose to reject a prenatal test, I am selecting to leave the fate of my foetus to chance. In so doing, am I not following a path without autonomy? Rosamond Rhodes takes this argument further:

If autonomy is the ground for my right to determine my own course, it cannot also be the ground for not determining my own course. If autonomy justifies my right to knowledge, it cannot also justify my refusing to be informed. I may not be aware of the moral implications of ceding autonomy by insisting on genetic ignorance, but the ramifications are there, nevertheless.¹³⁸

¹³⁷ National Academy of Science, "Social, Legal, and Ethical Implications of Genetic Testing," in *Ethical Issues in Biotechnology*, ed. Richard Sherlock and John D. Morrey (Lanham: Rowman & Littlefield Publishers, Inc., 2002), 376.

¹³⁸ Rosamond Rhodes, "Genetic Links, Family Ties, and Social Bonds: Rights and Responsibilities in the Face of Genetic Knowledge," in *Ethical Issues in Biotechnology*, ed. Richard Sherlock and John D. Morrey (Lanham: Rowman & Littlefield Publishers, Inc., 2002), 426.

This view of autonomy shows how women's rights to embrace or reject this technology on a personal level are being perverted. The social pressure derived from the existence of prenatal genetic tests that is placed on women renders obsolete their ability to make autonomous decisions. Although there is no overt coercion, this post-enlightenment belief in the value of scientific knowledge and its merits in aiding decision-making; could skew a woman's inclination to reject testing in convincing her to consider the 'good of society', or perhaps just in convincing her that her decision is less valid behind the veil of genetic ignorance. Let us consider the pressures that biologist Ruth Hubbard, brings to light:

Once a technique exists to identify a foetus that will be born with a particular disability, individual women and families become responsible for acting out these prejudices. If a test is available and a woman doesn't use it, or completes the pregnancy although she has been told that her child will have a disability, the child's disability is no longer an act of fate. She is now responsible; it has become her fault. In this liberal and individualistic society, there may be no need for eugenic legislation. Physicians and scientists merely provide the techniques that make individual women, and parents, responsible for implementing the society's prejudices, so to speak, by choice.... And once the means to avoid bearing a child with a particular disability are available, women who have medical and financial access to that so-called choice may not feel entitled to refuse.¹³⁹

Again, Mill cautions against the constricting opinions of society:

There needs protection also against the tyranny of the prevailing opinion and feeling.... There is a limit to the legitimate interference of collective opinion with individual independence: and to find that limit, and maintain it against encroachment, is as indispensable to a good condition of human affairs, as protection against political despotism.¹⁴⁰

He is very clear about the oppressive influence of prevailing discourses. Dominant social views of disability as a 'tragedy', as a 'genetic mistake' and as a 'burden' infiltrate the personal opinions of mothers who are in the midst of making reproductive decisions. There is a prevailing sense that ruling out foetal genetic abnormalities prior to birth is more socially conscious and more personally responsible than leaving the pregnancy completely up to chance. Thus most women seek out the testing. Neither the state nor the doctor places any overt force

¹³⁹ Ruth Hubbard, "Eugenics: New Tools, Old Ideas," in *Embryo, Ethics, and Women's Rights: Exploring the New Reproductive Technologies*, ed. F. D'Adamo and Joni Seager (New York: Haworth Press, 1988), 232-33.

¹⁴⁰ Mill, "On Liberty," 9.

upon the woman, and yet, social tyranny not only compels her, but wires her to believe that testing is the *best* option.

Another influence of social tyranny is the role it has played in transforming medicine into a discipline of objectivity that concerns itself not only with concepts of 'normality' versus 'abnormality', but also with 'fixing' the latter in order to more closely approximate the former. This tendency has influenced efforts to devise the aetiology of disease and disability, which in turn is at the root of the pressures felt by individuals to seek out genetic testing, as described in the previous section.

Molecular biologist Jackie Leach Scully explains, "In the twentieth century, medicine underwent a transformation in the foundational model used to comprehend deviations from health and to provide explanations for the occurrence of abnormality—a transformation that gave rise to the 'molecular model' of disease [and disability]." ¹⁴¹ This model embodies the touchstones of modern medicine: "the replacement of subjective self-reporting of disease with objective, preferably quantitative, data," ¹⁴² and the defining of abnormality in terms of deviation from the 'normal' state. The medical practice has therefore agreed on qualifying 'normality' as "the magnitude of deviation from certain numerical 'normal' ranges outside of which a person should be considered ill or disabled." ¹⁴³

Through the empirical definition of what is 'normal', and medicine's quest to 'repair' aberrations, medical knowledge has been accorded "a privileged position in defining disability based upon the assumption of medicine's value-free objectivity." ¹⁴⁴ Genetic medicine has both helped in the legitimization of this model and has been legitimized by this model. So often we hear of 'breakthroughs' in genetic science that claim to have identified the 'aberrant' gene for

¹⁴¹ Jackie Leach Scully, "A Postmodern Disorder: Moral Encounters with Molecular Models of Disability," in *Disability/Postmodernism: Embodying Disability Theory*, ed. Mairian Corker and Tom Shakespeare (London: Continuum, 2002), 48.

¹⁴² *Ibid.*, 49.

¹⁴³ *Ibid.*

¹⁴⁴ Peter Handley, "Theorizing Disability: Beyond 'Common Sense'," *Politics* 23, no. 2 (2003): 110.

abnormal states or behaviours.¹⁴⁵ The primacy of genetic science in the media, coupled with its sensationalist qualities, has caused it to absorb the attention of and assert its medical soundness to most individuals in liberal societies.

The implications for the disabled in liberal states are substantial. Handley expounds the frightful positions of 20th century liberal thinkers, John Rawls and Ronald Dworkin with respect to the medical model of disability:

John Rawls...appears to question the extent to which disabled people might possess the requisite capacities for modern democratic citizenship on the basis of their perceived limitations. For Rawls, citizens are 'fully co-operating member[s] of society over a complete life', which discounts those with 'permanent physical disabilities...so severe as to prevent persons from being normal and fully co-operating members of society in the usual sense.'

...Ronald Dworkin has a similar view of disabilities as 'natural disadvantages'. He goes so far as to cite examples of impairments such as limb paralysis and blindness that create 'special needs' that generate claims for compensation. Moreover, Dworkin adds that such disadvantages are sure to have a profound and adverse effect upon the extent to which one so impaired might lead the 'good' life.¹⁴⁶

Evidently, the immense validity attributed to the medical model of disability is also affecting the individual autonomy of parents who are given the option of prenatal testing. As explained above, a woman feels pressure to have the testing done not only because of a sense of responsibility, but also because she has been socialized to believe that disability is an aberration or a deviation from that which is 'normal'. If we are constantly bombarded with discoveries of genes for obesity, blindness, homosexuality, dwarfism, etc., it will be hard to see these and other deviations from the norm as anything but less desirable. Through the medicalization of all deviations, people view disability as a 'personal tragedy' and, thus, would rather ensure the birth of a 'normal' child than have to deal with that of a child with a medical 'deviation'. Consequently, the right not to know has become increasingly less exercised. Again, autonomy is compromised by societal norms of 'normality' and the 'good'.

¹⁴⁵ Scully, "A Postmodern Disorder: Moral Encounters with Molecular Models of Disability," 49.

¹⁴⁶ Handley, "Theorizing Disability: Beyond 'Common Sense'," 111.

For all the autonomy that prenatal testing provides an individual, there is a comparable amount of social and scientific pressure that at some point is not liberating but coercive. To guard against tyrannical social opinion, Mill advises rich public debate and decision-making among citizens as autonomous agents. He also advocates education and training so that each individual will have the opportunity to develop his/her faculties such that he/she will be capable of interpreting custom and experience in his/her own way.

Nobody denies that people should be so taught and trained in youth, as to know and benefit by the ascertained results of human experience. But it is the privilege and proper condition of a human being, arrived at the maturity of his faculties, to use and interpret experience in his own way. It is for him to find out what part of recorded experience is properly applicable to his own circumstances and character.¹⁴⁷

This prescription could be useful to a mother trying to decide whether or not to test her foetus.

4.4b Preserving Human Dignity

Kant's theory of the self holds as its central tenet that human life is an end in itself and never a means to an end.¹⁴⁸ Although Kant is a firm believer in rationally motivated actions, he does not view the moral nature of agency as residing within the desired end, but stemming "from the maxim by which it is determined, and therefore does not depend on the realization of the object of action, but merely on the *principle of volition* by which the action has taken place,

¹⁴⁷ Mill, "On Liberty," 72.

¹⁴⁸ It is important to note that Kant's maxim protecting the human as an 'end in itself' could be used as justification of the proscription of termination of any such pregnancy (i.e. as a pro-life argument). The purpose of my argument is not that. Such an argument would hinge on the definition of human life and whether a foetus fits that classification or not. The Kantian thread I wish to draw out is that these prenatal technologies force the need to distinguish some lives as more likely than others to qualify as 'means' to ends. My point is that disabled lives cannot be treated instrumentally while the non-disabled treated as ends. But it is precisely this inequality that is constructed through the use of prenatal genetic technologies. This inequity is what Kant's theory illuminates. I acknowledge that this argument of the instrumentalization of life raises questions regarding abortion from a pro-choice perspective, versus abortion subsequent to genetic testing. Although this question is beyond of the scope of this thesis, I must say the following. There is a fundamental difference between abortion based on a woman's desire not to have a child for whatever reason, and abortion based on the knowledge that one's child will have a genetic disability. In the former case, granted, the life of the foetus is being instrumentalized for the ends of the parent. However, if this could be considered discrimination it would be discrimination against the unborn. After an abortion of this nature, no one in society will suffer adverse consequences because of the abortion, other than, perhaps the parents who must then deal with their decision. In the latter case, it is not only the life of the unborn that is being instrumentalized, but also the life of the disabled. This results in a discrimination of those people already living in society who have the disability upon which the abortion was based.

without regard to any object of desire.”¹⁴⁹ Kant’s individual would act in accordance with the universally applicable imperative. We will recall that Kant believes that “an action done from duty must wholly exclude the influence of inclination, and with it every object of the will, so that nothing remains which can determine the will except objectively the *law*, and subjectively *pure respect* for this practical law, and consequently the maxim that I should follow this law even to the thwarting of all my inclinations.”¹⁵⁰ Since Kant’s individual is rational and moral, his actions must be in line with the categorical imperative so as to guard against the instrumentalization of human life and to prevent immoral acts that may be hurtful to others.

Turning once again to the subject at hand, I wish to show how Kant’s moral theory can assist in the creation of a more equitable social policy. Both use of and access to prenatal genetic technologies contravene the central Kantian tenet that seeks to preserve human dignity. These reproductive options do so not through easily traceable direct causal links, but through externalities that emerge peripherally. These shockwaves, however distant from the epicentre of genetic testing and abortions, present very real and very caustic effects for disability communities and individuals therein.

The argumentation in this section will proceed in the following manner. I will first discuss how Kant’s rational, moral self might act if faced with the option of undergoing prenatal testing. Second, I will highlight the practical difficulties that arise as a result of the distance between the consumer of the technology and the subjects of the negative consequences. Third, I will explain how adoption of the socio-political model of disability as the dominant discourse on the subject, may contribute to a shift in the medical/scientific hegemony that has led to the extensive legitimation of prenatal genetic technologies.

¹⁴⁹ Kant, "The Categorical Imperative," 539.

¹⁵⁰ Ibid., 540.

Perhaps the best way to proceed in the enterprise of determining how Kant's liberal self would act with respect to using said technology is to use the categorical imperative, in the same way that Kant himself does¹⁵¹, to establish the moral worth of the act. Kant reminds us of the categorical imperative: "Act as if the maxim of thy action were to become by thy will a universal law of nature."¹⁵² Taking up the case of Tanya and Nick once again, as rational beings they decided to opt for testing in the event that a genetic abnormality be detected in their foetus, so that they may have all the information necessary to make an informed decision. Since they have decided for themselves that they would rather not have a child with a disability, they ask themselves whether it would be contrary to their duty to undergo the testing and then abort. Should the maxim of their action become a universal law of nature? Their maxim: From self-love and from love of our future child, we adopt it as a principle to have our foetus tested for all possible genetic abnormalities when the birth thereof is likely to bring more evil than satisfaction to both ourselves and our future child. This is a difficult scenario to analyse. Were the maxim based solely on self-love, Kant would say that "a system of nature of which it should be a law to destroy a life by means of the very feeling whose special nature it is to impel to the improvement of life would contradict itself, and therefore could not exist as a system of nature; hence that maxim cannot possibly exist as a universal law of nature, and consequently would be wholly inconsistent with the supreme principle of all duty."¹⁵³ However, this analysis is not wholly accurate in this scenario because the termination of a potential life here may avoid suffering of both the parents and the unborn child.¹⁵⁴ Were this maxim to become a universal law, qualitative questions regarding the nature of suffering would arise. First, how can one

¹⁵¹ Kant uses the categorical imperative to analyse the moral viability of suicide in *Ibid.*, 541. I will employ the same format below in the analysis of the consumption of prenatal technologies.

¹⁵² *Ibid.*

¹⁵³ *Ibid.*

¹⁵⁴ I will not proceed with a discussion on the morality of abortion. That is not the issue at hand, nor is it relevant to my argument. I am not interested in the implications of prenatal genetic technology for the foetus, but for individuals who already live with disabilities.

predetermine how much suffering would ensue from the birth of a disabled child if one has never experienced it? Second, since there are extreme gradations of impairment within the spectrum of the genetic disorders identified by the tests, one universal maxim would be inadequate to deal with all the variations in genetic conditions of the foetus. Third, were this maxim to become a universal law of nature, it would lead to the discrimination of people with disabilities—most of whom those who undergo the tests will never know. In this third instance, human life is not being considered an end in itself, and thus contravenes that tenet of the categorical imperative.

In more practical terms, however, is it realistic to assume that Nick and Tanya should reject testing because their decision (in conjunction with that of millions of other expecting parents) will indirectly have profound consequences on the lives of people they do not know, even if they are certain that abortion would provide them with a better life? We have arrived at the zenith of the tension within this debate and its implications for social responsibility. This question is not easily answered.

From a theoretical perspective it could be resolved in one of two ways. The first, in the Millian tradition, would be to leave the autonomous choice of consumption up to the individual, all the while providing expecting parents with all possible information regarding genetic disorders and their impact on life. This may alleviate the tendency to abort with haste, prior to understanding how a disability may actually affect the child's and his parents' lives. The second, more along the Kantian road, might suggest a complete ban on prenatal tests (or at least those for less-severe disabilities) because of the external effects they have on people living with those conditions. Such a measure, however, would be difficult to rationalize without an overhaul of the social programs in place to support those individuals born with disabilities. This latter resolution would not stand in our liberal democracies, as protests decrying the restriction of freedom to information and of reproductive autonomy would quash any such movement. In

practice, any solution will have to be much more nuanced and incremental. As discussed above, the ubiquitous legitimization of prenatal genetic testing comes from norms and beliefs that are socially engrained. The disability community has created an alternate social model to replace the dominant medical model of disability.

The origins of the social model date back to a 1966 essay, *A Critical Condition*, written by Paul Hunt, a disabled British man.¹⁵⁵ He argued in his paper that “because people with impairments are viewed as ‘unfortunate, useless, different, oppressed and sick’ they pose a direct challenge to commonly held Western values.”¹⁵⁶ The *Western values* of which Hunt spoke were those rooted in the affluence of ‘modernity’. Because of their impairments, people with disabilities were labelled ‘unfortunate’ based on the view that they would be incapable of ‘enjoying’ the “material and social benefits of modern society”; they were thought to be ‘useless’ because they were “unable to contribute to the ‘economic good of the community’”; they were marked as minority group members because they were perceived as ‘abnormal’ and ‘different’.¹⁵⁷

Hunt’s writings laid the groundwork for what Mike Oliver, a disabled academic, termed ‘the social model of disability’ in 1983. The social model moves away from the medical model and instead “draws attention to the marginalizing impact of social and economic structures upon disabled people.”¹⁵⁸ These structures include physically inaccessible environments, work practices that conform to able-bodied workers, ‘enlightenment’ type attitudes toward disability, special rather than mainstream schools for disabled children.¹⁵⁹ The social model also argues for the prioritization of the self-defined needs of disabled people rather than the “medically

¹⁵⁵ Paul Hunt, "A Critical Condition," in *Stigma: The Experience of Disability*, ed. Paul Hunt (London: Geoffrey Chapman, 1966).

¹⁵⁶ Richard Light, *Social Model or Unsociable Muddle?* (Disability Awareness in Action: The international disability & human rights network, 2003 [cited November 30 2003]); available from http://www.daa.org.uk/social_model.html.

¹⁵⁷ Ibid.

¹⁵⁸ Handley, "Theorizing Disability: Beyond 'Common Sense'," 112.

¹⁵⁹ Ibid.

determined ascriptions of need that dominate policy responses to disability in the medical model.”¹⁶⁰

The Union of the Physically Impaired Against Segregation (UPIAS) developed Hunt’s work in the late 70s and made an assertion proposing “for the first time that disability was described in terms of restrictions *imposed* on disabled people by *social* organisation.”¹⁶¹ This led to the feminist-inspired distinction between *impairment* and *disability*. UPIAS defines the two terms as follows:

Impairment: lacking part or all of a limb, organ or mechanism in the body.

Disability: the disadvantage or restriction of activity caused by a contemporary social organization which takes little account of people who have physical impairments and thus excludes them from participation in mainstream activities.¹⁶²

It is therefore not the impairment that disables the disabled, but the social organization that is exclusionary of people with impairments. The crucial message to come out of this model is that social structure must change in order to accommodate people with impairments and not the other way around.

As Handley explains: “The social model challenges deeply embedded assumptions about disability and hints correspondingly at more radical policy responses to disability above and beyond medical interventions to rehabilitate the disabled person.”¹⁶³ This social formula not only is in line with the deontological notion of the self as an end, but it also seeks to dissolve the social tyranny to which individuals are subjected. Viewing disability as a socially imposed state protects the individual from being instrumentalized by suggesting that human life, regardless of its characteristics, is the ultimate bearer of dignity and should never be forced to conform to a socially prescribed identity. Such a model calls into question the fairness of the medical model and of the dominant discourse that impairments should be ‘fixed’.

¹⁶⁰ Ibid.

¹⁶¹ Light, *Social Model or Unsociable Muddle?*

¹⁶² Handley, “Theorizing Disability: Beyond ‘Common Sense’,” 112.

¹⁶³ Ibid., 113.

We can see that the disabled are also calling for autonomy in decision-making. They, too, desire the right to self-determine, to self-define and to act with individual agency. What makes them human and rights-bearing entities are the same qualities that bestow those identities unto the non-disabled. To appeal to the creation of policies that preserve their human dignity is to exercise their human and political rights, in the same way that women fought for the right to choose. And yet, the dilemma remains. An individual parent may consider limited access to prenatal genetic tests an infringement on her liberal right to self-determination, whereas an individual living with an impairment may consider unfettered access to the same test an infringement on her right to self-define. In the former case, the woman is denied access to information about her foetus, the acquisition of which may change the course of her pregnancy. The latter will be subject to all the connotations of 'abnormality' that accompany the philosophy that underlies the technology. The dissolution of the dominant scientific/medical view of disability will only be effected through a transformation of the social norms that have dominated for so long. I showed above how Mill's theory on social tyranny could help in the dissolution of many oppressive social opinions. The social model of disability is also a useful initiative in providing an alternative to the prevailing discourse. I think that both Mill and Kant would find the social model appealing as a way to ensure that human life not be instrumentalized in the reproductive genetic technology debate and that the influences of social tyranny be curtailed.

4.5 Conclusion

This chapter probed Locke and Mill for insights into the primacy of individual choice in modern medical practice. I argued that Locke's view of the body as property resurfaces in new and powerful ways in the face of the genetic revolution. Individuals feel a renewed sense of entitlement toward their bodies and, thus, feel justified in employing free-choice over them. Mill's concept of the free-choosing individual is applied disproportionately and erroneously in

the case of access to prenatal technologies. Liberal eugenics ensues. The lives of people living with disabilities are devalued. Delving more deeply into Mill, I discovered that social tyranny plays an enormous role in the legitimization of RGT. Mill helped to illuminate the effects of dominant discourses on medicine, disability and 'normality' and to provide practical guidelines for biotechnology policymakers. Finally, looking to Kant, I discussed how viewing the self as an end might help in guiding decisions toward more equitable social policy.

In this paper, I have argued that prenatal genetic technologies, although beneficial to many individuals planning for parenthood, may have severe external effects upon individuals living with disabilities. These consequences include the creation and perpetuation of a societal belief in the reduced value of the life of a human with a disability, the social, financial and medical discrimination of persons with disabilities, and the pressure to terminate pregnancies in which the foetus has a genetic 'abnormality'. These practices, having been collectively termed 'liberal eugenics', differ from the 'traditional' dictatorial practices of eugenics and, instead of being forced upon society through heavy-handed state policies, are unravelling in a decentralized manner, justified by appeals to individual autonomy.

In Chapters III and IV, I identified this conflict as stemming from socially embedded scientific and liberal norms. I discussed how liberal societies have come to view science as *good* and how this norm has contributed to the legitimation of individual access to prenatal technologies—a practice that leads to liberal eugenics. The argument then turned to liberal theory for explanations and answers to the rise of the primacy of individual choice. Locke helped us to understand why the body is held as sacred property. Mill's self helped us to understand the importance of individual reproductive autonomy, based on informed decision-making that is stimulated through access to this technology. Moreover, Mill's theory of social tyranny explained the many societal compulsions that subject women to testing under the pretence of 'informed choice'. Kant, finally, assisted in understanding the position of individuals living with disabilities who are fighting to make society see that a person or a foetus with a disability must not be instrumentalized, but must be treated as an end in itself. Both Mill and Kant provided suggestions for increasing the social equity of prenatal testing.

Although the aim of this paper was not to provide a solution to the conundrum (for, doing so glibly would cheapen the complexity and disregard the nuances of the problem), what I would like the reader to take away is the following. As we are presented with increasingly incredible technologies that seem to offer solutions to our many challenges, we cannot and we must not blindly accept them at face value. The field of genetics and its products are especially attractive to us as humans because it not only improves our quality of life (as many technologies do), but it also ostensibly has the capability to solve those mysteries that have perplexed humankind for millennia. As discussed above, I acknowledge wholeheartedly the myriad benefits of genetic technologies, but I strongly caution against placing too much faith in its stated abilities. The individual has the autonomous choice to subscribe to prenatal tests, but she has the duty to consider the collective implications of her individual act. To curtail individual access to these technologies is to undermine the importance of the right to control our individual bodies and uphold our reproductive freedom—rights for which women have fought vehemently. That said, there needs to be a greater awareness of the implications of those individual actions. As Aristotle teaches us, there is danger in allowing *techne* to claim the position of vanguard in scientific progress. As framework for morally responsible decision-making, as a forum for public discussion and consultation and as a socially conscious form of knowledge, *phronesis* must stand at the helm of genetic technological progress. Society must not be kept in its biased obscurity, blinded by the anticipation of scientific progress and unrestrained individual choice. Individual choosers are too distant from and unaware of the meaningful lives of people with disabilities. Through democratic public debate, through implementation of disability education campaigns in primary and secondary schools, and through prudent policymaking, individuals may have a greater opportunity to make *enlightened* autonomous decisions—a deeper individual autonomy by which people can refuse tests and not be made to feel irresponsible for doing so.

Since I identified the causes of liberal eugenics as lying within individual choices informed by social norms, I propose that changes must occur both on the individual level and on the larger, societal level. I see several ways to enhance awareness and to render the testing less scathing to those with disabilities. First, genetic counselling should not only take on the tasks of offering genetic information and of describing options, but it should also make consumers aware of the preconceptions we, as members of this society, have with respect to disabilities. This may appear inconsequential as a solution; however, considering the decentralized nature of the eugenics process I described, an attempt to influence each of the discrete decision-making centers (i.e. each mother), may actually downsize the aggregate consequence. Second, perhaps the range of information given to parents who undergo testing should be limited only to those life-threatening disabilities. Granted, creating this list will be problematic given that any such hierarchy still grades people with disabilities as less or more worthy of life. My aim in making this suggestion is to propose that if a child is to be born with a condition as minor as cleft lip, his life should never be in question as a result, before birth. There is no need for expecting parents to have this information. Third, a mother should never be made to feel that it is her 'responsibility' to have her foetus tested; moreover, neither she nor her child should ever be punished either through access to medical services or through insurance refusals. This must be made explicit through legislation. Fourth, on the wider social scale, both institutional and social education programs must address the tyrannical power of social opinion. Ethics courses must *always* accompany their scientific equivalents.

In terms of recommendations for further research, I put forward the following. There is room for both quantitative and qualitative studies in the field of genetic technologies and disability studies. On the qualitative side, a study that follows pregnant women and their partners through the prenatal testing system would be very interesting. The investigation could look at how they came to their decisions to have the testing or not, why they decided to abort or

not, what information they were given by the medical professionals, and if they feel it is important to consider the externalities of the use of this technology. A quantitative analysis of the numbers of consumers who accept/reject this technology and the reasons for which they reject it may be useful in the determination of the percentages of individuals who are aware of the external implications of prenatal tests.

Other areas that I would like to further examine would be the impact of other RGTs, such as genetic engineering, on the creation of a genetic underclass/overclass. Does this technology impinge upon the essence of our humanness? Will this lead to irreparable changes? Might this trend mushroom beyond control and attempt to exterminate all disability from society? These are frightful questions; however, they must be posed. If science dares venture into the unknown waters of human genetic manipulations, then someone must dare ask the questions of sociological consequence. Policy has not been able to pre-empt science running amuck; perhaps those who dare to ask trenchant questions will.

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