NEO-LIBERAL EUGENICS?
PRENATAL TESTING AND THE "INSOURCING" OF BIOPOLITICS

by

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Abstract

This essay seeks to address some of the social concerns surrounding the practice of prenatal testing in a preliminary fashion, through a review of the existing literature and research on the topic. The focus is placed on a discussion of the claims that prenatal testing constitutes a new form of eugenics in that it is primarily concerned with the diagnosis and therapeutic abortion of fetuses that have disabling, but not imminently life-threatening conditions, and a theoretical contextualization of how prenatal testing represents a larger shift in contemporary governance of health from the state as biopolitician to the individual as biopolitician. The essay begins with a summary of prenatal testing practices and terminology, followed by a brief history of eugenics, human genetics and genetic counselling. Next, an assessment of prenatal testing and the operation of biopolitics is made followed by a discussion of how prenatal testing exposes the limits of Foucault's concept of biopolitics. Nikolas Rose's reconceptualization of biopolitics as riskpolitics, molecularpolitics and ethopolitics under the prevailing ideology of neo-liberalism is then used to frame the new operation of biopower. Finally, the arguments for and against the characterization of prenatal testing as a eugenic practice are examined followed by a discussion of the concerns that surround this practice. This essay concludes that a clear historical lineage can be traced between contemporary prenatal testing and previous eugenic movements and that prenatal testing could be constituted as eugenic in that it is leading to a significant reduction in the number of children born with certain disabling conditions. However, the terminology of eugenics draws attention away from the ultimate discussion of whether or not this technology is discriminatory and how might the implicit forms of discrimination be rectified. A number of specific and realistic recommendations for doing this are suggested.
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Introduction

We have entered a fundamentally new age of existence. In late modernity we have discovered the tools of “bare life” and have begun to exercise a new form of biopolitics unlike any we have seen before. As Nikolas Rose (2001) indicates, we have turned to the politics of life itself, in which humans are conceived as biological entities which can be regulated and controlled at the molecular level. In the past half-century we have isolated the biological medium of “heredity,” namely DNA, and in 2003 successfully completed the mapping of the human genome—the code of human life. With the ability to see into the life codes of people, and even future people (fetuses), we have developed the technology to move beyond simple actuarial calculations concerning a person’s future health events in terms of population segmenting and risk profiling and pedigree analysis; now we have also developed the ability to look into the genetic code of individual human beings and see their future. Future health risks are increasingly becoming future health certainties. Or at least so we think.

This shift to a “geneticized” personhood, or what Rose (Novas & Rose 2000, Rose 2001) calls ‘somatic individuality’, has had a profound effect on biological reproduction. The types of children that one gives birth to are no longer simply the outcome of “life’s lottery”; rather, we have developed, and increasingly utilize, the means to detect the status of a fetus long before it is born. With this information we can now affect what types of babies are born by deciding what types are not. Genetic and chromosomal analyses are used to detect whether a fetus has an “abnormality” or “congenital defect” and the decision whether or not to give birth to that future child is made. We can now take a preventative approach to a whole range of “diseases” through prenatal testing and therapeutic abortion.
The interesting observation that is now made by disability advocates and other critics of these practices is that the majority of the attention in prenatal testing is directed toward conditions that may affect the physical abilities or social adjustment of a large number of people, but do not necessarily pose an immediate threat of death, nor a drastically truncated life expectancy. The most prevalent of these include spina bifida, cystic fibrosis, oral facial clefts, and Down syndrome (which is a chromosomal, rather than genetic condition). This observation has led some to argue that we are entering a new era of eugenics, where we are again attempting to use social programmes to manipulate the types of people who are born. As Dario Padovan states:

Although there has yet been no return to eugenics in its earlier malevolent and racial form, we may already have reached the ‘backdoor to eugenics’ in the form of health through screening, treatment and therapies (2003: 491).

Furthermore, “the new eugenics demands that individuals [as opposed to the state] take responsibility for arbiting normality” (Roeher 2002: 10, italics in original).

The argument that we are entering a new eugenic era has predominantly come from the disability rights movement and is based on the sentiment that the procedure of aborting disabled fetuses implies that the life of a disabled person is not worth living. As the disability rights advocates at the Roeher Institute ask:

Is a biomedical conception of health that construes disability as a “flaw” or “defect” to be eliminated or corrected, and that obscures social factors that affect the health and well being of people with disabilities, inherently eugenic in nature? (Roeher 2002: 7).

This is precisely the question which I attempt to resolve in a preliminary way in this paper. My thesis is that prenatal diagnosis represents a specific formulation of
biopolitics under the rubric of what Rose calls riskpolitics, molecularpolitics, and ethopolitics (Rose 2001). This latest practice of biopolitics inaugurates an era in which judgments of worth with regard to what kinds of people deserve to be born have become inescapable. Specific to the rise of these new strategies is the shift from overtly state-oriented applications of health governance toward a neo-liberal and individual choice orientation of health, what I refer to as the “insourcing” of biopolitics from the collective social body to the individual citizen. However, these individual choices based on judgments of worth are being made at a time where discrimination against certain genetically and chromosomally based conditions is prevalent. The problem is that this overall culture of discrimination influences individuals’ reproductive decisions toward “preventing” these types of people from entering into existence, regardless of their overall life chances (or other options). Consequently, I argue, a new form of neo-liberal eugenics based on the controlling logic of risk management, the sovereignty of individual choice and the hegemony of “normalcy” has replaced the older state-managed eugenics of the social body.

In exploring these issues I will demonstrate how prenatal genetic testing represents a new form of biopolitics—the interest of the state in the maintenance of the health of the population (Foucault 1984, 1990)—and I will argue that this new biopolitics is inherently tied to a new form of eugenics. I will first provide some background on prenatal diagnosis, the history of eugenics and the birth of genetic counselling. I will then focus on prenatal testing as a practice of traditional Foucauldian biopolitics and then update this conceptualization with regard to Nikolas Rose’s (2001) reformulation of biopolitics as riskpolitics, molecularpolitics and ethopolitics in the genetic era in order to highlight the limitations of Foucauldian bio-political analyses of contemporary genetic
medicine. Following this historicization of eugenics and prenatal testing, and the theoretical contextualization of the practice, I then engage in an analysis of the arguments for and against prenatal testing as a eugenic enterprise in order to support the claim that this technology has eugenic potential. Finally, I address the issue of eugenic practices of prenatal testing by providing a number of recommendations for future policy and guidelines.

In evaluating the eugenics argument, my focus will be on the testing for certain conditions where life chances are significant yet “prevention” is still seen as an appropriate form of treatment through prenatal testing and therapeutic abortion. These conditions, such as cleft palate, spina bifida and Down syndrome constitute the bulk of these disorders detected and aborted through prenatal testing, where Downs alone accounts for approximately fifty percent of all screening detections (Health Canada 2002; Roeher 2002). My concern in this paper is not to provide an evaluation of those conditions where death is certain to occur within a short time after birth, such as Tay Sachs or Trisomy 13. This does not mean that a critical analysis of prenatal testing and potential termination of fetuses with these conditions is not worthwhile. Rather, by leaving aside a discussion of the ethics of what conditions are selected as worthy of testing, I aim to address the broader question of whether prenatal testing itself constitutes a new form of eugenic practice.

What is Prenatal Testing?

Before embarking in a discussion of social considerations of prenatal testing, it is useful to first introduce some of the technical background of what prenatal testing entails.
Reviewing the science, terminology and application of prenatal testing provides a common starting point from which to begin a discussion of this topic.

First introduced in the 1970’s, prenatal testing has subsequently become a part of routine prenatal care in most industrialized countries. In general terms, prenatal testing refers to the medical practice of collecting information about a fetus during pregnancy in order to determine if it is affected with any number of congenital conditions. Typically this ultimately involves the collection of a cellular sample from the fetus in order to determine if the fetus has any genetically or chromosomally based disease, disability or other condition that are detectable by current tests. There are a number of methods of obtaining the genetic information from the fetus, with the focus of each being the ability to sample and achieve test results within the first twenty-two weeks of pregnancy in order to allow for potential termination of the pregnancy. The decision of what to do with the pregnancy is left entirely to the parents and is often mediated by a genetic counsellor. Depending on the desires of the parents, the test results are used as a basis for terminating the pregnancy or to allow the family and medical professionals to prepare for the care of a child with special needs. While each of these options following a prenatal diagnosis is complex, it is the potential for termination (i.e. abortion) that is the most ethically and socially challenging, and therefore the central focus of this paper.

Access to prenatal testing services in Canada is currently regulated and limited in availability. In British Columbia, testing is limited outside of the Victoria and Vancouver areas as there is a nation-wide shortage of properly trained and certified genetic counsellors (Roeher 2002). For this reason, testing is limited to women who are known

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1 In Canada there is presently no criminal prohibition against performing abortions beyond 22 weeks; however, it is unusual for abortions to be performed beyond this point. Other countries such as the UK that have legal cut-off limits allow provisions for abortion beyond the legal cut-off in situations where there is a substantial risk that the child will be born with a severe disability (Roeher 2002).
to have an increased risk of having a fetus with a genetic or chromosomal condition, such as women who have a family history of a certain genetic condition or women over the age of 35—the age above which the risk of chromosomal aberrations increase significantly. Testing is also offered to women who are found to have fetuses that exhibit signs of a congenital malformation through routine screening. The reason for these restrictions is to limit access to these scarce resources and to limit exposure to the risks of invasive prenatal testing. Thus testing is only offered to women who are determined to have a greater statistical risk of having a fetus with a disabling condition than the statistical risk of miscarriage associated with invasive testing procedures. As the British Columbia Ministry of Health states in their guidelines on access to prenatal testing:

When a foetal abnormality which is associated with an increased risk of foetal chromosomal anomaly is detected on a prenatal ultrasound and is the only indication for prenatal cytogenetic testing, consultation with a certified clinical geneticist or maternal foetal medicine specialist is mandatory. When the clinical geneticist determines that the risk of foetal chromosomal anomaly is equal or greater than 0.5 percent, then prenatal cytogenetic testing should be offered (British Columbia Ministry of Health 2000 in Roeher 2002: 25).

Prenatal testing is broken down into two main types of procedure: screening and diagnosis. Prenatal screening is limited to typically inexpensive and non-invasive techniques that are used on virtually all pregnant women to detect potential problems, while diagnosis of the condition is made by more invasive techniques once a problem is suspected. The most common techniques that are offered for prenatal screening are ultrasound, maternal serum screening (MMS), and the techniques for diagnosis include amniocentesis, with chorionic villi sampling (CVS) gaining popularity recently due to the
much earlier detection-time associated with this type of sampling. These methods of
diagnosis are the favored means of obtaining chromosomal and genetic samples from the
fetus because they can be implemented within the twenty-two week abortion window. In
addition to the timing concern, the potential risks of the more invasive procedures to the
mother and fetus are also taken into consideration.

Detailed ultrasound is the most widely used method of prenatal screening and is
recommended for all pregnancies between eighteen and twenty weeks of gestation in spite
of there being ongoing concerns about potential risks associated with ultrasound
(Lippman 1991, Beech 1999). Ultrasounds are used to look for major congenital
anomalies, as well as soft markers that indicate an increased risk of a chromosomal
abnormality such as Trisomy 21 (Down syndrome) or Trisomy 13 (which is fatal).
However, because the fetus must be large enough and sufficiently developed enough to
allow for analysis of the structure of the major organs, not much time is left for
intervention by abortion.

Maternal serum screening, MMS, is a screening blood test available to pregnant
women at 15 to 20 weeks gestation. In this test, a small blood sample is taken from the
pregnant woman and is tested for the levels of alpha-fetoprotein (AFP), which is
produced by the growing fetus. Higher levels of AFP indicate an increased risk of the
child having a chromosomal condition such as Trisomy 13 and Down syndrome (Trisomy
21) and neural tube defects such as spina bifida as compared to the usual risk associated
with a 35-year-old woman having a child with these conditions. The reason for the 35-
year-old comparison standard is that this is the age at which the background risk of a
woman having a child with a chromosomal or neural tube defect is equal to the risk of
spontaneous miscarriage associated with amniocentesis—the most common type of
prenatal testing\textsuperscript{2}. The main advantage with the MMS is the relatively non-invasive nature of the test, which poses no threat to the fetus. However, the test is only an indicator of whether or not the fetus is \textit{not} affected. False negative results are extremely rare, whereas false positive results are common. The likelihood that a positive result is a true positive is about 1 in 31 for women younger than 35 and 1 in 40 for women older than 35. This fact necessitates that many women will suffer undue stress and anxiety over their test result, and, as I discuss later, may increase the chances that they will consider a therapeutic abortion. On the other hand, a negative screen is correct 99 percent of the time. Because MSS is inexpensive and easily administered, it has become a routine part of prenatal care in spite of the exceedingly high rate of false positives.

Amniocentesis is the most widely used means of obtaining genetic samples for diagnosis directly from the fetus. These samples allow for an exact determination of the fetus' chromosomal and genetic status; however, the procedure is more invasive and bears a 0.5 percent risk of spontaneous miscarriage. Amniocentesis involves the insertion of a needle through the mother's abdomen or through the vagina and cervix into the amniotic fluid sack surrounding the fetus. Several cubic centimeters of fluid that contains sloughed off skin cells from the developing fetus are removed, which are then analyzed and a diagnosis made. Amniocentesis can be conducted fifteen weeks or later in gestation, and after the samples are collected the stray cells in the fluid must be given time to divide several times before there is a large enough sample for analysis. As a result, one of the main criticisms of amniocentesis is that it leaves little time from when the results are obtained until the twenty-two week abortion cut-off for a decision to be made.

\textsuperscript{2} Note: the birth rate of children with chromosomal and neural tube defects increases with the maternal age of the mother.
Chorionic villi sampling (CVS) is a recent alternative to amniocentesis. CVS can be done very early in the pregnancy, although it involves an estimated 1 to 4 percent increased chance of miscarriage and there has been some suggestion that it may cause some birth defects (Mennuti 1997). Like amniocentesis, CVS involves the insertion of a needle into the woman's abdomen or through the cervix. However, rather than taking an amniotic fluid sample, a sample of the chorionic villi—the small extrusions of the developing placenta, which is composed of fetal tissue, and hence fetal chromosomal and genetic make up—is removed. The benefit of this type of sampling is that it can be done much earlier as the placenta is developing and it yields a sufficient sample size to allow for immediate analysis.

Both amniocentesis and CVS allow for the evaluation of the fetal chromosomal complement for abnormal copy number and large-scale rearrangements as well as genetic markers for neural tube defects. Other genetic tests can be performed but only if the medical professional is specifically looking for them, as it is not feasible to screen each fetus for all known genetic conditions. As a result, chromosomal and neural tube defects are the most widely tested for, which, although convenient, raises some issues due to the fact that Down syndrome and spina bifida, the two most commonly occurring chromosomal and neural tube defects, are for the most part non-life threatening. Severe fetal conditions such as Tay Sachs are presented as the touchstones for the merits of prenatal testing, but are only tested for when there is a known risk. This begs the question: why are only these predominantly non-life-threatening conditions being widely screened for and the option of abortion given to parents? Implicit in this question, which is often asked by critics of this practice, is the claim that offering testing and therapeutic abortion for these conditions constitutes a return to eugenics, by favouring one type of
person over another. To properly examine this claim without falling into the trap of using "eugenics" as a dismissive term, the history of eugenics and how it relates to contemporary genetics must be understood.

_Eugenics, Genetics and the Emergence of Genetic Counselling_

**History of Eugenics**

Eugenics is defined as "the science of improving the physical and mental qualities of human beings through controlling the factors influencing heredity" (University of California-Davis 2001 in Roeher 2002: 14). As such:

Eugenics sought to improve the body politic and relieve it of the economic and social burdens of disease and degeneracy in the future by acting upon the reproductive decisions and capacities of individuals in the present (Rose 2001: 3).

Eugenics officially began in 1883 when Charles Darwin's cousin Francis Galton coined the term from the Greek word _eugenes_ which means "good in birth". Galton defined eugenics as:

the science of improving stock, which is by no means confined to questions of judicious mating, but which...takes cognisance of all influences that tend on however remote degree to give the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable than they otherwise would have (Galton 1883: 24 in Paul 1995: 3).

With the rediscovery of Mendel's work on inheritance, eugenics, with its emphasis on human heredity, flourished as the new science of genetics supported the idea that physical

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3 Gregor Mendel was a Moravian monk who determined the mathematical ratios of trait heritability in peas through extensive botanical studies on breeding and inheritance. This formed the scientific foundation for the understanding of inheritance patterns, and consequently the foundation of genetics. Mendel's results were published in 1865, but went unnoticed until the first years of the twentieth century.
and behavioural traits were biologically determined and passed from generation to generation (Kevles 1999). Historically the traits focused on included such characteristics as “feeble mindedness”, a general catch-all term for people believed to be mentally retarded, which led to other behaviours such as alcoholism, prostitution, pauperism and criminality. Today these behaviors are largely attributed to social factors, but in the early days of genetics they were attributed to bad genes, or defects in heredity. Consequently, a whole range of social problems were seen to be genetic in nature and the study of human genetics and eugenics were intimate bedfellows. During the 1910s and the 1920s, eugenics was simply considered the application of human genetics, and most eugenicists were also human genetics researchers and vice versa (Paul 1995).

The driving force behind the development of eugenics in the last decades of the nineteenth century and the first part of the twentieth century was the belief that civil society was creating an untenable balance in social reproduction. Specifically, the problems of “degeneracy” and “immorality”, in the forms of “feeblemindedness” and its associated problems, were seen to be growing worse as “civilized society now kept alive the physically and mentally weak” (Paul 1995: 4). Influenced by Darwin’s work on evolution, the fear among those holding dominant positions in society was that the “worthiest” individuals were reproducing at a rate much slower than the “degenerates”, and that such an imbalance would result in the evolutionary degeneration of the “race”. As Diane Paul summarizes:

Paupers and imbeciles now survived and bred their like, while the middle class exercised reproductive restraint. Thus it seemed that the beneficial effects of natural selection were checked or even reversed (1995: 6).
Early eugenic writers in the latter part of the nineteenth century were quick to point out that the lower classes were out-reproducing the middle and upper classes, but were loathe to claim outright that active measures must be taken to combat this problem. Charles Darwin was among this group when in his 1871 book *Descent of Man* he warned that evolutionary regression would occur if the lower classes continued to outbreed the middle and upper classes, but maintained that aid must still be given to those in need and did not propose any specific eugenic solutions. It was after the rediscovery of Mendel's work at the turn of the century, which gave scientific credence to genetic heredity, that eugenics really captured the scientific (and popular) imagination and active measures of controlling human reproduction were openly discussed. The first decade of the twentieth century saw the establishment of organized eugenics movements in Europe and North America and the belief that the only way to save the “race” was to practice widespread selective breeding (Paul 1995).

A two-pronged approach to dealing with the problem of heredity was suggested by eugenicists, one encouraging the reproduction of those with “desirable” hereditary traits and one discouraging the reproduction of those with “undesirable” hereditary traits. These approaches came to be known as “positive” eugenics and “negative” eugenics. Positive eugenics led to establishment of programmes such as “better baby” contests and “fitter family” competitions, which became standard fixtures at state fairs alongside livestock judging. Negative eugenics, on the other hand, led to the more nefarious eugenic programmes such as forced sterilization and even euthanasia (Kevles 1999). Paul makes the observation that support for negative eugenic measures has an inverse correlation with economic prosperity. What was unthinkable in the prosperous 1920’s became reality in the 1930’s in the form of forced sterilization for the institutionalized.
One interesting and often overlooked aspect of the eugenics movement was that it provided a common ground of agreement between social conservatives and social progressives. For progressives, eugenics provided a means by which social improvement might occur, particularly as many social problems were seen to be hereditary in nature. For the conservatives, eugenics was seen to be a useful way of preventing the proliferation of the poor and criminal elements, and cutting the cost of caring for "degenerates" (Kevles 1999). In fact, "apart from the Catholic Church, Britain’s Labour Party, and some liberal individuals, there was little moral opposition to eugenics before the Second World War" (Paul 1995: 11). The majority of the criticisms of eugenics were directed toward specific eugenic measures and to the racial and class biases that were often reflected in them, and not to the endeavor as a whole.

The promotion of eugenics by both the left and the right problematizes our contemporary disdainful retrospective view of the endeavor as being a fascist and racist enterprise. Forced sterilization programmes have been implemented in states that cross the political spectrum, from Nazi Germany to Social Democratic Sweden. By the 1930’s over half the states in the US had passed eugenic sterilization laws, as well as Alberta and British Columbia in Canada. The predominant difference between the more progressive states and the more conservative states was the difference in focus of the implementation of negative eugenics. In Sweden, and to a lesser extent, Canada and the United States, negative eugenic practices were less concerned with racial purity and nationalistic endeavors and focused more on the individual well-being and the health of the population.

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4 Although British Columbia passed a eugenic sterilization law allowing the forced sterilization of those in institutions, this law was enforced very little (Kevles 1999). Alberta on the other hand, was the only jurisdiction in the British Commonwealth to implement and actively enforce compulsory sterilization (Kevles 1999). By the time the legislation was repealed in 1972, almost 3000 people had been forcibly sterilized (Horner, n.d.).
(although in North America the foreign born were disproportionately targeted). Under this guise, sterilization was seen as a medical benefit, and was actively practiced in Alberta up until 1972 and in Sweden until 1975 (Wahlsten 1997, Tannsjo 1998, Kevles 1999).

Eugenics in Nazi Germany operated under the guise of “Racial Hygiene”, and was concerned with the nationalistic endeavor of protecting of the “German” race from corruption by those with undesirable heredity. The Nazis started with the same types of sterilization laws as were in place in the US and Canada, which targeted “genetically determined conditions such as ‘inborn feeblemindedness, schizophrenia, manic depression, hereditary deafness, blindness, epilepsy, Huntington’s disease, severe malformations and alcoholism’” (Hume 1996: 2). In 1939 the Nazi eugenic programme reached its apogee after already sterilizing between 300,000 and 400,000 people, when it shifted from sterilization to euthanasia. By the time the programme was discontinued, mainly because of church and family protests, it is estimated that close to 500,000 people with disabilities had been killed (Ibid). It is necessary to point out that it was through the influence of eugenic thinking that the Nazis implemented their “final solution” to the supposed Jewish—and Gypsy, Homosexual, Russian, Polish, Jehovah’s Witness—threats to German racial purity.

The Shift from Eugenics to Human Genetics

At the beginning of the 1930’s, the world economic crisis and rise of Nazism saw many geneticists and eugenicists move to the political left. As socialists, Marxists, and liberals embraced racial and class equality, a leftist approach to reforming eugenics began to take shape. An increasing sentiment that eugenics needed to be freed from its inherent
class and racial bias led to the promotion of a new eugenics free of social bias, but still in 
favour of sterilization of the “unfit” (Paul 1995). By the end of 1930’s the shift towards a 
reformist eugenics, free of class and racial bias was well underway, as the center of 
gravity of the eugenics field shifted from the mainline conservative Eugenics Record 
Office (which eventually closed in 1939) to the American Eugenics Society, which was 
under the direction of Frederick Osborn, a prominent reformist eugenicist. However, 
these steps towards a politically neutral eugenics movement were derailed in the 1940’s 
as the atrocities of the Nazis came to light. As a result of the exposure of the brutality of 
Nazi eugenic programmes, by the late 1940’s eugenics as a whole had fallen out of 
popularity and was largely dismissed by the public (although the term eugenics continued 
to be used by the scientific community until the 1960’s). Eugenics societies reacted by 
denouncing Nazi bigotry and turned their focus towards the more politically neutral 
endeavours of birth control5 and human genetics as avenues for manipulating human 

Although human genetics was considered a separate field of study from eugenics, 
a considerable overlap between the two has traditionally existed and the distinction 
between the eugenics organizations and human genetics has not been easy to sustain. 
This conflation of the two aspects of bioscience predates the decline of eugenics 
following the Second World War. Many famous eugenicists, such as Charles Davenport, 
were also involved in the study of numerous genetic diseases in humans such as 
Huntington’s, as well as other “conditions” such as “nomadism” and “cheerful 
temperament”. The same is true for the funding of human genetics, where with the

5 The American Eugenics Society is largely considered responsible for the dissemination of birth control 
information and advocacy in the 1950’s, having established the American Birth Control League, the 
International Planned Parenthood Federation and the Population Council.
exception of the American Cancer Society and the US Public Health Service, virtually all sponsors, including the Rockefeller and Carnegie foundations, had eugenic motives (Paul 1995). Among geneticists in the first half of the century it was believed that advances in human genetics would provide physicians with "the necessary information for setting up eugenic and euthenic [the bettering of the conditions of humans through the improvement of their environments] programmes for the protection of society" (Lawrence Snyder 1937: 706 in Paul 1995: 124). This intermixing is reflected in the American Society of Human Genetics, founded in 1948, in which five of its first six presidents also sat on the board of directors of the eugenics society.

Although the public had turned their back on "eugenics" following World War II, it was in the two decades following the war that the scientific community gradually resigned themselves to the fact that any successful eugenic programme was going to have to operate under a different name. The symbolic end of scientific eugenics in name came in 1968 when the eugenics society changed the name of its journal from *Eugenic Quarterly* to *Social Biology*. In discussing the name change, Frederick Osborn commented that:

The name was changed because it became evident that changes of a eugenic nature would be made for reasons other than eugenics, and that tying a eugenic label on them would more often hinder than help their adoption. Birth control and abortion are turning out to be great eugenic advances of our time. If they had been advanced for eugenic reasons it would have retarded or stopped their acceptance (Osborn 1977: 7 in Paul 1995: 125).
The Development of Genetic Counselling

One of the other avenues for expanding eugenics after it had become publicly disreputable in the 1940s explored by eugenics societies was genetic counselling. During this time, the American Eugenics Society, along with a number of other eugenics societies began exploring the possibility of opening hereditary clinics, where clients who were concerned about their reproductive possibilities could come and seek the advice of a professional geneticist. Initially the majority of geneticists involved in heredity counselling advocated directing the client toward the more eugenically favourable outcome (Paul 1995).

In 1947, human geneticist Sheldon Reed first coined the term “genetic counselling”. Reed was one of only a few geneticists at the time who advocated a form of genetic counselling that is based on an ethic of neutrality with respect to reproductive decisions. His reasoning for advocating non-directive genetic counselling was to further distance genetic counselling from eugenics and also based on the assumption that the majority of people who seek out genetic counselling have a well developed sense of social and moral responsibility and are therefore most likely to ultimately make eugenic reproductive decisions (Roeher 2002, Paul 1995). As Reed states:

[This] practice of divorcing the two concepts of eugenics and genetic counselling contributed to the rapid growth of genetic counselling. Genetic counselling would have been rejected, in all probability, if it had been presented as a technique of eugenics (Reed 1974 in Roeher 2002: 18).

However:

If our observation is generally correct, that people of normal mentality, who thoroughly understand the genetics of their problems, will behave in the way that
seems correct to society as a whole then an important corollary follows. It could be stated as a principle that the mentally sound will voluntarily carry out a eugenics programme which is acceptable to society if counselling in genetics is available to them (Reed 1952: 43 in Paul 1995: 128)

Although genetic counselling was established officially in 1947 and “heredity clinics” became available in several states, few people actually sought the counsel of geneticists. For the first two decades of their existence, heredity clinics had little to offer their clients except vague estimates of the risk of having a child with a particular genetic condition of concern. The only way to prevent having an affected child was to abstain from reproducing. It was not until the legalization of abortion, with the landmark Roe versus Wade decision in 1973 in the US and the 1969 law allowing therapeutic abortion followed by the 1988 Morgentaler ruling in Canada, that a tangible option could be provided to prospective parents through genetic counselling. The legalization of abortion, along with the development of amniocentesis which allowed for genetic and chromosomal tests to be done on fetuses, resulted in the explosion of growth in the genetic counselling field.

Occurring simultaneously with the legalization of abortion and the subsequent growth of genetic counselling was a shift in public attitude about reproductive responsibility. Prior to the 1960’s it was taken for granted that modern civil society as a whole ought to have a legitimate interest in reproduction. By the 1970’s this attitude seemed to have largely been reversed, and the dominant sentiment was that reproduction was an entirely private affair, and that social concerns should be divorced from these decisions (Paul 1995). The ethos of genetic counselling followed this trend. As the principle of reproductive autonomy replaced reproductive responsibility, the attitude of
the majority of genetic counsellors fell in line with the principles of non-directiveness espoused by Reed in 1947. By the end of the 1970s, the consensus among counsellors was that the aim of genetic counselling is “to inform, to educate, to convey value-free facts and probabilities about genetic conditions, perhaps even to deal with psychological problems, but never to advise or counsel” (Twiss 1979: 201 in Paul 1995: 130). Today this attitude is foundational to the genetic counselling professional code of ethics and is indicative of an overall restructuring of healthcare delivery and, as I shall argue below, the application of biopolitics in the contemporary genetic era.

**Prenatal Testing and the Execution of Biopower**

Prenatal testing can be shown to be an aspect of Foucauldian-style governmentality that is unique to the genetic age of late modernity. These practices illuminate Michel Foucault’s analysis of biopower, but they are unique in the form they take in that they are increasingly shifted from the state to individual decision-makers. In this regard, prenatal diagnosis highlights the limits of Foucault’s concept of biopolitics and the need to update the theory with respect to the recent technological advances of the geneticized age and the emergence of neo-liberalism—a re-conceptualization that Nikolas Rose provides.

Biopolitics is the word Michel Foucault uses to describe the approach to social regulation and control that emerged from the classical age and typifies the modern form of what he calls “governmentality.” The exercise of governance through biopolitics is summarized as a result of the historic shift from the exercise of power through the threat of death to a model of governmentality based on the maintenance of life through the control over health. As Foucault states in the *History of Sexuality, Volume 1*:
The disciplines of the body and the regulations of the population constituted the two poles around which the organization of power over life was deployed. The setting up, in the course of the classical age, of this great bipolar technology—anatomic and biological, individualizing and specifying, directed toward the performances of the body, with attention to the process of life—characterized a power whose highest function was perhaps no longer to kill, but to invest life through and through (1990: 139).

This passage describes the dichotomy that is established between the discipline of the individual body and strategies to obtain a desired result for the social body as a whole. The primary project of the state engaged in biopolitics is the regulation and maintenance of the population en masse in order to increase its utility, and to maximize its health, welfare and productivity. This objective is achieved by the subjugation of the individual—the transformation of the individual into a "docile body"—which is achieved through the deployment of the technologies of disciplinary power. For Foucault, "a body is docile that may be subjugated, used, transformed, and improved" (Foucault 1984a: 180). The technologies of discipline seek to shape individual bodies and enforce subjugation and docility through surveillance, examination, and what Foucault calls "normalizing judgment," in which each individual is compared to the norms of the larger group and judged according to his or her level of conformity. This process serves to draw strict boundaries between "normal" and "abnormal" so that in disciplinary regimes "the whole indefinite domain of the non-conforming is punishable..." (Foucault 1984a: 194). The non-conforming, or un-healthy element, is "punished" or "cured" as pathology, disease and illness, requiring strict programmes of classification, intervention, examination, and, potentially, exclusion or extermination. This strategy requires the
complicity of the docile patient for its implementation. It is necessary to note that the objective of the deployment of what Foucault calls biopower is not necessarily the subjugation of the individual for his or her own good, but the subjugation of the individual in order to improve the overall health and utility of the population. Rose suggests that the negative eugenic programmes of the twentieth century and the desire to eliminate undesirables from the body politic were fundamentally based on this biopolitical rationale:

Some locate the wish to control the biological make-up of the population at the very heart of modernity. Thus for both Giorgio Agamben and Zygmunt Bauman the thanatopolitics of population purification is imminent within the very project of biopolitics: to manage the health of the ‘body politic’ inescapably requires the control and elimination of ‘foreign bodies’ (Rose 2001: 2).

It is also necessary to note that disciplinary power is not simply a coercive power executed by the state, as is the practice in institutions such as schools, prisons and the military, but is above all a relational form of power that calls on individuals as responsible agents to voluntarily engage in discourses of expert knowledge in order to render themselves docile. This is the form of biopolitics that is commonly seen in the regulation of pregnancy, as women willingly and actively engage in medical and mass media discourses of self-regulation.

The association between overall fitness and utility highlights an important relationship in Foucault's writing between health and economics, or more specifically, between the state of one's health (well or ill) and one's capacity for economic production. As Foucault states:
The biological traits of the population become relevant factors for economic management, and it becomes necessary to organize around them an apparatus which will ensure not only their subjection but the constant increase of their utility (1984b: 279).

Consequently the hospital was transformed in the 18th century from an institution for warehousing the ill—which represented a direct drain on the economy—to a location for healing and socially re-integrating the ill in the interests of economic productivity (Foucault 1984b). A similar economic motivation for improving the health of the population was behind the implementation of eugenic sterilization laws in the 1930’s (Paul 1995), and is arguably a basis for offering prenatal testing in contemporary pregnancy care.

The term subjugation or subjection can be misleading for readers of Foucault, as it tends to hide the enabling aspects of the operation of power. Foucault sees power as a relational process that is inextricably linked to knowledge (what he refers to as knowledge/power, or pouvoir/savoir). Thus power, through knowledge, is “linked to a whole series of positive and useful effects which is [its] task to support” (Foucault 1984b: 172). For example, medicine in the disciplinary age is responsible not just for the health of the individual, but for collectivist endeavors such as epidemiology and public hygiene, which help to maintain the overall health of the entire population. These health disciplines have ameliorated the living conditions of every individual and of the population en masse. For example, epidemiological knowledges gained through surveillance and other normalizing practices have revealed that the risk of having a child with a chromosomal trisomy increases with advanced maternal age. This subjugation of the individual has exposed a whole range of positive factors for older women to consider.
who want to have children—specific risk factors which can be made knowable and life choices which can be made accordingly. Thus, according to this relational view of power the benefits resulting from these advancements of health knowledge are understood to be a direct result of the subjugation and discipline of the individual conceived as a “case” through examination and comparison.

Pregnancy represents one of the focal points for biopolitics as it is the process by which the population reproduces itself on both the social and individual level. From this perspective, prenatal testing represents a specifically biopolitical desire to screen the future population for congenital disease by subjecting pregnant women to programs of surveillance and examination. Biopolitical intervention in pregnancy thereby involves a re-conception of childbirth and childhood as a medical problem and the requirement that the family prioritize the health of its children in the interest of the operation of biopower. As a result: "health, and principally the health of children, becomes one of the family's most demanding objectives" (Foucault 1984b: 281). The impetus of raising a child that will become a future adult that is useful is one of the primary functions of the family.

The family is assigned a linking role between general objectives regarding the good health of the social body and individuals' desire or need for care. This enables a “private” ethic of good health as the reciprocal duty of parents and children to be articulated onto a collective system of hygiene and scientific technique of cure made available to individual and family demand by a processional corps of doctors, qualified and, as it were, recommended by the state (Ibid: 281).

The family's responsibility for the health of the children is the mechanism through which pregnancy enters the realm of biopolitics. As the care of the child and the ability to
raise it into adulthood is one of the primary functions of the family, proper prenatal care during pregnancy also becomes just as important. The desire is to give birth to a child that has the best life chances of reaching adulthood and having a high degree of utility. As a result, a whole range of technologies of discipline and biopower are routinely incorporated into proper pregnancy care. Knowledge generated by constant observation of pregnant women has led to the development of certain disciplinary routines that should be followed in order to insure the ‘healthiest’ pregnancy/fetus possible. The pregnant woman is made a “docile body”, subjected to constant surveillance through scheduled doctor’s visits, ultrasounds, screens and blood tests (along with public scrutiny, such as jeers and glares if a pregnant woman drinks alcohol for example). The woman is also expected to engage in self-surveillance, for example, by monitoring her diet, refraining from the consumption of certain substances, engaging responsibly with popular discourses of proper forms of health maintenance by reading books and magazines that explain what is necessary to have a healthy pregnancy and consequently a healthy baby. The purpose of these discourses is to appeal to the pregnant woman to engage in specific practices, or forms of self-governance, that will increase the health chances of the fetus that she is carrying (a practice widely criticized by feminist writers as male experts come to dominate the discourses of proper pregnancy-care).

Although pregnancy is largely seen as a private affair, the interest of the state in the administration of biopolitics underlies pregnancy and prenatal testing. In the case of prenatal testing, surveillance, in the forms of risk profiling, screening and testing, is put into practice for the purpose of deciding if the fetus will be fit or useful enough to enter the social body. As agents of examination and surveillance, today’s doctors are at least as important as they were previously in their role as guarantors of the health of the social
body. In reading the medical literature on prenatal testing and in talking to medical practitioners, it is not uncommon to come across arguments about the cost to health care in the context of discussions of the ethics of these medical practices. For example, social and economic costs were a contributing factor in determining the 35 year-old risk equivalency when health analysis first drafted a policy on the availability of prenatal testing. As Kuperntann et al discuss in their historical analysis of the rationale for the 35 years threshold for testing, one of the main arguments for this age limit was “economic analyses suggesting that at this age prenatal diagnosis was ‘cost beneficial’” (1999:161), which suggests that the costs incurred by offering testing would be more than compensated for by the savings associated with averting the births of infants with Down syndrome.

As one of the principal agents in the operation of biopolitics, the doctor gains a politically privileged social position. Through this role, the doctor becomes the great advisor and expert, if not in the art of governing, at least in that of observing, correcting, and improving the social "body" and maintaining it in a permanent state of health (Foucault 1984b: 284).

This historical shift from doctor as individual therapist to doctor as biopolitician marks the entrance of social concerns into the healing arts. In the governance of health, the doctor inhabits a specialized biopolitical position as the provider of health information and advice to the family as the executor of health programmes designed to invoke their responsibilization as executors of their own health.

The Foucauldian view of the doctor as biopolitician tending to the social body is no longer the norm in prenatal healthcare practices. In late modernity, this paternalism is waning in the current culture of neo-liberalism, which emphasizes individual
responsibility, litigation and risk management. Genetic counsellors are leading the way of the medical profession's slow shift away from paternalism to non-directiveness and ultimate respect for individual autonomy over other ethical principles. In fact, many suggest that genetic counselling is a "disciplinary mechanism that enlists pregnant women to become self-regulating and self-governing" (Roeher 2002: 97) insofar as the moral responsibility of the health of the fetus falls on their shoulders. This is the process which I refer to as the insourcing of biopolitics, by which the individual is given greater responsibility as she is included as a key agent in state's directive of governing health. More and more, healthcare delivery is taking on a consumerist model where proper care is based on individual choice after receiving the facts and risk assessments from medical professionals. The impetus of traditional biopolitics as outlined by Foucault remains intact, although the agents of execution have changed from agents of the state to individuals. As Deborah Lupton summarizes:

A crucial aspect of governmentality as it is expressed in neo-liberal states is that the regulation and disciplining of citizens is directed at the autonomous, self-regulated individual...Rather than mainly being externally policed by agents of the state, individuals police themselves, they exercise power upon themselves as normalized subjects who are in pursuit of their own best interests and freedom, who are interested in self-improvement, seeking happiness and healthiness (1999: 88).

We now tend to view health as an object to be pursued for its own sake, or what Rose calls the "will to health". As reproductive decisions are left to the individuals involved, the role of medical professionals becomes more to provide information than to give advice. However, it would be wrong to assume that this ethic of non-directiveness
involves abandoning all forms of state influence in reproductive decision-making. The overall health and utility of the body politic is still a primary concern in offering (and funding) programmes such as prenatal testing, even as the role of the expectant parent is increased through respect for the autonomy of the individual in making her own reproductive decisions.

This shift to a consumer model of biopolitics is highlighted in Nikolas Rose's contemporary re-assessment of Foucault's work in light of recent advances in biomedical science. According to Rose:

The contemporary state does not 'nationalize' the corporeality of its subjects into a body politic on which it works *en masse*, in relation of the body politics of other states competing in similar terms. The state is no longer expected to resolve society's needs for health. The vitality of the species—the nation, the population, the race—is rarely the rationale and legitimation for compulsory interventions into the individual lives of those who are only its constituent elements. In this domain as in so many others, the images now are of the enabling state, the facilitating state, the state as animator (2001: 6).

In this new form of biopolitics, the state provides the means by which individual population members may maintain their own health and well being, but it is up to those individuals to engage as active "animated" agents in their own bio-upkeep—what Rose refers to as the enhancement of their "somatic individuality" (Novas & Rose 2000).

Every citizen must now become an active partner in the drive for health, accepting their responsibility for securing their own well-being. Organizations and communities are also urged to take an active role in securing the health and well being of their employees and members. This new 'will to health' is increasingly
capitalized by entrepreneurs ranging from the pharmaceutical companies to food retailers. And a whole range of pressure groups, campaigning organizations, self-help groups have come to occupy the space of desires, anxieties, disappointments and ailments between the will to health and the experience of its absence. Within this complex network of forces and images, the health-related aspirations and conduct of individuals is governed 'at a distance', by shaping the way they understand and enact their own freedom (Rose 2001: 6).

This change is occurring in large part as a result of technological advances in genetics and prenatal testing capacities, the dark history of eugenics, as well as a shifting ideological climate. Our increasing exploration of genetics and disease along with the rise of neo-liberal political ideologies and the rise of "risk" discourses have contributed to the transformation in the way that biopower is executed. According to Nikolas Rose, the discourses of risk and genetics in the neo-liberal era have led to the reformulation of biopolitics as risk politics, molecular politics and ethnopolitics.

**Prenatal Testing as Risk politics**

In the latter half of the twentieth century risk has become the central concept around which people and institutions are organized. Institutions such as the legal system and the healthcare system are now primarily concerned with the distribution and preemption of risk, in contrast to the previous focus on justice, dangers and cures. This shift in thinking toward risk is what Ulrich Beck (1992) describes as the characteristic of reflexive modernity, or second modernity and provides the basis for our new "risk society." As Ericson and Haggerty note:
Risk society is comprised of institutions that organize on the basis of knowledge of risk. These institutions expend a significant proportion of their resources on the production and distribution of knowledge of risk. This knowledge is used to manage populations, provide security, and take risks (2002: 238).

The execution of biopolitics has also taken on the character of risk management in the 'risk society' of late modernity. Rose (2001) outlines the ways in which biopolitics has become risk politics, by shifting the focus from the management of populations by changing material conditions to the management of populations by the identification and prevention of risk. In discussing biopolitics as risk politics, Rose states that:

[the] relation between the biological life of the individual and the well-being of the collective...is no longer a question of seeking to classify, identify, and eliminate or constrain those individuals bearing a defective constitution, or to promote the reproduction of those whose biological characteristics are most desirable, in the name of the overall fitness of the population, nation or race. Rather, it consists in a variety of strategies that try to identify, treat, manage or administer those individuals, groups or localities where risk is seen to be high. The binary distinctions of normal and pathological, which were central to earlier biopolitical analyses, are now organized within these strategies for the government of risk (2001: 6-7).

This type of biopolitics is a mode of governing the future through the management of potentialities. Through the endless collection and analysis of risk information, risk is problematized, rendered calculable and governable. So too, through these efforts, particular social groups or populations are identified as 'at risk' or 'high risk', requiring particular forms of knowledges and interventions. Risk,
from the Foucauldian perspective, is a moral technology. To calculate a risk is to master time, to discipline the future (Lupton 1999: 87).

This marks a point of departure from the operation of traditional biopolitics in that it represents, at least partially, a move away from the face-to-face surveillance of dangerous individuals and groups for disciplinary and therapeutic purposes, to the management of "impersonal 'factors' which make a risk probable" (Rabinow 1996: 100). Thus, biopolitics has been reformulated in terms of risk management in contemporary neo-liberal society.

Pregnancy, and prenatal testing in particular, is indicative of this type of biopolitical programme. In the mid-20th century, healthcare took on the practice of risk profiling in order to identify those who fell within groups that have a significantly higher risk of some condition. The impetus for this profiling derives from the ability to intervene preventatively, before symptoms develop (Rose 2001). Pregnant women are profiled by their doctor, obstetrician, or midwife and if allocated to a high risk group for having some complication, including the chances of having a child with congenital disability, they are subjected to an increased regimen of surveillance and examination, such as ultrasound, amniocentesis, MMS, chorionic villi.

This practice of risk management—riskpolitics—focussed on the health of the expectant mother has historical roots going back to the eugenics movement of the early 20th century. Under the eugenics programme, the risk being managed was the perception that the growing population of the poor, feeble minded, disabled, or degenerate, individuals was being supported by the welfare state that threatened to lower the nation's 'stock' (Paul 1995, Rose 2001). Consequently a number of technologies were put in place in order to segment the population into risk groups and a number of policies emerged in
order to curb the reproduction of those perceived as "unfit", famously including forced sterilization and euthanasia. The rubric of risk management underpinned the eugenic establishment of the field of genetic advising and heredity clinics, whose major focus was the prevention of birth defects. In the closing decades of the 20th century, this practice continued in the form of prenatal testing and screening of "pregnant women whose age of family history placed them in high-risk-groups, coupled with the option of termination" (Rose 2001: 9).

The language of prenatal testing is steeped in discourses of risk. Pregnant women are divided into risk groups based on their comparison to population as a whole as determined by epidemiological experts, such as advanced maternal age, or by a number of risk-exposing screening tests such as MMS. Based on their ascription to high-risk categories, women are then referred to genetic counselling for further individualizing analysis. The genetic counsellors are trained risk-assessors and begin the encounter by proving the pregnant woman with an individualized risk assessment, along with other relevant facts. At this point the pregnant woman is expected to take on the role of risk-manager in deciding the next steps in the progression of her pregnancy, which mainly involve the decision whether or not to undergo amniocentesis and, potentially, therapeutic abortion.

One of the advantages that has arisen from the use of prenatal testing is that risk variables can now be broken down with near certainty on an individual level. As Rose points out:

Now it seems that 'smart' programmes of pre-emptive intervention can be devised that target only those individuals predisposed to a particular condition. This thinking underpins the types of genetic counselling that have become routine since
the 1970's: the screening of pregnant women in 'high-risk' groups; the widespread use of amniocentesis to detect foetuses with genetic abnormalities; the offer of therapeutic abortion for foetuses who test positive; and the increasing resort of 'high-risk' parents to IVF [in-vitro fertilization] coupled with pre-implantation diagnosis in such situations (2001: 12).

This individualizing specificity allows women the opportunity to make reproductive decisions with certainty where this may not have been possible before. In this sense, prenatal testing is proving to be an enabling technology as women who are pooled in 'high risk' groups can now seek out definite pregnancy outcomes rather than simply rely on the odds that they may have an affected pregnancy.

This does not mean that risk is eliminated, however. Prenatal testing is fraught with risk, the most notable of which—besides having a child with a congenital disability or disease—is the risk of spontaneous abortion as a result of the test itself. Not only is risk the language of communication in the genetic counselling encounter, it is also the logic by which access to prenatal testing and genetic counselling is granted. Under current practices, prenatal testing is only available for those deemed to have an increased risk of having a child with a genetic condition. The most common risk factor that determines access to prenatal testing is advanced maternal age. As stated earlier, the risk of the fetus having a chromosomal aberration increases as the pregnant woman gets older. Currently the minimum age cut off for offering prenatal testing to older women is 35. The rationale for choosing the age of 35 is entirely based on risk balancing whereby the risk of having a child with a chromosomal trisomy at this age is equal to the risk of spontaneous abortion associated with amniocentesis. Thus, if women are 35 or older, it is considered less risky to expose them to the possible iatrogenic effects of the testing than
not testing them and potentially increasing the chances of them having a child with Down syndrome. Although the numbers may balance, they are by no means equal. The decision to equate these two risks highlights the fundamental values underlying the testing procedure: that having a child with Down syndrome is on par with not having a child at all. Or looked at the other way, it is assumed to be better to deliberately risk the destruction of the fetus, normal or not, than it is to potentially have a child with Down syndrome.

The above discussion of Rose's concept of biopolitics as riskpolitics is useful in understanding the shift from the governance of individuals to the governance of risk. However, it does not adequately address the link between the governance of those with "defective constitutions" or the reproduction of those with "desirable biological characteristics" and the shift to the governance of risk. What is missing from Rose's discussion is an examination of how the risks to be tested for are constructed as risky. More specifically, with regard to prenatal testing, how is the possibility of giving birth to a child with a genetically based disability or condition that is not immediately life threatening constructed as and accepted as a legitimate risk to be avoided?

Strong social constructionists argue that collective fears such as those we today call 'risk' are created through discursive techniques, rather than existing as dangers grounded in a material reality. As Lupton states:

It has been argued that according to the Foucauldian perspective, risk strategies and discourses are means of ordering the social and material worlds through methods of rationalization and calculation, attempts to render disorder and uncertainty more calculable. It is these strategies and discourses that bring risk
into being, that select certain phenomena as being ‘risky’, and therefore require management, either by institutions or individuals (1999: 102).

If we take such a view about risk in discussing prenatal testing, then we must address how and why the possibility of having a child with a congenital disability is discursively created as a risk.

According to Mary Douglas, all "culture needs a common forensic vocabulary with which to hold persons accountable and further to risk is a work that admirably serves the forensic needs of the new global culture" (1990: 1). In other words, in the individualizing culture of late modernity, risk is now synonymous with danger. Risk has lost its previous meaning of indicating a situation where a positive or negative outcome is possible, and now simply refers to the negative outcome alone. Because risk has taken on the meaning of danger, it has the same cultural roles as danger does in facilitating the ordering and regulation of individuals and groups. Risk gives legitimacy to institutional and group decisions and the hopes and fears of a collective group. As Douglas states:

Risk, danger, and sin are used around the world to legitimate policy or to discredit it, to protect individuals from predatory institutions or to protect institutions from predatory individuals… The dialogue about risk plays the role equivalent to taboo or sin, but the slope is tilted in the reverse direction, away from protecting the community and in favour of protecting the individual (1990: 5,7).

In prenatal testing, this shift is seen in the individualizing approach taken to reproduction and is the way that the genetic risks of reproduction are constructed. The risk that is present in reproduction, that is, mediated through prenatal testing, is constructed as a risk to the pregnant woman. It is the risk of not getting the type of child that is desired. However, clearly the community also has an interest in the types of people that are born,
given that it is the community that will be directly engaged in the socialization of the child and will bear the costs borne by the health care and education systems. In moving away from eugenics of the past, and as Douglas suggests, as a result of the increasing individualization of our western mass culture, risk is presented as the domain of the woman's reproductive freedom.

This individualizing frame of reference helps us to see how some risks are accepted as something to be concerned about whereas others are not. Ian Hacking (2001) has developed a useful theory concerning the mechanisms for inclusion in what he calls the "collective risk portfolio", that is, the sum of risks that are perceived as more threatening to a collective group of people or culture. "A risk portfolio is just that set of hopes but especially fears that moves you, that you feel strongly about" (Hacking 2001: 14). He states that in order for a risk to be accepted into the universal risk portfolio it must represent a threat to the purity of the center, meaning the mainstream population. The fundamental presumption behind this argument is that risks are ultimately managed—accepted or rejected—on the basis of the perceived threat of that risk. If the risk is presented as pollution, it satisfies the necessary condition of entrance into the collective risk portfolio. The birth of a child that is different is perceived as polluting the domains of the "normal" family, or "normal" child.

Biopolitics in the risk era, what Rose calls riskpolitics, serves a similar purpose as that which characterizes traditional biopolitics in providing a logic by which individuals govern themselves. Increasingly individuals are called upon to ‘do the right thing’ in their decision making in the face of risk. In neo-liberal societies, individual governance is outsourced to the individual actor; however, this personal governance takes place
within a web of state sanctioned and expert mediated risk discourses. As Lupton states in discussing pregnancy:

Many of the discourses of risk that surround the pregnant woman suggest that it is her responsibility to ensure the health of her foetus, and that if she were to ignore expert advice, she is culpable should her baby miscarry or be born a defect. The pregnant woman, therefore, is positioned in a web of surveillance, monitoring, measurement and expert advice that requires constant work on her part: seeking out knowledge about risks to her foetus, acting according to that knowledge (Lupton 1999: 89-90).

As a result:

Risk avoiding behaviour...becomes viewed as a moral enterprise relating to issues of self-control, self-knowledge and self-improvement. It is a form of self-government, involving the acceptance and internalization of the objectives of institutional government (Ibid: 91).

Although risk is presented through expert discourses and is a technology of individual governance in contemporary neo-liberal society, the interpretation of what risk means is highly subjective. Psychometric researchers have found that lay people tend to overestimate risk related circumstances if they can envision themselves in that position (Lupton 1999, Kolker & Burke 1994). In prenatal testing this leads to the overestimation by those women who may have an increased risk of having a child with a genetic disability of the actual likelihood of such an occurrence. This hypothesis is supported by the work of Rapp (1999) and Kolker & Burke (1994) who found that the majority of lay people given risk analyses tend to overestimate the meaning of these risk statistics. For example, a one in two hundred chance (0.5 percent) of having a child with Down
syndrome, based on maternal age, is seen by many as a serious risk. In most cases, risks that are statistically insignificant loom large in the imagination of those presented with the task of managing these risks. As one worried father in Rapp's study states: "This is the first time that one in two hundred looks like bad odds to me" (quoted in Rapp 1999:70).

However, the tendency to overestimate risks when the consequences are potentially devastating is not universal among pregnant women facing these decisions. The Kolker & Burke study also found that women with higher levels of education, particularly those with some graduate or professional education, were less likely to have an exaggerated perception of risk probabilities than those with less education. In interviewing a large number of women undergoing genetic counselling and prenatal testing, Rapp (1999) found that lay perceptions of risk vary significantly across class and cultural lines, and vary with the number of children the woman or couple already have. Most notably, Rapp found that women who have had a number of previous children are less likely to be concerned by the statistics given for the risks associated with advanced maternal age, and tend to place more trust in their bodies' abilities to produce healthy kids, given that they have a track-record of healthy kids. First-time parents of advanced maternal age, who incidentally tend to be middle-class professionals, have less childbearing experience from which to draw on and tend to be more concerned with the associated risks.

This scenario is problematic in a prenatal testing environment where risk is the central language of communication and the values of individual autonomous decision making and "value-neutrality" are normalized (Rapp 1999). As Rapp states:
Statistics may offer a comfortable framework for information-seeking, medically compliant patients, especially those with some advanced education (read: middle-class), but they often gloss over the lived reality of less privileged women (1999: 69).

As one astute genetic counsellor interviewed by Rapp comments:

How do we convey a chromosome risk when a low-income pregnant Afro-Puerto Rican woman experiences a 100 percent chance of running out of food stamps this month, a 25 percent risk of having one son or brother die in street violence, and an 80 percent chance of getting evicted by the end of the year? A one-in-180 chance of having a child with a chromosomal abnormality at age 35 is probably the best odds she’s facing (1999: 69).

Obviously different life circumstances affect a person’s perception of what is and what is not a serious risk. Clearly, given that risk is subjectively assessed, the communicating in the language of risk in the genetic counselling encounter is not necessarily an effective means of conveying objective or relevant information. Objectivity, in these circumstances, is a misnomer in spite of statistically accurate risk predictions.

When biopolitics is reformulated as riskpolitics as we increasingly organize our institutions around discourses of risk, governance of health is increasingly outsourced to the individual agent in the form of risk management. This trend is nowhere more apparent than in the management of pregnancy. The language of risk calls upon the individual to engage in proper practices of care (typically defined by professionals), and hence in appropriate self-governance in order to minimize risks and hence maximize health. Thus it is at this intersection between technologies of the self and discourses of risk that biopolitics becomes riskpolitics.
Prenatal Testing as Molecularpolitics:

As eugenics fell out of favour with the public following the Second World War, genetics increasingly became dissociated from the broad categorical thinking that underscored the earlier eugenics movement. The focus of genetics shifted away from the appearances of pathology and normality in the understanding of disease to emphasize the underlying genetic determinants at the molecular level. As geneticists increasingly moved to an examination of genetics on a molecular level, our view of life and human biology mutated to follow suit. Human bodies were previously viewed on the level of cells, tissues and organs, as perceived in the examination room or dissection table. However, the shift in genetics toward the molecular level changed our vision of human biology to a sub-microscopic molecular level. The cell and its organelles were supplanted by molecules and atoms as the primary unit of analysis of biology (Rose 2001).

With this shift to a molecular vision of the body came an associated change in the vocabulary with which to speak about the biology of human life. Gone was the language of mechanics, physics and chemistry, which was replaced with the language of communications theory and linguistics. The new language of biology is one which is expressed in terms of information, messages, programmes, coding and decoding. As Nikolas Rose summarizes:

In the genomic discourse that took shape over the closing decades of the 20\textsuperscript{th} century, life was imagined as sub-cellular processes and events, controlled by a genome which is neither diagram nor blueprint but a digital code written on the molecular chromosome. This is the 'language of life' that contains 'the digital instructions' that make us who we are (Rose 2001: 13-14).
This process of viewing our bodies, and specifically articulating ideas about health and illness on a genetic level, is what Abby Lippman refers to as the "geneticization" of identity and the reduction of the body to its genetic components. As Lippman defines her neologism:

Geneticization refers to an ongoing process by which differences between individuals are reduced to their DNA codes, with most disorders, behaviors and physiological variations defined, at least in part, as genetic in origin. It refers as well to the process by which interventions employing genetic technologies are adopted to manage problems of health. Through this process, human biology is incorrectly equated with human genetics, implying that the latter acts alone to make us each the organism she or he is (1991: 19).

As Novas and Rose state:

Geneticization is seen as an individualizing tactic that redirects scarce resources away from social solutions to social problems and represents a threat to doctrines such as equal opportunities as well as to ideas of free will, intentionality and responsibility (2000: 489).

As the view of the body has shifted to the submicroscopic molecular level, our relationship with our bodies has changed as well. Increasingly the human body is understood in molecular and, specifically, genetic terms, and the self-governance associated with the new neo-liberal biopolitics is expressed at this molecular level. This is what Rose refers to as molecular politics: the operation of biopolitics on a genetic level, and the new "genetic responsibilities" that this specific paradigm of the body creates. Associated with the increasing "geneticization" of medicine and our bodies, and with the rise of molecular politics is a transformation in our concept of personhood toward what
Novas and Rose (2000) call the “somatic individual.” The “somatic individual” refers to a new form of personhood based on a genetic understanding of the body accompanied by new forms of “genetic responsibility” and corresponding self-governance. In the genetic era, where disease is reconceived on a genetic level and bodies are seen as “genetically risky”, individuals are induced into new relationships between themselves, their future and their relatives and endowed with new responsibilities associated with these relationships (Novas & Rose 2000). As genetic research uncovers the tools of life itself, natural life increasing falls under the realm of culture through the practices of exploring and mapping genomes and manipulating them through genetic engineering (Rabinow 1996). Thus,

Natural life can no longer serve as the ground or norm against which a politics of life may be judged. Dilemmas about what we are, what we are capable of, what we may hope for, now have a molecular form. Biopolitics now addresses human existence at the molecular level; it is waged about molecules, amongst molecules, and where the molecules themselves are at stake (Rose 2001: 17)

The concern of biopolitics in the new genetic era becomes the governance of molecules within people rather than simply the disciplining of individuals themselves. However, the individual is still called upon to engage in forms of self-discipline that are specific to this genetic reconception of health, mainly in the form of responsibility to those with whom one shares one’s genetic endowment.

Prenatal testing follows this type of molecular politics. The subject of the tests administered in prenatal testing is not the fetus per se, nor the expectant mother, but the molecules within the fetal DNA and chromosomes. In prenatal testing, pregnant women and fetuses are regulated based on their genetic endowment. In cases where a genetic
condition is known to exist in the family, the pregnant woman is redirected towards
genetic counselling and the option is given to undergo testing in an attempt to regulate the
transmission of unfavourable molecules. However, the desire is not specifically for the
elimination of unfavourable molecular combinations that lead to unfavourable conditions
as was the case with earlier eugenics movements; rather this type of molecularpolitics is
enacted in the surveillance and active management of molecules with the aim of
knowingly eliminating or reproducing them.

This induces the second aspect of molecularpolitics: relational responsibility. The
introduction of genetics into the realm of healthcare and biopolitics has created novel
ways in which we think about the responsibilities of pregnancy and reproduction. No
longer is the mother simply responsible for ensuring that she meets the material needs of
the future child while in utero, for example through proper diet, but she now bears a
responsibility to safeguard the genetic make-up of the fetus as well. This responsibility is
enacted through engaging in the prenatal testing encounter, whether it is simply by seeing
a genetic counsellor, or undergoing amniocentesis and therapeutic abortion.

The main criticism raised by those who challenge the process of geneticization is
that the reduction of all aspects of illness to a genetic level ignores other factors of illness
and results in a new form of biological determinism. According to this argument, the
 geneticization of illness is an individualizing tactic which diverts attention away from
other contributing factors to illness. For example, many other factors contributing to the
health of the fetus, such as low birth weight—which is frequently associated with
maternal poverty—pose a much higher risk to the overall health of the fetus than do
genetic risks. However, these non-genetic risk factors are increasingly ignored by the
hegemony of genetics (Rapp 1999). The view of illness is thereby diverted away from
social, psychological or environmental factors and towards a focus on the individual’s genetic inheritance. This essentializing perspective on illness threatens social values of equal opportunity, free will, and responsibility (Novas and Rose 2000).

The individual affixed with a genetic label can be isolated from the context in which s/he became sick.... The individual, not society, is seen to require change; social problems improperly become individual pathologies (Lippman 1992: 1472-3).

And as the Roeher Institute points out:

The geneticization of medicine further enables this notion [of disability as abnormal], locating the cause of disability and illness in a person’s genes rather than in the social, economic, political and cultural environments in which a person lives (2002: 10).

Not only does this tendency divert attention away from a consideration of other contributing factors for disease; it also has the effect of reducing individuals to the sum of their genetic composition. Once a person is found to have the genetic markers of a genetic disease, his or her entire personhood is conflated with that diseased genetic endowment regardless of whether or not he or she is symptomatic or asymptomatic: the individual with the gene for Huntington’s disease, for example, is tied to that identifier and corresponding identity from the moment the diagnosis is made, although it may be up to sixty years before any real symptoms develop. In this regard, the geneticization of medicine fixes people in new and immutable identity categories, resulting in their permanent objectification under the gaze of biomedical science. This is problematic in prenatal care as genetic concerns with the fetus tend to overshadow other concerns which can have a greater impact on the immediate health of the child once born, such as
Nutrition and low birth weight. Once prenatal testing labels a fetus as having a genetic condition, the stigma of that condition becomes totalizing regardless of the degree to which it may actually affect the life of the future child.

Although this view of how geneticization leads to a novel type of biological determinism is popular among critics, Novas and Rose (2000, Rose 2001) are quick to point out that geneticization has an enabling aspect that must not be overlooked. Critics of geneticization claim that genetic reductionism leads to the essentialization of individuals in terms of their genetic make up, thereby locking them in a powerless position, unable to do anything to change their genetic inheritance. Novas and Rose challenge this view of the geneticized individual as passive and powerless:

Today, as at the birth of clinical medicine, the sick person bears their illness within their corporeality and vitality—it is the body itself that has become ill. But this somaticization of illness did not, in fact, mandate the eternal passivity of the patient. In fact, clinical medicine, increasingly over the last half of the twentieth century, constituted the patient as 'active' subject—one who must play their part in the game of cure.... The same is true of the role of contemporary medical genetics in the fabrication of the person genetically at risk. The patient is to become skilled, prudent and active, an ally of the doctor, a proto-professional—and to take their own share of the responsibility for getting themselves better (2001: 489).

Endowed with a genetic constitution, the individual with a hereditary disease bears a relational responsibility to his or her family and future offspring. Thus, the individual is now obliged to play an active role in the maintenance of his or her health and those of her
offspring. In the case of reproduction, this is done by making autonomous decisions based on information obtained through genetic counselling and prenatal testing.

With the ongoing geneticization of health and illness, the form of biopolitics that Foucault has described has taken on a new form. As Novas and Rose note in their discussion of the birth of what they call the “somatic individual”:

When an illness or a pathology is thought of as genetic, it is no longer an individual matter. It has become familial, a matter both of family histories and potential family futures. In this way genetic thought induces ‘genetic responsibility’—it reshapes prudence and obligation, in relation to getting married, having children, pursuing a career and organizing one’s financial affairs (200:487).

Thus as Rose reminds us, testing fetuses for genetic disease is part of the genetic responsibility that a person at risk of passing on a genetic condition has toward herself, her baby, and to the rest of society more generally.

Prenatal Testing as Ethopolitics:

Risk assessments, particularly when they result from predictive genetic testing, are inherently problematic. Although many conditions are certain to arise as a result of genetic or chromosomal aberrations, what is not certain is the degree to which the condition will be expressed. For any number of genetically based conditions a whole range of severity from mild to extreme may be expressed. One must only look to individuals with spina bifida to see that although they carry the genes for the condition, the symptoms may range from an innocuous limp to paralysis and mental retardation. As we are not able to predict the severity of the genetic condition that is detected in prenatal
genetic testing, specifically with regard to conditions that are not immediately or necessarily fatal, we are frequently induced to ascribe judgements of worth to individuals with certain disabilities. As Rose states:

> While the calculation of risk often seems to promise a technical way of resolving ethical questions, these new kinds of susceptibility offer no clear-cut algorithm for the decisions of doctors or their actual or potential patients. In this space, biopolitics becomes ethopolitics (2001: 12).

Rose (2001) defines ethopolitics as "the politics of life itself and how it should be lived" (p.18). In other words:

> ...ethopolitics concerns itself with the self-techniques by which human beings should judge themselves and act upon themselves to make themselves better than they are. While ethopolitical concerns range from those of lifestyle to those of community, they coalesce around a kind of vitalism: disputes over the value to be accorded to life itself: 'quality of life', 'the right to life' or 'the right to choose', euthanasia, gene therapy, human cloning and the like. (Rose 2001: 18).

As biology increasingly falls under the realm of choice, as is the case in prenatal testing, ethopolitical concerns develop. In the prenatal testing encounter, what is at stake is not simply an individual decision about whether or not one chooses to have a child that is diagnosed to have a certain congenital condition; rather, it is a decision based on the understanding of life itself and what types of life are better than others. Ethopolitics, as expressed in prenatal testing, represents the interjection of culture into "natural" biological functions, through "techno-science" in the form of the culturally mediated endeavors of genome mapping and genetic testing (Rabinow 1996). Finally, the "natural" make-up of the future population is altered by culture as reproduction is made amenable
to choice through prenatal testing. This represents a substantively different practice than that of eugenicists in the early part of the twentieth century as it involves the biological intervention directly on the genetic level—the level of life itself—particularly as genetic interventions are sought for genetic diseases.

With this reconceptualization of personhood on the biological level of the individual ‘ethos’, Rose argues that the conception of biology as destiny is consequently being challenged. This suggestion counters those of other writers that the genetic era has led to an increase in biological reductionism in both science and popular culture (see Lippman 1991). For Rose, it is the fact that biology increasingly falls under the realm of choice that is challenging the equation of biology with destiny. Rose suggests that it is precisely through the rise of ethopolitics and what he calls ‘the will to health’ that ‘genetically at risk’ individuals are able to come together as unified interest groups and influence the direction of biomedical research and the deployment of biomedical technologies. As Mary Douglas comments in reference to these new categories or labels:

[Institutions do not just produce labels, the labels] stabilize the flux of social life and even create to some extent the realities to which they apply....This process Hacking calls 'making up people' by labeling them 'the sheer proliferation of labels during the nineteenth century may have engendered vastly more kinds of people than ever the world knew before.' ...As fast as new medical categories (hitherto unimagined) were invented, or new criminal or sexual or moral categories, new kinds of people spontaneously came forward in hordes to accept the labels and to live accordingly. The responsiveness to new labels suggests extraordinary readiness to fall into new slots and to let selfhood be redefined...
People are not merely re-labeled.... The new people behave differently than they ever did before (Mary Douglas, quoted in Beck 1999:94).

The result of this process is what Rabinow (1996) refers to as “biosociality”. He suggests that the new genetic categories of illness will likely lead to the formation of new groups as individuals embrace their genetic endowment as a collective identity. These groups will take on the role of experts of their particular shared condition complete with “medical specialists, laboratories, narratives, traditions, and a heavy panoply of pastoral keepers to help them experience, share, intervene, and ‘understand’ their fate” (Rabinow 1996: 102). It is through the enactment of biosociality that the Canadian Down Syndrome Society, for example, can organize together based on their chromosomal constitution and “challenge the vectors that lead from biological imperfection or abnormality to stigmatization and exclusion” (Rose 2001:19). This is precisely what occurs in response to the eugenic concerns surrounding prenatal testing—specific interest groups organized around a shared genetic identity resist the perceived eugenic aspects of prenatal testing in various ways. The disability rights movement, which is largely responsible for the criticism of prenatal testing, is predominantly composed of such interest groups organized around a common biosociality.

These new forms of identity based on the embracing of genetic constitution are not necessarily free of older stigmas associated with the conditions which are being re-claimed. As Rabinow points out,

Older forms of cultural classification of bio-identity such as race, gender, and age have not any more disappeared than medicalization and normalization have, although the meanings and the practices that constitute them certainly are changing. Post-disciplinary practices will co-exist with disciplinary technologies;
post socio-biological classification [i.e. new genetic classifications] will only gradually colonize older cultural grids (1996: 103).

Thus, the pre-existing cultural stigma given to disability will not immediately be supplanted by new genetic classifications that seek to undermine these stigmas through the use of the language of genetics.

Rose and Rabinow’s insight addresses the enabling aspect of ethopolitics, as the overarching framework within which criticism of biopolitical programmes such as prenatal testing can be waged. However, when Rose states that prenatal testing as a preventative strategy is done purely because effective treatments for these genetic conditions have yet to be developed, he overlooks a fundamental issue, which is the rationale for “preventing” these specific conditions. He is correct in suggesting that when biology is understood to be malleable, judgements of worth based on perceptions about quality of life become inevitable. But it is the basis on which these judgements of worth are made that is at issue. I argue that these judgments of worth are made in a context that biases the outcomes insofar as they lack a critical understanding of what differentiates disability from illness, and are based predominantly on incomplete lay understandings of the causes and consequences of the conditions being ‘prevented’. This is precisely the issue to which disability rights activists refer when claiming that prenatal testing constitutes a return to eugenics—that ethopolitics introduces social prejudices into decisions about “life itself.”

**Prenatal Testing as the New Eugenics?**

Discussions of the practice of prenatal testing often include the debate between abortion and reproductive freedom. However, the main debate that has arisen over this
practice is between the medical practitioners who support prenatal testing as a tool for informing a person’s reproductive decisions with regard to congenital disease, on the one hand, and disability rights advocates who argue that this is a eugenic practice based on the assumption that life of a disabled person is not worth living, on the other (Shakespeare 1999). It is this latter debate that shall discuss in this section.

Diane Paul (1995, 2005) offers a useful general summary of the three main arguments for and against the claim that prenatal testing conflicts with the disability rights movement. Briefly stated, the three arguments against the claim that prenatal testing is eugenic are: 1) prenatal testing and the decision to abort are voluntary, whereas eugenics is inherently coercive; 2) there is no social agenda that drives the practice of prenatal testing—it is an individual choice; 3) it is based on science that is not motivated by racial or class discrimination. The main arguments made by those who claim that prenatal testing is a eugenic practice are: 1) prenatal testing may not be coercive, but the practice does involve a number of mechanisms of persuasion; 2) the very existence of prenatal testing services that are limited to certain genetic conditions serves a social agenda that presupposes that these conditions are undesirable and should be prevented; 3) in spite of the fact that individuals are free to make their own reproductive choices, the net effect of these individual choices is an overall decrease in the number of people being born with these conditions. I shall address each of these arguments in turn.

**Persuasion vs. Coercion**

It is necessary first to highlight some of the ways that these claims that prenatal testing is eugenic are made. There are several arguments that persuasion is a predominant component in prenatal testing. The first is that the individuals involved in prenatal testing
often make their decisions based on a sense of obligation to do the right thing and not necessarily on what is right for them. This is demonstrated in d’Agincourt-Canning’s (2006) work that found that with regard to genetic testing for breast and ovarian cancer, women tend to make decisions based on a sense of their embodied self, their relational self and their civic self, a result supported by the work of Nina Hallowell on the same topic (Hallowell 1999). Although this evidence is from a different type of genetic testing, the results are potentially applicable in that they trouble the assumption that an atomistic, disinterested individual makes autonomous decisions about medical procedures, including prenatal testing. This research shows that a sense of doing what is right for others along with a sense of civic duty often informs the ways that people make decisions with regard to genetic health. In other words, the responsibilization that is associated with procedures of governmentality does not just result in docility, it also engages people to think about decision-making in certain ways, most importantly with regard to civic obligations and abiding by certain discourses of health and responsibility. These subtle feelings of obligation to do what is perceived to be the right thing with regard to health are tied up with the way that prenatal testing is routinely offered. Routine tests such as ultrasound and blood tests are often done without first obtaining proper informed consent (Lippman 1991). An obvious example of how the routinization of these tests can create feelings of obligation is the California law stating that doctors are legally required to offer a test for neural tube disorders to all pregnant women (ibid., Saxton 1998). Since these practices are presented and legally sanctioned as routine, they exert persuasive influence on people’s decisions to undergo prenatal testing. The tests are presented in such a way as to suggest that if a pregnant woman is a responsible citizen, she ought to have the tests done. These tests are offered to the pregnant woman based on the same assumptions
made by eugenicists in the early days of genetic counselling: that the conditions tested for are bad and most responsible people would want to avoid them. Hence termination in the case of a positive diagnosis is the inherently desired outcome. This does not mean that women's decisions in this case are any less autonomous, or that they are spuriously based on a sort of "false consciousness". Rather, these tacit forms of persuasion cast one outcome as better than the other. Given that relational responsibility, including civic responsibility, is a criterion in the decision-making of most women, these subtle influences may affect the actual choices made.

Finally, an element of persuasion is also present in the implicitly directive ways in which genetic counsellors occasionally counsel their patients (Michie et al. 1997). Despite upholding an official commitment to non-directiveness, many professionals do not counsel clients in a way that legitimates the choice to continue a pregnancy where a genetic condition is detected (Asch 2003). This claim is supported by the research done by Lippman and Wilfond who found that doctors and genetic counsellors have drastically different approaches when counselling parents with a newborn with a genetic condition in contrast to the counsel they give to expecting parents with a fetus with the same genetic condition (Lippman & Wilfond in Asch 2003). When counselling parents of a newborn with a genetic condition such as Down syndrome, the focus tends to be on the positive aspects of the condition and the ways in which their child's life would be like a 'normal' child’s. However, when counselling expectant parents with a fetus that is diagnosed with the same condition, the focus tended to be on the medical complications and the difficulties that the child will experience. What is worth noting in this practice is that the expectant parents are in a position in which abortion is an option for them in dealing with the affected fetus. Given that they are put in the position of deciding whether or not to
abort the fetus, they are thus forced to pass judgment on the worth of the life of a person with Down syndrome based on their idea of the disabled person’s quality of life. If the counsellor disproportionately emphasizes the negative issues associated with Down syndrome, then these quality-of-life assessments will be based on a biased view of what it means to live with a particular disabling condition. The parents of the child with Down syndrome are not in this same position.

Another troubling finding of Michie et al., supported by a number of other researchers, is that genetic counsellors tend to be more directive in favour of termination when they are counselling individuals who appear to be poor (Wertz & Fletcher 1997, Roeher 2002, Michie et al 1997). Asch suggests that these forms of directiveness are in part due to the fact that “[genetic] counsellor education contains little opportunity for contact with disabled children or adults in non-medical settings where clinicians could observe how people with disabilities manage day-to-day life” (2003: 334). My own discussions with genetic counselling students at UBC reflect this claim.

The idea of the primacy of a “value-free” genetic counselling encounter is also problematic. In attempting to provide a counselling session that is value-free, a standard that most counsellors strive to achieve, the important task of the counsellor to engage in critical self-reflection is often over-looked (Sullivan and Heng in Roeher 2002). Because counsellors are seen as simply providing the facts, there is little perceived requirement for them to analyze their own thoughts and positions on what the best decision as a result of prenatal testing is. The belief that one can simply relay medical facts is naïve as such facts are always mediated or understood through personal frames of reference. The desire for objectivity often overshadows the need for counsellors to engage in critical self-reflection in order to assess, or at least be conscious of the ways that their own personal
thoughts and feelings toward the situation may be influencing the way they present the “objective” facts. “It can be said that all medical and scientific endeavors proceed replete with values; thus, the options that counsellors suggest are not really “value-free”” (Roeher 2002: 93). As Rapp (1999) points out, it is difficult to accept true value-neutrality in prenatal diagnosis when the technology underlying the purpose of the counselling session was developed to identify and eliminate fetuses. Consequently, without engaging in this type of practice, a form of latent influence may occur. Although some are critical of the entire idea of non-directive and value free counselling, if one is to subscribe to this approach, all aspects of influence must be assessed.

One example of how counsellors typically fail to critically assess what their opinions are and separate them from the counselling encounter is evident in the recent analysis of data collected in 1985 by Wertz and Fletcher (Wertz and Fletcher 2001 in Roeher 2002). In the study, 683 geneticists in 19 nations were asked about the degree to which they agree with the American Society of Human Genetics’ definition of “non-directiveness”, which is stated as follows:

1. Helping clients understand their opinions and the present state of medical knowledge, so they can make informed decisions;
2. Helping clients adjust to and cope with their genetic problems;
3. The removal or lessening of patient guilt and anxiety;
4. Helping clients achieve their personal goals;
5. The prevention of disease or abnormality.

It was found that close to 100 per cent of those who responded agreed with this definition. The problem with this definition, however, is that it promotes a dualistic and incongruent concern for non-directiveness while simultaneously striving for the prevention of disease
or abnormality. It must be noted, however, that the data for this study was gathered in 1985, during the relative infancy of genetic counselling as a mainstream medical profession. In the past 20 years counsellor attitudes toward the definition of non-directiveness may well have changed. For this reason, it would be useful to follow up this survey to see if the results would be similar. That being said, the results of Wertz & Fletcher’s 1995 international study on the attitudes and practices of genetic counsellors found that twenty percent of genetic counsellors in English-speaking and northern European countries—which all have an explicit commitment to non-directiveness in their counselling practices—felt that given the availability of pre-natal testing it is not fair to society for a couple to knowingly give birth to a child with a serious genetic disorder (Wertz & Fletcher 1997).

Another difficulty that faces genetic counselling today is a lack of professionals to offer non-directive counselling. In North America there are far fewer professionally trained genetic counsellors than there is demand for their services (Roeher 2002, Paul 1998). Consequently, much of the counselling offered to patients is done by family doctors and obstetricians, who are not only usually trained to be directive, but are also liable to face malpractice suits if tests are not encouraged.6

Another challenge to the non-directive role of the genetic counsellor is that biotechnology companies often make money by selling predictive tests and governments

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6 In recent years there have been a number of successful wrongful birth lawsuits against doctors—cases where the parent is the plaintiff suing the doctor for failing to provide adequate information that would have led them to not have the child in the first place. These cases include the H. (R.) vs. Hunter in 1996 and Krangle vs. Brisco in 1997, both of which the doctors were found to be negligent of not recommending genetic testing when children with congenital conditions were born. In the H. (R.) vs. Hunter case, the plaintiff was awarded $3 million in damages, and in the Krangle vs. Brisco the plaintiff was awarded the cost of caring for the child up to age 19 and any income loss associated with having to care for the child (Roeher 2002). Given the substantial monetary awards given to the plaintiffs it is clear why professional guidelines for doctors recommend that all eligible pregnant women are offered testing (Paul 1995, Saxton 1998).
and insurance companies often save money by having people use them. From the perspective of both interest groups, the more women screened and tested, and the more affected fetuses aborted, the better the programme is working. As governments continue to favour the prevention of disability, biotech companies continue to market tests, and doctors continue to provide tests for legal rather than medical reasons, the pressure toward testing and termination dominates the background against which the genetic counsellors operate.

Social Agenda vs. Social Stigma and Aggregate Elimination

Those who argue that prenatal testing is a eugenic practice also rely on claims that a social agenda is evident in the design of the tests themselves. According to this argument, the current practice of limiting prenatal testing to only a limited number of testable conditions constitutes a policy of discrimination. This testing is only offered for those who are at risk of having a child with a disability and are offered in such a way that termination is normally the only option that is chosen or rejected. Although prenatal testing is based on individual choice, the types of conditions that are permitted for testing are based on professional standards of practice and market forces in the form of tests available (SOGS 2001). However, it can be assumed that the government sanctions the permitted testable conditions given that the Canadian government, for example, has only disallowed testing for the sex of the fetus. In this sense, the prohibition of testing for one biological trait is a de facto endorsement of the other tests being offered. It may be suggested that the motivation of the government in supporting these tests is the economic benefit associated with the reduction in the number of children born with disabilities.
However, this can also be seen as indicative of the extent to which the modern state understands its job as maintaining the overall health of the population (Foucault 1990).

The underlying contention between disability advocates and healthcare practitioners is derived from their fundamentally different ways of viewing prenatal testing. This difference hinges largely on the definitions and models of disability that each party begins with. Generally speaking there are two main models of disability that are widely used: the medical model, and the social constructionist model. The medical model of disability is the dominant model used by most people, including lay people and medical practitioners. This model sees the person’s disability as being the sum of the person’s problems. In this model, it is the disability itself that is the problem and not the social context of having a disability in a world where disability is stigmatized. When the medical model sees disability as a medical problem and presents this problem in the medical language of disease, and then the principal question becomes how to alleviate or prevent this disease. This is the model that informs prenatal testing for disabling conditions.

On the other hand, the social constructionist model sees society’s continued discrimination against people with disabilities as the main source of the disabled person’s problems, rather than the disability itself. Specifically, this model approaches the disabled as a social group or minority group who are set apart from the majority by a difference of abilities. This way of seeing disability is not easily sustained in a world where the medical model is predominant. One way of conceptualizing this problem is to consider the practice of prenatal testing, but replace the word disability with woman, or Chinese, or homosexual, or any other group that has been or still is discriminated against in Canadian society. It would seem absurd by most to suggest that homosexuality is a
problem that can only be fixed with medical intervention and prevention, as is currently said of congenital deafness, for example. As Sharp and Earle state in regard to the social construction of disability:

> It may be that in the current social and economic environment, disabled lives are not worth living; however, that is not a consequence of impairment itself, but instead of prevailing social and economic conditions which militate against individuals leading full and satisfying lives (2002:140).

For example, being confined to a wheelchair before accessibility laws were passed may have led to a less than full life as result of systematic barriers limiting physical access to all social locations. This is clearly not a direct result of being confined to the wheelchair, per se, but also a result of the lack of social spaces that are accessible to people in wheelchairs. This same argument can and is made with regard to other kinds of physical and cognitive disabilities. Thus as Hume reiterates:

> It is not the disability so much which restricts equality and full participation in society, but the combination of social stigma, systematic barriers and persistent use of demeaning devaluing language (1996: 4).

The dominance of the medical model of disability in prenatal testing is apparent in the language that is used in the field. Virtually all groups invested in prenatal testing exclusively use the medical language of disease, deformity, or abnormality when discussing disability. The Roeher Institute (2002) conducted a basic content analysis of all texts used in genetic counselling courses across Canada in order to evaluate the language used to describe genetic differences. They found that genetic and chromosomal conditions such as Down syndrome are almost unanimously referred to as “disease”, “abnormality”, “malformation”, et cetera. The nearly exclusive use of the devaluing
language of disease when discussing these conditions in the classroom setting is training future genetic counsellors to have a negative view of these conditions before they enter the counselling setting. Given the prevalence of these attitudes toward disability, it is dubious to believe that all prenatal testing decisions are of equal worth. With the exclusive use of the devaluing medical language of disease and abnormality, it is assumed that to keep a child with a genetic or chromosomal condition is to willingly invite disease into the world. By presenting disability with negative language, the presupposition that these conditions are bad is inherent in any discussion about whether or not to terminate an affected pregnancy. Consequently, “prenatal testing is constructed as a way of avoiding “disaster” (Lippman 1991: 23).

The Eugenic Effect of Reproductive Choice

The arguments for the aggregate eugenic effect of prenatal testing is supported by the data published by Health Canada in their “Congenital Anomalies in Canada: A Perinatal Health Report” from 2002 (Health Canada 2002). The report addresses the state of a number of congenital anomalies, such as Down syndrome and neural tube disorders, based on data collected from all provinces and territories by the Canadian Congenital Anomalies Surveillance System (CCASS). Specifically this report discusses the risk factors, provincial and federal prevalence rates, and the impact of prenatal diagnosis on birth prevalence for Down syndrome, neural tube defects such as spina bifida, congenital heart defects, oral facial clefts and limb reduction defects. They found that prenatal testing was responsible for a significant reduction in the birth rate of a number of the conditions tested for. Specifically they report that testing for Down syndrome and neural tube defects has had the greatest effect on the number of people born with these
conditions and that prenatal diagnosis of oral facial clefts “may have an impact on the birth prevalence in cases where other associated anomalies are detected” (p.25). In discussing Down syndrome the authors state that:

As a proportion of all recorded cases affected with DS, 53.2% were prenatally diagnosed and electively terminated. The rate of pregnancy termination of DS ranged from 26.7% in Alberta, Canada, to 84% in Paris, France. The prevalence at birth of DS decreased over seven years in many programmes that showed the highest rates of terminations, suggesting that a high proportion of prenatally diagnosed cases were terminated (Health Canada 2002: 42).

The other conditions discussed in the report were not found to be significantly affected by prenatal testing predominantly as a result of a lack of good testing.

These findings are supported by the work of Caraveo et al. (2003) and Sibbald (2003), who found that there has been a relative reduction in the number of children born with Down syndrome in the past few years in both British Columbia and Alberta. Both authors suggest that this reduction is likely the result of prenatal testing for these conditions and subsequent abortion.

This aggregate effect of prenatal testing is one of the main concerns of those who argue that this is a eugenic practice. On a large scale, these individual choices are having the effect of eliminating (or at least noticeably reducing) people with congenital disabilities from the social body. Thus, a laissez-faire eugenics (Kitcher 1996) is having the same net effect as the eugenics movement did in the previous century.

Aside from these concerns with the practices of prenatal testing, critics also have a number of concerns about the potential outcomes that may result from this practice. One of these concerns is the potential that disability may eventually become distributed along
class lines. This is particularly true in the U.S., where access to the best forms of health care is limited to those who can afford to pay. Amniocentesis and the resulting chromosomal analysis cost approximately $1200 to $1500 in the U.S. and are only available to those who can afford to pay the bills. This raises the concern that if prenatal testing is used more exclusively by the higher classes of society, ostensibly genetic disease may become distributed along class lines. The rich can afford to avoid having disabled children, whereas the poor cannot. Thus, genetic diseases will become “lower-class” diseases (Kitcher 1996). In Canada, however, universal health care eliminates this issue and the finding that genetic counsellors are more directive toward termination when counselling those of lower socioeconomic status suggests that the opposite may be occurring here. When assessing these concerns, one must also keep in mind the large number of people morally opposed to abortion that will not engage in this practice. A more realistic claim may be that genetic and chromosomal disability might become distributed along pro-life, pro-choice lines.

Regardless of the potential distribution of genetic disease across classes of people or communities of belief, the more immediate concern is the potential for the social devaluation of disability. As congenital disabilities become concentrated in more marginal social locations, the universality of these conditions will diminish and one can expect to see a resulting increase in the stigma attached to these conditions. It is argued that the overall result will likely be a decrease in funding for care programmes, advocacy groups and research (Kitcher 1996). However, this may not prove to be the case as more and more identify with new disease categories and these “new kinds of people” organize under a collective moniker.
Another concern that critics have raised regarding prenatal testing is that disabilities may wind up being perceived as the unfortunate result of careless or socially irresponsible parents and not as serious conditions requiring care, understanding and advocacy. The danger here is that universal healthcare may cease to cover the treatment of these conditions if they are seen as something that the parents knowingly failed to prevent. The darkly ironic aspect of this possibility consists in the fact that most disability is not congenital.

Although there are a number of potential outcomes that may result from prenatal testing and therapeutic abortion, many of which are contradictory or speculative at best, it is necessary to consider them all seriously. Regardless the results of the implementation of this technology, at very least people need to be made aware of these issues. By speculating about the negative impact of prenatal testing we can make sure that we are not promoting unseen or unanticipated consequences.

**Conclusion: Some Problems and Recommendations**

The difficulty that must be confronted in discussing eugenic practices is the disparate history of eugenics. Today, the term eugenics is so firmly entrenched in negative connotations that the diverse history of those pursuing this scientific discipline is eclipsed by the few monsters of the field. As a result the term is bandied about more as a debate stopper or accusatory statement than as a real point of discussion. Because of the politically charged nature of the term, there are few that wish to realistically explore the connection between eugenics and modern day genetics. In order to address this issue adequately an informed contextualization of the eugenic movement must be made. This does not mean simply claiming that all prenatal genetic testing is eugenic and is therefore
as insidious as Hitler’s euthanasia programmes, nor does it mean that eugenics is predicated by definition on coercion and therefore this moniker does not apply to prenatal testing. Eugenics in reality has always been a multidimensional endeavor, advocated by countless individuals with a wide range of personal and political motivations. At best, an all-inclusive working definition of eugenics that would encompass the full range of the movement might be understood generally to encompass “the desire to change the distribution of births in the population ‘for the better’.”

The underlying logic of the old eugenics which is taken offense to nowadays is that individual rights are subjugated to the benefit of society. This is entirely reversed today where individual rights are paramount over any social concerns. It is this logic that forms the basis of the coercion/non-coercion debate around the question whether prenatal testing constitutes a eugenic enterprise. If we accept coercion as a defining element of eugenics, then Frederick Osborn, Havelock Ellis and Francis Galton—all pioneers and leaders of the eugenics movement—could not be considered eugenicists (Paul 1995). What would be a more astute point of delineation would be that eugenics was originally predicated on the belief that the individual was secondary to the greater good of society. Although this is not the case today, such a point of argument does not necessarily mean that prenatal testing is not a eugenic endeavor. We can say that prenatal testing is based on the ethos of non-directiveness and the supremacy of the individual’s reproductive autonomy. However, the impetus behind providing these tests to individuals is to allow them to make a state sanctioned decision as to whether or not certain specific types of people enter their family and hence the social body. When looked at against the background pressures directing the individual toward termination of an affected pregnancy—such as the value-laden language of medicine towards disability, or the sense
of responsibility to others that is imparted in the individual through a lifetime of social discipline—prenatal testing begins to look a lot like an attempt to change the distribution of births in the population in order to reduce a less desirable aggregate trait.

If we use Rose’s more general definition of eugenics as the desire to “improve the body politic and relieve it of the economic and social burdens of disease and degeneracy in the future by acting upon the reproductive decisions and capacities of individuals in the present” (Rose 2001: 3), the data on birth distributions of Down syndrome in British Columbia and Alberta suggests that prenatal testing is having just this effect. Consequently it is impossible to argue that this is not a eugenic practice if the impetus and ends are the same. The question becomes not whether or not prenatal testing and preventative abortion is an eugenic practice, but is this practice unethical and if so, how might it be changed so as not to be? I suggest that the fundamental issue to be addressed is the specific targeting of disabilities in offering prenatal testing, based solely on a stigmatizing medical model of disability that equates disability with disease. As Diane Paul eloquently summarizes:

As a story of destructive state power, the history of eugenics teaches one lesson. As a story of attitudes toward people with disabilities, it teaches another. The first reinforces the view that reproduction should remain a private affair. The second leads us to reflect on attitudes toward the disabled, those whom Margaret Sanger [a liberal feminist eugenicists in the first part of the twentieth century] as well as Adolf Hitler thought “should never have been born.” In the second story, acts are not benign simply because their agents are private citizens. Indeed, if we insist on absolute reproductive autonomy we must accept the use of genetic technologies to prevent the birth of those who are unwanted for any reason: that they will be the
“wrong” gender, or sexual orientation, or of short stature, or prone to obesity, or.... Used this way, medical genetics will surely reinforce a host of social prejudices. A history of eugenics that is sensitive to its complexities alerts us to the fact that genetic technologies present more than one kind of danger—and that if we are not very careful, we may avoid one only to court another (1995: 135).

The “new eugenics” based on individual choice represents the logical offshoot of the new biopolitics—riskpolitics, molecularpolitics, ethopolitics—much as the old eugenics was a clear derivation of the old biopolitics steeped in discourses of nationalism and national servitude. As traditional biopolitics shifts to a new formulation based on the “will to health” under the ideologies of post-modernism and neo-liberalism, a new form of eugenics is following suit. The basic impetus is the same—to affect the types of individuals born. However, the rationale is no longer racial or nationalistic, but individualizing and family oriented. In this paper I traced a clear historical lineage between present day prenatal genetic testing and the organized eugenics movements of the past. Following this historical lineage, it is clear that today’s genetic practices, such as testing the fetus’s genetic (and chromosomal) constitution, represent an offshoot of the old eugenics and fit into a general definition of eugenics. The difference today is that the eugenic options presented to parents in the form of therapeutic abortion of a disabled fetus are not intended to change the overall gene pool of the population, as was dreamed of by early eugenicists—geneticists realized early on that this eugenic pursuit is not a feasible endeavor, if not for social and political reasons then at least from a genetic standpoint given the number of carriers of recessive alleles in any given population. However, the combined effects of prenatal testing are clearly affecting the make up of the social body, and hence the types of people that are born. Thus it is difficult to argue that
a consequentialist eugenics based on a consumer model of health and individual choice is not occurring.

The specter that always haunts this discussion is the dark history of compulsory (and exterminist) eugenics. The term “eugenics” has become so vilified as a result of the atrocities committed under the worst negative eugenics programmes that any discussion of eugenics is overshadowed by these negative implications. Hence a historically balanced discussion of eugenics under all its “positive” and “negative” guises, from its Marxist and Socialist to Fascist supporters, is rarely possible. Although it is always useful to have a historically situated understanding of the ideas and practices one is discussing, perhaps in the case of the new eugenics, what I term “neo-liberal eugenics”, the eugenics moniker is best left behind in favour of a more contemporary and less emotionally charged terminology, as was advised by Frederick Osborn in 1968. Perhaps if we use the contemporary language of discrimination, a more effective discussion of the core issues of prenatal testing and therapeutic abortion for disabled fetuses will be possible. Although this would be a more effective way to advance the discussion on prenatal testing, it also divorces our current practices from their historical roots, thereby obscuring the mistakes that have been made in the past.

As Diane Paul points out with regard to the issues around eugenics raised by prenatal testing, “we will have a hard time thinking through, much less resolving politically [these issues], for those who are most concerned with these particular (mis)uses of genetics tend also to be the most committed to the principle of reproductive autonomy” (1998: 109). But this is a question that needs to be answered. Old eugenics began as a well-intentioned programme to reconcile civil society’s support of the poor and disabled with the then recent theories of evolution and the survival of the fittest.
However, this well-intentioned programme wound up promoting (however unintentionally) horrendous atrocities against the most disenfranchised people in society. Prenatal testing is also based on good intentions and, like the old eugenics, prenatal testing also has the same potential to prevent the inclusion of certain types of people in the body politic through interventions in reproduction. For this reason, it is a practice that needs to be thoroughly examined with special attention to the ways in which the justification for exclusion is constructed in both discourse and practice. Although this practice does represent a fundamentally new shift in the operation of biopower which is outsourced to the individual citizen, we must be certain that in doing so we do not inadvertently repeat our past mistakes. We have attempted to avoid these mistakes by outsourcing the decisions of who is born and who isn’t to the individual, but, as Paul highlights, “to retreat from politics is ultimately to embrace the market” (1998: 111). Hence, as we liberalize reproduction and the choice of the types of lives to come, we inevitably embrace the commodification of reproductive choices and the consumerization of life itself. The very real potential outcome is a *laissez-faire* eugenics, based on the desire for normalcy and the exclusion of ‘undesirable’ difference.

Providing the previous historical and theoretical analysis of prenatal genetic testing and the eugenic debates that surround it would be fruitless without using it to make suggestions for how to move forward with this issue. In this essay I have argued that the specific targeting of disabling genetic (and chromosomal) conditions that are not immediately life-threatening for therapeutic abortion is based on and perpetuates a discriminatory view of disability and difference based primarily on a medical model of disability and disease. This view underlies the debates between the medico-genetic community and the disability rights community. The only way to adequately and
realistically address this divide, without resorting to an abolitionist argument, is to bring all sides to the table with equal voice. For this reason I recommend the following principles be included in any further debate, discussions and decision-making regarding prenatal genetic testing:

- Representation of all voices in policy and/or guidelines decision making, including medical professionals, mothers, disability rights advocates/people living with disabilities
- Increased involvement with disabled people outside of a medical setting in the education of genetic counsellors and education based on more than just a medical model of disability
- Providing expectant parents access to people with disabilities and families supporting members with disabilities living in the community as part of the counselling encounter
- A critical re-examination of the conditions offered for testing that is informed by both the medical and social constructionist models of disability
- A strong commitment to reducing discrimination toward people with disabilities and maintaining support for the disabled regardless of whether or not the disabilities are seen as preventable
- A requirement that genetic counsellors present all aspects, good and bad, of the condition that they are counselling expecting parents about; this must be done early in the counselling process so as to ensure a truly informed decision
- Respect for the right of mothers to make autonomous reproductive decisions, free of coercion, persuasion or manipulation
Bibliography


