THE ETHICS OF PRENATAL GENETIC TESTING:
EUGENICS, DISABILITY RIGHTS, AND REPRODUCTIVE FREEDOM

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ABSTRACT

Many predict that our new understanding of human genetics will soon lead to the development of new treatments and cures for genetic diseases and disabilities. At the current time, however, this understanding has lead primarily to the development of numerous diagnostic tests used to determine if people or fetuses have a given disorder. This thesis will engage in an ethical investigation of the most widely available testing technology in Canada -- prenatal genetic testing.

This investigation will begin with an analysis of the “eugenics critique” of prenatal testing. This analysis will examine the connection between the current practice of prenatal testing and the historical eugenics movement. This will be done to ascertain if there are any moral and ethical implications for prenatal testing, as it is often suggested, which flow from this connection. I will conclude that there are some legitimate moral concerns which grow out of this critique. They are concerns that prenatal testing is practised in such a way that it respect reproductive freedoms, value pluralism and the dictates of justice.

The moral concerns outlined by the eugenics critique will supply the framework in which the remainder of my investigation will take place. I will examine claims made by disability rights advocates that prenatal testing discriminates against the disabled and denies them their fundamental right to exist. In the end, I will argue, that the disability rights advocates fail to substantiate their claims, but they do highlight concerns about the coercive nature of the testing system and concerns that decisions made within it are often based on stigma and stereotype.

I will conclude that the concerns highlighted by the eugenics’ and disability rights’
critiques can only be addressed if we ensure that prenatal testing takes place within a context which allows parents to make decisions based upon their own values. If this is to be done (as it is currently not the case), then the roles of key figures in the testing system must be reevaluated. In particular, genetic counsellors must give up their strict adherence to the ethic of non-directiveness and they must use the genetic counselling session to correct for the pressures that currently undermine parents’ rights to reproductive freedom.
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INTRODUCTION

The Human Genome Project's goal of sequencing the entire human genome has raised expectations that new ways to test for and treat genetic disease and disability will soon be developed. Many predict that gene therapies will soon be viable and useful tools that will occupy a prominent role in medical efforts to combat disease and disability. The development of such therapies and other techniques for correcting a wide range of genetic disorders may be in our future, but it is not here yet. The reality of the present situation is that our new understandings of genetics has led primarily to the development of diagnostic tests used to determine whether people or fetuses have a given disorder. The focus of this thesis is an ethical investigation of the testing technology which is most widely available in Canada, prenatal genetic testing.

The Prenatal Testing System

Before I begin this investigation a discussion of what these tests are and how they are offered is required. The majority of my discussion in this thesis is relevant to prenatal testing in general and to testing in North America in particular. However, when, in Chapter 3, I make specific suggestions for how the prenatal testing system might be altered, these suggestions are intended only for the Canadian system. I do not extend my suggestions wholesale to the American system, because how testing is offered can vary widely from state to state, and thus my suggestions would only be relevant to some states. However, some testing programs in the U.S. function in ways which are similar to the testing system in Canada. Accordingly, in the
course of my discussion, I will refer to data from the U.S. that I take to be relevant to our practice in Canada.

Since there are a number of different tests and screens that are now available in Canada the ethical implications of each could be discussed independently; however, I am concerned in this thesis with prenatal testing understood as a system of tests. I will in the body of my thesis, therefore, rarely discuss the tests individually, and only when there is a relevant distinction to be made between them. As I am interested, in this thesis, in the complete process of testing, my discussion will include all aspects of the testing system from the referral system, to the tests themselves, and finally to the options available to parents following testing.

What Are The Tests?

Prenatal diagnosis is now available for hundreds of genetic conditions including chromosome abnormalities, inborn errors of metabolism, neural tube impairments, and single gene disorders. The two most common diagnostic tests used to detect these conditions are amniocentesis and chorionic villus sampling. Amniocentesis is the most common invasive prenatal testing procedure in Canada. The process involves extracting fluid from the uterus using a needle inserted through the abdominal and uterine walls. The fluid taken contains fetal cells that are grown in culture and examined to detect genetic abnormalities. This test is normally carried out between 15 and 17 weeks gestation. Chorionic villus sampling (CVS) involves taking samples of the fetal membranes that extend from the uterine wall (the chorionic villi). These membranes are then examined to detect different genetic abnormalities. This test can be carried
out several weeks earlier in pregnancy than amniocentesis, but cannot diagnose some disorders (eg. neural tube defects). Both of these tests are covered by provincial health plans.

The testing system in Canada not only uses diagnostic tests, but employs prenatal screens as well. Prenatal screens do not diagnose genetic conditions, but rather identify women who are likely to be carrying an affected fetus. There are two main screening tests routinely offered to pregnant women in Canada. They are maternal serum alpha-fetoprotein testing (MSAFP) and what is known as the triple screen. Both screens are relatively uninvasive and are tests done on a pregnant woman's blood. MSAFP testing measures the levels of alpha-fetoprotein (AFP) in maternal blood. Higher than normal levels of AFP can indicate that the fetus the women is carrying has a neural tube defect such as anencephaly or spina bifida. The triple screen measures the levels of three different indicators in the maternal blood sample, and is useful in detecting women who are at high risk for having a child with a chromosomal disorder such as Down's Syndrome.

How Are The Tests Offered?

At the core of the testing system in Canada are 22 genetic testing centres which provide both amniocentesis and chronic villus sampling. These testing centres are generally situated in university medical centres or tertiary care hospitals associated with a university. Both the testing equipment and personnel required to administer the tests are highly specialized and hence testing is only offered to women who have been identified as being at an elevated risk of having a fetus with a genetic disorder.
Women are referred for testing at a genetic testing centre by one of the over 10 000 specialists and family and general practitioners who see pregnant women. The majority of referrals are made by obstetricians and GPs. In 1990, 78% of the women who were referred for testing were done so on the basis of “advanced maternal age”. Any woman who is over the age of 35 is at an elevated risk of having a fetus with a genetic disorder. The remaining referrals were made because of an existent family history of genetic abnormality, or because of the results of MSAFP or triple screen testing. Both of the prenatal screens are now offered routinely by OBs and GPs to pregnant women. These practitioners generally collect the samples then send them to one of the 22 genetic testing centres, or to one of the numerous “outreach centres” for analysis.

All women who are referred for testing go through a genetic counselling session before the test is administered. The goal of this session is to ensure that the woman being tested understands the nature and the risk of the test that will be performed, and to ensure that the choice the woman makes about testing is an informed one. The counselling sessions vary in length depending on the disorder tested for and the reason for referral: an average genetic counselling session lasts about an hour. The duties of genetic counselling fall to people with varying professional and educational backgrounds. Genetic counselling sessions, for those referred for advanced maternal age or because of the result of a genetic screen, are generally carried out by nurses who have had special training in genetics, or by OBs or GPs. Counselling duties for referrals for family history are generally more complex and require complicated statistical analysis and clinical interpretation. Referral of this sort usually require the expertise of a medical geneticist. Genetic counselling is also being carried out with increasing frequency by trained
genetic counsellors. These counsellors hold masters-level degrees in genetic counselling. Genetic counselling programs, currently offered at two universities in Canada, train students in both genetics and counselling to ensure that they have the required skills and knowledge to convey the complex information in a sensitive manner to the client.

The Royal Commission on Reproductive Technology reported that of the over 22000 women referred for testing in 1990, less than 10 percent refused the test. The reasons for refusal varied, but the most common reason given was concern about the risk to the fetus from the testing procedure (both amniocentesis and chronic villus sampling carry a small risk of miscarriage). Of those who received a positive diagnosis more than 80% chose to have a therapeutic abortion, as in almost all of these cases no other therapeutic options were available.

The Benefits Of Testing

The ability to test prenatally for genetic disorders is an extremely significant development in medical genetics, whose application and proliferation, it is claimed, is and will continue to be universally beneficial. The two greatest benefits claimed for genetic testing are that it allows us to prevent or ameliorate disabling conditions which are genetically based, and that it grants parents greater reproductive choices. I will begin my ethical investigation of prenatal genetic testing from the assumption that these putative benefits, when taken at face value, offer sufficient reasons to engage in such testing.

There are a number of ways in which our ability to prevent and ameliorate disabling conditions has been substantially bolstered by the development of prenatal testing technology.
They are as follows: 1) It allows us to prevent disabilities, through abortion, by diagnosing fetuses which have genetic disorders that will result in disabiling conditions. 2) It allows us to prevent or ameliorate disability through detection and prenatal treatments. These treatments may include changes in diet or supplements for the mother (prebirth), or the use of pharmaceutical or surgical interventions. 3) It allows us to prevent family disruption through prenatal preparation carried out by the family. This may be achieved through the family’s gathering of information about the disorder diagnosed and by the preparation of the home environment to ensure that it will accommodate a child who will have the disorder that has been diagnosed.

Prenatal testing also substantially expands the array of reproductive choices that are available to parents. The most significant expansion in this regard, is that parents are now offered choices concerning what “kinds” of children to have, since they can choose through abortion or medical interventions not to give birth to a child with a diagnosable disorder. It also allows parents who are either at known risk of having a child with a diagnosable disorder or who are known carriers of genes associated with a genetic disorder, to attempt to have children without the concern that they will have a baby with that disorder. Before prenatal testing was widely available, parents in these situations may not have attempted to have children out of fear of having a child with a severe genetic condition. Prenatal testing also offers parents an expanded time frame in which to make choices regarding what and how to make changes to the family environment to ensure that it will accommodate a child with a genetic disorder.

Though prenatal testing has significantly expanded both our ability to prevent disabilities
and the array of reproductive choices available to parents, there are relevant limits to the existing technology. At the current time, of the over 400 gene mutations that can be tested for, only a handful of the genetic disorders which result from them have any form of available treatment. No researcher has yet attempted to treat a genetic disorder in-utero with gene therapy and thus far only fifty fetuses have undergone in-utero surgery (all of these surgeries were undertaken to repair neural tube defects). The reality of our current prenatal testing practices is that a positive diagnosis leads primarily to a decision about whether or not to abort the affected fetus. In Canada, as noted above, women currently abort fetuses which have been diagnosed with a genetic disorder at rates of higher than 80%; in the United States, for some disorders such as Down’s Syndrome, women choose abortion following a positive diagnosis at rates of higher than 95%.

Eugenics, Disability Rights, and Reproductive Freedom

As stated above, the benefits that prenatal testing is purported to offer are substantial and in themselves answer questions about the value of testing and why we might want to use it. That these benefits exist, however, has not been enough to quell concerns that the use of this testing technology is morally problematic. Many have argued that there is good reason to condemn the practice or at least severely limit its application. I will begin my investigation of the ethics of prenatal genetic testing with the much voiced concerns about prenatal testing’s troubling connection with the eugenics movements of the last century. Many critics of prenatal testing harbour lingering suspicions that the so called “new genetics”, and in particular the practice of prenatal genetic testing, is little more then a version of the “old eugenics”. Eugenics, it is
claimed, poses a serious threat to society, a threat that may be realized in the present proliferation of prenatal genetic testing.

In Chapter One, I will analyse systematically what I call the “eugenics critique” of prenatal testing. Much of the debate surrounding this critique has been centred on the question of whether or not prenatal testing is, in fact, a eugenic practice. It is often assumed that to show that prenatal testing is eugenic is enough to indicate that this practice is morally problematic. Those who condemn prenatal testing on this basis usually rely on implied connections between the current testing system and some of the most dubious practices carried out in the past century in the name of eugenics. In an attempt to address these concerns, I will begin my analysis of the eugenics critique by examining whether or not it is reasonable to claim that prenatal testing is eugenic. This will require a short discussion of the history of eugenics and an examination of how eugenics is typically defined. I will argue that there is good reason to believe that prenatal testing is eugenic, and that our current practice has much in common with some aspects of the historical eugenics movement. Whether or not this fact signals that prenatal testing is morally problematic, however, requires the elucidation of a further question: What, if anything, is wrong with eugenics? I will, therefore, in the second half of Chapter One discuss some plausible answers to this question.

I will argue that the eugenics critique poses three distinct questions for our prenatal testing system which must be addressed to ensure the ethical use of this technology. They are as follows: 1) Does our current use of this technology respect a pluralism of values in regards to what constitutes a valuable human life? 2) Is our current practice just? In short, are there burdens
that accompany the putative benefits, and if so, are they equally distributed and do they represent too high cost for those who must bear them? 3) Does our current testing practice respect parents’ rights to reproductive freedom? Do parents have the practical ability to use or refuse testing in the context in which it is currently offered. These concerns provide the moral framework in which the remainder of my discussion of prenatal testing takes place.

The concern for a respect for a pluralism of values concerning what constitutes a valuable human life will not be addressed directly as a separate concern in this thesis. Instead, it will remain as an underlying theme in both Chapters 2 and 3. It is my contention that the greatest evils of the eugenics movement resulted, in large part, from the intolerance of difference and the disrespect of human variability exhibited by many of the key figures in this movement. This theme will repeatedly surface in the remaining chapters in relation to prenatal genetic testing and will inform the subsequent discussions of justice and reproductive freedom. In particular, in chapter 2 the issue of a respect for a pluralism of values is a central component of the “disability rights critique”, as this critique argues that the testing system does not value, and in fact degrades, those with physical and mental capacities which are not “normal”. Further, chapter 3, the questions of what constitutes a valuable human life and on what basis this judgement should be made, are an integral parts of the choices that parents make concerning prenatal testing. How these questions are answered and by whom, have an effect on the choices that parents do make and in some cases determine whether or not their rights to reproductive freedom are respected.

In Chapter 2, I will take up the issue of justice. In particular, I will address a substantial and complex critique that is commonly referred to as the “disability rights critique” of prenatal
testing. The proponents of this critique are sceptical of claims made of how universal the benefits are from the use and proliferation of prenatal testing. They argue that these benefits are not available to everyone and that providing these benefits often comes at the cost of justice. To support this claim two main arguments are made. The first claims that our current practice of prenatal testing discriminates against those with disabilities by forcing unjustified burdens upon them. These burdens result in violations of their most basic rights, and, as a result, prenatal testing should be prohibited or at least strictly limited in its application. The second suggests that the approach prenatal testing takes to securing the benefits of preventing disability misunderstands the root causes of disability, and, consequently, misunderstands what justice dictates in response to the problem of disability. This argument is based on the claim that whether or not someone is disabled is in large part determined by the social environment in which any given physical disorder is manifested. Justice dictates, on this view, that we work to reshape the social environment in order to allow those with physical disorders to be fully functioning and successful participants in society. In this context then, prenatal testing, as it most often aims to prevent disabilities by averting the expression of certain physical characteristics, is fundamentally misguided in its approach to procuring the benefits it purports.

The disability rights critique fundamentally challenges the practice of prenatal testing, as it would undermine the very basis on which prenatal testing is justified. If those who advance this critique are correct in their estimate that the benefits of prenatal testing are not universal and only procured with some at a cost to others, then this would certainly raise doubts as to whether or not the use of this technology is warranted. I will argue, however, that the disability rights
critique, though it does highlight some valid ethical concerns, does not offer grounds for prohibiting or limiting the use of prenatal testing. In the final analysis, this critique fails to substantiate its claims that our current practice of prenatal testing is unjust. It fails because it neither demonstrates a necessary connection between the putative burdens and the practice of prenatal testing, nor demonstrates that justice speaks solely against and not for the approach that prenatal testing takes to preventing and ameliorating disabling conditions.

Though I will argue that the disability rights critique fails to substantiate its claims about the injustices of prenatal testing, it does emphasise a number of legitimate concerns about the use of this testing. In particular, it identifies the dangers of employing our testing technology in an environment which often misunderstands disabilities and makes judgements about those with disabilities based on stigmas and stereotypes. It also makes clear that the possibility of alleviating the disabling effects of a genetic disorder through changes to the social environment is often under appreciated by those who offer testing to the public. These two concerns, among others, will be addressed in Chapter 3.

Further, I will argue in Chapter 3 that the legitimate concerns emphasised by the disability rights critique can be addressed if prenatal testing is practiced in such a way that it ensures that parents' rights to reproductive freedom are respected in the process. I will challenge the assumption that because prenatal testing offers parents a wider array of reproductive choices, that it ensures parents agency in an expanded realm of reproductive freedom. I will argue that this is a mistaken assumption, as the availability of more choices does not necessarily entail expanded freedoms. Whether or not a wider array of choices will lead to
greater freedom depends upon the environment in which these choices are made available. I will argue that the legal, social, and institutional context in which the choices about prenatal testing are currently made, is such that parents' rights to reproductive freedom are routinely challenged. In particular, parents' practical ability to refuse testing is often undermined in the current system and the choice to bring a child with a diagnosable disorder to term is not equally respected within that system.

As I claimed above, ensuring that parents' rights to reproductive freedom are respected will help to alleviate many of the concerns highlighted by the disability rights critique. This is so, I will argue, because these rights can only be respected if parents make truly informed choices concerning prenatal testing. Ensuring that parents make informed choices will require that they are made aware of the fact that some of their beliefs concerning disability may be based on stigma and stereotype. In particular informed choices can only be made when parents in all cases make their own choices concerning prenatal testing and do so with full knowledge that life with a disability is not always synonymous with a life not worth living and that those who do have disabilities have gifts and talents which are to be valued alongside the gifts and talents of those who are able-bodied. Further, the possibility of informed choice requires that choices are made in full view of the possible alternatives, and thus parents must be conscious of all the legitimate approaches that do exist to ameliorate disability in their children (i.e. changes to the environment that can be made to alleviate the effects of certain disorders).

If parents' rights are to be respected, and if reproductive choices are to be made based on a pluralism of values concerning what constitutes a valuable human life, then there are some
substantial changes which must be made to the way these choices are currently offered. I will conclude with some suggestions as to how the prenatal testing system can be changed to ensure that reproductive freedoms are protected. It is my belief that if these changes are made, then the threat posed by eugenics and the legitimate concerns highlighted by the disability rights critique can, to a large degree, be met.

Finally, as evidenced above, many of the ethical concerns addressed in this thesis will surround the much used option of selective termination. Hence, my investigation of prenatal testing will, at times, take me dangerously close to the ethical controversy surrounding abortion itself. However, the arguments that I will address, and the positions I will defend do not turn on the highly controversial issues of the moral status of the fetus, and whether or not abortion is morally equivalent to infanticide. I will not attempt to resolve these larger questions which concern abortion itself as they fall outside the scope of this thesis, and do not require resolution for the project I will be engaged in.

The testing system in Canada is becoming more pervasive. Most pregnant women in Canada now, in the course of their pregnancy, come into contact with the testing system. Those who are identified at higher risk for carrying a fetus with a diagnosable genetic disorder, in some parts of the country, are now almost assured of being referred for genetic testing. There is nothing, at this time, to suggest that the move to ensure wider access to prenatal testing in Canada will slow down. As prenatal testing continues to proliferate, and as it becomes a routine part of the process of reproduction, there are a number of moral pitfalls that will need to be
negotiated. It is important, therefore, that we closely examine and continuously reevaluate this changing technology in order to better understand what its proliferation means for Canadian society. It is my hope that this thesis will help to achieve this end, as it is only through a clearer understanding of what this technology means that we can be assured of its ethical use.
CHAPTER 1: EUGENICS IN THEORY?

Daniel Wikler writes in *From Chance to Choice* that if today’s study of genetics is “understood as the second of two eras in which the science of heredity was promised to offer great benefits for mankind it is inevitable that it proceeds in the shadow of eugenics”.¹ James B. Watson, the first director of the Human Genome Project, warned at a 1989 conference in San Diego that when applying our new understanding of human genetics “we have to be aware of the really terrible past of eugenics”.² Troy Duster writes metaphorically that “when eugenics reincarnates this time, it will not come through the front door, as with Hitler’s Lebensborn project. Instead, it will come by the back door of screens, treatments, and therapies.”³ Finally, Abby Lippman writes in definitive language that “though the word ‘eugenics’ is scrupulously avoided in most biomedical reports about prenatal diagnosis, except when it is strongly disclaimed as a motive for intervention, this is disingenuous.”⁴

These individuals all claim that there is at least some relation between the past eugenics movement and our present use of genetic technologies, however, each differs in his/her belief

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³ Troy Duster, *Back Door To Eugenics* (New York: Routledge, 1999), p. X.

concerning the character of this relation and its implications for the use of these technologies. Lippman and Duster, for example, find it unproblematic to speak of eugenics in terms of its effects; this allows them to assert that prenatal genetic testing is eugenic. Watson, however, discusses eugenics in terms of an individual’s intentions as opposed to simply the effects of an individual’s actions. He is thus reluctant to label prenatal testing (and genetic testing in general) as eugenic, but admits that these technologies possess a eugenic potential. In spite of this, all agree that there is such a thing as the threat of eugenics and that this threat has direct ethical implications for the practice of prenatal genetic testing.

In this chapter I will address what might be called the “eugenics critique” of prenatal genetic testing. Directly addressing this critique, however, is problematic as there is not a general consensus on what precisely the this critique is. This lack of consensus exists for two main reasons. The first, as was demonstrated above, is that there is no common and generally agreed upon understanding of how broadly or narrowly the term eugenics is to be defined. This fact results in varying opinions as to whether prenatal genetic testing, as it is currently practiced, should be understood as a form of eugenics. The second reason stems from a disagreement about why exactly an action’s status as eugenic is cause for concern. It is almost universally agreed that the eugenics movement of the past century was responsible for some terrible moral infractions. Disagreement persists, however, about whether these infractions were the result of erroneous beliefs and dubious methods employed by just some past eugenicists, or they resulted because there is something inherently wrong with eugenics in general.

The task of this chapter will be to unravel the meaning of the ‘eugenics critique’ as it
pertains to the practice of prenatal genetic testing; what threat, if any, does the spectre of eugenics pose? To achieve this goal two questions must be asked and answered. First, does this critique pertain at all, that is, is it legitimate to understand prenatal genetic testing as part of a “new eugenics”? To answer this question, I will give a brief overview of the history of eugenics and will examine different ways in which eugenics is typically defined in order to establish if these definitions offer a suitable description of prenatal testing. I will argue on the basis of my investigation that eugenics, by any reasonable definition, can be understood to include prenatal genetic testing in at least some circumstances. This conclusion however, is in itself uninteresting as regards the ethical implications of the ‘eugenics critique’ for prenatal testing, as it says nothing about what ethical implications flow from it. A further question remains to be asked: what, if anything, is wrong with eugenics? The answer to this question is often assumed to be obvious, but as we shall see, this is far from the truth. My attempt to answer this question will involve an examination of the evils which are associated with eugenics. This examination will be undertaken to ascertain if these evils are inherent to eugenics or if they are contingent upon the methods which are used to serve eugenic ends. If the former is found to be true, prenatal testing’s status as eugenic could on its own condemn the practice. If the latter is found to be true, the evils identified as part of the “old eugenics” cannot on their own serve to condemn our modern practice, but may, nevertheless, be used to mark some of the boundaries of an ethically acceptable use of prenatal testing.
What is Eugenics?

A Brief History

Eugenic ideas are not new and in various guises can be traced back at least as far as Plato. The modern interest in these ideas, however, was initially fuelled by one man, Francis Galton. Galton coined the term ‘eugenics’ in his *Inquires into Human Faculty and Development* where he defined it as “the science of improving stock -- not only by judicious mating, but by whatever tends to give more suitable races or strains of blood a better chance of prevailing over the less suitable than they otherwise would have had.”

Before he had coined this term, Galton had published his eugenic ideas in, *Hereditary Genius*. In this book he investigates the origins of natural ability by examining those men of exceptional talent who had lived in the two centuries preceding him. He took as his standard of natural ability the enjoyment of a reputation as a “leader of opinion ... or as an originator”. Galton discovered in the course of his investigation that a large proportion of such men were blood relatives, and inferred from this that heredity must not only account for physical features, but accounts for much of our talents and characters as well. Based on this inference Galton concluded that it would not only be possible, but “quite practical to produce a highly gifted race of men by judicious marriages during several consecutive generations”.

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6 Quoted in: Kevles, p.3.

7 Quoted in: Kevles, p.4.
mankind) that was to hold great sway in the thinking of many scientists, politicians and indeed much of the general public in North America and Europe in the half century to follow.

In the first decade of the 20th century, Galton's ideas began to take hold and gain wide acceptance. This acceptance was in part fuelled by a rediscovery of the now well known experiments carried out thirty years earlier on the hybridization of plants by Gregor Mendel. The increased understanding of heredity that came with the study of genetics was clearly relevant to those interested in eugenics. Those on the cutting edge of research in genetics were also often strong proponents of eugenics as well; in fact, one of the first presidents of the American Genetics Society was concurrently head of the American Eugenics Society. Charles Davenport, for example, a key figure in the American eugenics movement was a respected scientist who did some of the earliest work on understanding the genetic character of Huntington's Chorea and epilepsy. Davenport founded the Eugenic Record Office, a research group charged with carrying out eugenic research and cataloguing hereditary data, in the U.S. in 1910. Roughly coinciding with its founding was that of the Eugenic Education Society in Britain (with Galton serving as honourary president), and the Racial Hygiene Society in Berlin.

With the popularity and enthusiasm for eugenic ideas came various proposals for ways in which these ideas could be implemented in practice. Proposals were put forward for both 'positive' eugenics (measures taken to increase the breeding of the 'best stock') and 'negative' eugenics (measures taken to prevent or discourage the breeding of those deemed unfit). In some countries eugenicists had great success in having their eugenic proposals enacted into law, while others shied away from overtly coercive measures. In Britain, for example, there was little
support for legislation which would serve eugenic ends. Thus, as Diane Paul notes, the Eugenics Education Society in Britain, understanding the reluctance for legislation, “concluded that the only realistic chance of altering the distribution of births lay not in the direction of compulsion, but in education, persuasion, and inducement.”8 Others were not so shy. In the U.S., by 1914, over 30 states had enacted laws which could annul the marriages of ‘idiots’ and the insane and restrict marriage between those who were ‘feebleminded’. Between 1907-1917 fifteen states enacted sterilization laws which allowed for the sterilization of “habitual or confirmed criminals...and also included within the scope of most statutes were epileptics, the insane, and idiots in state institutions.”9 More than 60,000 sterilizations were carried out in the U.S. under such laws over a forty year period. The U.S. was not alone in its success in enacting eugenic laws; the provinces of Alberta and British Columbia in Canada and a number of Scandinavian countries also enacted sterilization laws.

Of course, the darkest pages in the history of eugenics were written in Germany under the Third Reich. The Nazis had been in power only two months when the first sterilization laws were established, calling for the sterilization of the feebleminded, the hereditarily blind and deaf, and for a long list of others who were believed to have ‘undesirable’ hereditable traits. Sterilization laws, tragically, were only the first stage in the Nazis’ eugenic solutions to social problems which culminated in the extermination of millions, through euthanasia and murder, who


9Kevles, p.100.
had been deemed genetically unfit and burdens on society.

The early eugenics movements in the U.S. and Britain were dominated by those whom Daniel Kevles has classified as "mainline" eugenicists. This movement is remembered mainly for its dubious scientific claims concerning the inheritance of certain behavioural and mental characteristics and for its beliefs about the distinct genetic characters of different races. But in addition, mainliners are remembered for frequently holding blatantly racist and classist views. These features of the mainline eugenics movement also characterized the Nazi movement. These questionable views subscribed to by the mainline and Nazi eugenicists are not, however, indicative of the movement in general.

As the Nazi eugenic movement gained momentum, many eugenicists in the U.S. and Britain began to distance themselves from the mainline eugenics movement. Hermann Muller, a nobel prize winning American geneticist and eugenicist, wrote in 1935 that the eugenics movement had become the home of pseudoscientific beliefs and of "advocates of race and class prejudice, defenders of vested interests of church and state, Fascists, Hitlerites and reactionaries generally."10 Those eugenicists who agreed with the sentiments of Muller's statement were not necessarily led away from eugenics altogether, but rather set out to reform the movement. These so-called 'reform' eugenicists attempted to rid eugenics of its race and class biases and of its pseudoscientific beliefs concerning the heritability of various behavioural and mental characteristics. These new eugenicists unlike their mainline predecessors were usually of the political left. They still held high hopes for the biological improvement of humanity, but were

10 Quoted in: Kevles, p.164.
generally much less sanguine about using coercive measures to achieve this end, and also were cognisant of the fact that nothing was certain about what role heredity played in the achievements of individuals and populations.

The goals of eugenicists differed as widely as the methods they proposed to attain them. Some eugenicists had ends in mind that can only be described as utopian. Galton with his hopes for the development of a “highly gifted race of men” being a clear example. Others felt eugenic policies were required to avoid the deterioration and ultimate destruction of the human race. Hermann Muller’s concern with “genetic load” (the accumulation of deleterious genetic mutations through breeding) falls into this category. Muller warned that if eugenic policies were not initiated the human beings of the future “would be devoted chiefly to the effort to live carefully, to spare and to prop up their own feeblenesses”. However, not all held such high hopes for what eugenics could accomplish or for what disasters it could avert. Some felt eugenics could only be used to achieve much more modest ends. Lionel Penrose a reform eugenicist, for example, felt that the most useful and practical outcome of eugenic policies would be to lower the incidence of hereditary diseases such as Huntington’s Chorea by convincing parents who were at heightened risk for giving birth to a child with Huntington’s not to reproduce.

Following World War II when, at the Nuremberg trials, the extent of the Nazi crimes became clear, the popularity of eugenic ideas began to quickly decline. As it was the Nazis who had most enthusiastically embraced eugenics, news of their crimes threw a dark shadow over eugenics in general. As Dan Wikler notes “what had in the prewar years been a virtual consensus

11 Quoted in: Kevles, p.260.
in favour of eugenics among genetic scientists disappeared in a decade."12 The once popular and well funded eugenic societies in the U.S. and Britain closed their doors due to lack of support, and the American Eugenic Society journal “The Eugenics Review” changed its name to the “Journal of Social Biology”.

As demonstrated above, the history of eugenics is one which involved a wide range of beliefs concerning heredity, race, and what constitutes appropriate social goals. The main characters in this history came from various nations in both North and South America and from across Europe, and from all sides of the political spectrum ranging from left wing socialists to staunch conservatives. The eugenic programs initiated by these historical actors varied widely in both their methods and goals. As a result of this diversity, making sweeping claims about the content of the past eugenics movement is difficult and can be misleading. Furthermore, it makes identifying what precisely constitutes eugenics equally difficult. I will now turn to this task, because if we are to make any judgement as to whether or not prenatal genetic testing constitutes a “new eugenics”, we must first be certain of how we are to define ‘eugenics’ in general.

Eugenics Defined

Any attempt to define ‘eugenics’ invariably begins with Galton’s original definition. I will restate his earliest formulation here: “the science of improving stock—not only by judicious mating, but whatever tends to give the more suitable races or strains of blood a better chance of

prevailing over the less suitable than they would otherwise have”. This definition of eugenics seems unreasonably narrow to connote what it is now commonly understood to mean, since it restricts eugenics to science, that is, to the study of a means of improving human “stock”. It is clear that eugenics is now understood not only as the study of improving human stock, but as a certain class of actions which achieve or aim to achieve this end. If the definition of eugenics were restricted to study, it would be plausible to assume that eugenics is relatively benign and hardly a cause for anxiety as regards its possible relation to prenatal genetic testing. A controversy exists, however, over whether eugenics can be best defined by simply expanding Galton’s definition to include actions which achieve or attempt to achieve the end of improving human “stock”. Some argue that a definition of eugenics which simply renders Galton’s original formulation active is not succinct enough to provide a good explanation of what eugenics actually entails.

Diane Paul has identified some typical fault lines which some have employed to demarcate eugenics from other practices (often medical genetics), effectively narrowing its definition. One such fault line finds coercion as the point of demarcation. In a definition focusing on coercion, a practice can be identified as eugenic only when, in the act of improving or attempting to improve the human “stock”, a person or institution “interferes with or controls or imposes particular reproductive options” on others. This definition certainly justifies any concern that may exist about the practice of eugenics, as under this definition eugenics entails an

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13 Quoted in: Kevles, p. IX.

undermining of reproductive freedoms. Making coercion an essential characteristic of eugenics is often used as away to demarcate the “old eugenics” from the study and practice of modern medical genetics. For example, the genetics textbook used at the University of British Columbia Faculty of Medicine claims “current understandings of genetics provides little scientific support for eugenic programs, all of which must entail subjugation of the interests of the individual to the interests of society, and thus loss of personal freedom.” It is assumed that the whole of medical genetics is not coercive and thus its practice can not be eugenic. Whether or not prenatal genetic testing in particular falls underneath this definition, however, depends upon how coercion itself is defined. As Paul points out, coercion can be understood in different ways depending upon our understanding of freedom.

Freedom is typically defined by moral and political theorists in two different ways. It can be understood as negative freedom, meaning that one is free to act so long as others do not act in such a way as to restrict one’s action (e.g. I am free to walk in central park at night so long as no one physically stops me from entering the park). Or as positive freedom, which may require others to act to ensure that one is free to do something (e.g. I am free to walk in central park at night only if others through their actions can assure me that it is safe to do so). If freedom is understood as only negative freedom, one is coerced “if actively prevented from attaining a goal”. If freedom is understood to include positive freedom, then “we are free to choose only when we have the practical ability to agree or refuse to do something.”

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If freedom is defined negatively, the current practice of prenatal genetic testing could reasonably be demarcated from eugenic practices, as prenatal testing is not legally mandatory for any disorders in Canada. A definition of eugenics coupled with a theory of negative freedom is, however, historically problematic. As stated above, not all eugenicists were prepared to make their eugenic proposals mandatory, but rather stressed that any measures taken should be voluntary; many of the ‘reform’ eugenicists subscribed to this line of thinking. Such a definition would exclude a large segment of what is traditionally understood to be part of the historical eugenics movement and thus can be rejected on this basis.

If freedom is defined positively, then prenatal genetic testing could not, as a whole, be demarcated from eugenics. Whether the practice is or is not to be considered eugenic would depend upon the specific circumstances under which specific individuals are being tested. For example, parents may not be considered free to use genetic testing if their financial situation makes it impossible for them to care for a severely disabled child. On a positive understanding of freedom, they would be required to use testing in order to ensure that they are in a position to abort any fetus with a diagnosable disorder which they are not in a position to afford. Thus, even on such a narrow definition, prenatal genetic testing could, in many cases, be considered eugenic.

An alternate way in which eugenics is demarcated from other practices is by identifying the presence of a social intent. Paul writes, “policies are characterized as eugenic if their intent is to further a social or public purpose such as reducing costs or sparing future generations
unnecessary suffering”.\textsuperscript{17} This definition, at first glance, would seem to exclude prenatal genetic testing and it is often employed to do just that. Whether or not to use testing technology is a decision left up to parents and is often justified as a tool which grants parents a wider array of reproductive choices. Their choices reflect their individual motivations which are most likely inclined towards goals which are private and familial as opposed to social. It is unlikely that those who are tested (at least in any significant numbers) use the test to consciously further a social or public purpose; the conscious intention is presumably not the betterment of the population, the species, or the ‘gene pool’, but the betterment of their individual and family situation.

If a social intent is understood as a prerequisite of a eugenic action, this makes plausible the assertion that prenatal genetic testing falls outside its purview. Though it makes this assertion plausible, it is not definitive. Whether a social intent excludes prenatal testing depends upon how parenthood itself is understood. Glenn McGee writes “regardless of whether [parents] consciously deliberate about the best outcomes for the human species, the decisions concerning which children will be born (at what time, to whom) are made within the ethos of the community. Thus we can conclude that parenthood is social.”\textsuperscript{18} Our reproductive decisions, McGee argues, are subject to social pressures and inevitably are in part based upon social values: “Babies are not made by rational calculators, they are made by human beings saturated with

\textsuperscript{17} Paul, “Eugenic Anxieties”, p. 69.

culture". Moreover, choices made about prenatal testing necessarily involve doctors, nurses, and genetic counsellors all of whom, in Canada, work within a publicly funded health care system. The choices that are made available to parents concerning prenatal testing, are so because of government health care policy. When these factors are taken into consideration it becomes clear that the choices that parents make about prenatal testing are not strictly private. The decisions they make are inevitably influenced by the many people who are involved in them and the choices made available and deemed appropriate are in part defined by their social and institutional context. Thus, if one accepts that our parenting decisions, at least to some degree, are ‘socialized’ decisions, then it is feasible that our decisions are based in part on social concerns and thus express a social intent. If “parenthood is social”, then prenatal genetic testing could still fall under a definition of eugenics which required a social intent.

Finally Paul identifies an ‘effects’ definition of eugenics. Such a definition is unconcerned with motivations and intentions which are often difficult to ascertain, but looks only to the consequences of people’s actions. Under this broad definition, eugenics does not require an existent social intent, but can be understood as the unintended result of cumulative individual actions which have broad population effects. If our private decisions have nothing at all to do with a desire or an attempt to improve the population, or the species, but nevertheless have an effect which could be understood as just such an improvement, then these cumulative actions are eugenic. Clearly, prenatal genetic testing can be considered eugenic on an ‘effects’ definition. The practice of prenatal genetic testing is already pervasive in our society, and currently women

\[19\] McGee, p. 12.
abort at very high rates when disorders are detected. As a result, prenatal testing can plausibly be understood to ‘improve’ the population by effectively lowering the number of people in that population with diagnosable disorders.

I have argued above that on any plausible definition of eugenics it is reasonable to place prenatal genetic testing under its purview. I grant that this is not a clear-cut conclusion, but that it is plausible is all that I require for my purpose. If I have made conceivable the assertion that prenatal testing is eugenic, then this should be impetus enough to take seriously the “eugenics critique”, and thus to address what it means in terms of its ethical implications for prenatal genetic testing.

What Is Wrong With Eugenics?

There are some obvious answers supplied to the above question by the history of eugenics. I will take for granted that the racist and erroneous scientific beliefs, which characterized much of the ‘mainline’ and Nazi eugenic movements, played a large part in some of the most morally reprehensible practices we ascribe to them. These wrongs are, of course, inexcusable, but if it is these wrongs which are implied in a ‘eugenics critique’ of prenatal testing the critique is, in my view, relatively uninteresting. Undoubtedly, it is beyond debate that prenatal genetic testing should not be racist, nor should it be based on anything but a clear understanding of genetics. I will further take for granted that these errors are neither essential to eugenics nor does their absence exonerate it.

What then, makes up the substance of the ‘eugenics critique’? What precisely is the
threat which eugenics poses? Dan Wikler has identified “five candidates” which he suggests are possible wrongs inherent to eugenics, three of which I will address: “replacement”, “value pluralism”, and “justice”. I will add to this discussion two other candidates: “playing God”, and “reproductive freedom”. It is these five wrongs, with which eugenics is often charged, that I take to be the most likely basis for condemning eugenics. I will now turn to an investigation of whether these candidate wrongs are, in fact, both of valid ethical concern and inherent to eugenics.

Candidate I: Playing God

The immense power, which our ever growing understanding of human genetics grants us, has led to fears that in our use of this power we are guilty of “playing God”. One of the first to articulate a theological resistance to the application of our genetic knowledge was Paul Ramsey. Ramsey, in condemnation of all forms of genetic engineering (of which he considers eugenics a species) writes, “men ought not to play God before they learn to be men, and after they have learned to be men they will not play God”.22

Though many people agree with Ramsey that we ought not to play God, it is not always clear what is meant by this phrase, nor why eugenics might be considered an instance of it. Allen

20 Wikler, “Can We Learn?”, pp 183-194.

21 Wikler does address violations of reproductive freedom as one wrong committed in the name of eugenics, but feels it is obviously not an inherent aspect of eugenics as this would exclude voluntary eugenic proposals. Though I agree with Wikler, I shall argue that reproductive freedom should be regarded at least in part as a positive freedom and thus just because a proposal is voluntary does not rule out a possible violation of reproductive freedom.

Verhy in his paper "Playing God and Invoking a Perspective" translates the phrase to mean "to encroach on those areas of human life where human beings have been ignorant or powerless, for there God rules, and there only God has the authority to act". To argue that eugenics requires that we play God in this sense, one must assume that “god designed a system, namely natural evolution, in which we all participate, but over which we have no dominion.” We need not question the validity of this assumption to realize that an argument that depends on it to condemn eugenics will be difficult to get off the ground.

If we are forbidden to act in ways which will somehow effect the supposed “grand design” of natural evolution, this prohibition extends far beyond eugenics. All of our reproductive choices have effects on the ‘gene pool’, and thus have effects on the way in which our species will evolve. Likewise, as John Harris notes, “people naturally fall ill and naturally have reparable defects; if the practice of medicine has a coherent aim it must be seen, if anything, as the comprehensive attempt to frustrate the course of nature.” If actions which apply genetic information and technology for eugenic ends are to be condemned for requiring that we “play God”, an ontological difference between eugenics and the host of other purposeful human actions which could be understood as having an effect on the evolution of our species, must be established. It is my opinion, that there are no plausible grounds on which this ontological

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24 McGee, p. 45.

difference can be established. As a result, the concern that eugenics requires that we “play God” is not, in fact, a concern at all.

Candidate II: Reproductive Freedom

Whereas concerns about playing God are concerns that eugenics requires humans to be active in realms that are properly reserved to God, concerns about violations of reproductive freedom are concerns that eugenics requires governments and institutions to be active in realms that are properly reserved to individuals. Undoubtedly, the gross transgressions of reproductive freedoms carried out at the behest of various eugenics movements in the past account for some of the most repellent actions associated with eugenics. The forced sterilization of thousands in the U.S. and Germany and the segregation of those who were deemed unfit to reproduce, by today’s standards, are nothing short of horrific. Our abhorrence to these actions is a result of the exalted position in which we now place reproductive freedom.

John Robertson argues that reproductive freedom is now considered to warrant such an exalted position because “control over whether one reproduces or not is central to personal identity, to dignity, and to the meaning of one’s life”. The decision to reproduce for many is a defining moment in their life since it is an expression of who they are and a central component of their life plan. To take away a person’s ability to make reproductive choices, in a very significant way, denies them the right to express their own identity and radically obstructs their ability to pursue their own version of a good life. For this reason, overt violations of

reproductive freedom are simply unacceptable.

Overt violations of reproductive freedom, however, are not an inherent part of eugenics. ‘Reform’ eugenicists like Hermann Muller, supported only voluntary eugenic proposals. Others such as Daniel Kevles, who understand our current practice of prenatal genetic testing to constitute a “new eugenics”, finds it relevantly dissimilar from the “old eugenics” based on our unwillingness to actively violate these freedoms. Thus, the violations carried out by the “old eugenics” offer us a blatant moral shortcoming which we can easily identify and use as one possible basis to distinguish acceptable eugenic practices from those that are clearly unacceptable.

Reproductive freedom, like most other complex forms of freedom, is not clearly definable as either a negative or positive freedom, but is best understood as some mixture of the two. Violations of the negative component (i.e. overt interferences with a person’s reproductive choices) are themselves easily identifiable, and in cases where an agent’s expression of this freedom does not result in another’s harm are uncontroversially objectionable. However, violations of the positive aspects of reproductive freedom are not as easily identifiable, nor are objections to them uncontroversial. To what extent we are required as a society to ensure a person’s practical ability to make reproductive choices is an issue of intense debate. Equally debatable is how we are to recognize when one’s practical ability to make a reproductive choice has been violated. Thus, though violating reproductive freedom is not an evil inherent to eugenics, debates about what constitutes such a violation and what we are obliged to do in response to them will inevitably accompany it.
Candidate III: Value Pluralism

Related to concerns about a disrespect for reproductive freedoms which have been the result of eugenics programs in the past, are concerns about a possible disrespect for the values on which reproductive choices are based. Eugenics is often charged with an inability to respect different values and understandings of what constitutes human improvement. As eugenics requires a decision as to what types of people should and should not be brought into this world, it requires a standard on which to make this judgement. Without recourse to an objective standard, we are forced to make decisions as to what constitutes a valuable human trait and type and what does not. The history of eugenics offers numerous examples of how, when faced with this decision, a natural response for many was to make this choice based upon personal values and perspectives and to disregard other possible perspectives.

Daniel Kevles, for instance, recognized that if Galton “had been more self-aware he might have understood that his proto-eugenic pronouncements” concerning the character of genius “celebrated the social milieu” in which Galton was immersed.27 Likewise, the Nazi’s obsession with the purity of an aryan race and the obvious class biases of the ‘mainline’ eugenicists in general, all serve as examples of people finding their standard of human excellence in their own reflection. “We might suppose, therefore, that what is wrong with eugenics is a denial of the plurality of ideals of a valuable human life.”28 On this critique, we are perhaps incapable of

27 Kevles, p. 5.

28 Wikler, “Can We Learn?”, p. 189.
seeing beyond our own horizons of value. Thus, any standard of human excellence which is used to establish which reproductive decisions are eugenic and which are dysgenic will unavoidably exclude some equally valid perspective.

Wikler argues that an inability to respect a pluralism of values concerning what are to be considered valuable human traits is not an inherent difficulty for eugenics. It is conceivable to him that certain traits may be considered valuable by people from widely varying cultural, religious, and economic backgrounds. Intelligence and good health, for instance, will not likely be challenged if placed on a list of universally valuable human traits. Thus, if eugenics confines itself to those traits on which there is widespread agreement about their value, it will avoid the problem of value pluralism.

I accept Wikler’s conclusion that there will be traits whose value we can all agree on, but this is a cautious acceptance. This caution derives from the fact that many of the terms on which we may plausibly agree do not necessarily have stable meanings which can be cleanly defined. Words, for example, such as “health”, “disease” and “disability” do not have a direct and necessary correlation with a physical reality. Abby Lippman argues that “disorders and disabilities are not merely physiological or physical conditions with fixed contours. Rather, they are social products with variable shapes and distributions”.29 How we understand words like “disorder” and “disability” is in part socially constructed, and the nature of this construction is dependent upon the specific cultural and historical context in which these words are situated. We must be sensitive to this fact when we lay claim to these terms as examples of human traits.

29 Lippman, p. 17.
which have a status we can all agree on. We may find that our agreement depends upon a knowledge of the conditions and circumstances which shaped the meanings of these concepts, and as a result, what we consider appropriate responses to these concepts may change. Eugenics then is not inherently at odds with value pluralism, but it requires a widespread acceptance of traits which are considered valuable or valueless, and this acceptance cannot be based on a presumption that these traits have definitions which are universally applicable and universally understood.

Candidate IV: Replacement

As shown above, ensuring that our selection of valuable human traits and types respects a pluralism of values can be problematic. There are some, however, who claim that there is a more fundamental issue raised by eugenics. Wikler writes in From Chance to Choice, that “eugenics sought human betterment, but in a distinctive way: by causing better people to be born, rather than by directly bettering any people.” This fact is troubling as it suggests that the motivation behind eugenics is not beneficence, but rather a desire for the existence of certain kinds of people. Eugenics does not cure any diseases nor does it actually improve anyone’s natural abilities, rather it selects those for existence who are less likely to have certain diseases or who will be more likely endowed with certain preexisting natural abilities. Through eugenics we choose which kinds of people shall inhabit the earth rather than directly benefitting those inhabitants; “that may be acceptable as a basis for choosing friends, or even employees...but it is not a particularly

30 From Chance to Choice, p.46.
noble social aspiration.”

As Derek Parfit has demonstrated in Reasons and Persons, decisions which aim to benefit those in the future, but have this ‘selective’ character, often result in paradoxes as to how these actions are to be understood. Actions such as controlling the growth of the world’s population to ensure that those who live in the future will not be burdened by overpopulation, or refusing to have a child until one is financially secure to ensure the child will have such fundamentals as food and shelter, intuitively can be considered benefits to the future world population and to the future child. The paradox arises as these actions cannot, on a normal understanding of the principle of beneficence, be considered benefits. For an action to be considered a benefit usually requires that a person’s situation be improved by that action or, conversely, that its omission result either in that person’s situation not being improved or being worsened. The above actions do not have this effect as they determine whether or not these people will exist at all. If, for example, we do not make efforts to control the world’s population, this cannot constitute a harm to future generations as it is this very omission which will be the cause of that particular future generation’s existence. In the same way, controlling world population does not benefit future generations because it does not result in an improvement of their situation, as there is no prior state in which they will have been worse off. The paradox arises here, Parfit claims, not because the beneficence of these actions (controlling world population and choosing to have a child when one is financially and emotionally secure) is in question, but only because it is theoretically

31 Wikler, “Can We Learn?”, p. 187.

problematic to state a principle of beneficence which can make sense of these unique circumstances. This is not to say that no such principle exists.

Eugenics inherently involves ‘selective’ decisions which have effects on who will and who will not exist. This does not mean that these decisions cannot be beneficent, although finding a principle of beneficence which can make sense of them is problematic. To claim that ‘selective’ decisions cannot be beneficent clearly flies in the face of our intuitions on this point, as was demonstrated by the examples given above. I conclude, as does Wikler, that just because eugenics is necessarily ‘selective’ does not in itself condemn it.

Candidate V: Justice

Wikler writes “the central moral problem of eugenics is akin to the perennial ethical quandary of public health, which seeks to benefit the public but in some cases exacts a penalty, such as quarantine or involuntary vaccination, on some individuals”.\textsuperscript{33} The history of eugenics can be told as a story of individuals and groups being forced to shoulder unevenly distributed burdens in the hopes of ensuring benefits for others. The ethical quandary, of which Wikler speaks, is sorting out when the price that individuals might pay for the benefit of the majority is a price too high. The past forced sterilizations, segregation, and murder of those who possessed “undesirable” genes, from our present perspective represent far too high a price and thus blatantly unacceptable injustices. These examples, however, all involved extreme violations of personal liberty, and there is nothing, as noted above, that requires that eugenics take part in such

\textsuperscript{33} Wikler et al, \textit{From Chance to Choice}, p. 52.
violations. But, are violations of personal liberty the only unevenly distributed burdens incurred by eugenics and if so is their unequal distribution unjust? These are extremely complicated questions, and their answer depends upon what duties justice is understood to prescribe and what actions are to be considered burdens.

Ruth Hubbard, for example, argues that “our job, as a society, is not to weed out those who do not conform to particular standards, but to make it possible for different kinds of people to live their lives as fully as they can” (Hubbard, p.235). In Hubbard’s view justice dictates that we expend our energies making the society we live in as accessible as possible to all kinds of people, and to ensure that everyone can hope to flourish within it. Allen Buchanan, on the other hand, argues “the interest in having access to a [society] in which one can participate effectively and the interest in having access to the most productive [society] in which one can participate successfully... are legitimate interests.” Accordingly, if eugenics can ensure a more productive society by ensuring that it is peopled by more productive members, then not to use it may in some cases constitute an injustice. Thus, opposing understandings as to the dictates of justice, result in divergent beliefs about whether eugenics can or cannot be used in a just fashion. Issues of justice, in particular sorting out when the burdens of some justify benefits to others and when they do not, are contentious and complex and require further elucidation. There is nothing, in my view, to suggest that in theory eugenics cannot respond to the dictates of justice, but as


demonstrated above what these dictates are is contentious. Thus, like debates about how far our reproductive freedoms are to extend, debates about what is and what is not, just will inevitably accompany the practice of eugenics.

I have argued two points in this chapter. First, prenatal genetic testing is a eugenic practice. Second, in my investigation of the wrongs which it is assumed eugenics represents, I concluded that though numerous evils have been carried out in its name there is nothing which is inherently wrong with eugenics. The fact that prenatal genetic testing is eugenic is not enough to condemn the practice, or to assume that it is inherently morally problematic. The eugenics critique, therefore, does not condemn the practice of prenatal genetic testing. This is not to say that it offers nothing to an ethical investigation of prenatal testing. On the contrary, taking account of the evils which are typically and historically associated with eugenics has highlighted which evils are of concern and which are not. I have argued above that concerns that eugenics requires that we “play God” are not valid. Likewise, the fact that eugenics is inherently ‘selective’ does not bar it from being carried out in a spirit of beneficence. Beyond “playing God” and “replacement”, the eugenics critique does offer some issues of valid ethical concern. The threat of eugenics, in my view, can be reduced to legitimate concerns about respect for reproductive freedoms, value pluralism and justice. It is to these concerns that I now turn.
My ethical investigation of prenatal genetic testing began with the assumption that this testing results in substantial benefits not only to individuals, but also to society. As was noted in the introduction one of the primary benefits prenatal genetic testing provides is that it allows us to “prevent” or ameliorate disabling conditions that are genetically based. It provides this benefit in the following three ways: 1) It allows us to prevent births through abortion, by diagnosing fetuses which have genetic disorders which will result in disabling conditions. 2) It allows us to prevent or ameliorate disability through medical interventions such as surgery or dietary changes. 3) It prevents disruption in the family by giving them time to prepare for a child who will have a disability. As the great majority of the genetic disorders tested for have no available treatments or viable medical interventions, it is the first and third options which are the most common methods provided by prenatal genetic testing for preventing or ameliorating disabling conditions. The claim that preventing or ameliorating disabling conditions can be considered benefits both for those who may have the disabling condition and for society at large is relatively uncontroversial and so too is the goal of providing these benefits. 1 How this goal is to be achieved, however, is not.

As outlined in the previous chapter, the ‘eugenics critique’ of prenatal testing identified justice as a key concern, a concern I will address in this chapter. In short, I will investigate

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1Some members of the deaf community have argued that being a member of the “deaf culture” is a substantial benefit and thus inventions such as cochlear implants that can in some cases prevent or ameliorate deafness may be undesirable as they would exclude people from this “culture.”
whether or not prenatal testing offers the benefits purported in a manner which is just. The focus of my investigation will be on what has come to be known as the “disability-rights critique” of prenatal testing. This critique, advanced by some of the prominent scholars in the disability rights movement, is sceptical of the approach prenatal testing takes to achieve the putative benefits and particularly the much used option of abortion. Those who advance this critique claim that prenatal testing, though it may provide the benefits of preventing or ameliorating disability, does so in a way that results in fundamental injustices that must be addressed if the use of this technology is to be ethically acceptable.

To support this claim two main lines of argument are advanced. The first asserts that with the benefits provided by prenatal testing come associated burdens that are unfairly distributed. That is prenatal testing only provides its benefits to some while exacting a price on others. In order to ensure the ethical use of testing, this unfair distribution of the benefits and burdens must be rectified. These burdens, it is believed, result from two main sources: from the “expressive” character of prenatal tests which are followed by abortion, and from a problematic conception of parenthood that prenatal testing propagates. The second line of argument advanced relies on a claim that what makes any disorder disabling is in large part socially constructed. Prenatal testing benefits individuals and society as it attempts to prevent or ameliorate the expression of genetic disorders, as opposed to attempting to prevent the social conditions which make these disorders disabling. Those who advance this line of argument claim that this approach to disability is fundamentally misguided. Justice dictates, in their view, that society work to alleviate disability by focusing on reshaping the social conditions which cause an
individual’s physical characteristics to be significantly disabling, instead of working to reshape individuals to ensure that they can function unimpaired within the preexisting social conditions.

**Do The Burdens Outweigh The Benefits?**

In this section I will examine two arguments which claim that there are significant burdens which must be shouldered by certain segments of the population as a result of the proliferation of prenatal genetic testing. As noted above, it is claimed that these burdens are unfairly distributed and that they represent too high a cost for those who must shoulder them. As a result our current practice of prenatal testing should be prohibited or at least extremely limited in its application if it is to be just. The two arguments examined here, I will call the “expressivist objection”, and the “parental attitude argument”.² I will conclude on the basis of my investigation that although these arguments highlight areas of valid ethical concern, these concerns can be addressed without prohibiting or limiting the current practice of prenatal testing.

*The Expressivist Objection*

A central claim of the disability rights critique is that the use of prenatal genetic testing to selectively abort fetuses diagnosed with genetic disorders sends a hurtful message to those living

with disabilities. It is believed that abortion following prenatal diagnoses suggests that the existence of a single genetic or physical trait is enough to justify not bringing people with those traits into the world; we need not know anything else about the person to know that their existence should be avoided. As a result, this practice sends the message that disability devalues those who have them and that those living with the disabilities tested for do not have the right to be born. Marsha Saxton articulates the expressivist objection in the following way:

“The message at the heart of widespread selective abortion on the basis of prenatal diagnosis is the greatest insult: some of us are ‘too flawed’ in our very DNA to exist; we are unworthy of being born...Fighting for this issue, our right and worthiness to be born, is the fundamental challenge to disability oppression; it underpins our most basic claim to justice and equality—we are indeed worthy of being born, worth the help and expense, and we know it.”

If it is found that prenatal testing does in fact express this hurtful message, then this would certainly represent an unacceptable injustice as it would represent “a violation of [disabled persons’] fundamental right, the right to be regarded as persons of equal worth.”

Those who advance the expressivist objection, most prominently Adrienne Asch, Martha Saxton and Nancy Press, all claim that this critique of selective abortion following prenatal testing should not be taken as a critique of abortion in general. If the expressivist objection were to

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3 It is important to remember that in Canada women choose to abort fetuses diagnosed with disorders at a rate of higher than 80%. In the U.S. the abortion rate for some disorders, such as Down’s Syndrome, is as high as 95%. The expressivist concern is a widespread concern.


reduce to an argument against abortion generally this would not only be an unacceptable result for those who support it (most strongly support a women’s right to abortion), but it would rob this objection of its particular significance (that the use of prenatal testing and abortion represents a violation of the rights of those living with disabilities and not of the fetuses who are aborted). Clearly if the expressivist objection is to support the particular claims it makes, a distinction must be made between the expressive character of selective abortion following prenatal diagnoses and all other abortions.

Adrienne Asch has suggested that an “any/particular” distinction can do precisely this work. She argues that the negative message is sent in cases of prenatal diagnosis and selective abortion, because in these cases women are rejecting a particular fetus. This fact makes these cases significantly different from all other abortions because they are “a response to characteristics of the fetus and would-be child and not to the situation of the woman”.

In most other cases of abortion, Asch argues, it is the situation that the woman is in which is the deciding factor in the termination, and thus any fetus would be aborted in these cases (eg. the woman is not financially or emotionally prepared to have a child). Those who advance the expressivist objection, generally agree that the “any/particular” distinction is enough to support their claims.

This distinction, however, has not gone unchallenged. James Lindeman Nelson, for example, asserts that the distinction Asch makes does not clearly demarcate selective abortion following prenatal diagnosis from other abortions. Nelson argues that many abortions have a selective nature, and that women abort fetuses all the time because of a particular characteristic of

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6 Asch, p.82.
their fetus. It is clear that the other types of abortions that he points to do not express any negative attitudes towards those who are living with these characteristics. Nelson employs the following example to justify his claim. A woman decides to abort because she does not want to have a fourth child and that this characteristic of the prospective child (that it will be the fourth born) is the only reason she has chosen abortion. Does this action “suggest that this women is sending a message that she devalues fourth-borns, or that she is expressing contempt about large families?”7 In the case Nelson describes it would be implausible to suggest that the woman’s actions send a hurtful or disparaging message to all fourth-born children. He concludes on the basis of this example (and others like it) that the “any/particular” distinction does not do the work Asch and others want it to. If Nelson is right that the expressivist critique does not clearly describe why abortions following prenatal diagnoses have a distinctive character, then it must either be taken as a critique of a much wider range of abortions or as no critique at all.

Nelson’s objection to the “any/particular” distinction, though it does demonstrate that abortions other than those following prenatal testing may be based on a particular characteristic, fails to recognize an important nuance of Asch’s distinction. The critical difference between abortion in the case that Nelson describes and abortion following prenatal testing, is that in Nelson’s case it was always an unwanted pregnancy. A mother of three, who only wants three children knows before she becomes pregnant that she does not want a fourth child. The hurtful message that the expressivist argument points to is derived from the fact that the parents in these

cases want to have a child, but following prenatal testing they decide to abort "on the basis of one new fact about the baby-- that it will have some sort of disability." It is the change of heart on the basis of this one new fact that gives the "any/particular" distinction its force, and in my view allows it to successfully demarcate selective abortion following prenatal testing from other abortions.

A much more powerful critique of the expressivist objection comes from Allen Buchanan. Buchanan argues that for the expressivist objection to be sound it "must show that it is motivationally impossible or irrational both to devalue and seek to avoid disabilities while at the same time valuing equally individuals who have disabilities." Buchanan argues that there are a number of reasons why parents may choose to abort a fetus that has been diagnosed with a genetic disorder. Many of the reasons do not require a belief that people who do have this disorder are not as valuable as others or that they do not have a right to be born. Parents who choose abortion when they discover their child will have a genetic disorder may do so for numerous reasons. They might want to avoid, for example, a situation which may seriously strain a marriage, family and/or social resources, strains which conceivably can result from the birth of a child with a severe genetic disorder. This decision could also be based simply on a desire to have a child who will not be limited in his abilities or opportunities. All of the above

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reasons for abortion are plausible and rational responses to a prenatal diagnosis of a genetic disorder. It is clear that what is devalued, in these cases, is the disabilities themselves and the negative effects that disabilities may have, not the people who have disabilities. There is nothing rationally inconsistent with a person desiring to avoid the birth of a disabled child, while believing that people with disabilities are deserving of equal respect and have every right to exist. Thus, Buchanan concludes that no negative judgements are necessarily expressed about the value of those living with disabilities, or about their right to exist when parents choose abortion after a prenatal diagnosis.

Buchanan does not deny that in some situations parents who do choose to abort following a prenatal diagnosis may do so based on the negative judgements purported. That this is the case is clearly regrettable, and to be critical of these individual motivations is justified. “The expressivist objection must show more than this, however. It must show that the very decision to attempt to avoid defects that cause disabilities devalues people with disabilities”.10 Buchanan’s argument, that the decision to avoid disability by using prenatal diagnoses and abortion is not necessarily motivated by a judgement that people with disabilities are less valuable or that they do not deserve to be born, is convincing. This argument goes a long way to defusing the expressivist objection; however, it is not definitive.

Buchanan’s argument relies on a presumption that what an action can properly be said to express is defined solely by its motivation. Thus the practice of selective abortion following prenatal testing, in Buchanan’s view, can only express a negative judgement of people with disabilities.

disability if this negative judgement is a prerequisite to being motivated to engage in this practice. The causal relation between the motivation of an action and what that action expresses or means, however, is not as straightforward as Buchanan would have us believe. It is clear that some actions can have a meaning which is not causally related to the motivation of the action. James Nelson offers an example of flying the flag of the Confederate States of America over the State House in South Carolina as an action whose meaning is not defined solely by its motivation. “For some South Carolinians, the flag’s display duly honours a rich heritage for which their ancestors fought and died. For others, it sends the despicable message that killing and dying in the defense of slavery is a heritage worth honoring.”¹¹ Honouring a rich heritage may certainly be the motivation behind flying the confederate flag, this fact however, does not negate the possibility that flying the confederate flag sends a message to some that is racist and degrading. The meaning of flying the flag and the message it expresses is defined as much by history and social context as it is by the motivations of those who choose to fly it. The flying of the confederate flag can quite legitimately be said to express a negative message, though the expression of this message may not be the desired result of those who choose to fly the flag nor is any judgement about the history of slavery in America their necessary motivation.

Nelson’s example is a good one and at least opens the possibility that prenatal testing followed by abortion may have a meaning or might express a message which is independent of the necessary motivations involved in making such a choice. There is of course a crucial difference between flying a flag and choosing abortion after prenatal diagnoses. Flags are generally well

¹¹ Nelson, p. 196.
recognized symbols that have a generally agreed upon significance or meaning. Flying the confederate flag cannot mean whatever we want it to mean; history and social context clearly dictate this meaning. Selective abortion following prenatal diagnoses is certainly not a symbolic act in the same way that flying a flag is. There is no generally agreed upon meaning of the use of testing technology, and thus to claim that prenatal testing in its current context expresses a distinct message is not plausible. Nelson’s example, however, does point to the importance of attempts to unravel and understand the meaning of this technology, a task to which this thesis is in part dedicated.

What the use of these tests does mean is not strictly a matter of the individual choices involved, but is in part dependent upon the background conditions, social and historical, in which testing takes place. Claims made about what testing means to our society and what their proliferation expresses about our society cannot be answered simply by examining the possible individual motivations of those involved, viewed solely within the clinical context. If how we are to understand prenatal testing were limited to such a view then its meaning and what it expresses are clearly benign. This meaning and what it expresses are not so clearly benign when prenatal testing is placed within the historical context of eugenics in general and when societies’ attitudes towards and misconceptions about those with disabilities are examined. It is only by coming to terms with this social and historical context that we can be sure of the meanings of prenatal testing and the messages its use expresses. Moreover, the clearer we are about the meaning of the use of this technology the more confident we can be that we are using it in an ethical way.
The expressivist objection, in the final analysis, does not offer grounds on which to condemn or limit the practice of prenatal testing and selective of abortion, but as stated above it reinforces the importance of understanding and evaluating this technology within its historical and social context. It is within an examination of this context that, in my view, the legitimate concerns of the expressivist critique lies. The background in which testing currently takes place is not such that the message sent by this testing in general is clear and unambiguous and thus does not constitute a violation of the rights of those living with disability. That said, I am sympathetic to the concerns of the disability rights community and I understand why they might feel uncomfortable with the proliferation of testing. This discomfort results, in large part, because all too often the motivation behind the use of testing is based on a negative judgement of those living with disability. The legitimate concern that the expressivist critique points to is not that testing in general expresses a negative message, but that many of those who choose to use testing may do so for the wrong reasons. Some choose abortion following prenatal testing based on beliefs that people living with disabilities are less valuable than able bodied people or that they are such a burden to society that they do not have the right to be born. That these choices are made on this basis is of valid concern, but these concerns are not the result of testing and these concerns can be met without condemning the use of testing or severely limiting its application. There are changes within the testing system, however, that can be made to alleviate these concerns. Most important among these changes are ensuring that parents using testing make informed decisions which are based on stigmas or stereotypes and ensuring that parents understand that having a child with a disability is not a necessarily negative experience. How
urgent these concerns are and how they might be met will be discussed in depth in the following chapter.

**Parental Attitude Argument**

The parental attitude argument asserts that prenatal testing indicates a problematic conception of an attitude towards parenting. Like the expressivist objection, the parental attitude argument it is in part concerned with the message that prenatal testing sends, in this case not to those with disabilities, but to our society's children. This argument, however, is not only concerned with the message that is sent, but claims that this practice results in and encourages behaviours and attitudes that are undesirable and ultimately result in substantial burdens for our children. Since I have already discussed the problems of arguing that prenatal testing in general sends a particular message, I will not focus on this component of the argument, but rather on the attitudes and behaviour that the proliferation of testing is believed to manifest.

Leo Kittay argues that as a result of prenatal testing “the family starts to seem more like a club, and less like a family. In a club the members are selected based on one characteristic or another. This leads one to believe that if for some reason the characteristic is no longer attributable to the individual... The membership in the group and the ‘love’ that results can vanish”.12 Our parental duties to our children become conditional on whether or not our children possess certain characteristics. This tends towards commodifying our children; we no longer accept them as is, but pick and choose them based on whether or not certain genetic

characteristics are present.

This tendency is often condemned when discussed in relation to non-therapeutic genetic and medical interventions. For example, many are troubled by the fact that our growing knowledge of genetics may someday allow us to select children who have a certain eye colour, who will be a certain height or who will be more physically attractive. Those who support the parental attitude argument claim that what concerns us in these fictional non-therapeutic cases is equally present in prenatal testing for genetic disorders—a selective mentality which is not only evidence of a "preoccupation with what is trivial [the traits our child will have] and ignorance of what is profound[the value of the child as a whole]”, but will have adverse effects on our children and the future of our society.¹³

The commodification of our children is morally problematic because it treats our children as something other than ends in themselves. We should, it is argued, “care about raising whatever child we receive and about the relationship we will develop, not about the traits the child bears.”¹⁴ Further, it is believed that this selective mentality, the "club" mentality, threatens the possibility of a parent’s unconditional love for her child. This to some is simply unacceptable, as it is assumed that unconditional love is crucial to (perhaps definitional of) good parenting. The parental attitude argument then, claims that the proliferation of testing introduces and supports a way of thinking which threatens the proper functioning of the basic unit of our society and ultimately makes victims of our children. We, as a result of testing, begin to treat our children as

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¹³ Asch and Parens, p. 18.

¹⁴ Asch and Parens, p. 18.
objects which we require to live up to certain physiological standards, and thus deprive them of an open and accepting family environment which they not only deserve, but require to mature into healthy and productive adults.

The claims made in the parental attitude argument are certainly serious, but, as I shall argue, rest on an unfounded assumption. This unfounded assumption is that there is only one legitimate and worthwhile approach to having and rearing children. William Ruddick has labelled the approach on which the parental attitude argument rests, the "maternalist" approach to parenthood. A parent who is a maternalist is strongly committed to two beliefs, 1) motherhood begins at conception and 2) that good parenting is defined solely by a duty to protect and nurture one's child. It is the "maternalist" conception of pregnancy and motherhood, Ruddick argues, which gives rise to the assumption that "a mother who wants a child should want any child that she gets" and that if she does not she is not fulfilling her maternal duties. It is this maternalist assumption which gives rise to the parental attitude argument.

The maternalist conception, though endorsed by many, is not the only legitimate and productive conception of parenthood. Ruddick suggest two others, "projectivisism" and "familialism", neither of which give rise to the maternalist assumption, nor, I will argue, lead to the disastrous results pointed to in the parental attitude argument. Projectivist parents "think of


16 Ruddick, p. 95.
pregnant women as making a child, not as carrying or nurturing one. Like maternalists, pregnant projectivists will attend to diet and habits, but not as obligatory protection of a child, but rather as prudential protection of their maternal project”. Projectivists make plans and set goals for what they want their “project” to amount to. For example, their parental project might be to raise a child who will become a certain kind of adult or who will eventually achieve a particular goal.

The familialist parent is concerned with satisfying certain family goals. Thus “what prompts a familialist to become pregnant is not some general desire to create new life, or to have a child to love and rear, but rather a particular desire to start a family, or to give her partner a child and her parents a grandchild”. The familialist may have a child only in order to ensure that the family name or lineage is carried on, or that their family business will have someone to run it after they retire.

Both the familialist parent and the projectivist parent may likely use prenatal testing in order to ensure that their prospective child will have the traits required to achieve the goals they envision for them (this could require medical interventions where possible and also therapeutic abortion). It is important to emphasize the point that the goals set by the parents will not necessarily be competitive in nature; the parents may not desire to give birth to the ‘best’ possible baby. A parent whose passion is music, for example, might want only to ensure that their child will not be deaf in order to secure the possibility that their child too may develop this

17 Ruddick, p. 99.

18 Ruddick, p. 102.
passion. Setting goals for one's children and using prenatal testing to help ensure that they will achieve these goals does not necessarily lead to a quest for "perfect" babies, as it is sometimes assumed.

Both the familialist and the projectivist approaches to parenthood are legitimate and morally acceptable forms of parenting. There seems to be nothing inherently wrong with parents wanting their children to achieve certain things or to grow up to be certain kinds of people, even in cases where this is the sole reason they have children. Furthermore, within certain limits, we do not require parents to support all of their children's endeavours or qualities. The parent who is passionate about music may insist that their child spend more time practicing piano than they do on the basketball court. A focus on particular qualities or traits of a child need not have a negative effect on that child. There seems nothing in the projectivist or familial approach to parenthood which would necessitate that the environment in which this child lives would not be a loving and nurturing one, even if this environment were supplied solely to ensure that the child were psychologically fit to achieve the goals the parents envision.

"Critics will predict serious trouble ahead for both child and mother, given these shaping control efforts. Were illness or accident to deprive such a musical child of her capacities, they would expect the disappointed mother to lose or deny affection". 19 That this may happen is certainly a concern, but Ruddick claims, the systematic studies done on children who have failed through illness or accident to realize parents' hopes, simply do not support the claim that this is a common occurrence. That this is so is not particularly surprising. Projectivist and familialist

parents are not necessarily callous or unfeeling people and they are as likely as maternalists to
develop a strong relationship with their child and to love and care for that child. It is certainly not
a necessary result that projectivist or familialist parents would discontinue their love and
affection for their children if unforeseeable events thwarted their projects.

There also exists the more likely possibility that children as they grow up will reject the
goals or the life their parents have envisioned for them. This is of course a common occurrence.
Once again there is nothing in this possibility that could be used to claim that parents who do set
goals for their children and do everything, within reasonable limits, to ensure that their children
do achieve those goals, are not good parents, or that their love is conditional on them achieving
these goals. Even the most fanatical “hockey dads” and “ballet moms” often graciously accept
their child’s decisions to give up the quest for the NHL or the National Ballet School. In the face
of this opposition they need not withhold their love for their children, nor do we require these
parents to support the goals their children set for themselves.

Parents, to be good parents, need not be maternalists and thus need not subscribe to the
maternalist assumption that a mother “should be happy with whatever child she gets”. Projectivist and familialist parents, through prenatal testing, may want to do whatever is possible
to ensure that their children will have the traits and capacities which will allow their children to
fulfil the goals they set for them. There is no reason to assume that these conceptions of
parenthood will have the bad effects on our children that the parental attitude argument predicts.
In conclusion, the central claims of the parental attitude argument - that prenatal testing is

20 Ruddick, p. 97.
evidence of a problematic conception of parenthood that fosters unacceptable attitudes and behaviours towards our children - is simply not justified.

The Social Construction of Disability and The Dictates of Justice

The final argument I will examine presents a formidable challenge to the practice of prenatal genetic testing. Unlike those examined above, this argument does not claim that there are unjustified burdens for a minority group which are associated with testing that outweigh the possible benefits it may confer. The argument examined here, which I will call the “social construction” argument, asserts that the very approach which prenatal testing takes to conferring these benefits (preventing or ameliorating disability) is fundamentally flawed. On this critique using prenatal testing to help ameliorate or prevent disabilities misunderstands the cause of disabilities and thus is misguided in its approach to them.

Those who support the social construction argument identify a crucial distinction between disorders and disabilities, which they claim is under appreciated by those who support the proliferation of the testing technology. A physical disorder, on this view, is not in itself disabling, but it is the social environment in which that disorder is placed which determines if having it is to be considered a disability. Thus a “a person who uses a wheelchair is not ‘hopelessly confined’ in a wheelchair-accessible building. A deaf person is not isolated from the outside world by his or her deafness so much as by the unavailability of sign language
interpreters, telecommunication devices for the deaf, and closed captioning on television.” The traits that people do or do not have may be physical facts, but the disabilities they lead to are social constructions.

Two examples will help to clarify the importance of this distinction to our understanding of disability. N. Groce’s study of a late nineteenth-century Martha’s Vineyard village offers a good example of how social context can shape the experience or perception of disability. In the village she studied an unusually large number of those living in the village were deaf. Because of the large number of people who were deaf, all hearing inhabitants learned and spoke sign language from a young age. As a result, being deaf in this community had no significant effect on the social life or work prospects of those who were deaf and thus being deaf ceased to be a significant or overly disabling characteristic. Another example (this one fictional) is that of a person born with dyslexia who lives in a non-literate culture. This mental disorder in a non-literate context would have no socially significant task associated with it that the individual would not be able to perform and thus it would not be disabling. However, in a culture such as our own where literacy is almost a prerequisite for effective participation, this disorder can be significantly disabling. These examples underscore the point that though disorders may constitute inabilities not all of them result in disabilities, because it is only “those that interfere with the performance of socially


significant tasks that count as disabilities.”

The distinction made between disorders and disabilities, and examples such as those above, are used by those who advance the social construction argument to arrive at two different, but related conclusions. These claims are often conflated, but I will deal with them separately as they have very different implications. The first conclusion drawn is that disorders are in themselves neutral characteristics and thus many of the things which we typically call disabilities are in fact only “forms of variation”. The second is that because disability is in large part socially constructed, justice dictates that we expend our energies to reduce the social factors which limit the opportunities and prospects of those living with disabilities as opposed to eliminating the disorders which are the bases of the disabilities.

**Forms of Variation**

Deborah Kent supports the first conclusion when she writes: “I will always believe that blindness is a neutral trait, neither to be prized nor shunned.” If, as Kent suggests, blindness and other disabilities are the result of neutral characteristics, then the benefits we have to this point presumed prenatal genetic testing offered are not as uncontroversial as they may seem.

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23 Buchanan, “Choosing”, p. 38.


Those who draw this conclusion claim that prenatal genetic testing is in fact a discriminatory practice, shrouded in the cloak of beneficence. To make this point, the disorders tested for are often compared to other physical traits such as skin colour or sex, which because of their social construction sometimes are accompanied by significant disadvantages. Philip Ferguson writes, "disability, like race and gender, is a complicated blend of physiology and culture inevitably viewed through the lens of our own personal history. Unlike race and gender, it is still permissible in our society to portray disability as clearly undesirable."  

If disabilities, because they are based on neutral characteristics, are in fact only forms of variation, then prenatal testing is clearly morally problematic. Prenatal testing on this view is not part of a therapeutic process and the benefits it was believed to offer rely on a misguided belief that disabilities are in themselves undesirable. In this light, prenatal testing is portrayed as repeating some of the mistakes of the old eugenics, in particular favouring traits and human types which are based on a narrowly conceived notion of a valuable human being. Where the old eugenics was often racist and classist in its estimation of human value, prenatal testing is "ableist". Prenatal testing followed by abortion becomes the equivalent of selection for non-medical traits such as sex (in North America there is general agreement that this is an unacceptable practice), and medical interventions such as gene therapy used to prevent or cure disability, akin to using gene therapy to ensure that a child’s skin is a certain colour.

To draw the ‘forms of variation’ conclusion from the distinction of disorder from

disabilities and from the fact that disability, to varying degrees, is socially constructed is a mistake. To those living in the Martha's Vineyard town Groce describes, being deaf may have been a relatively minor inconvenience when considered in light of the opportunities open to those who were deaf. That being deaf in this community was significantly less disabling and thus significantly less undesirable than it may be in other communities does not mean that not being able to hear is a neutral characteristic, which may be good for some and bad for others. When this inability is viewed against the background of standard human functioning it is clearly not a neutral characteristic.

There are certain characteristics and abilities which can be placed under the category of standard human functioning. The majority of human beings, for example, can see, hear, walk and, if given the chance, can learn to read and write. Though there will always be controversial cases, there is a range of human functioning which can be properly described as "standard". This standard of human functioning allows us to determine which activities humans "should" be able to perform and what potentials humans "should" have. Having any disorder, be it diminished mental capacities or an inability to walk, hear or see, is clearly a deviation from the standard of normal human functioning. Judged against this standard these inabilities can not be understood as neutral characteristics as these inabilities inherently preclude some possibilities which fall within the range of activities which humans are typically able to perform. Even though the extent to which these disorders foreclose socially relevant options is dependent upon their social context, they can not be understood as neutral as these physical disorders, by definition, place the people who have them below the standard of human functioning.
A person with Down's Syndrome may never be able to discuss philosophy because of an inability to grasp abstract concepts and a blind person will never be able to watch a sunset. Arguably, in both cases, these are worthwhile and important experiences that human beings are generally able to take part in. Thus, these disabilities are not merely forms of variation which society need embrace, in the same way that it should embrace different races or genders, as the disorders on which they are based inherently preclude some worthwhile and valuable possibilities. The closure of some possibilities is inherent to the disorders on which the disabilities are based and for this reason they cannot be considered neutral forms of variation, and are best understood as inherently undesirable. Preventing and relieving disabilities, therefore, can be properly understood as a benefit both for those who have the disability and for society.

*Preventing Disability: Change Society or Change People*

To object to prenatal genetic testing on the basis of the fact that disability is in large part socially constructed, does not rely on the claim that disorders are neutral characteristics or that disabilities are not inherently undesirable. Many of those in the disability rights community readily acknowledge that some aspects of disability do not result from their interaction with the environment, but are inherent in the characteristic itself. They grant, therefore, that disabilities are inherently undesirable and that attempts to alleviate or prevent them is a desirable goal. However, some do object to the way in which prenatal testing attempts to achieve this goal.

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27 This is not to say that benefits can not accompany disabilities. Having a disability may help develop one's strength of character or may grant one a valuable membership in a community (eg. The deaf community). These benefits, however, are not foreclosed to able bodied people, whereas the opportunities lost due to disability are not retrievable.
They challenge this technology’s focus on eliminating or suppressing the expression of certain physical characteristics. To make this challenge those in the disability rights community stress two points: 1) Though certain disorders may be inherently disabling, the extent to which they foreclose the options of those who have them is in large part socially constructed. 2) Moreover, there may be ways to construct our social environment, so that people with disabilities are able to experience the joys and garner the benefits that are typically provided by the options that are foreclosed to them. M. Ferguson writes:

“The point is not so much whether a blind person cannot enjoy a Rembrandt, but whether social arrangements can be imagined that allow blind people to have intense aesthetic experiences. People in wheelchairs may not be able to climb mountains, but how hard is it to create a society where barriers are removed to their experiences of physical exhilaration? Someone with Down’s Syndrome may not be able to experience the exquisite joy of reading bioethics papers and debating ethical theory, but that person can experience the joy of thinking hard about something and reflecting on what he or she really believes. The challenge is to create the society that will allow as many different paths as possible to the qualities of life that make us all part of the human community.”

Those who support Ferguson’s view claim that we ought to focus our energies on making our society as accessible as possible, to allow people with all sorts of different mental and physical capacities to live full and worthwhile lives, and not on “weeding out those who do not conform to particular standards”.29

The basis of the above argument is that any adequate theory of justice must make provisions for the equal opportunity of all people. If a society is to be just, efforts must be

28 Asch and Parens, p. 25.

made to ensure that it is constructed in such a way that all of its members have an equal opportunity to achieve the goals they set for themselves, to function successfully within that society, and to be allowed access to the benefits which are associated with membership in that society. To what extent justice dictates we make efforts in this direction is of course debatable. Prenatal testing most often attempts to eliminate disabilities by making it possible to prevent the expression of certain physical characteristics (once again either through abortion or medical intervention) and thus attempts to ensure that the individuals born into society have certain requisite capacities which will allow them to be successful members of that society. These efforts, it is argued, are misguided as they are not those dictated by justice. Thus “instead of attempting to eliminate disabilities by changing individuals, the goal should be to change society so that the genetic conditions some individuals have are not disabling”.

This conclusion, drawn from the fact that disability is in large part socially constructed, offers a substantial challenge to our current practice of prenatal testing. If it is true that justice dictates that we change society and not those who are or will be in it, then this would offer grounds on which strictly to limit its application. The only acceptable application of prenatal testing would be to use the information provided to prepare families for the birth of a child with a genetic disorder. However, there is a response to this challenge which has been recognized by Allen Buchanan. Buchanan points out that this version of the social construction argument rests on a misconception that justice speaks only to the broadening of access to society and ensuring that as many people as possible can participate effectively in it. Countering the obvious interest

30 Buchanan et. al., From Chance To Choice, p.262.
that individuals may have in being granted access to and being able to participate effectively in a society, is an interest "abled" individuals can have in being participating members in a maximally productive society. This latter interest, which Buchanan calls the "maximizing interest" is an equally legitimate interest and, as a result, claims as to what justice dictates concerning how we attempt to prevent or ameliorate disabilities is not as straightforward as the social construction argument suggests.\footnote{Buchanan, "Choosing", p. 36.}

Focusing efforts on ensuring that various social environments are as accommodating as possible to those who have limited physical or mental capacities may in some cases have an effect on how productive those social environments are. To make this point, Buchanan employs the example of a card game. If a group of people ranging in age from 5 to 50 want to play a game of cards in which everyone will be able to successfully participate, they will have to play a game whose rules can be understood by everyone. In this situation it would be unlikely that the game chosen would be contract bridge, as the rules and nuances of this game are too complicated for the average 5 year old. It is more likely that they will end up playing a game like "go fish" whose rules are relatively simple and which would grant a 5 year an equal opportunity to participate and to be successful in his playing. Though choosing "go fish" grants everyone an equal opportunity to play the game and to be successful in their playing, it robs some of the adults of the benefits of playing a game, like contract bridge, which is more suited to their abilities and more enjoyable for them.

Buchanan takes the decision of which card game to play to be analogous to decisions
which we can make about the "institutional infrastructure of social interactions". The institutional infrastructure defines the *rules* of effective participation in a society. This infrastructure, including laws, social practices, and norms of conduct sets certain limits and prerequisites on how to participate effectively within society and thus on who can participate effectively. Buchanan admits that we do not ever make a choice (like in the card game example) as to which institutional infrastructure we will take part in, but there are decisions which can be made to influence the infrastructure which we find ourselves in.

The institutional infrastructure in which we function in Canada is one which requires complex literacy and numeracy skills to be effective participants. These skills allow us to take part in the complex social interactions that are part of our everyday life, and without these skills one may be barred from effective participation and thus denied the benefits of full participation. Those who are significantly cognitively impaired, for example, do not have the requisite literacy and numeracy skills, and as a result, are often not granted the benefits of full participation. Those who are cognitively impaired therefore, have an interest in making choices concerning the institutional infrastructure, which would waive or lessen the complex literacy and numeracy skills that are currently required for effective participation. Making choices which achieve this end, though they would allow for greater access and would ensure that those with diminished mental capacities could participate effectively, would likely have an adverse effect on the productivity and efficiency of our current institutional infrastructure. A concrete example to illustrate this point would be making our public school classrooms accessible and functional for children who

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32 Buchanan, “Choosing”, p. 41.
are significantly cognitively impaired. One likely result of making our classrooms accessible in this way, would be a slow down in the rate at which the curriculum is covered in these classes, and thus a lessening in the content covered by the curriculum. As this example suggests "participation by 'disabled' individuals can cause discoordination and can reduce the benefits which the 'abled', might otherwise reap from the form of interaction in question."\textsuperscript{33}

The examples given above are meant to make clear the point that justice does not speak solely in favour of focusing our energies to ensure that our society is one in which everyone can participate effectively. "The interest in having access to a [society] in which one can participate effectively, and the interest in having access to the most productive [society] in which one can participate successfully... are legitimate interests for those who have them, the problem of justice cannot be resolved by simply dismissing either interest and fully satisfying the other."\textsuperscript{34}

Buchanan’s insight that the so called “maximizing interest” is a legitimate interest and that this interest may come into conflict with others’ interests in inclusion certainly does not undermine claims that we should make significant efforts to ensure that our society is accessible to those with disabilities, and that these efforts are dictated by justice. This insight, however, makes plain the fact that it is a mistake to assume that the equal opportunity provision of justice supports an unlimited obligation on the part of the “abled” to modify the institutional infrastructure to ensure the broadest possible access, to meet the interests that those with disabilities have in inclusion. The maximizing interest supports, in some cases, efforts to change

\textsuperscript{33} Buchanan, “Choosing”, p. 41.

\textsuperscript{34} Buchanan, “Choosing”, p. 44.
the individuals who will function in the institutional infrastructure to ensure they have the requisite capacities to be effective participants without jeopardizing the productivity or efficiency of that infrastructure. Prenatal testing, as it offers us the power to limit the physical expression of certain disorders, in some cases can be understood as a way in which to prevent disabilities without sacrificing the maximizing interest.

This insight concerning the dictates of justice regarding approaches to preventing or alleviating disabilities, does not in itself give us any guidance as to how to weigh the two interests involved. I grant that in general much weight should be given to the interest in inclusion and where there is a minimal cost to the maximizing interests, every effort should be made to satisfy people’s interest in inclusion. That much weight should be given to the interest in inclusion, however, is not enough to justify claims that prenatal testing is fundamentally misguided in its approach to disabilities. Prenatal testing is able to prevent and alleviate disabilities without jeopardizing the efficiency and productivity of the institutional infrastructure and is, therefore, in some cases supported by the dictates of justice. I conclude that the social construction argument, because it mistakenly assumes that justice speaks only in favour of a broadening of access to society, is not justified in its claim that prenatal testing as it is currently practiced is inherently unjust and misguided in its approach to disability.

The disability rights critique claims that the current practice of prenatal testing is unjust and that this fact offers sufficient grounds on which to limit or condemn the practice. It supports this claim with two main lines of argument. The first suggests that prenatal testing results in
burdens which are unequally distributed and that these burdens are too much to bear for those who are forced to shoulder them. The second argues that prenatal testing, as it focuses on limiting the expression of certain physical characteristics, is not carried out in a response to the dictates of justice and is thus fundamentally misguided in its approach to disability. These two general arguments made by the disability rights critique, in my view, highlight legitimate threats of injustice which are involved in the practice of prenatal testing. In particular, the first line of argument identifies the dangers of employing this technology in a social environment which often misunderstands disabilities and makes judgements about those with disabilities based on stigma and stereotype. The second rightly emphasizes that many disabilities can be alleviated by simple changes to the society in which we live and that the possibility of making these changes is often under appreciated. The fact that these arguments express genuine concerns, however, does not change the fact that these arguments do not support the claims that they make.

Both the expressivist objection and the parental attitude argument failed to support their claims that prenatal testing results in burdens which are too great to bare. The expressivist objection fails in this regard, because even if abortion following prenatal testing is understood as a public act whose meaning is not directly connected to the motivation for carrying out this action, what is expressed in this act is not clear and unambiguous. The parental attitude argument fails to meet its objective, as it relies on the mistaken assumption that there is only one legitimate form or conception of parenting.

The social construction argument, in both forms I have discussed, is also not justified in its claim that prenatal testing is fundamentally misguided in its approach to disability. The first
form of this argument relies on the mistaken conclusion derived from the fact that disability is in part a social construct, that disorders are neutral characteristics and disabilities only forms of variation. The second rests on the assumption that justice speaks only in favour of broader inclusion for those with disabilities in the institutional infrastructure. As Allen Buchanan has demonstrated, this assumption does not take into consideration that the maximizing interest is a legitimate interest.

As noted above, the concerns highlighted by the disability rights critique are legitimate concerns. The efforts made by the disability rights community to educate the public to the nature of disability and to advocate changes which could be made to allow for more effective participation in society by those with disabilities are both needed and laudable. Though these concerns in themselves do not offer grounds on which to condemn or severely limit the application of prenatal testing, they must be taken into consideration when making decisions as to how these tests should be offered to the public. As will be demonstrated in the next chapter, the reason these concerns must be taken into consideration is derived from the right to reproductive freedom to which the parents using the technology are entitled. I will argue that if prenatal testing is to be practiced in such a way that it respects these rights, the system of testing must not only take into account the many stigmas and stereotypes that are held concerning disability, but it must recognize that changing society so that it is more accessible to those with disabilities is a legitimate approach to preventing and ameliorating disability.
The analysis of the “eugenics critique” of prenatal testing carried out in chapter 1 revealed that prenatal testing’s status as eugenic does not in itself signal that the practice is ethically problematic. This analysis placed prenatal testing within its historical context and highlighted the moral transgressions of the “old eugenics”, thereby offering some guidance of what not to do if the mistakes of the past are to be avoided. Chapter 2 identified legitimate concerns about a narrow understanding of disability on which the system of prenatal testing is premised and that decisions made concerning disability in this system may be informed by stigma and stereotype. In this chapter, the concerns identified in Chapter 2 and the guidance offered in Chapter 1 will converge.

As discussed in the first chapter, one of the most glaring moral transgressions of the “old eugenics” was that it did not always respect people’s right to reproductive freedom; the most obvious examples being the forced sterilizations and segregation of those deemed unfit to reproduce. Coinciding with its disrespect for reproductive freedom was a disrespect for a pluralism of views concerning what constitutes a valuable human life. Those who were barred from reproduction were often the victims of race and class biases. That these moral blunders associated with the “old eugenics” should be avoided in our practice of prenatal testing is clear, but that they pose any real threat is not as obvious. In Canada’s current political and cultural context, overt violations of reproductive freedom and a blatant disrespect for value pluralism on a par with that which took place in the past seems nearly impossible. For example, a government
sponsored mandatory testing and termination program is an unlikely threat. Prenatal testing and terminations based on this information are voluntary and will most likely remain so. Further, prenatal testing is defended not only on the basis that it doesn’t threaten reproductive freedom because it is voluntary, but that it actually expands these freedoms. Prenatal testing now offers parents more choices concerning what kinds of children to have, as they can choose through abortion not to have children with diagnosable disorders. As well, parents who are at known risk to have a child with a certain genetic disorder, who previously may not have attempted to conceive a child, can now become pregnant “risk free” as they will be able to detect this abnormality in utero. Finally, it is claimed that parents who use testing and diagnose a genetic anomaly in utero, but who do not wish to terminate the pregnancy, now have an extended time frame in which to make choices about how to prepare for the arrival of a child who may have a disability.

I do not dispute the fact that in the final analysis parents do have the choice to use or refuse testing (i.e. testing is not mandatory), and that they do have the choice to do whatever they want with the information gained through testing. But, to assume that because testing is voluntary it does not interfere with one’s right to reproductive freedom is to assume that voluntary choices are ipso facto free. Furthermore, to claim that prenatal testing expands one’s reproductive freedoms because it offers parents choices that were not previously available, assumes that an expansion of the realm of choice necessarily entails an expansion of freedom. It is these assumptions that I will challenge in this chapter. I will argue that ensuring that choices are voluntary and expanding the range of individual choices does not always ensure the protection
or expansion of individual freedom. Voluntariness and the availability of a wide array of choices are central components of freedom. To focus solely on these components, however, is to gloss over the critical effect that the social context in which these choices are made available has on the expression of one’s freedom. As was highlighted by the disability rights critique of prenatal testing in Chapter 2, this social environment is one which often takes a narrow view to possible approaches to disability and often makes decisions concerning disability based on stigma and stereotype.

In particular, I will argue that, in the current context, parents’ practical ability to refuse testing and, in lieu of a positive test result, the ability to refuse abortion, is seriously impeded by the way in which the tests are carried out, and by the social context in which they take place. As a result, parent’s rights to reproductive freedom are routinely challenged throughout the testing process and their ability to express their own values as to what is to be considered a valuable human life is diminished. It is in this regard that the threat of eugenics is a real one, and that the concerns highlighted by the disability rights critique becomes critical. I do not claim that all parents who use testing will have their rights violated or their values challenged. The test for whether freedom and value pluralism are sufficiently respected is not based on a head count; those in the minority are to be equally respected. Nor do I claim that this is the necessary result of testing per se as there are ways in which this problem can be remedied. I will, therefore, at the end of this chapter offer some practical ways in which the challenges to reproductive freedom posed by testing might be met. Before I make this argument, however, more must be said about the right to reproductive freedom itself. Why is it so important that it be protected, and what is
its moral basis? And, crucial to my argument in this chapter, what are its limits; does the right to reproductive freedom include the right to have a child with a diagnosable disorder? It is to these questions that I will now turn.

The Right to Reproductive Freedom: Its Bases and Limits

Reproductive freedom is generally understood to mean simply freedom within the activities associated with reproduction. This rather obvious definition, unfortunately, does not suggest an obvious set of actions to which it applies. It is generally assumed that the right to reproductive freedom at least includes the right to choose with whom and when to procreate, the right, in most circumstances, to choose how many children to have (possible circumstances in which the choice of the number of children one has is no longer a right will be discussed later in this chapter), and now, controversially, the right to choose what kind of children to have. It is the right to this last component of reproductive freedom which is my concern in this chapter. In this section I will argue that our right to choose what kind of children to have does have a strong moral foundation, and I will discuss some of the most plausible arguments which would limit our freedom in this regard. In the final analysis, I will claim that a right to reproductive freedom does include, in almost all cases, the right to have a child with a diagnosable disorder, and thus the right to refuse testing should be closely guarded.

Dan W. Brock argues that the moral bases of the right to reproductive freedom can be found in three separate interests. They are an interest in self-determination, in individual good or welfare, and in equality (in particular gender equality). These separate interests are not mutually
exclusive and "each captures something important about reproductive freedom so that a full account of a moral right to reproductive freedom must incorporate all three."\(^1\)

Our interest in self-determination is based in our capacity to form and pursue a life plan. We, as rational beings, form values and preferences and make choices based on these values and preferences that have both short term and long term effects on our lives. Our values and preferences are subject to change over time, and as a result our plans are constantly in flux; they are forever being formulated and reformulated. What is constant in this process is our interest in forming these plans and making choices based on our changing values. We value this ability in and of itself, because not only is our interest in self-determination constant it is implicit in all of the choices that we make. Brock, following Rawls, has characterized it as a highest-order interest.\(^2\)

The choices and plans that we make are not all equally important and valuable: "Other things being equal, the more central and far-reaching the impact a particular decision will have on our lives, the more substantial our self-determination interest in making it."\(^3\) It is clear that the sorts of decisions involved in reproductive freedom are extremely personal decisions that have far-reaching effects on people's lives. The choice of what kind of children to have (a choice that is inevitably a part of decisions surrounding prenatal testing) is certainly no different in this

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2 Brock, p. 48.

3 Brock, p. 49.
regard. This right then is of significant moral importance primarily because of the substantial interest in self-determination which is involved in these decisions.

The right to reproductive freedom is also based on an interest in the good or welfare of the individual. There are numerous, different ways in which this good can be assessed. For example, individual good is sometimes associated with desire satisfaction. Something is good for the individual if it results in that individual satisfying the desires that he or she has. Individual good can also be measured or assessed by the presence of certain positive conscious experiences, most commonly pleasure or happiness. Finally, individual good can be assessed on the basis of certain objective standards (eg. health). I believe it is fair to say, that in general terms, a right to reproductive freedom does support or enhance the individual good. In most cases the right to reproductive freedom allows us not only to satisfy our desires, but contributes to the happiness of those involved and promotes commonly recognized objective components of the good. With regard to the choice to decide the kind of children we want to have, the future child’s individual good and the good of others in society is involved in these decisions. Thus the right to choose what kind of children to have can be supported or challenged by the individual good of the future child and by the individual good of others who are effected by this choice. I will return to this point when discussing the limits of reproductive freedom.

The final base of a moral right to reproductive freedom is found in the moral principle of equality. The principle of equality is used to support the right to reproductive freedom based on the premise that gender is not a morally relevant characteristic. That is, regardless of a person’s gender they should be treated with equal respect. They should be afforded the same
opportunities, and should be granted equal access to economic and social benefits. If this premise is accepted, then it is clear that the biological fact that only women get pregnant should not result in discrimination against women. It should not systematically bar them from access to the economic and social benefits open to men and it should not be used to undermine women's interests in self-determination and individual good. The right to reproductive freedom ensures women an increased dominion over their bodies and allows them to make decisions about reproduction that in the past have diminished their abilities to pursue their interests. Ensuring the right to reproductive freedom thus enhances equality.

As shown above, the right to reproductive freedom has a strong moral basis in the interests of self-determination, individual good, and equality. It is for this reason that it is crucial that it be vigilantly protected, and, as the history of eugenics reminds us, when it is not the results can be disastrous. Reproductive freedom, however, is not an absolute right and it does have moral limits which are relevant to prenatal genetic testing. One such limit is grounded in an interest in preventing potential harms to children. This limit is relevant only in cases where a mother intends to bring a fetus to term. Some argue that children can be harmed by actions that were taken before they were born and consequently have a right to be protected from these actions.

There are two relevantly dissimilar ways in which it is argued that a child can be harmed prenatally. A child can be harmed by actions of the mother or others while the mother is pregnant (e.g. substance abuse on the part of the mother during pregnancy), or a child can be

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4 The debate over abortion is of course relevant to this claim, but as my concern is with harms to children (not fetuses), this debate need not be rehearsed here.
harmed by the act of procreation itself. It is the second claim which is relevant to the argument that I make in this chapter. If a child can be harmed in the act of procreation, then it might be assumed that to bring a child into the world in this harmed condition constitutes a wrong to that child. Some have suggested that the wrong done in these cases is that bringing a child into the world in a harmed condition is a violation of the future child’s rights. This right has been expressed as the right to an “open future”, or to an “unrestricted life”. The “rights-based” approach to prenatal harm has been used to establish, in some cases, a “right” to be “unconceived, aborted, or re-formed”. If a rights-based approach can plausibly be used to argue that in cases when a child will be born in a harmed condition, it has a right not to be born, then this right clearly conflicts with parents’ rights to reproductive freedom in the context of prenatal testing. It suggests that this freedom might be limited in cases where it is possible to avoid bringing a child into the world when it is known that this child will be born in a harmed condition.

To suggest that harms done to a child before birth justify undermining reproductive freedom is only plausible in a limited number of cases. This is because “procreation itself is plausibly held to be a wrong to the child brought into existence only if the child’s existence is so burdensome and without compensating benefits to it that its life is reasonably held to be, from its


It is only plausible in these cases because the choice involved in the cases we are interested in (prenatal diagnosis, and as almost no medical interventions exist, the termination of affected fetuses) is one which involves what Parfit calls a "same-person" choice. The choice, in the great majority of cases, is not between the birth of a child with a diagnosable disorder or one born without, but between a child with a disorder and no child at all. If life with any given disorder does not restrict a child to a life in which the burdens will necessarily outweigh the benefits, then the act of bringing this child into the world cannot be considered a wrong done to the child and thus not a violation of its rights. Genetic conditions which might meet the standard of a life "not worth living" are relatively rare, and most conditions diagnosed by prenatal genetic testing allow for a life which has substantial compensating benefits. Thus in the majority of cases, there is no case to restrict parents' right to reproductive freedom by restricting their right to have a child with a diagnosable disorder.

I grant that children can be harmed by the act of conception and that in cases where the child’s life is one that is not worth living, I grant that parents may have acted wrongly in bringing this child into the world. I say ‘may’ here simply because I am not totally convinced of this fact. I find “vitalist” arguments, that life itself can be understood as a compensating benefit and is thus preferable to no life at all, a plausible position. I am convinced that it is not irrational for parents

7 Brock, p. 56.


9 Tay-Sachs is an often used example of a disease which renders a life not worth living. Babies born with Tay-Sachs typically have a life expectancy of two to three years and in that time most are unable to ingest food without aid, and are in constant and substantial pain.
to believe that even in the case of such terrible diseases as Tay-Sachs it is still in the best interests of their child to be brought into the world.

The claim that parents may have wronged their child by bringing it into existence in a condition in which life offers few compensating benefits does not justify a restriction of their reproductive freedoms. As Brock observes “public policy in this area is politically and ideologically charged because the actions harmful to the fetus are largely done only by women... And because coercive policies or laws designed to prevent risks or harms to a fetus can be deeply invasive of the pregnant woman’s privacy, liberty and self-determination.”

Further, in the cases we are interested in, the only option available, in most cases, to avoid the harms done to the child is abortion, which is a morally controversial procedure. For these reasons, even those who argue vehemently that it is morally wrong to bring a child into the world whose life is not worth living, shy away from claiming that this fact justifies overriding the mother’s right to reproductive freedom. It is generally agreed that establishing any coercive measures in this regard is simply not justified. That is, the harms done by establishing any policy which implicitly or explicitly restricts reproductive freedom in this regard, would be on measure more harmful than allowing parents to make the decision of whether or not their child should be born. The substantial interests of the parents involved (self-determination and individual good) and the societal interest in equality, clearly override the rights of the child not to be born in a harmed

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10 Brock, p. 58.

Moral limits to reproductive freedom can also be based on harms done to others. If there is a plausible harm done to others in the act of reproduction, then there may be grounds to restrict reproductive freedom. Brock observes: "it is clear that on both the self-determination and individual good or welfare defenses of reproductive freedom, the more an individual’s reproductive freedom has an unwanted, adverse impact on the self-determination or welfare of other individuals, the weaker the individual’s moral claim to make the reproductive choice."  

For example, where overpopulation in a country is a heavy burden restricting the right to have a lot of children or perhaps any children, may be justified.

There are some who believe that it is socially irresponsible to have a child with a disability because there are elevated financial health costs involved in rearing children with disabilities which, in a publicly funded health care system, fall to people other than the parents. The financial burden imposed on others that may result from allowing parents to choose to have children with diagnosable disorders in our current context, is not a plausible limit on reproductive freedom. It is not plausible because the strength of the moral claim others may have against an individual’s right to reproductive freedom in these cases is relatively weak. The extra health costs associated with having a child with a disability will be distributed over a large population. The economic burdens for other individuals will have a negligible impact on others’ interests in self-determination and individual good; restricting individual reproductive choices in this way would have a large impact on these interests. Any economic burdens associated with raising a child with

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12 Brock, p. 58.
a disability clearly do not justify any restriction of individual reproductive freedom in Canada.

As shown above there are certain plausible moral limits to reproductive freedom which pertain directly to the practice of prenatal testing. That avoidable harms are inflicted on children and that burdens are imposed on others offer moral reasons why reproductive freedom might be limited in the realm of prenatal testing. I have argued that these moral limits do not justify limiting parents' rights to have a child with a diagnosable disorder. Thus within the context of the system of prenatal testing, limits placed on parents' practical abilities to have children with diagnosable disorders are clearly unacceptable.

Challenges To Reproductive Freedom

As I stated at the beginning of this chapter, it is often argued that as long as prenatal testing is practiced in a way that supports individual choice, it does not threaten reproductive freedoms, but actually expands these freedoms. This argument is based on the implicit assumption that expanded realms of choice necessarily result in increased freedom. As Gerald Dworkin has pointed out, this is not always the case.\(^\text{13}\) When new choices arise, whether or not they will expand freedom depends upon the environment in which they are available. In some cases the availability of new choices can come at the cost of freedom.

There are numerous reasons why new choices can result in diminished freedom. The first is that with new choices come new responsibilities. New choices grant us agency in realms which hitherto were left to fate, chance or to others. The result is that "once I am aware that I have a

choice, my failure to choose now counts against me". Bearing the responsibility of new choices is not necessarily a bad thing, and as Dworkin asserts is often a sign of moral maturity. However, the fact that we can now be held accountable for choices that were not previously available to us can have a strong influence on the decisions that we make when faced with these new choices. Depending on the costs that are associated with these responsibilities, these new choices may in fact restrict our freedoms.

New choices can also result in pressure to conform. The mere fact that a choice is available may in some social contexts necessitate that we make use of this choice. Dworkin offers as an example the practice of duelling. He claims one of the main justifications for making duelling illegal in the U.S. was that when it was legal, some people were “forced to manifest their courage and integrity in ways that they wished to avoid." The mere fact that duelling was an option in a context in which it was the accepted form of settling disputes, forced people, in order to maintain their integrity, to use that option.

Finally, if choices are to enhance freedom they must be informed. Thus, when new choices are made available, we are forced to acquire new information that will allow us to make informed choices. Depending on the complexity of the knowledge required and the time constraints involved, making an informed choice may be very difficult. We may be forced in some situations to rely heavily on the opinions of others who understand the complexities involved. In doing this we, out of necessity, give up some of our freedom in order to make a

14 Dworkin, p. 67.

15 Dworkin, p. 69.
The different ways that Dworkin identifies in which new choices may constrict freedom are all relevant to the practice of prenatal testing. The information required to make an informed choice requires us to rely heavily on health care providers for easily understandable and objective information; under the time constraints involved we have little choice but to trust that this information is objective. Moreover, the responsibility of choosing what kind of child to have is now placed on parents, and they are held accountable for their choices. If a child is born with a diagnosable disorder, this is now, in part, understood as the result of the choice of the parents and not simply a chance occurrence. As well, doctors and other health care providers are now responsible for ensuring that parents are aware of their choices, and that they have enough information to make an informed choice. Doctors are now held responsible if parents make choices which are considered to be ill informed. Finally, the social and institutional pressures to conform to certain standards of "good parenting" are considerable; as prenatal testing is now more often being placed under the rubric of standard prenatal care, this may result in pressure for responsible parents to use these tests, even if the test's applications are contrary to their own values.

In this section, I will examine the environment in which the choices made available by prenatal testing are encountered. This will include an examination of the legal, institutional and social context in which prenatal testing takes place. This examination will serve to make plain some of the assumptions that are often the basis of the decisions involved. As well, it will uncover the vested interests of those who play key roles in this decision-making process. It is
my contention that when these tacit assumptions and the vested interests are made plain, it becomes clear that the pressures associated with the choices of prenatal testing significantly impair parents’ practical ability to refuse testing and a subsequent abortion. As Barbara Katz Rothman puts it, “in gaining the choice to control the quality of our children we may be losing the choice not to control the quality.”

The Tacit Background

The term ‘geneticization’, coined by Abby Lippman, is one often used to describe an emerging trend in the general focus of our health care system. Lippman argues that our discourse about health problems and their solutions is framed with increasing frequency by our understanding of genetics: “Though it is only one conceptual model, ‘genetics’ is increasingly identified as the way to reveal and explain health and disease, normality and abnormality.” The genetic model identifies health problems and their solutions as occurring in individuals and defines those individuals on the basis of their genetic code. It is Lippman’s contention that ‘geneticization’ now poses a real threat to other discourses and conceptual models of health care. How we approach and manage disease and disability is being narrowed to the point that proposed solutions to these health problems take only one form and that is a genetic solution.

One example of Lippman’s concern is found in prenatal care. Low birth weight is the


leading cause of infant morbidity in the United States, and it is known that it can be combated with such “low tech” approaches as ensuring pregnant women are provided with essential nutritional and social services.\(^{18}\) The amount of government health care dollars spent in the U.S. on these initiatives, Marsha Saxton argues, is disproportionately low compared to the amount spent on genetic testing and screening for genetic disorders which are relatively rare.\(^{19}\) One plausible explanation for this disproportion is the preference given to the genetic model.

In line with Lippman's claims about how “geneticization” narrows the focus of our approach to health problems is what is known in contemporary disability studies as the “medical model” of disability. The medical model is generally understood to be the dominant framework in which disability is understood in the health care system in North America.\(^ {20}\) This model understands disability as solely the product of biological determinism or personal tragedy. It therefore considers disability as a wholly physical phenomena which affects only a small portion of the population. On this model the rational and beneficent approach to disability is one which seeks for the disabled individuals a medical cure; it hopes to eradicate the disability by focusing on its physical manifestation in the individual.

As was discussed in Chapter Two, there are other approaches to disability which challenge the medical model and understand disability within its social, as opposed to its

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\(^{18}\) Lippman, p. 20.


individual and physical context. These so called social models of disability generally distinguish disorders from disabilities. Disorders are understood as physical phenomena which are not necessarily disabling. What determines if a disorder is disabling is at least in part determined by the society in which it exists. The approaches to disability prescribed by social models focus on eradicating the social obstacles that make disorder disabling as opposed to eradicating or "curing" the physical impairment itself.

My point here is not that the genetic approach to health or the medical approach to disability are not legitimate and constructive approaches. As I argued in Chapter Two, in relation to prenatal testing specifically, these approaches to disability are legitimate approaches. Further, I do not believe that these frameworks in themselves pose a serious threat to parents' practical abilities to refuse testing. More must be said on this point. However, other legitimate approaches do exist and thus our health care system should not be understood as "neutral" in its approach to disability, as there is an ideological framework in place which minimizes the importance of other approaches.

The very existence of the testing technology and how it is offered expresses a bias in the approach to disability: "[The] existence and routinization of the technology implies anything but neutrality. It assumes that scientific and medical resources should be placed in the service of prenatal diagnosis and potential elimination of fetuses bearing chromosome problems."\(^{21}\) The implied message in the proliferation of testing technology is that there is something about the disorders that are tested for, and in particular those that are "routinely" tested for, that the

parents should know about and that may require medical attention. To use Lippman’s language, the emphasis on the genetic and medical approaches to disability found in health care settings coupled with the routinization and proliferation of testing, results in the “construction of the need” for prenatal testing. Expectant parents, concerned about the possibility that their child may have a disability, are confronted with a system which has a tendency to understand this concern in only one way; as a concern about the individual fetus’ genetic constitution and what that constitution may tell us about the future child’s physical condition. The use of prenatal testing becomes the obvious way in which these concerns may be addressed. When a disorder is diagnosed, the only therapeutic option, in almost all cases, is abortion. Within the framework of ‘geneticization’ and the medical model of disability, what one is to do when faced with concerns about the health of their future child is clear.

How this ideological framework undermines parental choice is manifested in concrete ways. Nancy Press, in a study on how women make the choice to take part in prenatal screening, found that this decision was heavily biased by the fact that the test was offered as a “routine” test and part of the “standard of care”. She claims that the broad patient acceptance of prenatal screening “has been accomplished through the absorption of this new [screening] under the rubric of an older and non-controversial, medical practice--routine prenatal care.”

The broad institutional support in the obstetrics community has fostered the impression for parents generally that this screen, like good prenatal care generally, is “a maternal obligation whose

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neglect could have serious negative consequences for their fetuses."  

What is particularly interesting in Press' findings is that very few women even addressed the fact that abortion is the only therapeutic option available in the event that the test returns a positive result. The routine nature of the test, and that it had been subsumed under the rubric of standard prenatal care, resulted in women giving relatively little thought to the possible outcomes of the test; the women, in general, felt that in taking part in the test they were doing everything possible to ensure the health of their baby. As Press observed "when screening becomes just another blood test, it ceases to be something about which a deliberate patient decision need be made."  

The routinization of genetic testing makes a refusal of the tests seem like a preposterous decision. Press' findings are even more significant when coupled with the Royal commission's findings that of the doctors in Canada who routinely screened patients prenatally only 35 percent actively sought informed consent for this screening.  

Since amniocentesis is much more invasive than prenatal screening, it is not in danger of being presented as "just another blood test". However, the notion that prenatal screening is simply part of good prenatal care is a belief held by many parents about this more invasive procedure as well. There is evidence which demonstrates that because amniocentesis is commonly understood under the rubric of good prenatal care, women come under considerable

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24 Press, p. 988.

25 Royal Commission on Reproductive Technologies, Proceed With Care (Ottawa: Canada Communications Group, 1993), p. 790.
societal pressure to use it. Troy Duster in an interview with a woman who refused testing reported this conversation:

"Everywhere I went, acquaintances of only a few months would 'inform' me that amniocentesis was available to detect if my pregnancy was 'normal'. ... I began to realize what they were implying... that any sane woman over 35 with an ounce of brains would have amniocentesis. 'Do you have religious objections?' they'd ask. As if being crazy or stupid or religious were my only options."²⁶

Duster claims that this personal account is "corroborated by interviews done with women in several countries in which prenatal testing is available".²⁷ When prenatal testing is presented straightforwardly under the rubric of good prenatal care, then the pressure to conform to this standard of "good parenting" can be considerable.

As Duster's interview shows, parents do not enter hospitals, doctors offices, or genetic counselling sessions without any preconceived ideas about disability. To discuss the general public's conception of disability is difficult as widely varying conceptions exist. However, some common themes do exist and some blatant misconceptions are worth noting. Marsha Saxton, a disability right's activist and a woman with Spinabifida, writes:

"We live in a culture obsessed with health and well-being. We value rugged self-reliance, athletic prowess, and rigid standards of beauty,[ as a result ] the disabled person in our society is the target of attitudes and behaviours from the able-bodied world, ranging from gawking to avoidance, pity to resentment, or from vastly lower expectations to awe."²⁸

²⁶ Troy Duster, Back Door To Eugenics (New York: Routledge, 1990), p. 79.

²⁷ Duster, p. 79.

Saxton argues that these attitudes exhibited towards those with disabilities are in part based upon some common misconceptions about disability. The most widely held misconception being that disability necessarily entails immense suffering on the part of the person living with the disability and on that person's family.

The language of disability and of birth defects often conjures up images for parents of severely ill individuals who are either in constant pain or who are eternally dependant on others to enable them to perform the most basic tasks of everyday life. In short, the images conjured up are often of lives that are, if not miserable, at least full of daily and constant suffering. Saxton grants that it is undeniable that some disabled people are forced to deal with considerable pain and inconvenience due to their physical impairments. However, she believes that "as a group, people with disabilities do not 'suffer' any more than any other group or category of humans. Our limitations may be more outwardly visible, our need for help more apparent, but like anybody else, the suffering we may experience is a result of not enough human caring, acceptance, and respect."  

The genetic disorders that are tested for vary widely in their physical manifestations, as do the physical manifestations within a given disorder. In extremely severe disorders such Tay-Sachs or Lesch-Nyans disease the physical suffering involved can not be understated. However, in a disorder like Down Syndrome, which is the most diagnosed disorder using amniocentesis, the physical manifestation is highly variable, ranging from severe to mild retardation (with most

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29 Saxton, "Born and Unborn", p. 308.
falling into the middle range), heightened risks of heart problems and leukemia, and life expectancies now in the range of 40 years. Rayna Rapp, in her anthropological research on prenatal genetic testing, observed that most people, except for those who have had direct experience with children with Down’s Syndrome and other chromosomal abnormalities, demonstrated very little understanding of the possible range in the physical expression of these disorders.\(^{30}\)

There is also a common belief that raising a child who is disabled will inevitably result in a great strain on the family. Because of the extra physical care that is often required in raising a child with a disability, some assume that parenting in these cases will be an extremely burdensome activity, and that having a child with a disability will exert unmanageable stress on the family. There is evidence to support that having a disabled child can be stressful for the family, as it often involves caretaking duties which go beyond the standards of “normal” child care. This added stress, however, does not appear to have a great effect on the general “success” of the family. The Hastings Center reports that “families that include disabled children fare on average no better or worse than families in general. Some families flounder, others flourish.”\(^{31}\)

They base this claim on studies which examine indicators of familial success (standard of living, rates of divorce etc.), in both families with and without disabled children. Further, many parents express great joy and report much parental fulfilment in raising a child with a disability.

\(^{30}\) Rapp, p. 89.

For many, choices about prenatal genetic testing will involve thinking seriously, for the first time, about disability and what it will mean for their child and their family. Some of the common misconceptions about disability will inevitably be brought to bear on decisions parents make about prenatal genetic testing. In my view, the pressures of ‘geneticization’, and the medical model of disability do not serve to dispel these misconceptions, but in fact cater to them. There is good ethnographic evidence to support this claim as well.

Rayna Rapp reports this conversation of a doctor explaining what disorders are tested for and why:

"we’re only looking for fetuses whose inherited material don’t give them a chance of a good life, who will have severe handicaps, where life will become very hard for the family. I’m sure you know that in this society, the responsibility for a handicapped child rests on the mother’s shoulders.”

Rapp claims that the type description of testing given above is common. The tenor of this description fits well with what I have described as the medical model of disability. It is implied in this quote that the disorders tested for require immediate medical attention. The reason given that they do require this attention is based on a description of the disorders tested for which supports rather than challenges some of the common misconceptions about disability (i.e. that having a disability will negate “the chance of a good life”).

What I have called the “tacit background” of prenatal testing in itself offers significant challenges to reproductive freedom. Parents’ abilities to be informed about disability is diminished by the common misconceptions that exist. Further, the institutional and social

32 Rapp, p. 90.
pressures which are exerted by this tacit background can be considerable. More challenges exist, however, many of which result because vested interests exist in ensuring that women use testing and terminate pregnancies when disorders are diagnosed. I will now turn to an examination of these interests and how they conflict with parents' rights to reproductive freedom.

**Vested Interests**

Some of the central figures involved in parents' decisions about prenatal genetic testing have vested interests in the outcomes of parents' choices. I will argue that doctors, genetic counsellors, and health care policy makers all have a vested interest in ensuring parents use the testing technology. The interests of these central figures in this outcome are grounded in a desire to protect themselves from legal liability, to spend health care dollars in an efficient and cost-effective manner and a general interest in public health. These vested interests can come into direct conflict with parents' practical ability to make choices which are contrary to these interests.

Legal liability for neglecting to properly counsel patients on the risk of giving birth to a child with a genetic disorder has become a real concern for obstetricians and genetic counsellors alike. So called “wrongful birth” lawsuits have been brought against doctors and obstetricians and have held them liable when they fail to properly inform patients if they are at risk for giving birth to a child with a disorder. Wrongful birth suits are brought on behalf of parents against physicians, in an attempt to collect from the doctor costs that are spent on caring for the child who has a genetically predictable disorder.
The first wrongful birth suit was successfully tried in a New York State Court of Appeals in 1978. In that case, a 37 year old woman who had given birth to a child with Down Syndrome sued her doctor for damages for neglecting to inform her that women over the age of 35 are at higher risk for giving birth to children with Down Syndrome, and for not offering her amniocentesis. The woman was successful in her case. That court case set a precedent for numerous similar cases which have been brought to trial in the last 20 years. Wrongful birth suits have also been brought before the courts in Canada, but none thus far have been related directly to prenatal genetic testing. However, in a related case in Quebec in 1986, a wrongful birth claim was allowed. In Engstrom v. Courteau, a man had a vasectomy after his first child was born with hereditary cataracts (a condition he himself suffered from). In a subsequent marriage, his vasectomy operation was proven to be faulty and his second wife became pregnant and gave birth to a second child with the disorder.33

The fact that precedent has been set in wrongful birth cases in both Canada and the U.S. presents obstetricians and genetic counsellors with an interest in ensuring that parents use testing. Strictly speaking, health care professionals need only inform parents if they are at risk and must offer tests to these parents if they wish to avoid being held liable in wrongful birth suits. However, even though they need only “offer such tests, if parents decline, doctors justifiably will be concerned that the parents have not adequately understood the value of such tests and that this lack of understanding is attributable to their failure to recommend such

33 Royal Commision, p. 792.
tests.\textsuperscript{34} In situations in which parents wish to refuse testing, the doctor’s interest comes into conflict with the parents’ right to choose. This conflict will inevitably lead, in some cases, to doctors and counsellors putting pressure on parents to ensure that they make the legally conservative choice.

Beyond health care providers’ interest in avoiding legal liability there is an interest in cutting costs and ensuring that the treatments offered make economic sense. Particularly in a publicly funded health care service, the cost of offering treatment is one of constant concern. The tools of cost-benefit analysis are now a familiar part of the policy making process on what and when services and treatments should be offered to the public.

The tools of cost-benefit analysis are of course a part of the policy setting process surrounding prenatal genetic testing as well. Numerous studies have been done to discover if the widespread use of prenatal diagnosis will in the long run help to save health care dollars. In one study carried out in the U.S. on the cost effectiveness of the “triple screen” test for Down Syndrome, it was argued that the test is cost effective. They based this claim on a cost analysis which claimed “a person with Down Syndrome costs approximately $196 000. This includes health, education and ‘residential’ costs.... This gives a favourable benefit-cost ratio for the triple screen that costs only about $100 000 per fetus found with Down Syndrome.”\textsuperscript{35} This analysis depends upon an assumption that there will be a high acceptance rate of the triple screen tests

\textsuperscript{34} Sheppard, p. 776.

and that a positive result will be followed by a therapeutic abortion. As it stands now this is a well founded assumption.

Beyond the fact that the rather callous manner in which this study places a single dollar value on a human life may be offensive to some, there is nothing in my view which is inherently wrong with this type of cost-benefit analysis. The cost-effectiveness of a treatment should be a part of the puzzle when deciding policy around prenatal testing. It has been noted by many, however; that applying the standard of cost-effectiveness to prenatal genetic testing does result in conflicts with the stated goals of this testing. That is, if the stated goal of prenatal testing is to enhance reproductive choice for parents through the dissemination of genetic information, this goal may be in conflict with the cost-effective goal of reducing the number of births of children who would have disabilities. As Erik Parens and Adrienne Asch observed in reference to a CF testing program, one such conflict may be manifested in the genetic counselling session: “in tension with the genetic professionals stated goal of educating individuals, those who pay for such education do so in part with a view to reducing the number of- and costs associated with-children born with cystic fibrosis.”\(^\text{36}\)

Another conflict between cost-benefit goals and the goal of expanding reproductive freedom arises in the question of accessibility: for whom should the testing services be made available? In Canada, the Royal Commission On Reproductive Technologies, found that in some genetic testing centres a policy is in place which does not allow testing to women who state that

\(^{36}\) Asch and Parens, p. 8.
they will not consider abortion as an option if a disorder is diagnosed. In a study carried out in
the U.S., it was found that one third of obstetricians surveyed require women to agree to
terminate an affected fetus before referring them for diagnostic testing. The reason for the
denial in both cases was that testing was considered an unnecessary expense if the woman is not
willing to consider an abortion in the event of a positive diagnoses.

The vested interests of ensuring that women do not give birth to children with diagnosable
disorders are not always manifested in relation to the cost of having a disabled child. The vested
interest involved is sometimes simply an interest in public health which is manifested in a
doctor's desire to avoid the birth of a disabled child. There are good ethnographic reports which
demonstrate how the doctor's interest in these cases, albeit a legitimate interest, conflicts with parents' right to reproductive freedom.

David T. Helm reports this exchange as one that is not out of the ordinary following a
positive diagnosis of a genetic abnormality:

"Obstetrician: You have to move quickly. There is a doctor at [Hospital X] who does
late-term abortions.
Mother: No, I told you I'm not going to have an abortion.
Obstetrician: Talk to your husband. You might want to think about it." 39

Helm interprets this exchange as one in which a doctor is clearly unwilling to accept the mother's

37 Royal Commission, p. 808.

38 Tom Shakespeare, "Choices and Rights: Eugenics, Genetics and Disability Equality,"

39 Asch and Parens, p. 9.
stated decision not to terminate her pregnancy. The doctor in this case is hoping that after a
discussion with her husband and some further thought, she will decide that terminating the
pregnancy is the best option. Helm’s findings are also supported by the findings of the Royal
Commission on Reproductive Technology which found that “a disturbing proportion of
physicians do not accept the principle that patients should make their own informed choice
about whether to have PND [prenatal diagnoses] and whether to have an abortion after diagnosis
of a fetal disorder”. Unwillingness to accept the woman’s choice forces her into a position in
which she must defend her choice and the values on which this choice is based. Having to build
such a defence is one which she should not have to build as it is within in her rights to make such
a choice. The fact that it is her doctor who is challenging her choice is particularly grievous as he
is in an inherent position of authority, and his challenge, therefore, substantially undermines her
ability to refuse abortion.

Marteau and Drake, in a study conducted in 1995, found that “where women gave birth
to people with Down’s Syndrome, having declined the opportunity to have prenatal screening,
they were consequently more likely to be blamed for their situation.” Rapp has shown that
this blame often comes from their own doctors. She reports this conversation of a woman who
had given birth to a child with Down’s Syndrome: “My doctor was so angry with me. He
couldn’t believe I didn’t take the test. ‘How could you let this happen’ he yelled at me. ‘You’re
40!’”. If the right to reproductive freedom does include the right to have a child with a

40 Royal Commission, p. 766.

41 Shakespeare, p. 676.

42 Rapp, p. 263.
diagnosable disorder, which I have argued that it does, then the doctor's suggestion that the woman has done something wrong is misguided. Though it may be true that the woman is responsible for the birth of a child with Down's Syndrome as testing technology makes this choice available, she is certainly not culpable for this choice. Thus no one is justified in blaming women for the choice to give birth to a child with a diagnosable disorder. The fact that this threat of blame exists, even if unjustified, undermines women's practical ability to make the choice to have a child with a diagnosable disorder and thus undermines their right to reproductive freedom.

I have argued that within the social, legal and institutional environment in which the choices of prenatal genetic testing are made available, significant pressures are exerted on parents to make use of the testing technology and the therapeutic option available. I have supplied some ethnographic and anthropological evidence to support this claim. Through this argument I have attempted to demonstrate the shortcomings of models of personal autonomy which support prenatal testing by focusing on the voluntariness of testing and the expanded realm of choice that testing offers. To focus only on these aspects of the choices involved, underappreciates the social aspects of these choices. When these aspects are taken into account, it is clear, in my view, that prenatal testing takes place in an environment which undermines parents' reproductive freedom, because it challenges parents' rights not to use testing, and their right to continue a pregnancy which may result in the birth of a child with a diagnosable disorder. Parents' rights are challenged in this environment because the technology, the institutional ideology and societal conceptions of disability are not neutral in their approach to genetic disorders and the disabilities they may lead to. As well, there are vested interests involved which conflict with parents' rights to refuse testing.

These challenges to reproductive freedom are substantial. It is my contention, however,
that the challenges can be met. In the following section I will suggest some ways in which these challenges can be mitigated to ensure that parents can make informed choices about prenatal testing which are based on their own values. For this to be made possible some steps must be taken to ensure that parents have the practical ability to refuse testing and a subsequent abortion.

Meet The Challenges To Reproductive Freedom

I have shown above that ensuring the choices involved in prenatal genetic testing are voluntary does not ensure that parents’ rights to reproductive freedom are protected. The reason for this is that the legal, social, and institutional environment in which these tests takes place militates against the possibility of free choice. In my view, it is unlikely that the pressures exerted in the wide context I have examined can be minimized by changing the nature of this context in any significant and timely way. The efforts of the disability rights movement to dispel many of the common misconceptions held about disability in the wider community is a good step in this direction. I support them in their efforts, but this is of course a long term and slow process. I believe that the pressures exerted on women to use the testing technology can, in part, be minimized by changing the way in which these tests are offered to parents. Central to this process is the genetic counselling session. In this section, I will argue that genetic counsellors can play an important role in ensuring that reproductive freedoms are protected in the process of genetic testing, even within the context in which these tests now function. To do this, however, the model on which the counselling sessions and the training of genetic counsellors is now based will have to be modified.

Genetic counselling emerged as a separate profession in the late 1960’s when the first university program was offered at Sarah Lawrence College in Bronxville in 1969. The
philosophy to which the first genetic counsellors subscribed was that of "non-directive" counselling. "Individualistic, client-centered therapy became the orthodoxy of the new profession--its goal was to strengthen the patient's decision-making processes and clarify the patient's preferences and values." This non-directive goal was not always the accepted standard in genetic counselling. When Sheldon Reed, an American geneticist, first coined the term in 1947, there were many in the genetics community who felt the counselling session should be directive. That is, it should be used to convince patients of their responsibility to help society achieve eugenic goals. The development of non-directive counselling emerged in direct response to the abuses of reproductive freedom and value pluralism that took place as part of the old eugenics. It was hoped that a commitment to this philosophy would help distance genetic testing from this dubious aspect of its eugenic legacy.

Genetic counselling is now a routine part of prenatal genetic testing in North America. There are now over 27 genetic counselling training programs across North America, three of which are in Canada. The commitment to non-directive counselling is still the orthodoxy of the genetic counselling profession. The stated goal of those in the profession is still to assist parents in making informed decisions about genetic tests based upon their own values. It has now become the standard belief that to achieve this goal requires that counsellors be "value neutral" in their dissemination of genetic knowledge. Counsellors should try to "suppress the expression of the values and biases that they bring to their work in order to respect their patients' autonomy." If it were possible for counsellors to realistically achieve their goal of ensuring that


44 Wachbroit and Wasserman, p. 104.
parents make informed decisions based on their own values, then the concerns that I have raised about the respect for reproductive freedom in prenatal genetic testing could in a large part be laid to rest. There are, however, a number of barriers that exist which prevent counsellors from achieving their goal. These barriers must be taken down if the counsellors will be able to ensure that parents' rights to reproductive freedom are protected.

The first barrier which prevents genetic counsellors from achieving their goal is that the training centres for genetic counsellors cannot keep pace with the proliferation of the testing technology. There are simply not enough trained genetic counsellors to keep up with the demand. This means that counselling duties often fall either to geneticists who work at genetic training centres or to practising physicians (obstetricians and general practitioners). The Royal Commission On Reproductive Technology found that physicians were the least likely to be strongly committed to ensuring that patient autonomy was protected in the counselling session, and geneticists were less likely to be committed to this goal than genetic counsellors. Thus, if the genetic counselling session is one which is to help parents make informed decisions based on their own values, either more genetic counsellors need to be trained or the other health care providers who provide counselling must be educated in the importance of ensuring patient autonomy. It is the former which I believe to be the more plausible course of action.

The second of these barriers is that by the time women enter their first counselling session with a trained genetic counsellor some may have already undergone a genetic test. In Canada, genetic screening, in particular the "triple screen" used to detect chromosomal abnormalities and neural tube defects, is offered routinely to all pregnant women, most often by obstetricians and general practitioners. As was discussed above, because this is not an

45 Royal Commission, p. 790.
exceedingly invasive test (blood test), most women take the test without giving much thought to what the test is used to detect or what the options are if the test returns positive. Prenatal screening does not identify with certainty that a genetic anomaly is present, but only identifies if the mother is at a higher risk for giving birth to a child with such an anomaly. Thus, after a genetic screen the mother will be referred for further genetic testing. The problem with the presentation of the prenatal screen as something which does not require substantial deliberation is that it enters women into the testing system without preparing them for the choices they may need to make down the road.

The Royal Commission found that many women reported feeling that they were “swept along by an imposing process” once they were in the system of testing. Even though genetic counselling is offered to women before further testing, it makes little sense to say they have a right to refuse such tests when they have already been identified as being in an elevated risk category by a previous test, and have been automatically refereed for this further testing. To achieve their goal, genetic counsellors must be involved from the outset of the testing process. This means that women should receive genetic counselling before they are brought into the testing system, that is, before they are prenatally screened for susceptibility for genetic abnormalities. This counselling session, among other things, should inform women of the choices that they may face later, and should clearly lay out the options which will be available to them. Their involvement from the beginning of testing will help to counteract the effect of the routinization of the tests, by making it clear that prenatal testing (including screening) is something which requires deliberation and a thoughtful choice.

The third and most crucial barrier which prevents counsellors from achieving their goal of

46 Royal Commission, p. 770.
allowing parents to make informed choices based on their own values is of course the pressures exerted on women in the environment in which this counselling takes place. Genetic counsellors subscribe to a philosophy of non-directiveness and value-neutrality in a social, legal, and institutional context which is anything but value-neutral and non-directive. As Troy Duster, observes: “genetic counsellors are probably, as professionals, indeed neutral... However, the individual neutrality of the counsellor is not the issue.”47 As I have argued in this chapter, the broad context in which testing takes place militates towards women not only using the tests, but terminating pregnancies when disorders are diagnosed. Genetic counsellors’ goal of protecting parents’ rights to reproductive freedom is not only not supported by the strong adherence to value-neutrality, but this adherence actually undermines this goal. To be strictly value-neutral in the specific context of the genetic counselling session will not successfully protect reproductive freedoms in the wider context of testing in general, as a value neutral stance does nothing to mitigate the pressures that exist; counsellors must actively work to achieve this goal.

If the genetic counsellor is to play a role in protecting the reproductive rights of parents, then the philosophy of value neutrality should in the strict sense be given up. I do not mean by this that the counsellor should try to impose some of their own values on parents. What the counselling session should try to do is develop an environment which is, as much as possible, free from the pressures which exist to make choices about prenatal testing. Thus, in its current context the counselling session will have to play a “corrective” role; that is, it will have to offer information and experiences which will help to correct for the pressures which do exist to use testing and to abort fetuses with genetic abnormalities.

There are a number of ways in which genetic counsellors can play this corrective role.

47 Duster, p. 76.
The first is that genetic counsellors should attempt to bring the tacit background of genetic testing into the foreground. Richard Wachbroit claims that there is good “psychological research to suggest that social pressures may have a greater effect on behaviour when they are part of the unspoken background, and that, in fact, explicit attempts to control behaviour often backfire, provoking autonomy-preserving defiance.”  

48 The genetic counsellor should openly discuss the institutional, social, and legal pressures that exist to use the testing technology (including their position in this framework), and should attempt to elicit discussion about whether these pressures are justified. Direct discussions should be had about the values that are involved in such decisions and that are the basis of existing pressures. In this way the subversive pressure exerted by the tacit background can, in part, be alleviated.

To combat the many misconceptions which surround disability and disorder that are held in our society and to offer an alternative to the medical model, parents should be granted access to information and to people who hold contrary views. Tom Shakespeare suggests that “disability equality resources could be balancing the ‘medical tragedy’ information with more realistic accounts of living with a disabled child.”  

49 The availability of another perspective will help foster informed choice by making it clear that there is more than one viable approach to dealing with disabilities.

Another corrective measure is to give parents the chance in the counselling process to meet with families who have refused testing and have had children with disabilities, but have not regretted this choice. This approach has been used in a genetic testing clinic in New England with

48 Wachbroit and Wasserman, p. 109.

49 Shakespeare, p. 678.
impressive results. In this program, parents are encouraged to meet and interact with families who have children with Down’s Syndrome (this is the disorder they most commonly test for). This New England clinic has reported a termination rate of fetuses diagnosed with Down’s Syndrome at 62%, substantially lower than national average of nearly 95%. I am not suggesting the goal of a good counselling program should be to lower the rate of terminations. The measurement of the effectiveness of a counselling service should not be based on the numbers of women who do or do not abort. The effectiveness should be measured by how well informed parents are and by whether, following the counselling session, they are in a position to make a decision based on their own values. It is obvious I believe, that the result of the New England program has been to better achieve this goal by helping more parents understand that living with a child with Down’s Syndrome is a realistic and viable option.

I have argued in this chapter that even though no prenatal genetic tests are mandatory in Canada, this fact is not enough to ensure that parents’ rights to reproductive freedom are protected in the testing process. The broad context must be taken into consideration when judging if our system of prenatal testing does sufficiently protect reproductive freedom. I have attempted to demonstrate that substantial pressures are exerted on parents not only to use the testing technology, but also to abort when a genetic abnormality is diagnosed. In my view to leave these pressures unchecked undermines parents’ rights to reproductive freedom. It is imperative, therefore, that these pressures be addressed. I have suggested a number of ways in which genetic counsellors can be more effective in their role of protecting parents’ rights to reproductive freedom by taking an active role in mitigating the pressures that do exist.

The suggestions I have made above will not, of course, alleviate all of the pressures facing parents to make choices to use testing and to abort. To completely alleviate these pressures,
however, is not required for the right to reproductive freedom to be sufficiently protected. In my arguments I have emphasised the importance of taking into account the social aspects of decisions when assessing individual autonomy. This emphasis, however, should not be taken as evidence of an extremely fragile view of individual autonomy. Any realistic view of autonomy must allow that individuals can make free choices even in the face of substantial pressure. I have tried to demonstrate that in our current use of prenatal testing these pressures will often prove too much. We must, therefore, change the way in which these choices are offered in order to make room for reproductive freedom.
CONCLUSION

Our ever increasing understanding of genetics and of the human genome in particular has given us new tools with which to cure disease and prevent disability. It also has given rise to great hopes of the development of new and unthought of powers in this realm. Our ability to test prenatally for genetic disorders that result in disease and disability is one tool that has grown out of the “new genetics” which is commonly used to achieve this end. The benefits for parents and for future children that flow from this technology cannot be understated. It is the existence of these benefits which has resulted in the rapid proliferation of prenatal testing in Canada. This proliferation has occurred to such a degree that it can now be said, without exaggeration, that prenatal testing has become a common part of the reproductive process in this country. The great majority of pregnant women in Canada will come into some degree of contact with the prenatal testing system, even if only through a suggested referral to a genetic testing centre or through taking part in a prenatal screen. These tests are now often presented and understood as simply a routine part of good prenatal care. In my view, there is no legitimate evidence to suggest that this technology does not produce the benefits purported, and in the final analysis, I believe that it should be made widely available to women in Canada. This conclusion, however, does not come without a caution. If we are to be certain of the ethical use of this technology, now and in the future, we must keep the context in which this testing takes place in clear view.

I began my investigation of the ethics of prenatal genetic testing with an analysis of what I called the “eugenics critique”. It is my contention that prenatal genetic testing justifiably falls in
the shadow of eugenics on any plausible definition of eugenics. This argument serves to situate prenatal genetic testing within its proper historical context, and thus demonstrated the need for any ethical investigation of prenatal testing to take account of this history, and to understand the ethical implications which flow from prenatal testing’s eugenic legacy.

Through my analysis of the eugenics critique and my attempts to come to terms with this eugenic legacy, three valid moral concerns come to light for the current practice of prenatal testing. They were that prenatal testing make room for a pluralism of values, that prenatal testing is just, and that prenatal testing respect reproductive freedoms. The three valid moral concerns identified in Chapter 1 provided, in turn, the framework in which the remainder of my investigation took place. That is, I limited my investigation to questions concerning whether or not prenatal testing as it is currently practiced, is just; whether or not it respects the reproductive freedoms of individuals who engage in it; and whether or not it allows for the expression of a pluralism of values as to what constitutes a valuable human life.

In Chapter 3 in my investigation of the just use of prenatal testing, I examined what is commonly known as the disability rights critique. This critique advances two main arguments that conclude that prenatal testing results in fundamental injustices for some segments of society, and thus should be prohibited or at least limited in its application. The first line of argument attempted to substantiate this claim by demonstrating that the benefits that prenatal testing offers are not universal, and are secured for some only at costs to others. The costs that some are forced to bare, it was claimed, represent an unacceptable and basic unfairness thereby supplying the grounds on which to limit the application of prenatal testing. The second line of argument
pointed to the fact that disability is, at least in part, a social construction. This fact was used to support the claim that the approach prenatal testing takes to preventing and ameliorating disability is misguided. Justice dictates, on this view, that society work to restructure the social environment so that it is accessible and functional for people with a wide range of physical and mental abilities. Prenatal testing, conversely, works to ensure that people born into society have the requisite physical and mental capabilities needed to be functioning participants in the preexisting social context. Thus prenatal testing is not responsive to the dictates of justice and therefore, is an unacceptable approach to preventing disability.

I argued that the disability rights critique, in the end, is unsuccessful in supporting its claims that prenatal testing is inherently unjust. It was through my discussion of this critique, however, that some aspects of the current, social context relevant to the ethical use of the testing technology were distinguished. The disability rights critique highlighted concerns about the fact that prenatal testing often functions in an environment which has a limited understanding of disability, often makes judgments concerning disability based on stigma and stereotype, and often under appreciates the different approaches that can be taken to address the disabling effects of a genetic disorder.

Much of Chapter 3 was dedicated to elaborating the concerns highlighted by the disability rights critique, by investigating the social, legal, and institutional context in which testing takes place. It is my contention that the concerns raised by the disability rights critique can be addressed if parents' rights to reproductive freedom are sufficiently protected within the testing system. My investigation of the threats to reproductive freedom that exist in our current
testing system made plain that the context in which testing takes place often impedes both parents' practical ability to refuse testing, and in lieu of a positive diagnosis, their ability to refuse therapeutic abortion. That these impediments exist, undermine parents' ability to make choices based on their own values.

For reproductive freedoms to be respected in the current context, I argued that the genetic counselling session should in part play a corrective role. That is, it should attempt to mitigate the existent pressure to use testing, and should ensure that parents' understand that having a child with a disability is not an unbearable or impossible proposition, but on the contrary can be an extremely enriching and fulfilling experience. This of course is not to say that there are no good reasons to use testing. There are numerous good reasons, all of which counsellors should be supportive of. However, the choices that parents make concerning prenatal genetic testing must be legitimate choices. That is, they must be both informed and made in an environment which ensures the practical ability to accept or refuse testing.

Prenatal testing offers us new and powerful choices, choices concerning the genetic character of our children. We now have the ability to choose not to have children with severe genetic conditions that are diagnosable. That these choices are available, in my view, is not in itself morally problematic. These are, in fact, extremely valuable and worthwhile choices, and as I have stated numerous times, there are great benefits that can result from their availability. What is of moral significance is how these choices are made. The value of these choices and the benefits that may result from them, are dependent upon the way in which these choices are offered and the way in which we arrive at decisions concerning them. If we are to use the choices that
prenatal testing makes available in a responsible and ethical manner, we must be certain that those using this technology are making decisions which appreciate the full range of available options. They must understand that the medical model offers only one viable approach to disability and that people with very different capacities are valuable members of society, who are deserving of equal respect. We must continue to reevaluate this technology as it continues to evolve to ensure that decisions are made in the above fashion. It is only when this is achieved, that prenatal testing can be carried out in a manner which pays heed to the concerns of the disability rights community. I am confident that in doing so, prenatal genetic testing will free itself of the dark shadow of eugenics.
Bibliography


