ABSTRACT

The Ethics of Using Genetic Technology in Relation to Reproduction

Hannah Fifer

Director: Jason Whitt, Ph.D.

A boom in the understanding of genetics since the mid-twentieth century has manifested itself in the development of various technologies related to the human genome. Among these technological developments are those relating specifically to reproduction. Parents now have the ability to detect chromosomal abnormalities during the course of a pregnancy. They also have the ability to screen for various genetic disorders among embryos before deciding which to implant in the uterus. Currently, research is underway exploring the possibility of altering the germline cells of parents in order to alter the genes of succeeding generations. The use of this technology is often to prevent certain types of people from coming into existence and to promote others. This thesis examines the available and emerging genetic reproductive technologies, their relation to eugenics, and some key ethical considerations for the Christian trying to assess the purpose and value of these various technologies.

APPROVED BY DIRECTOR OF HONORS THESIS:

_____

Dr. Jason Whitt, Institute of Faith and Learning

APPROVED BY THE HONORS PROGRAM:

_____

Dr. Elizabeth Corey, Director

DATE: _____

THE ETHICS OF USING GENETIC TECHNOLOGY IN RELATION TO REPRODUCTION

A Thesis Submitted to the Faculty of

Baylor University

In Partial Fulfillment of the Requirements for the

Honors Program

By

Hannah Fifer

Waco, Texas

May 2016

TABLE OF CONTENTS

Acknowledgments iii

Chapter One: Introduction 1

Chapter Two: Technology Now and in the Future 8

Chapter Three: Prenatal Screening and Diagnostic Tests 25

Chapter Four: Germline Gene Therapy and Enhancement 42

Chapter Five: The Return of Eugenics 62

Chapter Six: Christian Considerations 82

Bibliography 98

ACKNOWLEDGMENTS

I am deeply grateful to Dr. Jason Whitt for agreeing to journey with me in this process. Thank you for challenging me, and thank you for guiding me with patience and encouragement. I have learned a great deal and owe much of that learning to you.

I am also appreciative of Dr. Jonathan Tran and Dr. Bill Neilson. Thank you for serving on my thesis committee and giving your time to help me in this endeavor.

The support of my family was also vital to the completion of this project. Thank you for taking an interest in my thesis, for encouraging me throughout the process, and for celebrating the final product with me.

CHAPTER ONE

Introduction

Overview

Historically, humans have been devoid of many of the choices that exist today relating to reproduction. Whether to reproduce and with whom to reproduce have been choices made for centuries by some. For others, not even these are options. Now, even more choices exist due to discoveries about the genetic mechanisms relating to reproduction and the subsequent development of related technology. These developments have granted humans greater potential mastery over the process of reproduction. From Mendel's initial thoughts concerning the heritability of certain traits to present-day research conducted with the hope of altering the genetic material of germ cells, much has changed regarding the understanding of genetic material and its relation to the creation of organisms. This greater molecular understanding has led to the desire for greater control and an increase in choices on a grand scale.

Now presented with many more options than before, prospective parents must decide not only whether to reproduce and with whom, but they are confronted with choices about whether to undergo prenatal screening and diagnostic tests and whether to abort after receiving the results from these tests. In the future, parents may have to decide whether to alter their own genetic material in sperm and eggs cells in order to change the genetic material of all of posterity that stems from them. The technological advancements that have accompanied greater understanding of genetic material have

drastically altered the process of child-bearing in nations where the technology is ubiquitous.

This thesis aims to survey the ethics surrounding the use of reproductive genetic technologies which exist and those which appear to be on the horizon. The existence of certain practices which were formerly unavailable has not necessarily raised entirely new ethical questions, but it has caused certain ethical questions to be raised in a new light and with greater emphasis. Questions relating to disability and to which humans are worth creating (or allowing to live) are brought to the forefront with the examination of genetic reproductive technologies and their practices.

Tracing the Development of Reproductive Technology

In order to provide a more comprehensive perspective regarding genetic reproductive technology in the modern world, chapter two is devoted to describing the development of this technology since the mid-twentieth century. This chapter describes changes made to the realm of reproduction via technology. The changes have been especially dramatic regarding the testing available to prospective parents. In its nascent forms, reproductive technology lacked the ability to detect genetic diseases prenatally. Physicians knew the signs for certain diseases *after* children had been born, but detection of these traits could not be determined prenatally. The development of prenatal screening and diagnostic tests therefore marked a significant change in the realm of reproduction. With the advent of the clinical application of these procedures, parents and medical professionals now have the opportunity to detect conditions like Down syndrome not only before birth but, in some cases (e.g., chorionic villus sampling), after just ten weeks of pregnancy.

Screening and diagnostic tests provide an abundance of information that either was not available before their development or was not available at such an early stage of a pregnancy. The uses of prenatal screening and diagnostic tests have major implications that are discussed in a subsequent chapter. However, prenatal screening and diagnostic tests are not the only developments in genetic reproductive technology that are available. Preimplantation genetic diagnosis (PGD) has become clinically available in the past few decades and provides an alternative distinct from prenatal screening and diagnostic tests. PGD allows the genetic material of various embryos to be screened so that only those with desirable qualities are then implanted in the uterus. This, too, provides options that were previously unavailable.

The final part of the chapter on technology details developments in the realm of germline gene therapy. Unlike the other procedures previously mentioned, this technology is not yet clinically available. Research is under way so that the possibility of genetically modifying sperm and eggs cells becomes a reality. The realization of germline gene therapy would result in yet another option for prospective parents. With this technology, it would be possible to modify the genetic material of one generation so that every subsequent generation is then affected.

The development of technology relating to reproduction has been significant. With understanding of genetic reproductive technology, it is possible to ascertain some of the ethical questions that are raised in employing technology currently available and in supporting research for the continued development of others.

Prenatal Screening and Diagnostic Tests

The third chapter will examine prenatal screening and diagnostic tests. There are a multitude of voices to be found in support of and in opposition to the practices. From amniocenteses and chorionic villus sampling (CVS), karyotypes can be constructed, which show the chromosomal arrangements of a fetus. These screening and diagnostic tests have been employed in order to ascertain whether a fetus has chromosomal abnormalities like Down syndrome or Turner syndrome. Selective abortions then ensue for those who become aware of a specific trait in their fetus and decided to abort on account of that trait. PGD, which screens embryos instead of fetuses, results in a similar process. Rather than aborting a fetus based upon specific characteristics, specific genetic characteristics of embryos are examined in order to decide which should be implanted in the uterus.

Practices of screening and diagnostic tests raise questions as to what society deems valuable in human beings. Relatedly, it raises questions regarding which pregnancies should be allowed to continue to birth, or, in the case of PGD, which should be begun in the first place. Selective abortion following screening and diagnostic tests or deciding not to implant an embryo with a certain genetically based disability are actions which have the potential to affect those with disabilities currently or those who may be part of a disability community in the future. The possible effects of these practices in relation to those with disabilities will be considered.

Germline Gene Therapy and Enhancement

The fourth chapter examines germline gene therapy and enhancement. The presence of disabilities in the world is one of the driving forces behind the potential

development of germline gene therapy and enhancement. Though the therapy/enhancement distinction is a dubious one, ridding future generations of disabilities current ones have is one of the motivations underlying the research taking place in germline gene modification. As mentioned, this is technology which has not been developed to the point of clinical use. However, research is underway regarding methods to make it a viable option in humans. Furthermore, the purposes behind germline gene therapy and enhancement require consideration in order to understand what it is that humans seek. If the technology becomes available, decisions regarding its use must be made. Considering whether it may be used for "therapy" purposes as opposed to "enhancement" purposes is one component, but whether to use it at all should it be developed is an even more fundamental issue. In asking these questions, discoveries are made regarding what is thought to be valuable and what is considered an acceptable level of human mastery over reproduction.

The Return of Eugenics

Human mastery over reproduction is not a novel concept. The fifth chapter examines manifestations of this mastery. One of the ways human mastery has taken place in the past was in the form of eugenics. The atrocities that took place in Nazi Germany are well-known. Promotion of the Aryan race via stipulations regarding reproduction was a manifestation of eugenic practices of the time. Less well-known is that other nations have also enacted various laws and regulations in order to promote certain births and prevent others. In the United States specifically, eugenics took the form of sterilization laws and the promotion of fit families. Eugenics did much to shape history in the twentieth century, and with the development of new reproductive genetic

technologies, there has been a eugenic resurgence in the twenty-first. Prenatal screening and diagnostic tests largely serve as a means of negative eugenics, while carrying out germline gene enhancement would largely serve as a means of positive eugenics.

The nature and morality of the modern form of eugenics is in question. While that of the past has largely been deemed morally abhorrent, proponents of the new eugenics claim it is distinct from the eugenics of the past in significant ways. This chapter examines the positive and negative eugenics resulting from employment of reproductive genetic technologies in order to provide a greater base from which to determine whether the current practice of eugenics does significantly differ from the previous one.

Christian Considerations

The final chapter of this thesis succinctly relates what is offered by genetic reproductive technology. Following the discussion of what genetic reproductive technology can offer is a discussion of three concepts: the gratuity of life, sharing life together in dependence, and social justice. These concepts are ones to consider in conjunction with what genetic reproductive technology offers in order to better think about the role this technology should play in society today. Considering potential benefits in tandem with potential abuses allows a better understanding of decisions faced when considering the employment of genetic reproductive technology.

Though the gratuity of life, sharing life together in dependence, and social justice are not uniquely Christian ideas, they are ideas which may be difficult to implement in a liberal and post-Christian society. This chapter will include a brief discussion of the effects of a liberal society for those with disabilities. As mentioned in chapter two,

genetic reproductive technology has changed drastically over the course of a few decades and appears poised for continued change in the decades to come. Considering the gratuity of life, sharing life together in dependence, and social justice provides a framework within which genetic reproductive technology may be viewed, even as it continues to change in what it can offer.

CHAPTER TWO

Technology Now and in the Future

Introduction

This chapter traces the development of genetic reproductive technology from the mid-twentieth century to the present. A brief overview will be given of different processes that have become available to those seeking to reproduce over the past several decades. Beginning with technology that first allowed the genetic makeup of potential progeny to be observed to that which allows for the possibility of the genetic makeup of potential progeny to be altered, this chapter will examine the tools and processes that are currently available and will describe those which may be accessible in the future.

Newborn and Prenatal Screening and Diagnostics

Some of the first technology used in the realm of reproduction is that which comprises newborn screening. One of the most popular applications of newborn screening is that which detects the metabolic disease phenylketonuria (PKU) in newborns. In 1961, technology advanced to the point where newborns could be screened for PKU.[1] With this disease, a mutation in the phenylalanine hydroxylase (PHA) gene causes an increase in blood phenylalanine (Phe) levels, which can have major effects on the white matter of the brain in the central nervous system and lead to cognitive deficits.[2]

---

[1] Carole Kenner and Maribeth Moran, "Newborn Screening and Genetic Testing," *Journal of Midwifery Women's Health* 50, no. 3 (May 2005): 219-226. doi:10.1016/j.jmwh.2005.01.002.

[2] Charissa A. Dyer, "Pathophysiology of Phenylketonuria," *Mental Retardation and Developmental Disabilities Research Reviews* 5, no. 2 (January 1, 1999): 104–12, doi:10.1002/(SICI)1098-2779(1999)5:2<104::AID-MRDD2>3.0.CO;2-7.

Prior to the technological advancement allowing for newborn screening of the disease, PKU was usually detected later only when pediatricians noticed developmental delays.[3] The original method used to screen for PKU was a method that merely allowed for the testing of one disorder at a time; however, the development of tandem mass spectrometry (MS/MS) allows testing for 20-40 disorders with a single test by analyzing blood samples of infants.[4] Both methods are similar in concept, but MS/MS provides an efficient method of testing for numerous disorders, completing the analysis in a mere two to three minutes.[5] Today in the United States, babies' heels are pricked about 24-48 hours after birth to allow blood tests for multiple metabolic disorders using MS/MS.[6] The technology has become ubiquitous as all states are required to conduct newborn screening, though the specific number of conditions for which tests are conducted varies according to each state's discretion.[7]

Though newborn screening permits the detection of multiple disorders shortly after the birth of a child, technology exists that now allows certain detections to be made prenatally. Examples of prenatal screening include blood tests to screen for Rhesus D status (RhD); maternal serum biomarkers, ultrasound markers, and nuchal translucency

---

[3] Kenner and Moran, "Newborn Screening and Genetic Testing."

[4] Sandra A. Banta-Wright, "Tandem Mass Spectrometry in Newborn Screening: A Primer for Neonatal and Perinatal Nurses." *The Journal of Perinatal and Neonatal Nursing* 18, no. 1 (January 2004): 41-60.

[5] Morteza Pourfarzam and Fouzieh Zadhoush, "Newborn Screening for Inherited Metabolic Disorders; News and Views," *Journal of* Research *in Medical Sciences : The Official Journal of Isfahan University of Medical Sciences* 18, no. 9 (September 2013): 801–8.

[6] "Newborn Screening," *Genetics Home Reference*, February 29, 2016, https://ghr.nlm.nih.gov/nbs.

[7] "Conditions Screened By State," accessed March 4, 2016, http://www.babysfirsttest.org/newborn-screening/states.

(NT) used in various combinations to screen for Down syndrome (aneuploidy of chromosome 21); and fetal anomaly scanning where ultrasounds provide evidence of major fetal abnormalities or lack thereof.[8] If screening results in reason to believe that a disorder or abnormality exists, prenatal diagnostic tests are typically the next step. An important distinction to bear in mind is that a screening test that displays abnormal results is simply an indication of elevated risk for the specific item being tested. The screening itself does not result in a diagnosis. Therefore, diagnostic tests often follow those screening tests which have portrayed abnormal results.[9] The purposes and uses of screening and diagnostic tests will be examined further on; however, it should be noted that a great majority of disorders and conditions that are detected by prenatal screening and diagnostic tests do not have cures.[10]

Common prenatal diagnostic tests include chorionic villus sampling (CVS) and amniocentesis. CVS and amniocentesis both allow for karyotyping.[11] A karyotype is a pictorial representation of an individual's chromosomes and allows conditions like Down syndrome, Turner's syndrome, and other chromosomal anomalies to be detected. Technology allowing amniocentesis developed to the point where it could aid in prenatal diagnosis in 1960, while the technology for chorionic villus sampling was only in its

---

[8] Antina de Jong, Idit Maya, and Jan M.M. van Lith, "Prenatal Screening: Current Practice, New Developments, Ethical Challenges," *Bioethics* 29, no. 1 (January 1, 2015): 1–8, doi:10.1111/bioe.12123.

[9] Gwen Latendresse and Angela Deneris, "An Update on Current Prenatal Testing Options: First Trimester and Noninvasive Prenatal Testing," *Journal of Midwifery & Women's Health* 60, no. 1 (January 1, 2015): 24–36, doi:10.1111/jmwh.12228.

[10] Ibid.

[11] Boris Furman and Zvi Appelman, "Genetic Diagnosis in Multiple Pregnancies: Amniocentesis versus Chorionic Villus Sampling," *Ultrasound Review of Obstetrics & Gynecology* 5, no. 1 (March 2005): 69–74, doi:10.1080/14722240500074281.

nascent form at this time and would see major developments in the coming decades.[12] Though advancements within these methods themselves have been made,[13] advancements beyond these methods have also developed. The procedures used to diagnose Down syndrome provide an example of how screening and diagnostic technologies have changed over the years.

Screening for Down syndrome typically occurs before diagnostic tests are considered. This in itself is a demonstration of the advancement of technology. Amniocentesis and CVS were developed prior to some of the more advanced screening options which pregnant women are now afforded. Before these more sophisticated screening options became available, women with high-risk pregnancies (based upon less sophisticated screening techniques like maternal age) had the option of amniocentesis during the second trimester of pregnancy and later had the option of CVS during the first trimester of pregnancy.[14] Though these tests do allow a diagnosis to be made, women who opt for these tests incur both the invasiveness of the procedure and the associated risk of pregnancy loss.[15] The magnitude of the risk of pregnancy loss is not quite clear. An article published in January 2015 in which the results of a meta-analysis are given suggests that risks may be lower than are currently reported. There are reports that the risk of pregnancy loss after amniocentesis is about 1% and 1-2% after CVS, but the meta-analysis found that the risk of pregnancy loss before 24 weeks' gestation after

---

[12] Ruth Schwartz Cowan, "Aspects of the History of Prenatal Diagnosis," *Fetal Diagnosis and Therapy* 8, no. 1 (1993): 10-17, doi:10.1159/000263869.

[13] Furman and Appelman, "Genetic Diagnosis in Multiple Pregnancies."

[14] Latendresse and Deneris, "An Update on Current Prenatal Testing Options."

[15] Ibid.

amniocentesis and CVS is 0.1% and 0.2%, respectively.[16] The number of women undergoing these processes has the potential to decrease as the development of more sophisticated screening techniques allows for the accumulation of more information (via less invasive procedures) before undertaking more invasive diagnostic procedures.

Currently, a combination of screening factors may be used to determine whether a pregnancy is considered at high-risk for Down syndrome or not. One screening option that developed out of the desire to provide less invasive measures before turning to amniocentesis or CVS is the use of maternal serum for screening. In maternal serum screening, biochemical markers produced in the placenta are present in the mother's blood, so testing the serum component of the mother's blood provides an indication of the state of the fetus within her.[17] In 1984, maternal serum screening was offered for women younger than 35, but it only tested for a single marker.[18] In the 1990s, the procedure became a multiple marker test as other biochemical markers were tested and thus improved the detection rates for Down syndrome and Edwards syndrome (a result of aneuploidy of chromosome 18).[19] These markers include pregnancy associated protein (PAPP-A), human chorionic gonadotropin (hCG), alpha fetoprotein (AFP), uncojugated estradiol (uE3), and inhibin A (DIA).[20] Measuring AFP alone detects only a small

---

[16] R. Akolekar et al., "Procedure-Related Risk of Miscarriage Following Amniocentesis and Chorionic Villus Sampling: A Systematic Review and Meta-Analysis," *Ultrasound in Obstetrics & Gynecology* 45, no. 1 (January 1, 2015): 16–26, doi:10.1002/uog.14636.

[17] Latendresse and Deneris, "An Update on Current Prenatal Testing Options."

[18] "ACOG Practice Bulletin No. 77: Screening for Fetal Chromosomal Abnormalities," *Obstetrics & Gynecology* 109, no. 1 (January 2007): 217–28.

[19] Ibid.

[20] Latendresse and Deneris, "An Update on Current Prenatal Testing Options."

portion of Down syndrome occurrences, but adding uE3 and hCG to the screening of AFP increases detection rates.[21] Just the addition of hCG increases the detection of Down syndrome 40-50% when compared to only using AFP as a marker.[22] This multiple marker test (called the "triple screen" when including AFP, uE3, and hCG[23]) has become a common part of pregnancy care for not only those above the higher-risk age of 35, but also for younger mothers because of the test's low-risk and non-invasive nature.[24]

Often screening of maternal serum markers accompanies ultrasounds that are screening for Down syndrome by measuring the fetal nuchal translucency (NT). This is a measurement of the amount of fluid at the base of the neck of a fetus. It is done in the first trimester of pregnancy and alerts parents and healthcare providers to increased likelihoods of aneuploidy conditions such as Down syndrome. An ultrasound measuring the nuchal fold to be thicker than three mm may serve as an indicator of an aneuploidy condition and signals that further screening or diagnostic tests should be done.[25]

One of the most recent developments in prenatal screening is known as noninvasive prenatal testing (NITP). NITP is similar to the process of maternal serum screening in that the mother's blood is drawn and tested in order to accomplish the test. Thus, the procedure is noninvasive and does not pose a serious risk to the pregnancy as some other prenatal procedures have been known to do. With NITP, cell-free fetal DNA

---

[21] J. Christopher Graves and Karl E. Miller, "Maternal Serum Triple Analyte Screening in Pregnancy," *American Family Physician* 65, no. 5 (March 2002): 915-920.

[22] Ibid.

[23] Ibid.

[24] Latendresse and Deneris, "An Update on Current Prenatal Testing Options."

[25] Ibid.

(cff-DNA) that is found in maternal blood is tested for chromosomal abnormalities. Cff-DNA in maternal blood was first reported in 1997 and was initially used for purposes other than testing for chromosomal abnormalities. What was once used to test for gender and Rh blood antigen status developed into technology that became a screening test for conditions like Down syndrome. This form of the technology became clinically available in 2011, and it has been found to be a highly sensitive screening test for high-risk pregnancies. For Down syndrome and Edwards syndrome, the test has a 99% detection rate and a 0.1% false-positive rate. Detection rates for other conditions are not quite as high, and false-positive rates are higher when testing other conditions or women who are obese or of Afro-Caribbean descent. However, for much of the population, this procedure has the ability to provide highly accurate results via non-invasive methods. As of January 2015, the United States had four private companies providing NITP with prices ranging from $795 to $2,762 for each test. Whether this test expands in its current application to provide even more information to parents and whether it becomes a routine part of pregnancies is yet to be seen.[26]

Once screening procedures have been implemented, it is then that invasive diagnostic tests (like amniocentesis and CVS) are offered if the risk estimated from the screening is found to be greater than a certain cutoff (e.g., greater than 1 in 150).[27] CVS uses a small piece of placental tissue (called the chorion) that is obtained from the mother's womb to test for genetic disorders. The tissue can be supplied either through the cervix or abdomen of the pregnant woman using various methods. Methods which

[26] Ibid.

[27] de Jong, Maya, and van Lith, "Prenatal Screening."

decrease the likelihood of damaging the gestational sac and increase the likelihood of obtaining sufficient amounts of tissue are preferred because gestational sac damage and several attempts to obtain placental tissue increase the risk of miscarriage.[28] Amniocentesis is a second test commonly used as a diagnostic tool for conditions like Down syndrome. Like CVS, there is variability in the way in which the test is performed. Traditional amniocentesis involves the use of a syringe to extract amniotic fluid that surrounds the fetus for testing.[29] An alternative to the syringe technique has been developed and is known as amniovacucentesis. With this technique, a vacuum tube is attached to a needle inserted into the amniotic fluid that allows for automated aspiration of the fluid.[30] Despite the variability in practices of amniocentesis and CVS, the two diagnostic tests on the whole are frequently considered the logical step following abnormal prenatal screening results.

Preimplantation Genetic Diagnosis

Whereas the examples of CVS and amniocentesis demonstrate the ability of technology to provide information prenatally, there are further technological developments that provide information even before the implantation of an embryo into the uterus. One such technological advancement is the development of preimplantation genetic diagnosis. Preimplantation genetic diagnosis (PGD) is a technique that does not

---

[28] Carmen Young, Peter von Dadelszen, and Zarko Alfirevic, "Instruments for Chorionic Villus Sampling for Prenatal Diagnosis," *Cochrane Database of Systematic Reviews* (John Wiley & Sons, Ltd, 2013), http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD000114.pub2/abstract.

[29] Pavel Calda and Miroslav Brestak, "Amniovacucentesis vs Standard Syringe Technique for Amniocentesis: Experience with 1219 Cases," *American Journal of Obstetrics and Gynecology* 201, no. 6 (December 2009): 593.e1–593.e3, doi:10.1016/j.ajog.2009.06.023.

[30] Ibid.

apply to natural fertilization; it can only be applied in the case of embryos created *in vitro* (literally "in glass"). Human embryos result after an egg has been fertilized and persist until the beginning of the third month of pregnancy, after which they are called fetuses. PGD is a way of testing either *in vitro* embryos or *in vitro* oocytes (immature egg cells) for genetic abnormalities and is used as an alternative to prenatal diagnosis and abortion of pregnancy.[31] The first application of PGD occurred in 1968 when the technique was used in order to select for sex among rabbits. R. L. Gardner and R. G. Edwards, even in 1968, realized that their method provided a way for "controlling the sex ratio in the rabbit" though their procedure would "have to be modified for similar work on other species."[32] Gardner and Edwards also realized that among the implications of their experiment existed the possibility of detecting "autosomally inherited deformities from either parent."[33] Both of these insights (the possibility of expanding the procedure to other species and of determining characteristics beyond sex) have since proven to be well-founded. The former, application to other species, was realized among humans when the first clinical application of PGD occurred in 1990. At that time, the technique was employed in an attempt to avoid the implantation of embryos with recessive X-linked diseases.[34] Due to the nature of recessive X-linked diseases, typically only males are affected. In the first clinical application of PGD, the knowledge that males are

[31] JPM Geraedts and GMWR de Wert, "Preimplantation Genetic Diagnosis," *Clinical Genetics* 76, no. 4 (October 1, 2009): 315, doi:10.1111/j.1399-0004.2009.01273.x.

[32] R. L. Gardner and R. G. Edwards, "Control of the Sex Ratio at Full Term in the Rabbit by Transferring Sexed Blastocysts," *Nature* 218, no. 5139 (April 27, 1968): 346–48, doi:10.1038/218346a0.

[33] Ibid.

[34] A. H. Handyside et al., "Pregnancies from Biopsied Human Preimplantation Embryos Sexed by Y-Specific DNA Amplification," *Nature* 344, no. 6268 (April 19, 1990): 768–70, doi:10.1038/344768a0.

typically affected by recessive X-linked diseases resulted in the screening of embryos for sex so that only female embryos would be transferred.[35] Similar to what had been the interest of Gardner and Edwards with the rabbit embryos over two decades prior, the sex of these human embryos was of primary concern. Having the ability to accurately determine the sex of an organism by examining it in its earliest stages can now be used in order to select embryos of a specific sex to be implanted in the uterus in order to avoid certain X-linked diseases.

The other implication of Gardner and Edwards' work was that of expanding the application of PGD to include uses beyond merely determining the sex of an organism. This, too, is an example of something that was once merely an idea that has since been realized. One use of PGD other than selecting for sex is known as PGD with human leukocyte antigen (HLA) matching. HLAs are unique to each individual and are an important component in organ transplantation and bone marrow transplantation.[36] By combining PGD with preimplantation HLA antigen testing, embryos can be selected with more than just the sex of the embryo in mind. The combination of PGD with preimplantation HLA antigen testing allows for the "preselection of potential donor progeny for bone marrow transplantation."[37] When a member of a family is known to be affected by a particular disease in which bone marrow transplantation would be of great benefit, this application of PGD is available "to establish a pregnancy with particular

[35] Karen Sermon, André Van Steirteghem, and Inge Liebaers, "Preimplantation Genetic Diagnosis," *The Lancet* 363, no. 9421 (May 15, 2004): 1633–41, doi:10.1016/S0140-6736(04)16209-0.

[36] Abi Berger, "HLA Typing," *British Medical Journal* 322, no. 7280 (January 2001): 218.

[37] Yury Verlinsky et al., "Preimplantation Diagnosis for Fanconi Anemia Combined with HLA Matching," *JAMA* 285, no. 24 (June 27, 2001): 3130–33, doi:10.1001/jama.285.24.3130.

genetic parameters that benefit" said family member.[38] Those who are able to serve as bone marrow or other hematopoietic stem cell donors to their affected siblings are dubbed as "savior siblings."[39] The practice of selecting embryos for this purpose is one of the ways in which the applications of PGD have expanded. This is also an example of how PGD presents options that would likely be unavailable through prenatal diagnosis.

The International Working Group on Preimplantation Genetics produced a review of PGD ten years after its development, highlighting the unique ability of PGD to select based on HLA typing.[40] This group finds HLA typing via PGD to be an acceptable alternative to traditional prenatal diagnostic testing and subsequent abortion. Before PGD, parents who used IVF to create a pregnancy with the hopes of producing a savior sibling would have had to "blindly" implant embryos. If prenatal diagnostic tests show the resulting pregnancy does not produce a perfect match, then "clinical pregnancy termination…would likely be necessary."[41] PGD, on the other hand, is "perfectly acceptable because…only those few [embryos] representing a perfect match for affected siblings at need for a transplant are selected."[42] The International Bioethics Committee's 2003 report to the United Nations Educational, Scientific, and Cultural Organization (UNESCO) on PGD and germ-line intervention describes the ways the purposes of

---

[38] Ibid.

[39] Kimberly Strong, Ian Kerridge, and Miles Little, "Savior Siblings, Parenting and the Moral Valorization of Children," *Bioethics* 28, no. 4 (May 1, 2014): 187–93, doi:10.1111/j.1467-8519.2012.02001.x.

[40] "News Around the World: Tenth Anniversary of Preimplantation Genetic Diagnosis," *Journal of Assisted Reproduction and Genetics* 18, no. 2 (February 2001): 64–70, doi:10.1023/A:1026522422757.

[41] Ibid., 67.

[42] Ibid.

reproductive technology have changed with the advancement of technology and availability of new medical processes:

> The development of new technology during the past two decades has led to a shift in the perception of the purpose of medically assisted reproduction. IVF aims at having a child, PGD aims at having a healthy child and PGD/HLA testing aims at having a healthy and helpful child. Undoubtedly research and technology related to genetics will further develop in the years to come and will also provide new opportunities for couples to select their offspring.[43]

This application of PGD that results in the designation of certain children as "helpful" and others as, presumably, non-helpful is one that should be borne in mind while considering the uses of PGD and other reproductive technologies resulting in similar distinctions.

Another current application of PGD is using the technique in order to select against adult-onset diseases. Two common examples of adult-onset diseases are Huntington's disease and various types of cancer. An example with cancer specifically demonstrates how PGD provides different alternatives than prenatal diagnosis. PGD can be used for couples known to have inherited predispositions to cancer. In this instance, embryos that also have inherited a predisposition to cancer can be selected against with only the embryos showing to be free of the genetic predisposition being transferred.[44] Whereas a mere predisposition to cancer has not been considered cause for termination of an already established pregnancy, and therefore may be considered a limitation of prenatal diagnosis, with this application of PGD, embryos which demonstrate having the

[43] International Bioethics Committee, "Report of the IBC on PGD and Germ-Line Intervention," (2003).

[44] "News Around the World."

genetic predisposition to cancer are not implanted in the first place.[45] Similar procedures may be used when the fear of transmitting Huntington's disease to offspring is a concern. Huntington's disease is 100% penetrant and caused by a dominant allele. Unlike PGD uses for cancer in which predispositions are the primary concern, PGD use with Huntington's disease is for parents who suspect or know they themselves have Huntington's disease and want to select only the embryos that do not contain the allele to be implanted in the uterus during the IVF process. In either scenario, PGD is used as a means to provide for greater selectivity and control than are allowable via the earlier-developed prenatal diagnostic tests.

Germline Gene Therapy

Gene therapy is an area in genetic technology that is currently being developed. Researchers are considering both somatic and germline therapy, but only germline will be discussed here. Gene therapy among germline cells (reproductive cells) has the ability to affect those who do not directly receive gene therapy themselves. The progeny of those who receive gene therapy can be indirectly affected by the process if the cells undergoing therapy are of the germ-line type. Germ-line modification is currently at the forefront of genetic technology. In April 2015, Chinese scientists published an article reporting their methods for altering the genomes of human embryos.[46] Such alterations, if carried out in viable human embryos, would affect the human embryo in such a way as to potentially eliminate a genetic disease for that human. Furthermore, because the alteration would be

[45] Ibid.

[46] David Cyranoski and Sara Reardon, "Chinese Scientists Genetically Modify Human Embryos," *Nature*, April 22, 2015, doi:10.1038/nature.2015.17378.

made to heritable genetic material, the change would affect not only that single embryo, but any who inherit the genetic material that was first altered in this embryo.[47] If an altered human embryo develops so as to become capable of passing on its genetic material, the genetic material that is passed on will be the altered material of the original human embryo. Modifications of this type do not simply have the potential to rid one person of a genetic disease; they have the potential to prevent the transmission of genes contributing to that disease in subsequent generations.

As it currently stands, modifications of this sort have not taken place among viable human embryos. In the introduction of their paper, Liang et al. note that "ethical concerns preclude studies of gene editing in normal embryos."[48] To circumvent this particular ethical barrier, the researchers used embryos that consisted of three nuclei (one oocyte nucleus and two sperm nuclei).[49] These embryos were not viable and allowed the scientists to manipulate genes in a way they found ethically acceptable. The manipulation that took place among these embryos was in an attempt to modify the gene that contributes to a blood disorder known as ß-thalassemia.

The two conditions of ß-thalassemia typically requiring medical care are known as thalassemia intermedia and thalassemia major.[50] In its most severe forms, those with

---

[47] Ibid.

[48] Puping Liang et al., "CRISPR/Cas9-Mediated Gene Editing in Human Tripronuclear Zygotes," *Protein & Cell* 6, no. 5 (April 18, 2015): 364, doi:10.1007/s13238-015-0153-5.

[49] Ibid.

[50] Nancy F. Olivieri, "The B-Thalassemias," *New England Journal of Medicine* 341, no. 2 (July 8, 1999): 99–109, doi:10.1056/NEJM199907083410207.

ß-thalassemia may be dependent upon blood transfusions for the duration of their lives.[51] Children with severe forms of ß-thalassemia who do not receive adequate transfusions experience a number of difficulties. Among these possible problems are enlargements of both the spleen and liver, which may result in protrusion of the abdomen; potential growth retardation; and characteristics of a hypermetabolic state such as lethargy, frequent fevers, and poor musculature.[52] ß-thalassemia is but one example of a disorder that has been attributed to mutations in genetic material. Though it is the focus of the study discussed below, should the techniques used by Liang et al. be perfected, or should others arise, application could reach well beyond this single instance to a multitude of disorders whose etiologies have a genetic basis.

In an attempt to develop a method in which ß-thalassemia is prevented, Liang et al. employed complex techniques to modify the genetic material associated with this specific genetic disorder. The basic principle of the form of gene editing performed by these scientists is replacing mutated genes with those that are non-mutated. A system used in this endeavor is known as CRISPR/CAS9-mediated gene editing. The CRISPR/CAS9 functions to cleave endogenous genetic material (the genetic material native to an organism). In this instance, the target genetic material was the ß-globin gene (HBB), a mutated form of which is associated with ß-thalassemia.[53] Different mutations result in various manifestations of the disorder, but all mutations cause either a lack of

[51] Martin H. Steinberg et al., eds., *Disorders of Hemoglobin: Genetics, Pathophysiology, and Clinical Management*, 2nd ed. (Cambridge University Press, 2009).

[52] Ibid.

[53] Liang et al., "CRISPR/Cas9-Mediated Gene Editing in Human Tripronuclear Zygotes."

synthesis or a reduction of synthesis of the ß-globin chains of hemoglobin.[54] With a specific portion of the genetic material within HBB cut, repairs can be made that incorporate exogenous genetic material into the gene. This exogenous genetic material would be that which is not naturally produced by the body (which in the cases of ß-thalassemia is mutated), but that which has been supplied extraneously as a means of incorporating non-mutated genetic material.[55]

The complexity of gene editing is clear. The process itself and the technology used in the process require a great deal of precision and understanding. The results obtained by Liang et al. further demarcate the complex nature of undertaking the gene editing process. The scientists hoped that the repairs made to the cut DNA of HBB would result in the incorporation of the exogenous DNA via homologous recombination directed repair (HDR). However, they found the efficiency of HDR to be low. Furthermore, endogenous genetic material, specifically the delta-globin gene (HBD), competed with the exogenous material as the repair template, thereby resulting in mutations. Additionally, areas that were not targeted for cutting were found to have been mistakenly severed. Overall, the results suggested that while the idea is promising and functional in some regards, CRISPR/CAS9-mediated gene editing requires greater understanding and further subjection to experimentation before being clinically applied to viable human embryos.[56]

---

[54] Olivieri, "The B-Thalassemias."

[55] Liang et al., "CRISPR/Cas9-Mediated Gene Editing in Human Tripronuclear Zygotes."

[56] Ibid.

Conclusion

Genetic reproductive technology has changed significantly over the past few decades. The initial development of practices like prenatal screening and diagnostic tests have now resulted in practices which are commonplace for those experiencing pregnancy. Currently, developments are being made in modifying the human genome itself. Whether these developments result in ubiquitous employment of gene-altering technology is yet to be seen, but the realm of genetic reproductive technology on the whole shows no signs of becoming stagnant in the near future. With each development in technology that has become clinically available, choices have been made as to when, how, and for whom to employ the technology. The next chapters seek to illuminate how these decisions are being made and what paradigms are informing decisions regarding the use of the technology that is currently available and the allocation of resources to developing that which is upon the horizon.

CHAPTER THREE

Prenatal Screening and Diagnostic Tests

Introduction

Prenatal screening and diagnostic tests have become a routine component of the pregnancy process in many nations. This chapter examines some of the arguments for and against the now commonplace use of these tests. The majority of this chapter is comprised of conceptual approaches to the ethical issues of prenatal tests without being explicitly tied to the personal experiences and stories of people. However, in order to introduce some of the questions prenatal screening and diagnostic tests raise, the personal experiences of Brian and Stephanie Brock during the birth of their first son are shared.

In their account of the events leading up to the birth of their first child, Brian and Stephanie Brock provide a picture of the modern uses and purposes of genetic testing. Brian Brock is a theologian at the University of Aberdeen whose work relates to the interaction between Christianity and technology. His wife, Stephanie, has previous experience in the medical field as a registered nurse and is the mother to their three children. The Brocks are able to provide a personal narrative that raises questions about the uses of genetic testing. Rather than shy away from incorporating ethical questions about technology into their lives, they note that "technology is ourselves in action" and cannot simply be viewed as something external to the self.[1]

[1] John Swinton and Brian Brock, "Being Disabled in the New World of Genetic Testing: A Snapshot of Shifting Landscapes," in *Theology, Disability, and the New Genetics: Why Science Needs the Church* (New York; London: T&T Clark, 2007).

A major difficulty the Brocks dealt with concerning the health of their first child, Adam, involved genetic testing; however, most of their struggle came from deciding whether or not to have genetic tests performed *after* he was born. Though much of what the Brocks encountered regarding genetic testing took place after Adam was born, they also experienced pressure to undergo prenatal screening. The Brocks' first visit to a health center for the pregnancy resulted in healthcare professionals strongly urging them to perform a sonogram. Stephanie was four months pregnant at the time. Through later discussion, the Brocks learned that the reason they were being urged to undergo a sonogram was because the healthcare professionals wanted "to see if abortion was indicated."[2] The reason for the urgency of performing a sonogram was due to the fear that the legal cut-off date for an abortion was quickly approaching. The Brocks describe this as being the first time they were offered medical treatment which they did not seek. But what others considered treatment, they considered something else, for they "did not consider termination a 'treatment' for [their] child, nor diagnostic testing which was not directed at a proximate and remediable medical problem."[3] The prenatal screening they were encouraged to undergo was not for the purpose of discovering anomalies so that the Brocks would be prepared when giving birth or for discovering remediable health issues. The purpose of the screening, from the perspective of those at the clinic they visited, was to see if the Brocks' pregnancy had developed in such a way as to merit abortion.

After a long and difficult few months, Adam was eventually diagnosed with Trisomy 21. The Brocks had chosen to forego prenatal screening which could have given

[2] Ibid., 31.

[3] Ibid.

them the results before Adam's birth. They also did not rush to employ the genetic tests that ultimately confirmed Adam's Down syndrome. Not all would make the same choice the Brocks did in foregoing prenatal screening and diagnostic tests. Of those who would, not all would necessarily make the choice for the same reasons the Brocks made theirs.

The Brocks' story provides an example of those who do not view termination as treatment and who chose to abstain from prenatal screening and diagnostic tests. That they were given a son with Down syndrome makes their story especially pertinent to the remainder of this chapter, which places emphasis on the relationship between those with disabilities and prenatal screening and diagnostic tests. By examining the aims of prenatal screening and diagnostic tests and the ethical questions they raise, this chapter provides insight into how the choices regarding prenatal testing are made.

Disability Critique

The disability critique of prenatal testing stems from believing discrimination occurs when one group (in this case, those not closely involved with disability) lacks the ability to imagine another group (in this case, people with disabilities and their families) leads lives that are as equally satisfying and complex as their own.[4] This critique of prenatal screening and diagnostic tests is an important one to consider. The implicit purpose behind many prenatal screening and diagnostic procedures is to determine whether an abortion is "merited." What merits an abortion is not agreed upon unanimously, but as it currently stands, many of these tests seek to determine whether a fetus is affected by a disability with abortion following in the case that the fetus tests

[4] Erik Parens and Adrienne Asch, eds., "The Disability Rights Critique of Prenatal Genetic Testing: Reflection and Recommendations," in *Prenatal Testing and Disability Rights*, Hastings Center Studies in Ethics (Washington, D.C: Georgetown University Press, 2000).

positive for certain conditions. A literature review concerning the termination of pregnancies following a prenatal diagnosis of Down syndrome found termination rates in the United States to range from approximately 67%-85%.[5] Although this is lower than the 92% found in a literature review conducted earlier and among more nations than just the United States,[6] an article published in 2015 concluded that the number of babies born with Down syndrome "would have been significantly higher had prenatal testing not been available."[7] The disability critique prompts thinking about the purposes for and effects of selectively aborting following prenatal testing results.

The disability critique of prenatal testing results in two claims. The first is that "prenatal genetic testing followed by selective abortion is morally problematic."[8] The second claim contends that prenatal genetic testing followed by selective abortion is "driven by misinformation."[9] The first of these claims, that prenatal genetic testing followed by selective abortion is morally problematic, will be considered in this chapter. From the disability critique of prenatal genetic testing perspective, this claim is supported by several arguments. The first to be considered is the expressivist argument.

---

[5] Jaime L. Natoli et al., "Prenatal Diagnosis of Down Syndrome: A Systematic Review of Termination Rates (1995–2011)," *Prenatal Diagnosis* 32, no. 2 (February 1, 2012): 142–53, doi:10.1002/pd.2910.

[6] Caroline Mansfield, Suellen Hopfer, and Theresa M. Marteau, "Termination Rates after Prenatal Diagnosis of Down Syndrome, Spina Bifida, Anencephaly, and Turner and Klinefelter Syndromes: A Systematic Literature Review," *Prenatal Diagnosis* 19, no. 9 (September 1, 1999): 808–12, doi:10.1002/(SICI)1097-0223(199909)19:9<808::AID-PD637>3.0.CO;2-B.

[7] Gert de Graaf, Frank Buckley, and Brian G. Skotko, "Estimates of the Live Births, Natural Losses, and Elective Terminations with Down Syndrome in the United States," *American Journal of Medical Genetics Part A* 167, no. 4 (April 1, 2015): 765, doi:10.1002/ajmg.a.37001.

[8] Parens and Asch, "The Disability Rights Critique of Prenatal Genetic Testing: Reflection and Recommendations."

[9] Ibid.

Expressivist Argument

The expressivist argument challenges specific prenatal actions, but it does so from the viewpoint of those who have already been born. The expressivist argument against genetic testing to select against disability has the central claim that partaking in prenatal tests and subsequent selective abortion sends a negative and harmful message to those who are currently living with the traits being selected against.[10] According to Colin Gavaghan, who is not a proponent of the expressivist argument, the concern raised by the expressivist argument is one that "transcends political or religious views."[11] Much of the argument rests upon what is seen as the fallacy of allowing a part to stand in for the whole. According to Adrienne Asch, prenatal testing is something which affords a single trait the opportunity to stand in for the whole of a person.[12] For example, upon learning of a single trait like Down syndrome, a person who has undergone prenatal testing and decides to abort makes the decision based upon one trait that is revealed about the fetus. Whether the fetus has Down syndrome or not is given utmost importance without considering other traits of the fetus (e.g., temperament and personality) that could develop were the pregnancy not terminated. This, in effect, reduces the fetus (or embryo if applied to procedures like PGD) to a single, oft negatively-perceived trait rather than the myriad traits that will also shape the fetus if it is allowed to come to term, be delivered, and develop. Asch says many with disabilities, who themselves have

---

[10] Ibid.

[11] Colin Gavaghan, "Right Problem, Wrong Solution: A Pro-Choice Response to 'Expressivist' Concerns about Preimplantation Genetic Diagnosis," *Cambridge Quarterly of Healthcare Ethics* 16, no. 01 (January 2007), doi:10.1017/S096318010707003X.

[12] Parens and Asch, "The Disability Rights Critique of Prenatal Genetic Testing: Reflection and Recommendations."

experienced being reduced to a single trait, fear that prenatal genetic testing with the purpose of selecting against disabilities serves to perpetuate the tendency to discriminate based upon a single trait rather than viewing the person as a whole.[13] By allowing screening and diagnostic tests for disabilities to persist, with the consequence of abortion following if results are undesirable to parents, something is said about those who currently live with disability. Proponents of the expressivist argument suggest that by allowing the number of people with certain disabilities to decrease because some fetuses bearing these disabilities are never born, those who currently exist with the disabilities being selected against are being told that the world is better without their type.

Numerous scholars have acknowledged the expressivist objection and provided arguments against it. One such objection is founded upon the distinction between a person who may have a disability and a disability itself. Janet Malek argues that the use of reproductive genetic technologies (RGTs) does not necessarily connote negative attitudes toward those who are currently deemed as living with disability.[14] While some propose the actions of employing RGTs (like preimplantation genetic diagnosis) do not have a well-established societal message they convey,[15] Malek chooses to employ a thought experiment assuming the semantic arguments are lacking. Her experiments take the reader through various progressions of a similar scenario: being faced with the decision to accept or avoid a future disability. The first scenario described requires

---

[13] Ibid.

[14] Janet Malek, "Deciding against Disability: Does the Use of Reproductive Genetic Technologies Express Disvalue for People with Disabilities?," *Journal of Medical Ethics* 36, no. 4 (2010): 217–21.

[15] For further discussion, see Allen Buchanan et al. *From Chance to choice: genetics and justice*. New York, NY: Cambridge UniversityPress, 2000 and JL Nelson, "Prenatal diagnosis, personal identity, and disability," *Kennedy Inst of Ethics J* 10, no. 3 (2000):213-28.

imagining oneself at a crosswalk. Time freezes and a guardian angel makes known to you that crossing as you normally would will result in becoming a paraplegic after being hit by a vehicle. Malek then asks whether, when time unfreezes, you would proceed across the crosswalk or remain out of the way of the vehicle. Malek proposes that choosing not to enter the road is making a negative evaluation of losing the ability to walk, but it does not make a negative evaluation of people for whom walking is not a prospect. She applies the same situation to then choosing whether to allow a child to enter the crosswalk, which then morphs into choosing whether to conceive one month or the next given the knowledge that waiting prevents a disability, to employing preimplantation genetic diagnosis (PGD) for the selection of embryos without a paraplegic disability, to finally choosing to terminate a pregnancy of ten weeks in hopes of conceiving again upon learning the current pregnancy would result in a child with disability. Whether (in scenarios four and five) the embryo and fetus, respectively, have moral status still does not bear, according to Malek, on the message conveyed to those with disabilities if choices are made to avoid disability.[16]

Gavaghan also provides an argument against the expressivist objection on multiple accounts. He divides the expressivist argument into two main categories: objective and subjective harms.[17] The argument concerning objective harms is treated below. Concerning subjective harms, Gavaghan makes another division by distinguishing between those believed to be delivering the negative message to the

[16] Malek, "Deciding against Disability."

[17] Gavaghan, "Right Problem, Wrong Solution."

disabled: parents or society.[18] First, consider the message coming from parents. Gavaghan addresses the disabled person who struggles when wondering whether his parents would have chosen to have him had prenatal testing been available to them. A similar concern arises when Deborah Kent, a blind woman, discusses having a child with her husband. Upon learning her husband would initially be devastated by the news of a blind child, Kent concludes that her husband's position is the "product of a society that views blindness, and all disability, as fundamentally undesirable."[19] To this idea, Gavaghan alludes to history and notes that many who exist now would not have been born if their ancestors had been given choices and options (e.g., sex education or effective contraception) that exist today. That they may not have been born were these options available does not mean the options should be stripped away.[20] Even if their ancestors had chosen to have fewer children or children at a later time, they are not choosing against a particular *type* of child, Gavaghan notes. However, in response to this idea (what Asch has dubbed the "any-particular distinction"[21]), Gavaghan brings to mind those who choose to abort to avoid children born into poverty, into a large family, or to a teenage mother. If aborting due to disability conveys negative evaluations of those who are currently disabled, then aborting due to any of the reasons mentioned above conveys negative attitudes toward children born to families that are poor, large, or have teenage

[18] Ibid.

[19] Deborah Kent, "Somewhere a Mockingbird," in *Prenatal Testing and Disability Rights*, ed. Erik Parens and Adrienne Asch, Hastings Center Studies in Ethics (Washington, D.C: Georgetown University Press, 2000):58-9.

[20] Gavaghan, "Right Problem, Wrong Solution."

[21] Parens and Asch, "The Disability Rights Critique of Prenatal Genetic Testing: Reflection and Recommendations."

mothers,[22] an idea that is not often expressed and mitigates the strength of the expressivist argument. Second, Gavaghan discusses the idea that choosing to abort after prenatal tests reveal a disability means the parents are devaluing those with disabilities. Gavaghan argues this is not necessarily the case and that parents could be making the decision for a multitude of reasons (e.g., feeling unable to financially support a disabled child).[23] Finally, in response to the expressivist objection as propagated via parents, Gavaghan says that if prenatal options are not presented to parents now, then there will simply be another generation of people wondering what choice their parents would have made had they had the option.[24]

Gavaghan's societal objection to the expressivist argument is in some ways similar to Malek's argument against the expressivist argument. Like Malek, Gavaghan asks whether trying to rid society of a specific genetic disease results in devaluing the people who currently bear those same genetic diseases. This question pertains, in part, to the role disability may play in identification. S. D. Edwards treats this point in a discussion on the expressivist argument. He says few consider that disability can be part of a person's identity in a way having the flu is not.[25] Those who do not consider the identity component may say that just as flu vaccines do not make negative evaluations of people with the flu, so prenatal screening preventing disability does not make negative

[22] Gavaghan, "Right Problem, Wrong Solution."

[23] Ibid.

[24] Ibid.

[25] S. D. Edwards, "Disability, Identity and the 'Expressivist Objection,'" *Journal of Medical Ethics* 30, no. 4 (August 1, 2004): 418–20, doi:10.1136/jme.2002.002634.

evaluations of those with disabilities but simply the disability itself.[26] Even if a distinction between genetic disorder and person is not made, Gavaghan still thinks prenatal testing is permissible.

Parental Attitude Argument

In addition to the expressivist argument against prenatal testing for the purpose of selecting against disabilities, the disability critique to such testing also offers the parental attitude argument. Like the expressivist argument, the parental attitude argument claims prenatal testing to be morally problematic. Also like the expressivist argument, the parental attitude argument opposes selecting against disability on the basis of disallowing the part to stand for the whole.[27] This argument suggests there is a problem in the perception of parenthood if parents are dissuaded from bearing their child on the basis of a single trait. Rather than attempt to select for specific traits in their children, the parental attitude argument proposes parents acknowledge parenting is not about creating or selecting the perfect child, but is instead about the relationship created between parent and child regardless of specific traits of the child.[28] Erik Parens and Adrienne Asch note that according to the parental attitude argument, making the decision to select against having a child with disability via prenatal genetic tests demonstrates a poor conception of parenthood, one holding a "preoccupation with what is trivial and an ignorance of what is profound."[29] Another note of importance concerns an application of the parental attitude

---

[26] Ibid.

[27] Parens and Asch, "The Disability Rights Critique of Prenatal Genetic Testing: Reflection and Recommendations."

[28] Ibid.

[29] Ibid.

argument to non-health-related traits. Parens and Asch mention an interesting point by stating that "concerns about the selective mentality" regarding children come quickly to mind in relation to non-health-related traits, but those who dismiss the parental attitude argument in relation to disability may be criticizing an argument they would wish to employ in the context of traits such as eye color, sex, or intelligence.[30] However, given Gavaghan's proposition that governing authorities loosen restriction on PGD so it may be used for the screening of any trait (giving parents expanded decision-making power in reproductive choices),[31] it certainly is not guaranteed that non-health-related traits will be excluded from the realm of prenatal genetic testing if ideas such as Gavaghan's come to fruition.

Another limitation of the parental attitude argument, according to William Ruddick, is that it makes a "maternalist assumption," or assumes that any person wanting a child in general will be content with whatever child he or she receives.[32] However, not every parent approaches parenthood with this mindset, and Ruddick thinks there are other legitimate ways to think about the concept of parenthood. For example, if part of a parent's conception of parenthood involves a "familial" conception, then, for that parent, ensuring that he has a child who is able to bear children himself is important.[33] If the possibility of "grandparenthood" is an integral component of a person's conception of parenthood, Ruddick can conceive of people choosing to not have a boy with cystic

---

[30] Ibid.

[31] Gavaghan, "Right Problem, Wrong Solution."

[32] Parens and Asch, "The Disability Rights Critique of Prenatal Genetic Testing: Reflection and Recommendations," 18.

[33] Ibid., 19.

fibrosis who faces sterility and a shortened lifespan, and thus makes the possibility of grandparenthood a potentially slim one. Of course, the same parents who choose to abort a child who would have cystic fibrosis do not rid themselves of the possibility of giving birth to children who all choose celibacy (or do not give birth for some other reason) and never produce grandchildren for the parents though they have the physical capabilities necessary for reproduction.

Loss of Support Argument

A third argument against the use of prenatal screening and diagnostic tests resulting in selective abortion is known as the "loss of support argument." The loss of support argument suggests that as prenatal screening and diagnostic tests are used to select against those who indicate having a genetic disability, the support available for those who currently are disabled diminishes.[34] Proponents of this argument fear that as fewer and fewer people are born with genetic disabilities due to prenatal genetic tests, those who have already been born or who will be born with genetic disabilities will have less support and resources at their disposal. There may be less incentive to find "cures, treatments, or ways to improve the lives" of those who are affected by a particular disability.[35]

However, opponents of the loss of support argument claim it is not sufficient in providing a valid objection to the use of prenatal genetic tests.[36] One reason is doubt that

---

[34] Allen E. Buchanan et al., *From Chance to Choice: Genetics and Justice* (Cambridge, U.K. ; New York: Cambridge University Press, 2000):266-9

[35] Gavaghan, "Right Problem, Wrong Solution," 25.

[36] Buchanan et al., *From Chance to Choice*.

a decrease in the number of people with a certain genetic disability actually produces a decrease in support.[37] Were support to decrease, it would be an objective harm of prenatal screening and diagnostic tests. However, Gavaghan suggests it is possible support actually increases for those with genetic disabilities and that the supposed objective harm could actually be a potential objective benefit. He acknowledges it is reasonable to wonder whether accommodations will be made for those with disabilities if their numbers continue to decrease; however, he also finds it reasonable to think the plight of some may enhance. For example, with conditions like cystic fibrosis that can require access to organ transplantations, it is possible that with fewer people born with cystic fibrosis, those who do have it will have a greater chance of receiving the organ transplants they need.[38] Even if this were not the case, Gavaghan contends that rather than prevent prenatal screening from taking place in order to combat diminished support, perhaps it is better to guarantee support via other means instead of requiring parents to forego screening and diagnostic tests.[39] Furthermore, it has been suggested that in trying to prevent exclusionary practices, the loss of support argument is itself exclusive by discounting the "legitimate interests that persons have in not having disabilities."[40] One final consideration regarding the loss of support argument relates to technology that may be developed. If it becomes possible to alter genes of an embryo after identifying genetic causes of disability, then prenatal genetic tests, instead of leading to abortions, may lead to cures applied to an embryo. If that is the case, some propose the loss of support

[37] Ibid.

[38] Gavaghan, "Right Problem, Wrong Solution."

[39] Ibid.

[40] Buchanan et al., *From Chance to Choice*, 269.

argument must be rejected because the reasoning behind it would mean that if genetic interventions are to be avoided, then so are conventional medical interventions (e.g., treating babies' eyes at birth to prevent blindness).[41]

Peter Singer

One person who also has connected the concept of altering human embryos to prenatal genetic tests is Peter Singer. Singer is the Ira W. DeCamp Professor of Bioethics at Princeton University. Before expounding upon the connection Singer makes between prenatal genetic tests and genetically altering human embryos, it is helpful to understand why he supports prenatal genetic tests and the framework within which he makes the connection. In relation to criticisms against the use of prenatal diagnosis, Singer asks two orienting questions. He first asks, "How important it is to most parents to give their child the best possible start in life?"[42] He then asks, "How serious a reason does a woman need in order to be justified in ending her pregnancy?"[43] To the first, Singer answers it is usually quite important as evidenced by the number of books sold telling parents how to achieve the best for their children and the way in which parents make choices and sacrifices to place their kids in neighborhoods with the best schools and the like. To the second, Singer contends that a woman does not need much of a reason in order to justify abortion. Citing *Roe v. Wade,* Singer provides a reminder that a pregnancy in the United States can be terminated for any reason in the first and second trimesters. Furthermore,

---

[41] Ibid.

[42] Peter Singer, "Shopping at the Genetic Supermarket," in *Disability: The Social, Political, and Ethical Debate*, ed. Robert M. Baird, Stuart E. Rosenbaum, and S. Kay Toombs (Amherst, N.Y: Prometheus Books, 2009):312.

[43] Ibid., 312.

he does not believe a fetus has moral status[44] and, therefore, finds it even easier to justify abortion than if he were just relying upon *Roe v. Wade.*

With these two orienting questions answered, Singer proceeds to support the use of prenatal genetic tests. His position is made clear by one example in which parents decide whether to have a child with Down syndrome and another in which they decide whether to have a child when they can only afford a one-bedroom apartment. Relying upon the principle of giving children the best start possible, Singer says abortion in both cases is justified so long as parents believe it would be better to have a child without Down syndrome or better for their possible future child to have a room to himself.[45] The parental argument can be helpful to an extent in refuting this thought process. If parents are making a decision to prevent the birth of a child with Down syndrome because this is not the child they envision or desire, then they are lacking an understanding in what they should really seek in parenting and how "relatively unimportant are the particular traits of their children."[46] This idea is contested, however, if the particular trait a child will have results in a "disabling, excruciating, life-shortening disease," in which case, selecting against this child and for a disease-free one seems to many the "sensible thing to do."[47] Such considerations are heavier matters than what, in comparison, are the seemingly trivial desires of having a child who may have his own room.

---

[44] Ibid., 313.

[45] Ibid.

[46] Parens and Asch, "The Disability Rights Critique of Prenatal Genetic Testing: Reflection and Recommendations," 17.

[47] Stephen Wilkinson, *Choosing Tomorrow's Children: The Ethics of Selective Reproduction*, Issues in Biomedical Ethics (Oxford: Clarendon Press, 2010), 3.

In relation to disability, Singer does not shy away from saying there is an inherent inequality between those who have disabilities and those who do not, otherwise precautions such as the avoidance of alcohol to prevent birth defects would not be taken.[48] Singer proffers the "preventive principle," which says, "for any condition X, if it would be a form of child abuse for parents to inflict X on their child soon after birth, then it must, other things being equal, at least be permissible to take steps to prevent one's child having that condition."[49] For those who accept the justifiability of selecting against Huntington's disease (the genetic penetrance of which is 100%), it is no small step to selecting against genes that may be associated with breast cancer (the genetic penetrance of which indicates elevated risk, but not certainty of development), to then selecting for traits that would produce a child with traits that are better-than-average.[50] Being able to draw the line between selecting against disability and selecting for enhancing traits appears difficult when the primary guiding principle is giving children the best possible start.

If someone accepts the preventive principle, he must reject the idea that whatever combination results from the fertilization between sperm and egg is the combination that should come into existence unless the person "think[s] of the genetic lottery as no lottery at all, but rather, the workings of a divine Providence."[51]

---

[48] Singer, "Shopping at the Genetic Supermarket."

[49] Ibid., 317.

[50] Ibid.

[51] Ibid.

Conclusion

The various stances regarding the use of prenatal genetic screening and diagnostic tests require careful consideration. For those like the Brocks who had a very personal encounter with the issue, it certainly requires a great deal of thought. However, whether personally encountered or not, answering questions regarding the use of prenatal genetic testing will point to what society values. Furthermore, the ideas regarding prenatal screening and diagnostic tests will need to be considered increasingly as technology advances and public policies regarding these tests continue to be created.

CHAPTER FOUR

Germline Gene Therapy and Enhancement

Introduction

Unlike prenatal screening and diagnostic tests, gene therapy and enhancement involve the direct alteration of the human genome. Whereas prenatal screening and diagnostic tests allow certain embryos to be discarded in favor of others, gene therapy and enhancement have the potential to create the desired characteristics within an embryo from the start. Prenatal screening and diagnostic tests provide information which may result in the termination of a pregnancy given certain results from the test. Genetic modification could allow the creation of a specific pregnancy in the first place. Screening and diagnostic tests require decisions regarding what is. Genetic modification requires decisions regarding what could be.

Gene therapy is one of the most recent developments in the field of genetics and medicine and has been regarded as something which can drastically affect human health during this century. There are two types of gene therapy: somatic and germline. Somatic gene therapy is a matter of changing genetic material in an autosomal cell (i.e., in a cell that is not a sex cell). Germline therapy is a matter of changing the genetic material in a sex cell, or a gamete. The development of somatic gene therapy is further along than germline gene therapy, so a description of somatic gene therapy will provide greater understanding of the developments taking place in germline gene therapy. After developing a better understanding of what germline gene therapy is through an

explanation of somatic gene therapy, this chapter will examine important ethical issues regarding the use of germline gene therapy.

The underlying concept of somatic gene therapy is relatively easy to grasp; however, the manner in which the idea is realized is quite a feat. The basic concept of gene therapy is inserting genetic material into cells which will either prevent diseases from occurring or slow the progression of preexisting diseases. The insertion of genetic material into a target cell requires a ferry of sorts. Some type of carrier is needed in order to place genetic material that is extraneous to the cell into the cell. This carrier is known as a vector.[1]

The vectors which are currently used in gene therapy are categorized as two types: viral and non-viral (or DNA). Both viral and non-viral vectors have the ability to transfer genetic material directly into the human body. Non-viral vectors are more suitable to carrying large genes than viral vectors are. Also, because they lack a viral component, they pose less of a threat to a person's immune system than viral vectors do. Though non-viral vectors have certain advantages over viral ones, viral vectors are more efficient in delivering the desired genetic material to target cells. Various methods have been developed in order to transfer the genetic material from non-viral vectors into target cells, but despite advancement, viral vectors remain more efficient in delivering therapeutic genes than their non-viral counterparts. The very aspects of viruses which can make them so problematic for humans are the same ones which make them so valuable as resources for gene therapy. Viruses can be problematic because they have the

[1] Inder M. Verma and Matthew D. Weitzman, "GENE THERAPY: Twenty-First Century Medicine," *Annual Review of Biochemistry* 74, no. 1 (2005): 711–38, doi:10.1146/annurev.biochem.74.050304.091637.

ability to insert their own genetic material into host cells and then take advantage of the materials inside the cell to replicate and produce the proteins encoded in the viral genetic material. Gene therapy takes advantage of the fact that viruses can insert genetic material into target cells by first inserting the desired genetic material into the virus vector. At this point, the virus vector, now containing the therapeutic gene, is engulfed by the target cell and can then insert its genetic material into the target cell. The result is that therapeutic genetic material now exists in the target cell as opposed to merely residing in the viral vector. Various types of viral vectors are more properly suited to treat certain diseases than others, and recent clinical trials are delving into more applications of gene therapy. The potential applications of gene therapy appear to be ever-broadening.[2]

The modification of genes may take place either *in vivo* or *ex vivo*. *In vivo* modification requires directly subjecting a person to the genetic ferry where the carrier must find target genes and make alterations. *Ex vivo* modification involves removing cells that can differentiate into many types of cells (e.g., stem cells), altering these cells, and then returning the cells as a whole to the person in order for the therapeutic effects to be achieved.

Germline gene therapy in humans would involve similar techniques as those just described, but the target cells would be different. In germline gene therapy, the cells being targeted are either sperm or eggs cells that, if involved in the process of fertilization, would result in the creation of a zygote. The originally altered germ cells involved in fertilization would provide the genetic material from which the zygote develops. As the zygote develops and increases in number of cells, it will have cells with

[2] Dan Wang and Guangping Gao, "State of the Art Human Gene Therapy: Part II. Gene Therapy Strategies and Clinical Applications," *Discovery Medicine* 18, no. 98 (2014): 151-161.

genetic material matching that of the originally altered germ cells. The changes made in the sperm or eggs cells are thus transmitted to every subsequent cell that develops following the process of fertilization. It is for this reason that this chapter focuses on germline gene therapy. This type of therapy fundamentally changes the type of human being that results from the alteration, and it affects every subsequent human being produced through the altered lineage. Rather than changing specific types of cells in a person as somatic gene therapy does, germline gene therapy changes the nature of the cells that are in a human being from the very beginning of development.

As mentioned in chapter two, the technology associated with germline gene alterations is not at the point where it is viable for clinical use, but experiments and research are underway so that it may become available. There are significant ethical questions to ask regarding this technology. Not only this, but a better understanding of underlying values in society will be garnered by considering questions associated with this topic, whether germline gene therapy and/or enhancement in humans comes to fruition or not.

Germline Gene Therapy: Should It Be Banned?

The technology associated with germline genetic engineering is still under development. However, in April 2015, scientists published an article reporting a method for altering the genes of human embryos.[3] This method has yet to be conducted on viable human embryos due to stated ethical concerns,[4] but there are those who oppose further

[3] David Cyranoski and Sara Reardon, "Chinese Scientists Genetically Modify Human Embryos," *Nature*, April 22, 2015, doi:10.1038/nature.2015.17378.

[4] Ibid.

hindrances to the advancement of this technology and would advocate for its development so that it may become a clinically acceptable practice. One such person is Henry Miller. Miller played an important role in the licensing of human insulin and growth hormone in his service with the US Food and Drug Administration and went on to serve as the founding director of the FDA's Office of Biotechnology.[5] He provides the potential inheritance of sickle cell disease as an example of when germline gene therapy should be used.

Sickle cell disease is an autosomal recessive disorder. It causes the malformation of red blood cells, which, due to their non-circular shape, adhere to each other and cause blockages in blood vessels.[6] The diminishment of oxygenated blood that is able to flow through the vessels is a consequence of this blockage. Those who are born with sickle cell disease experience a number of difficulties and even face the possibility of death as a result of problems associated with the malformation of their blood cells. It is not surprising that according to Miller, the removal of the genetic material causing this disease and the addition of genetic material that prevents the misshaping of blood cells is an "appropriate—and, indeed, compelling—application."[7] As to those who discount the use of germline gene therapy in the future because it has not been perfected in the

[5] "Henry I. Miller," *Hoover Institution*, accessed February 21, 2016, http://www.hoover.org/profiles/henry-i-miller.

[6] Katharine Gammon, "Gene Therapy: Editorial Control," *Nature* 515, no. 7526 (November 13, 2014): S11–13, doi:10.1038/515S11a.

[7] Henry I. Miller, "Germline Gene Therapy: We're Ready," *Science* 348, no. 6241 (June 19, 2015): 1325–1325, doi:10.1126/science.348.6241.1325-a.

present, Miller strongly objects, questioning when it was they last witnessed someone with sickle cell suffer in the form of strokes, hemorrhages, and pain from the disease.[8]

It is not unprecedented for scientists to place a ban on the use of certain technology in the absence of assurance of the safety of that the technology. An example of this comes from the nascent stages of the very technology that now comprises a large part of the process of germline gene therapy. Known as recombinant DNA technology, this application of genetic understanding allows segments of DNA to be inserted into organisms in which they would not naturally be found.[9] The development of recombinant DNA technology in biology has been likened to the development of the atomic bomb for physics.[10] With both the development of recombinant DNA technology and the atomic bomb, entirely new realms were opened for the fields of genetics and physics, respectively. Accompanying these new realms were concerns regarding the wisdom of acting on these newfound discoveries and advancements. However, unlike the development of the atomic bomb, the development of recombinant DNA technology was in the eye of the public.[11] After its development, recombinant DNA technology was used to modify bacteria. The announcement of the genetic modification of a living organism (the first time this had been done) caused scientists involved with recombinant DNA technology to place a self-imposed ban on the use of genetic technology in this manner.

---

[8] Ibid.

[9] Guido Van Steendam et al., "The Budapest Meeting 2005 Intensified Networking on Ethics of Science," *Science and Engineering Ethics* 12, no. 4 (December 2006): 749, doi:10.1007/s11948-006-0067-y.

[10] Alex J Valentine, Aleysia Kleinert, and Jerome Verdier, "The 'Atom-Splitting' Moment of Synthetic Biology," *EMBO Reports* 13, no. 8 (August 2012): 677-679, doi:10.1038/embor.2012.95.

[11] Ibid.

This was considered an "unprecedented move in the world of biology."[12] However, it was also a relatively short-lived move. The ban itself took about a year of investigating in order to be issued, but it was only seven months after the ban when another conference (the Asimolar Conference on Recombinant DNA in February of 1975) was held which began the process of lifting the ban in light of the development of procedural safeguards.[13] The concern among scientists was that modified bacteria could result in disease or would be resistant to antibiotics if it was not contained in the lab.[14] One hundred forty researchers collaborated to determine proper procedures for handling the modified bacteria. They determined that the modified bacteria should be treated the same way that a high-risk lab would deal with dangerous viruses.[15]

Today, recombinant DNA technology comprises an important component of the science of genetics. One of its current applications has been aiding in the production of human insulin to treat diabetes. It is currently being used in the development of procedures on the frontier of science such as germline gene modification. What was at first considered potentially extremely hazardous has now become commonplace in the laboratory. It is no wonder there are those who suggest experimentation regarding germline gene modification continue. Though proponents of germline gene therapy recognize potential hazards, they also recognize potential life-changing advancements.

---

[12] Steendam et al., "The Budapest Meeting 2005 Intensified Networking on Ethics of Science," 752.

[13] Ibid., 753.

[14] Ibid.

[15] Ibid.

The question now is in regards to what has been made possible largely through recombinant DNA technology. The short-lived ban on the modification of living organisms via recombinant DNA technology was self-imposed by the scientific community and produced stringent guidelines. With these in place the technology was deemed acceptable and has become commonplace. Safety concerns (e.g., creating bacteria resistant to antibiotics) appear to have been the driving force behind the ban instituted in 1974. Similarly, safety concerns arise when considering modification of the human germline. For example, there are concerns regarding the effects germline modification will have on the generations succeeding the one initially modified. As much as is able to be determined without actually carrying out the process on human embryos, until modification takes place in a human embryo (and perhaps even after then), the effects of germline modification on the embryo as it develops are dubious. The effects on generations after the initial modification are even less certain. Though there is no way of telling exactly what the repercussions of the modifications will be on humans as they develop until they are actually tried, even if safety issues were of no concern, there are still other considerations that are pertinent to the question of whether germline gene modification ought to be technology that is employed upon its development or whether a ban on technology for the purposes of modifying the genes of the sex cells in humans would be more prudent.

Jürgen Habermas recognizes that throughout the history of medical technology, there is an oft-repeated pattern beginning with the development of technology, followed by debate regarding the technology, and concluded with an ultimate acquiescence to the technology. Habermas quotes Wolfgang van den Daele at length to describe the pattern:

> Time and again, from the beginning of vaccination and the first attempts at heart and brain surgery, going on to organ transplantation and the breeding of artificial organs and coming up again, today, with gene therapy, there have been debates over whether or not a limit had been reached, beyond which further extension of the instrumentalization of man cannot be justified even by clinical purposes. None of these debates has stopped technology.[16]

If gene therapy is merely another advancement in technology that produces unmerited fear in the public, then it seems it would only be a matter of time before any type of ban was deemed foolish and unnecessary. If, on the other hand, there are characteristics of gene therapy (in this case specifically germline therapy) which distinguish the process from other advancements in medical technology, those characteristics need to be made clear if germline gene therapy is to avoid being placed in the category of technological advances that were once rejected but are now customary.

Habermas provides a potential reason as to why germline gene therapy should not ultimately end up in this category. According to Habermas, altering genetic material in this way has the ability to alter people's moral status. Habermas focuses specifically on enhancement, but (as will be discussed later on) the distinction between therapy and enhancement is not a clear one. It seems that what Habermas proposes pertains to germline gene therapy generally. The reservation Habermas has regarding this mode of biotechnology is the effect it will have on the person who develops from the genetically modified sex cells and the relationship between this person and those who developed from unmodified sex cells. In thinking about the effects of germline modifications, Habermas draws upon the ideas of Ronald Dworkin and notes that "shifting the 'line between chance and choice' [that is, between what is inherited without choosing and

[16] Jürgen Habermas, *The Future of Human Nature* (Cambridge, UK: Polity, 2003), 25.

what is then done with what is inherited] affects the self-understanding of persons who act on moral grounds" because they are no longer the recipients of genetic material which came from "chance."[17] Peter Herissone-Kelly sums up the reservations Habermas has regarding germline modification nicely. He says the central component of Habermas' argument is that "genetically enhanced humans would have a sense of themselves as diminished in autonomy or agency as a result of their having been enhanced, and they consequently would be in some measure incapable of feeling responsible for the way in which their lives develop."[18] If this is the case, not only would it be problematic for the person genetically modified, but it would be problematic for those who were not in knowing how to relate to one another and in knowing how each should or should not be held accountable for actions.

Agneta Sutton, too, thinks germline gene therapy is problematic in ways that somatic gene therapy is not, but her approach is different than that of Habermas. She notes that somatic gene therapy would fall in line with the traditional use of medicine. In the Hippocratic tradition, the aim of medicine is "one of healing, or, if such is not possible, the alleviation of symptoms."[19] Sutton lumps germline gene therapy with prenatal screening and diagnostic tests that result in selective abortion because they all, in some way, deviate from the medical tradition of healing according to the Hippocratic Oath. Stefan F. Winter also opposes the use of germline gene manipulation, agreeing it

---

[17] Ibid., 28.

[18] Peter Herissone-Kelly, "Habermas, Human Agency, and Human Genetic Enhancement: The Grown, the Made, and Responsibility for Actions," *Cambridge Quarterly of Healthcare Ethics* 21 (2012): 202.

[19] Agneta Sutton, "A Case against Germ-Line Gene Therapy," *Ethics & Medicine: An International Journal of Bioethics* 29, no. 1 (2013): 17.

goes against the Hippocratic Oath, and applauds the Council of Europe's Convention on Human Rights and Biomedicine for banning germline gene manipulation.[20] Article XIII from the Convention on Human Rights and Biomedicine treats interventions on the human genome stating: "An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants."[21] This does not preclude the use of somatic gene therapy, but it does preclude germline gene therapy by way of the last clause. The first part of the statement alludes to ideals consistent with the Hippocratic Oath, while the part precluding germline gene therapy alludes to ethical questions that may be beyond its scope.

Germline Gene Enhancement

Thus far, the ethics surrounding the use of genetic reproductive technology have focused on germline gene *therapy*. However, it may also be possible to employ the same or similar technology in order to carry out germline gene *enhancement.* Distinguishing between therapy and enhancement poses a challenge. Some instances seem to fall readily into one category or the other, while others cause uncertainty about whether a distinction between therapy and enhancement can or should be made. Faith Lagay notes the facileness of recognizing an embryo altered for improved musical talent as an example of enhancement, or as she puts it, a process that lies outside the treatment purposes of

---

[20] Stefan F. Winter, "Our Societal Obligation for Keeping Human Nature Untouched," in *Engineering the Human Germline: An Exploration of the Science and Ethics of Altering the Genes We Pass to Our Children*, ed. Gregory Stock and John H. Campbell (New York: Oxford University Press, 2000), 116.

[21] Council of Europe, "Convention for Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Biomedicine: Convention on Human Rights and Biomedicine," *Kennedy Institute of Ethics Journal* 7, no. 3 (1997): 281, doi:10.1353/ken.1997.0021.

medicine.[22] Following the easy case is one that is more difficult. She asks readers to consider the case of an embryo that has been altered so as to provide an immune system that resisted the common cold and flu. This, she says, is not considered medical treatment, but it does seem to be a harder case to categorize than the musical talent example.[23] In considering which alterations constitute therapy and which enhancement, careful consideration must be given to the lack of a clear-cut distinction between the two.

The President's Council on Bioethics (PCB) under the presidency of George W. Bush considered this very distinction. The PCB was commissioned with the task of thinking about the uses and purposes of biotechnology and its recent or potential developments. Their report, *Beyond Therapy: Biotechnology and the Pursuit of Happiness*,[24] indicates that a distinction between therapy and something else will be made—something which evidently goes beyond the idea of therapy itself. One of the first subsections of the report is devoted to the idea of therapy versus enhancement. The report provides definitions for "therapy" and "enhancement" as a starting point. "Therapy" is defined as "the use of biotechnical power to treat individuals with known diseases, disabilities, or impairments, in an attempt to restore them to a normal state of health and fitness."[25] Alternatively, "enhancement" is defined as "the directed use of biotechnical power to alter, by direct intervention, not disease processes but the 'normal' workings of the human body and psyche, to augment or improve their native capacities

---

[22] Faith Lagay, "Gene Therapy or Genetic Enhancement: Does It Make a Difference?," *Virtual Mentor* 3, no. 2 (February 1, 2001), doi:10.1001/virtualmentor.2001.3.2.gnth1-0102.

[23] Ibid.

[24] President's Council on Bioethics (U.S.) and Leon Kass, eds., *Beyond Therapy: Biotechnology and the Pursuit of Happiness* (Washington, D.C: President's Council on Bioethics, 2004).

[25] Ibid., 15-16.

and performances."[26] The understanding of both concepts requires an understanding of what is the norm, since therapy is commonly viewed as that which brings an individual to a state of normalcy and enhancement as that which alters an individual already at a state of normalcy to something beyond it.

The nebulous nature of the concepts of "normal" and "healthy" is exactly why Leon Kass (chairman of the council) and other council members deem the therapy/enhancement distinction an insufficient means of addressing moral questions. There seem to be the more clear-cut cases of therapy (e.g., the alleviation of sickle cell disease), but then there are the ambiguous. An example given in the PBC report is that of characteristics that are normally distributed. The majority of the population falls within a certain range of a normally distributed characteristic and then there are increasingly fewer people in the ranges deviating (both above and below) the norm. The report specifically refers to intelligence as an example of a normally distributed characteristic that reveals the ambiguity of the idea of enhancement. Those on the lower end of the continuum may claim they are disadvantaged by being below the average, but those in the middle of the distribution may also claim they are disadvantaged due to those on the higher end with greater intelligence. If the distinction between therapy and enhancement is based on what is the norm, the council asks whether in this situation average intelligence serves as the all-important norm. If so, then those beneath the norm would be receiving "therapy" if alteration took place, while those with average intelligences would be undergoing "enhancement."[27] Is one denied the alteration because of his initial endowment? How

[26] Ibid., 16.

[27] Ibid., 18.

would standards be determined if those receiving "therapy" then change the average intelligence? These are the questions that arise when a distinction between therapy and enhancement is made and are questions the council recognizes in their report on biotechnology.

Michael Sandel, another member of the PCB, augmented his work with the PCB by writing *The Case Against Perfection: Ethics in the Age of Genetic Engineering*.[28] Here, he asks questions relating to what he calls genetic enhancement, which he contends people use "not to cure a disease but to reach beyond health, to enhance their physical or cognitive capacities, to lift themselves above the norm."[29] As previously mentioned, the distinction between therapy and enhancement is itself nebulous and not clearly defined; however, Sandel's purpose is to examine those instances in which disease or disability is not being prevented, but rather, those in which physical or cognitive abilities are being improved. He seems to be within the framework of the traditional distinction between therapy and enhancement, though he surely understands the limitation of this distinction having been a part of the PCB. Furthermore, Sandel focuses primarily upon the alteration of somatic cells. Even so, his thoughts regarding genetic enhancement more generally apply to genetic enhancement taking place in germline cells, as well.

In thinking about enhancement taking place via the germline, it is not enough, says Sandel, to object to the practice because it diminishes the autonomy of the life that develops from the genetic material. Rather than take the approach of liberal societies

---

[28] Michael J. Sandel, *The Case Against Perfection : Ethics in the Age of Genetic Engineering* (Cambridge, Mass: Harvard University Press, 2007), http://ezproxy.baylor.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=nlebk&AN=282827&site=ehost-live&scope=site.

[29] Ibid., 8.

which "reach first for the language of autonomy, fairness, and individual rights," Sandel suggests that dealing with the ethics of enhancement requires "confront[ing] questions largely lost from view in the modern world."[30] These are questions which teeter on the verge of the philosophical and theological, says Sandel, but he thinks asking them is the proper way of grappling with the ethics surrounding the use of genetic enhancement.[31] Sandel makes use of the example of enhancing athletes in their sports to convey many of his ideas. For example, genetically equipping an athlete with the ability to have an excellent jump shot diminishes that athlete's agency by increasing the attribution of success in his achievement to genetic enhancements rather than practice and hard work. This, however, is not the main issue. The main issue is the desire for mastery and control, which make appreciation for gifts and things beyond human control diminish or disappear altogether.[32] Sandel likens the use of enhancement to "the ultimate expression of the ethic of effort and willfulness, a kind of high-tech striving."[33] In a society like that of the United States, in which effort and self-sufficiency are applauded, genetic enhancement provides another means of striving. It allows the production of self-selected characteristics or, in the case of germline enhancements, characteristics chosen by parents or the "creators" of embryos. It provides one more way of bringing nature under control without having to lament or rejoice in what has been endowed naturally, in what has been acquired without choice, in what has been gifted.[34]

---

[30] Ibid., 9.

[31] Ibid., 9-10.

[32] Ibid., 27.

[33] Ibid., 29.

[34] Ibid.

Even if it is granted that the use of genetic enhancement diminishes or destroys the appreciation for that which is given and is beyond human control, it does not necessarily follow that people should *care* about losing a sense of giftedness in the world at the hands of dominion and mastery. Sandel claims these concerns do not belong to the religious alone. For them, it may be easy to recognize the importance of understanding that humans are not in total control and have received what they have because a Supernatural Agent ordained it. For the nonreligious and secular, however, Sandel claims that losing the appreciation of gift should still be a matter with which they are concerned because it will "transform three key features of [the human] moral landscape—humility, responsibility, and solidarity."[35] In brief, giving humans the ability to enhance their genes would create a type of *hubris* that would produce an unwillingness to accept the unbidden. Given the ability to control so much, Sandel thinks humans would lose the ability to restrain their desire for control, a prospect with a myriad of negative implications. One thing Sandel notes is that children would "remain indebted rather than responsible for their traits, though their debt would run more to their parents and less to nature, chance, or God."[36] Children who are enhanced or altered still receive something for which they are not responsible for choosing. However, parents' responsibilities increase with the choice to engage in gene therapy.

If germline enhancement becomes an option, parents are left with a huge responsibility of choosing to employ the technology or not when desiring to have children. Parents with access to prenatal screening and diagnostics already experience

[35] Ibid., 86.

[36] Ibid., 87.

the burden of technology, specifically relating to Down syndrome and other chromosomal abnormalities. Sandel writes:

> Prospective parents remain free to choose whether to use prenatal testing and whether to act on the results. But they are not free to escape the burden of choice that the new technology creates. Nor can they avoid being implicated in the enlarged frame of moral responsibility that accompanies new habits of control.[37]

Parents, even if they choose not to employ prenatal screening and diagnostic tests to make decisions about a pregnancy, still are burdened with the choice of choosing *not* to test. There is an immense weightiness to the decision when control over the termination or continuation of a pregnancy is given following the results of the test. This weightiness and responsibility which come from deciding about what already is would only increase when the decision is regarding what could be. The desire most parents have for their children to have "the best possible start in life,"[38] as Peter Singer puts it, becomes more complicated with the possibility of genetic enhancement. It could easily be argued that foregoing genetic enhancement would render a couple's child mediocre when they had the option to make him or her extraordinary. Those who refrain from genetic enhancement on religious, moral, financial, or other grounds would have yet another choice to defend in light of their responsibility to care for their children or give their children the best possible start.

Finally, concerning solidarity, Sandel claims that an increased responsibility for parents in using germline gene enhancement to alter their children would result in a decrease in solidarity. As medicine currently stands, those who are healthy are unable to

---

[37] Ibid., 89.

[38] Peter Singer, "Shopping at the Genetic Supermarket," in *Disability: The Social, Political, and Ethical Debate*, ed. Robert M. Baird, Stuart E. Rosenbaum, and S. Kay Toombs (Amherst, N.Y: Prometheus Books, 2009), 312.

attribute all of their health to themselves or the decisions their parents made. Were genetic enhancement to become the norm, "it would be harder to foster the moral sentiments that social solidarity requires" because a person's genetic nature would no longer be categorized as gift, but would be something for which credit can be taken.[39] When health is considered to be the result of gift, luck, or some other product outside personal control, helping those who have a less fortunate lot seems natural. People think, "That could have been me." If, on the other hand, health becomes something that is left largely to the devices of humans, that sentiment is removed, solidarity is diminished, and those who did not receive health via genetic enhancement may be left without the support of those who did. The ones left at the "bottom of society would be viewed not as disadvantaged, and so worthy of a measure of compensation, but as simply unfit, and so worthy of eugenic repair."[40]

The issue of decreased solidarity is tied to an increase in differences between those who choose to employ the technology of genetic engineering and those who do not. Supposing there were many who wished to use the technology were it to become available, the cost of the technology has the potential to create enormous rifts between the rich and the poor. Peter Singer favors the concept of a "genetic supermarket" in which consumers (parents) decide which traits they would like to select for in their products (children). Though this concept applies to prenatal diagnosis and abortion, preimplantation genetic diagnosis, and obtaining "genetically superior eggs, sperms, or embryos from people," Singer also acknowledges that a fourth option on the horizon is

---

[39] Sandel, *The Case Against Perfection,* 91.

[40] Ibid., 92.

the "genetic enhancement of our own embryos."[41] According to Singer, the strongest objection to the production of a genetic supermarket relates to Sandel's ideas regarding solidarity. The objection is that the genetic supermarket "is a threat to the ideal of equal opportunity."[42] Singer acknowledges that there is already a gulf between the opportunities held by the rich and those of the poor, but a genetic supermarket has the potential to exacerbate a pre-existing chasm. The question of justice arises in trying to determine whether people should have a right to germline gene engineering if it is deemed ethically acceptable and becomes available. Questions regarding who will have access to the technology and how that access will be granted are ones that will have to be considered. These questions harken back to the concerns Sandel raises regarding those who are left bereft of the technology of germline gene therapy by either choice or circumstance.

Conclusion

Germline gene therapy has the potential to enact enormous change in the realm of reproductive technology. With the development of this technology come hopes of eradicating genetic disorders such as sickle cell disease. However, the thought of developing and employing the technology causes others great concern. Some worry germline gene modifications would reduce the autonomy of those produced by the modifications. Others are wary of the unclear conceptions regarding what constitutes therapy and what enhancement. Seeking mastery to the point of *hubris*, reducing solidarity among humans, and losing the conception of giftedness are further concerns.

---

[41] Singer, "Shopping at the Genetic Supermarket," 326.

[42] Ibid.

This chapter implicitly suggests what a society values, but the discussion of eugenics in the following chapter provides a more overt avenue for understanding the values undergirding a society. Selective abortion following prenatal screening and diagnostic tests and germline gene therapy have both been implicated in a resurgence of a eugenic movement. The following chapter will examine the connection between eugenics and the genetic reproductive technologies examined thus far.

CHAPTER FIVE

The Return of Eugenics

Introduction

In the 1997 movie, *Gattaca*, a world set in the future keeps order and promotes advancement by maintaining a strict distinction between various members of society. Similar to a modern-day caste system in many ways, the order maintained in this society consists of two classes: the "valids" and the "invalids." The film follows the story of a family that consists of two boys. The oldest is an "invalid," while his younger brother is deemed a "valid." Vincent, the oldest, is conceived naturally. For his birth, Vincent's parents decide not to employ *in vitro* fertilization. This renders them without the opportunity to screen various embryos and leaves them bereft of options, consigned to whatever was conceived *in utero*. According to the futuristic tests conducted after his birth, Vincent's prospects for success in the world into which he was born are slim. He is myopic, has a congenital heart defect, and is expected to live just over thirty years. By virtue of his nature, he is relegated to the second tier of society. Vincent's parents are shown being turned away from a private school because Vincent is too great a liability and will not be covered by insurance. This is just the beginning of a series of limitations Vincent experiences as a result of genetic discrimination.

After seeing the dire consequences associated with natural conception, Vincent's parents decide to take advantage of the genetic technology available when creating their second child. A process similar to preimplantation genetic technology (described in the second chapter) is used in order to produce a child without Vincent's limitations. The

second child, Anton, is the result of an embryo that was selected for specific traits. Not only are certain diseases selected against, but traits like sex, eye color, and skin complexion are specifically selected. Anton develops into the child his parents were promised. Because of his superior genetic makeup, Anton has numerous opportunities available to him that are closed off to Vincent.

The movie progresses as it traces the life of Vincent and his pursuit of attaining a job as an astronaut. Though his genetic nature has technically precluded him from ever dreaming of qualifying for this position, Vincent's willpower and wit give him a chance. His actions and the development of his life cause viewers to question if, in this futuristic world, genes are granted too great an importance and humans are granted too much power in determining which types of people are worthy of coming into existence. It also promotes critical thinking about the technology available today and whether employing it leads to a type of genetic discrimination similar to what Vincent experiences in the movie.

History of Eugenics

Eugenics is defined as "the study of or belief in the possibility of improving the qualities of the human species or a human population, especially by such means as discouraging reproduction by persons having genetic defects or presumed to have inheritable undesirable traits (negative eugenics) or encouraging reproduction by persons presumed to have inheritable desirable traits (positive eugenics)."[1] Francis Galton, well-known for his contribution of the normal curve to the realm of statistics, was also the one

[1] "Eugenics | Define Eugenics at Dictionary.com," accessed March 9, 2016, http://www.dictionary.com/browse/eugenics.

to coin the word "eugenics" in 1883.[2] The Greek root of the word signifies "good in birth" or "noble in heredity."[3] Many of Galton's scientific endeavors were concerned with heritable traits. Many of his important contributions to the discipline of statistics were closely tied to his study of the heritability of certain traits in the human population. It was in studying the heritability of height and other traits that Galton conceived of the notions of regression and correlation, two integral components of the statistical world today.[4] Galton was intrigued by the notion of talents and intelligence being a product of ancestral descent and combined this notion with his mathematical prowess in his book, *Hereditary Genius.* The opening sentences of the book highlight what he thought should be the social implications if traits like intelligence are passed from one generation to the next:

> I propose to show in this book that a man's natural abilities are derived by inheritance, under exactly the same limitations as are the form and physical features of the whole organic world. Consequently, as it is easy, notwithstanding those limitations, to obtain by careful selection a permanent breed of dogs or horses gifted with peculiar powers of running, or of doing anything else, so it would be quite practicable to produce a highly-gifted race of man by judicious marriages during several consecutive generations…I conclude that each generation has enormous power over the natural gifts of those that follow, and maintain that it is a duty we owe to humanity to investigate the range of that power, and to exercise it in a way that, without being unwise toward ourselves, shall be most advantageous to future inhabitants of the earth.[5]

---

[2] Daniel J. Kevles, *In the Name of Eugenics: Genetics and the Uses of Human Heredity*, 1st ed (New York: Knopf, 1985), ix.

[3] Ibid.

[4] Ibid., 17.

[5] Francis Galton, *Hereditary Genius: An Inquiry into Its Laws and Consequences,* [2d ed.] (London, 1914), 1, http://hdl.handle.net/2027/mdp.39015002147646.

Galton held few qualms about treating the human race like the sweet-pea plants that he studied, desiring that the good should increase in number, while the bad be slowly diminished.[6]

In order to accomplish this feat, two lines of eugenics developed. The encouragement and promotion of mating among the fit is along the positive eugenic line. The discouragement and prevention of mating among the unfit is along the negative eugenic line. Both lines of eugenics point toward the common goal of bettering the human race. The characteristics of those in question, be it race, intelligence, or some other heritable trait, determine whether positive or negative eugenic practices are employed. For those with traits deemed desirable, positive eugenics apply. Negative eugenic practices occur among those with traits deemed undesirable.

Galton's eugenic thoughts, made known in the late nineteenth and early twentieth centuries, did not take long to gain in popularity. Galton's ideas began to gain traction in his own land of Britain, but they also began to gain popularity and credence in the United States and elsewhere. In Britain, Karl Pearson took up the mantel of Galton's eugenic ideas. Pearson would come to associate Darwinism with the ascendency of the fittest nation and proposed Parliament promote legislation that favored the eugenically desirable.[7] In Britain, the Eugenics Education Society (later renamed the Eugenics Society) was founded at the beginning of the twentieth century. The United States had established something similar with Charles Davenport at the helm. Davenport's Eugenic Record Office, a precursor to the American Eugenics Society that was founded in 1923,

[6] Kevles, *In the Name of Eugenics,* 3.

[7] Ibid., 23, 34.

advocated Galton's ideas in the United States as he sought to provide a means by which the reproduction of the unfit would end.[8]

Talks of sterilization (a form of negative eugenics) followed soon after the establishment of these organizations in both countries, with legislative support in the United States. A poll conducted by *Fortune* in 1937 showed that "sixty-three percent of Americans endorsed the compulsory sterilization of habitual criminals and that sixty-six percent were in favor of sterilizing mental defectives."[9] Henry Goddard, an American eugenicist, published a book earlier in the century that renders these results unsurprising. Goddard's book, *The Kallikak Family*, follows two distinct lineages that ensued following a Revolutionary War soldier's dalliance with a "feeble-minded" barmaid and a marriage with a woman from a good family.[10] The latter resulted in "another line of descendants of radically different character" than the first.[11] The family tree from the marriage is largely free from alcoholic, criminal, sexually promiscuous, and feeble-minded members. The same could not be said for the descendants resulting from the dalliance with the tavern girl. Goddard concluded that a high percentage of America's criminals were of feeble-minded descent. The feeble-minded were either a burden to

[8] Michael J. Sandel, *The Case Against Perfection : Ethics in the Age of Genetic Engineering* (Cambridge, Mass: Harvard University Press, 2007), 64, http://ezproxy.baylor.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=nlebk&AN=282827&site=ehost-live&scope=site.

[9] Kevles, *In the Name of Eugenics,* 114.

[10] Henry Herbert Goddard, *The Kallikak Family;a Study in the Heredity of Feeble-Mindedness,* (New York, 1912), http://hdl.handle.net/2027/uc1.b3972985.

[11] Ibid., 29.

society due to their dependence on others, or they burdened society with their criminal actions.[12]

The decade following publication of *The Kallikak Family*, the Supreme Court decision in *Buck v. Bell* gave the support of the U.S. Constitution to forced sterilization in the United States. Carrie Buck, a woman placed in a mental asylum, faced involuntary sterilization from those who deemed her an "imbecile."[13] During a time when eugenics was popular but sterilization considered constitutionally dubious, the Supreme Court gave credence to compulsory sterilization in an 8-1 decision. Referring to Carrie, Carrie's child, and Carrie's mother, Justice Oliver Wendell Holmes stated that "three generations of imbeciles are enough."[14] The ideas first proposed by Galton had developed further and transcended borders, finding their way into the laws of nations just decades later.

The negative eugenic practice of forced sterilization was supplemented with the positive eugenic practice of encouraging "fitter families." In the early 1920s, posters from the YMCA's Keeping Fit campaign explained that children inherited many qualities and that in order "to be strong, keen, efficient and great, there must be good blood back of them."[15] Looking at the traits of a spouse is important but insufficient. In order to produce the fittest families, it is important that "good blood" extend back to earlier generations. The promotion of certain children ("strong, keen, efficient and great") was a

---

[12] Ibid., 54-56.

[13] Victoria Nourse, "History of Science: When Eugenics Became Law," *Nature* 530, no. 7591 (February 25, 2016): 418, doi:10.1038/530418a.

[14] Quoted in Nourse, 418.

[15] Amy L. Hall, "Good Breeding: The Eugenics Temptation," *The Christian Century Foundation* 121 (2004): 24.

promotion of certain marriages and reproductive couples. Stunting reproduction among the feeble-minded was only a component of creating the America that many desired; it had to be accompanied by fostering the reproduction of the good-blooded with positive eugenic practices.

Well-known instances of positive and negative eugenic practices took place in Nazi Germany in the middle of the twentieth century. At the start of the twentieth century, Germany saw its birth rates declining drastically. The net reproduction rate in 1933 was 0.71, well below replacement rate.[16] This context provides aid in understanding some of the laws Germany implemented in the following years, though it certainly does not explain each component of every action. While discussions regarding the declining birthrate were taking place, there was also talk of eugenics or "racial hygiene," which resulted in the belief that only certain types of people should be the ones causing the birthrate to increase, while others should be sterilized and prevented from giving birth.[17] Adolf Hitler describes a racial purity he believed to be in accordance with nature in his book, *Mein Kampf*. He claims that mating which is not between two of exactly the same level is "contrary to the will of Nature for a higher breeding of all life."[18] This type of thinking led to the implementation of laws that affected Aryans and non-Aryans (specifically, Jews) differently. David, Fleischhacker, and Hohn describe the merging of eugenics and racial hygiene as the "central core of Nazi population politics."[19]

---

[16] Henry P. David, Jochen Fleischhacker, and Charlotte Hohn, "Abortion and Eugenics in Nazi Germany," *Population and Development Review* 14, no. 1 (1988): 88, doi:10.2307/1972501.

[17] Ibid., 88.

[18] "Mein Kampf: Nation and Race," accessed March 10, 2016, http://www.hitler.org/writings/Mein_Kampf/mkv1ch11.html.

[19] David, Fleischhacker, and Hohn, "Abortion and Eugenics in Nazi Germany," 89.

A result of Nazi politics was strict limitations of abortions, but only for those of Aryan descent.[20] In an attempt to increase the Aryan race and decrease the number of Jews, abortions by Aryans were forbidden, while those of Jews were allowed. Abortion laws were accompanied by sterilization laws, as well. In 1933, the Law for the Prevention of Hereditary Diseases in Future Generations was enacted, stipulating that people suffering from hereditary deafness or blindness, congenital cognitive disabilities, epilepsy, schizophrenia, and other traits deemed undesirable were to be prevented from producing offspring.[21] In this regard, the actions of Nazi Germany were not unlike those of the United States, as evidenced by *Buck v. Bell*.

The New Liberal Eugenics and Its Supporters

Eugenics is not something which can simply be relegated to descriptions of the past in history textbooks. The question today is not whether eugenics exists, but rather, what is the nature of the eugenics that exists. A distinction between the old and new (or liberal) eugenics is made by some. Current proponents, unabashedly acknowledging the existence of a new eugenics, claim that the eugenics that exists now differs from that which is associated with Nazi Germany and instances such as sterilization laws in the United States. Nicholas Agar, a proponent of liberal eugenics, claims that contemporary eugenics differ in important ways from the eugenics practiced in the early to mid-twentieth century. The distinction he makes rests primarily upon a distinction between authoritarian and liberal approaches to procreation. Agar claims that "old fashioned authoritarian eugenicists sought to produce citizens out of a single centrally designed

[20] Ibid., 94.

[21] Ibid.

mould, [but that] the distinguishing mark of the new liberal eugenics is state neutrality."[22] With the new eugenics, parents are given options and can decide for themselves what they wish for their children without intervention of the government. Old eugenicists "would do away with the ordinary procreative freedoms. Liberals instead propose radical extensions of them."[23] In the past, the state attempted to bring about its ideals via sterilization and the promotion of selective breeding. New eugenicists stray from the restrictive nature of the past by promoting parental choice and encouraging reproduction to take place as each individual couple sees fit.

Another claim made about differences between the new eugenics and the old is that the current eugenics is based on sound science, while the eugenics of the early twentieth century was based upon faulty and unfounded scientific assumptions. Agar likewise claims the motives are different. The primary distinction made by Agar rests upon who is making the decisions regarding reproduction and why. Individual parents make private choices free from government coercion, and their choices are made according to personal values and preferences. Although this sounds like a substantive difference between the two, even Agar notes how easily the new can slip into the old (if it has not already done so). After mentioning that those who wish to place constraints upon the use of genetic reproductive technologies will have a difficult time arguing for proposals of limitations, he notes the facility with which the new eugenics can become indistinguishable from the old. Certain suggestions regarding the way genetic reproductive technology should be used can lead to claims regarding which types of

[22] Nicholas Agar, "Liberal Eugenics," *Public Affairs Quarterly* 12, no. 2 (1998): 137.

[23] Ibid.

humans are worth producing. Were this to take place, the distinction between old and new eugenics would be dissolved in many regards. Agar notes this difficulty by alluding to the popular voices claiming technology should be used to avoid diseases or to do what is possible to promote a certain quality of life:

> As we will see, popular suggestions such as the avoidance of disease or the securing of quality of life threaten to smuggle into individual choices substantive views about human worth. If so, citizens will end up being engineered in accordance with a dominant set of values after all, and the new eugenics will collapse into the eugenics of old.[24]

According to Agar, requisite for the new eugenics to be different from the old is the maintenance of absolute autonomy of the parents in making their decisions. Yet even so, if parents all begin to make the same choices (e.g., a child who is blind and deaf is not one they wish to bear), then decisions are being made about what constitutes a valuable human being and what constitutes a pregnancy worth continuing.

Michael Selgelid, like Agar, does not deny the resurgence of eugenics in the use of new genetic technologies. He notes that there are a number who believe eugenics is a result of new genetic technology, but these same people who acknowledge it (e.g., Kitcher, Buchanan, Agar) "do not believe that eugenics *per se* is something we need to fear."[25] Selgelid notes that the history of eugenics makes it unsurprising that the term is used pejoratively, but he also notes that its current uses, though eugenic, are not necessarily bad.[26] As far as morally acceptable uses of abortion are concerned, Selgelid thinks termination following prenatal diagnosis is acceptable. Selgelid, relying upon

---

[24] Ibid.

[25] Michael J. Selgelid, "Moderate Eugenics and Human Enhancement," *Medicine, Health Care and Philosophy* 17, no. 1 (June 1, 2013): 6, doi:10.1007/s11019-013-9485-1.

[26] Ibid.

Ronald Dworkin, says abortion following prenatal diagnosis of a severe disability is "among the clearest cases where termination of pregnancy should be considered morally acceptable."[27] Alluding again to Kitcher and Buchanan, he says, "If prenatal diagnosis and selective abortion is ethically acceptable, then eugenics per se is not necessarily a bad thing."[28] Chapter three shows that the ethical acceptability of prenatal diagnosis and selective abortion is, of course, contested. Selgelid's primary concern regarding the new eugenics is not primarily the prevention of the births of certain types of people. He does, however, see potential for concern in the realm of enhancement. Granting parents the reproductive liberty of enhancing their children has the potential to undermine equality, and this, thinks Selgelid, is the primary question before the new eugenics. That enhancement technology may only be available to some and may help specific people at the detriment of others is the primary problem facing the new eugenics.[29] He, unlike Agar, is unconcerned with a predominate set of views causing the new eugenics to fall into the old. Instead, the biggest threat he sees to the new eugenics is the enhancement of reproductive liberty to the detriment of social equality.

Against The New Eugenics

Whereas the history of the so-called "old eugenics" includes the prevention of abortion among certain races, the story of what is being called the "new eugenics" includes the promotion of abortion in certain instances. Amy Laura Hall describes how questions of the old eugenics are resurfacing in the new. The old eugenics made a

---

[27] Ibid.

[28] Ibid.

[29] Ibid., 9.

distinction between "grade A" people and the rest, desiring that those of the "grade A" breed while others refrain from producing children.[30] The new eugenics claims to be different in this regard. Rather than prevent people from breeding, it merely suggests that people use the technology available to them to create children of the highest grade possible or of a grade they find desirable. Maintaining the grading system metaphor, it is as though those with disabilities of certain kinds are considered failing, assigned the grade of F. Parents, when they have the technology available to know which of their pregnancies would result in such a birth, are unwise to forego the technology or to use the technology without making the subsequent choice of terminating an "F" pregnancy. Hall refers to the *Buck v. Bell* case to make her point regarding the deficiency of the claim that genetic reproductive technology of today is not a new form of eugenics. Recalling the statement given from Justice Holmes regarding "three generations of imbeciles," she suggests that the more precise science of genetics and the options it offers do not preclude it from being eugenic. The new reproductive genetic technology of the past few decades would allow the genes of Carrie Buck's daughter to be examined in detail so that her genetic report card could be determined. Furthermore, had the genetic reproductive technology of today been available and used then, baby Buck (as Hall calls her) could have been screened for Down syndrome, Tay-Sachs, and the like, and upon the return of negative tests for these conditions, her birth could have taken place without fear of adding a burden to society or creating a child who will suffer.

[30] Hall, "Good Breeding: The Eugenics Temptation," 24.

Yet, the greater scientific accuracy and scope of the current genetic era begs new questions and does little to address lingering ones. Hall strings together a number of questions that shed light on the current use of genetic reproductive technology:

> This rendition of the new eugenics begs the basic question of eugenics: What if baby Buck had flunked out of kindergarten and every subsequent grade? What if she had eventually given birth out of wedlock? Would that have proven Holmes correct? Was it wrong to sterilize Carrie Buck only because, as it turned out, her child was not an "imbecile"? Was the old eugenics wrong simply because it was scientifically inaccurate? Was it wrong because it was state-coerced rather than freely chosen? Or was it wrong for a more fundamental reason, one that also implicates the new eugenics: because eugenics seeks fundamentally to locate a human being on a grid of calculable worth?[31]

The current use of genetic reproductive technology *does* grant parents, and mothers specifically, greater control over their births. Because technology like preimplantation genetic diagnosis is not mandated by the state and is an option parents make for themselves, it is, in some ways, distinguishable from old eugenic practices. However, differences like this one do not distinguish the current practices of genetic reproductive technology from the old eugenic practices entirely. When the question being asked is the last one that Hall asks (whether the new genetics erroneously places humans on a grid of calculable worth), the differences between current genetic reproductive technologies and previous eugenic practices are not enough to entirely distinguish the two. Current genetic reproductive technologies may take a different form than old eugenic practices and include a number of differences, but Hall suggests these differences are at a superficial level. When considering the fundamental values underlying the uses of prenatal screening and diagnostic tests with subsequent terminations of pregnancies, the screening of embryos in the process of preimplantation

[31] Ibid., 26.

genetic diagnosis, or the alteration of the genetic inheritance of a person through germline gene therapy, those underlying values, Hall argues, do not differ from the eugenics of the twentieth century. Despite all the changes that have taken place, at the core, that which is taking place now with certain uses of genetic reproductive technology is simply the old eugenics under a different guise.

Prenatal Testing and Negative Eugenics in Abortion

Prenatal screening and testing followed by abortion can be likened to a modern form of negative eugenics. Historically, negative eugenics prevented the coming together of certain people in the act of creating children. Currently, negative eugenics prevents the birth of certain children. It is as though the influence of negative eugenics has moved one step further down the line of the reproductive process. Rather than prevent conception, it now prevents birth.

Negative eugenics is often associated with race and social class, but it is also deeply associated with disability. Mary Meehan cites examples of philosophers as early as Plato and Aristotle to demonstrate how long eugenic thinking regarding those with disabilities has been taking place, claiming it is the deepest bias associated with eugenics.[32] Arguments for the prevention of those with disabilities vary, but one Meehan brings to the surface is economic motivation. She notes that eugenicists of the past appealed to the tax burden that increases with the births of those who have disabilities and require more care than the average citizen. This economic appeal is one Meehan believes to have continued throughout time as changes have been made in both eugenics

[32] Mary Meehan, "The Triumph of Eugenics in Prenatal Testing," *Human Life Review* 35, no. 3 (Summer 2009): 29.

and technology.[33] An example of this line of thinking from the 1970s comes from eugenicist Frederick Osborne who explains one of the reasons why the technology of prenatal testing and abortion was appealing to some. Though technology allowed the testing and termination of pregnancies affected by Down syndrome, it also allowed those affected by Down syndrome to live with a greater life expectancy. Osborn, as quoted by Meehan, laments that "with modern medical care they [those with Down syndrome] can be carried through to an age of thirty to forty years at an expense estimated at over $200,000 for each case of mongolism [Down syndrome]."[34]

The appeal to cost is easily applied to the defense of prenatal testing and termination today. Defenders of prenatal testing and subsequent abortion may claim families should have the choice to avoid giving birth to a child who will be economically draining on them as a familial unit. It can be argued that other members of society should have the choice to avoid supporting those who are affected by disability. If society is expected to bear the burden collectively to aid these families, those with beliefs like Osborn will be dissatisfied with the burden placed on society for problems which are not their own. Tristram Engelhardt recognizes the difficulty in making support for the disabled compulsory. He notes that society makes a distinction between the unfortunate and the unfair. That which is unfortunate will hopefully be responded to with compassion, but that which is unfair provides grounds for support that can be mandated by the state.[35] The goodness of charity toward those with disabilities is easier to establish

[33] Ibid., 30.

[34] Ibid., 31.

[35] H. Tristram Engelhardt, "The Unfair and the Unfortunate: Some Brief Critical Reflections on Secular Moral Claim Rights for the Disabled," in *Philosophical Reflections on Disability*, ed. D.

than the necessity of support via public policy and law.[36] The economic reason for preventing the births of certain types of people remains a concern today.

The promulgation of the eugenics movement in the earlier part of the twentieth century that sought to prevent the propagation of the disabled or "defective" into posterity via forced sterilization found another avenue in the later decades of the century. Rather than forced sterilization, the births of the disabled could be prevented with prenatal testing and abortion. Selgilad, referred to earlier, makes this clear. He says the practice of selectively terminating those diagnosed with severe disabilities fits within the category of eugenics, as it seeks to "improve human lives by employing an understanding of heredity in the exertion of control over who gets born or who reproduces."[37] Meehan traces the connection between the desire to prevent the births of the disabled as expressed in the earlier part of the century with the technology developed later in the century and widely employed today. By noting the ideas of Glanville Williams, a British eugenicist who stated that the "breeding of defectives is a horrible evil…far worse than any that may be found in abortion," Meehan demonstrates how the employment of different technology allowed the unaltered survival of numerous ideas.[38] Whether economic reasons are the primary justification or not is difficult to say, but the resistance to the birth of the disabled is one that has persisted into the twenty-first century. And like the

---

Christopher Ralston and Justin Ho, Philosophy and Medicine, v. 104 (Dordrecht ; New York: Springer Verlag, 2010), 229.

[36] Ibid., 233.

[37] Selgelid, "Moderate Eugenics and Human Enhancement," 6.

[38] Meehan, "The Triumph of Eugenics in Prenatal Testing," 35.

different technological avenues availed in the twentieth century, technology of the current century still provides pathways for the resistance to the birth of the disabled.

Germline Genetic Enhancement and Positive Eugenics

Whereas prenatal screening and diagnostic tests can be likened to historically negative eugenic practices, germline genetic enhancement can be likened to positive ones. With germline genetic enhancement, there is the possibility for the promotion of certain qualities. The Keeping Fit campaign promoted certain couples. Germline genetic enhancement has the potential to promote certain individuals.

However, as noted earlier, proposed differences between the old eugenics and the liberal eugenics cause some to hold the claim that the latter is morally acceptable even though the first resulted in morally abhorrent practices. Proponents of genetic enhancement say that to remove the coercive element from the process of reproductive decisions "is to remove the very thing that makes eugenic policies repugnant."[39] However, Sandel wonders whether the only questionable component of eugenics is its coercive nature. He suggests that despite the removal of a coercive element, liberal eugenics remains objectionable. Before examining other objections, it should be noted that Sandel is not convinced that the use of genetic reproductive technologies that allow for enhancement would not result in government intervention and coercion. To explain this, Sandel considers the concept of increasing intelligence among children. Those who are in the liberal eugenics camp care not whether enhancement occurs via education or genetic enhancement, so long as the enhanced capacity keeps the child's autonomy intact by not steering the child toward any one life plan. Sandel argues that given parents'

[39] Sandel, *The Case Against Perfection*, 68.

obligation to see to it that their children's well-being is promoted, an enhancement that becomes available genetically moves from a choice to an obligation, and just as states require parents ensure their children go to school, so too could they require that parents do not deprive their children of genetic enhancement to increase intelligence were such an option to become available.

If the genetic enhancement of the liberal eugenics movement were to result in options for parents that were untainted by coercion or force, Sandel would still find the practice objectionable. Two sperm banks are compared in order to ascertain whether a problem still exists with genetic enhancement even if it is consumer-driven. The first sperm bank, The Repository for Germinal Choice founded by Robert Graham, was not created in order to tailor to parents' preferences. Rather, it was created with the intent of improving the genes of future generations. The founder intended to collect the sperm of Nobel Prize-winning scientists but had to settle for "sperm of young scientists of promise" when Nobel winners refused.[40] The other sperm bank, California Cryobank founded by Dr. Cappy Rothman, is still in operation today. It is a for-profit company driven by the desires of consumers. A look at their website shows a number of profiles that can be sorted by height, hair color, ethnic origin, religion, blood type, and more.[41] Rothman claims to have "nothing but disdain for Graham's eugenics. And yet the standards Cryobank imposes on the sperm donors it recruits are no less exacting than

[40] Ibid., 73.

[41] "California Cryobank," accessed March 14, 2016, https://www.cryobank.com/search?listview=0#.

Graham's."[42] Sandel argues that anyone who has qualms about Graham's bank should have qualms about Rothman's. He asks:

> What, after all, is the moral difference between designing children according to an explicit eugenic purpose and designing children according to the dictates of the market? Whether the aim is to improve humanity's "germ plasm" or to cater to consumer preferences, both practices are eugenic insofar as both make children into products of deliberate design.[43]

This suggests that a person in favor of the market-driven practices of genetic enhancement is not as different from the supporter of old eugenic practices as one would like to think. In both instances, whether driven by the state or by individual persons, the genetic makeup of the next generation of children is deliberately manipulated by encouraging certain types of births and discouraging others.

Conclusion

This encouragement of specific births and discouragement of others is played out to the extreme in the opening example of *Gattaca*. While it is clear differences between today's world and the world of Gattaca exist, there are fundamental similarities which are cause for contemplation and concern. While those conceived naturally may not be categorized as "invalids," something is implied by offering abortions following prenatal screening and diagnostic tests and seeking to develop germline gene therapy. To simply give the option, without state coercion, implies there is reason for some births to be avoided and others to be promoted. Like Hall mentioned, eugenics seeks to place humans on a grid of calculable worth.[44] However, how worth is assigned and who gets to

---

[42] Sandel, *The Case Against Perfection*, 73-74.

[43] Ibid., 75.

[44] Hall, "Good Breeding: The Eugenics Temptation," 26.

make these decisions is unclear and worth examining further. The following chapter addresses some of these issues.

CHAPTER SIX

Christian Considerations

Introduction

The various views presented in this thesis regarding genetic reproductive technology demonstrate the great complexity which marks this realm of bioethics. Varying opinions about the purposes of the technology lend themselves to widely divergent views regarding its proper uses. Thus far, largely secular views have been presented. In a pluralistic society like that of the United States, religious ideas about genetic reproductive technology may be helpful in aiding the way people view the technology, but they face significant barriers in affecting public policy. This chapter will recount what genetic reproductive technology can offer. Following this will be a discussion of three concepts: the gratuity of life, sharing life together in dependence, and social justice. None of these is an exclusively Christian idea; however, each brings important considerations to mind for the Christian concerned with an appropriate response to the development and uses of genetic reproductive technology.

What Genetic Reproductive Technology Offers

Genetic reproductive technology has much to offer. Because of recent developments, technology allows the detection of multiple diseases and conditions prenatally. As mentioned in chapter two, the detection of chromosomal abnormalities in a fetus is possible through amniocentesis, and the genetic makeup of an embryo can be determined through preimplantation genetic diagnosis. Ascertaining various

characteristics of a fetus or embryo can allow parents to make preparations for birth that they would not otherwise have cared or known to make. For example, the mother who learns she is pregnant with a child who has cystic fibrosis has the ability to seek out other parents who have been through her situation. She can also prepare, at least somewhat, for the medical journey she and her child will undergo in managing a life with cystic fibrosis. In addition to seeking potential emotional support before the birth of a child with a disability, parents who receive a diagnosis prenatally have the ability to make practical preparations before the arrival of their child.

Because of prenatal screening and diagnostic tests, parents have the ability to put into place a number of helpful plans before the birth of their child. They can arrange for childcare for other children they may have. They may also start looking at childcare for the child which is about to be born who may require a unique caretaker or setting. With the knowledge provided via screening and diagnostic tests, parents can also make financial arrangements. Contacting insurance agencies and learning about governmental support available to parents of those with disabilities are steps that may be taken before birth occurs. This allows parents to have fewer things with which to concern themselves once their child is born. The support and preparation made available before the birth of the child with a disability would not be possible without recent developments in genetic reproductive technology.

Genetic reproductive technology can lead parents to prepare for a certain type of birth for which they would not otherwise have known to prepare, but it can also lead parents to terminate births for which they would not otherwise had a reason to abort. The category of abortion known as “selective abortion” is made possible largely by

technology such as prenatal screening and diagnostic tests. The majority of conditions tested during prenatal screening and diagnostic tests do not have cures.[1] Though screening and diagnostic tests could allow parents to make some preparations before birth, they do not usually allow treatment for those conditions to be given. Some parents, rather than have a child with an incurable condition, opt to terminate a pregnancy in which the condition has been made known by genetic reproductive technology.

If germline gene therapy and enhancement are developed, it would be possible for certain conditions to be removed from families. Though a cure for something like sickle cell disease would not be the result, the prevention of passing on the genes contributing to sickle cell would be possible. Proponents of the development of germline gene therapy advocate its advancement in the hopes of "rid[ding] families of monstrous genetic diseases."[2] As discussed in chapter three, drawing a line between therapy and enhancement is a difficult task. However, were germline genetic enhancement employed, it would be possible for families to not only prevent certain traits, but they would be able to promote traits they found desirable.

These are some of the benefits possible or hoped to be rendered possible by the development of genetic reproductive technology. Bearing the various applications of this technology in mind, concepts such as the gratuity of life, the need to share lives of dependency with each other, and social justice should also be considered by those wishing to make an informed decision regarding the proper and/or improper uses of

[1] Gwen Latendresse and Angela Deneris, "An Update on Current Prenatal Testing Options: First Trimester and Noninvasive Prenatal Testing," *Journal of Midwifery & Women's Health* 60, no. 1 (January 1, 2015): 24–36, doi:10.1111/jmwh.12228.

[2] Henry I. Miller, "Germline Gene Therapy: We're Ready," *Science* 348, no. 6241 (June 19, 2015): 1325–1325, doi:10.1126/science.348.6241.1325-a.

genetic reproductive technology. For Christians, some of these concepts take on a greater meaning or are more easily incorporated into a personal life of following Christ than they are into a nation as a whole.

The Gratuity of Life

Amy Laura Hall, who hints at the gratuity of life in her discussion of the Carrie Buck sterilization case mentioned in chapter four, makes it explicit in relating the story of Joanna Jepson.[3] Where arguments against positive eugenics may gain a more favorable hearing with the public, Hall thinks questioning the regular practices of screening and aborting fetuses or screening and discarding embryos is more difficult and "may call less for a publicly plausible moral argument than for a publicly embodied witness."[4] Jepson provides what Hall thinks may be the necessary public witness against negative eugenic practices. Jepson, who was born with a facial disfigurement, legally contested an abortion made on the grounds of a cleft palate diagnosis. The abortion took place after the English legal cutoff of twenty-four weeks, during which an abortion may only occur in certain circumstances regarding the mother (i.e., serious risk to her mental or physical health) or when "there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped."[5] Jepson argues that the diagnosis of a cleft palate does not constitute a serious handicap, but she also seeks to alter the perception of life itself. She seeks to help others see the giftedness of

---

[3] Amy Laura Hall, "Public Bioethics and the Gratuity of Life: Joanna Jepson's Witness Against Negative Eugenics," *Studies in Christian Ethics* 18, no. 1 (April 1, 2005): 15–31, doi:10.1177/0953946805052114.

[4] Ibid., 17.

[5] "Abortion Act 1967," accessed April 2, 2016, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215147/dh_132849.pdf.

life, whether that gift be in a person with a cleft palate, with Down syndrome, or some other disability.

Hall refers to the Beyond Therapy report by the President's Council on Bioethics and notes the distinction made between "screening out," "choosing in," and "fixing up."[6] She notes that the report focuses on the latter two, as screening out (i.e., prenatal tests and selective abortion) does not typically result in a child considered to be better than normal but simply in one who is normal. Hall does not blindly accept the distinction, noting:

> There is reason to pause with this early distinction. Is the primary problem the pursuit of 'better than normal children' generally? Or, is there a more fundamental problem with the pursuit of a child 'better' than the child born by chance? Couples do use 'screening out' in order to secure a 'better' baby than the terminated foetus or the randomly implanted embryo.[7]

Pausing to evaluate whether enhancement is really the source of concern as opposed to "therapy," Hall is able to question whether the root of the problem lies in trying to create humans who are better than average or if it is a problem more deeply rooted than that. Couples who engage in the process of screening out do not necessarily do it with the hopes of then having a child better than the average, but they do, Hall says, engage in the process in the hopes of having a child better than the one they received by chance or, for the Christian, one knit together by God in the mother's womb. Hall recognizes that a discomfort with positive eugenic practices like genetic enhancement does not preclude a discomfort with negative eugenic practices like prenatal screening and diagnostic tests followed by selective abortion. She also recognizes that with both

[6] Hall, "Public Bioethics and the Gratuity of Lif,." 21.

[7] Ibid.

practices, life is not counted as gratuitous. This, for both practices, is where she thinks the problem exists.

Turning to Jepson's own life as an example, Hall expounds upon the notion of the gratuity of life. One element of Jepson's life that gave her a greater voice in arguing against the abortion of those with cleft palates is that she is herself physically attractive following surgery correcting a facial deformity. Her ugly-duck-to-swan story has caused some to agree with Jepson that abortion of those with a cleft palate should not occur, but Jepson resists this telling of her story. Whether the cygnet has the possibility "through the miracle of modern surgery, [to] become the swan" is of zero import.[8] What matters is that Jepson's life was given.

Jepson has a brother with Down syndrome. He does not have the ability to undergo surgery to somehow rid him of his chromosomal abnormality. Yet, his "worth cannot be plotted along the coordinates of aesthetics and economics."[9] Jepson claims that no person's life can be assigned value this way, "that the value of each life is, in a fundamental way, not up for appraisal."[10] Any life, because it is a life, is valuable. Whether or not it is possible to witness direct benefits from a particular person's life is unimportant. In order for this to be better understood publicly, Hall posits that "Christians may need to speak explicitly in the public sphere about the gratuitous nature of every life, held as each is by the extravagant providence of God."[11]

---

[8] Ibid., 23.

[9] Ibid., 24.

[10] Ibid.

[11] Ibid., 30.

Thomas Reynolds, in *Vulnerable Communion: A Theology of Disability and Hospitality*,[12] expounds upon the idea of life as gift. He describes how the mere existence of a person, regardless of that person's ability, is sheer gift. He contrasts the economy of grace with the economy of exchange. In the economy of grace, every life is a gift. Those who are seen as weak and fragile guide those around them in a way of living that strays from the contractual relations characteristic of the economy of exchange.[13] Rather than evaluating a person's ability to provide some good before assigning value to that person, in the economy of grace, each person is recognized as being valuable simply because he is a person. There is no appraisal of the person other than an appraisal of magnificent worth that is contingent only upon the recognition of the other person's existence. In relation to those with disabilities, it is true that often they provide those around them with goods that are quite valuable. Perhaps, like Joanna Jepson's brother Alastair, they provide a unique perspective on life by noticing those who usually go unnoticed. Maybe they help those without disabilities recognize the vulnerability that is shared despite the difference in physical or mental abilities. There are a number of benefits that those with disabilities have the ability to provide; however, this does not give them their worth.

Accompanying gratuitous life is "gratuitous welcome."[14] A gratuitous welcome of another affirms the goodness of a person's existence simply because he exists.

---

[12] Thomas E. Reynolds, *Vulnerable Communion: A Theology of Disability and Hospitality* (Grand Rapids, Mich: Brazos Press, 2008).

[13] Ibid., 139.

[14] Ibid., 140.

Reynolds notes that "the fact of existence is a given, a grace received."[15] He can give no better account for his existence than anyone else in the world. Recognizing this about oneself allows one to receive others more easily. None is able to justify his existence, regardless of ability. All who are have been granted life apart from their own doing. Reynolds quotes Augustine, saying "being is good simply because it is (*esse que esse bonum est*)."[16] With this perspective, there is an ability to provide a gratuitous welcome to all gratuitous lives. Without selecting against or for certain traits, all lives are welcomed. All lives are counted as good.

Shared Lives of Dependency

In the preface to *The Future of the Disabled in Liberal Society: An Ethical Analysis*, Hans Reinders doubts liberal democracy will be able to provide the necessary support for people with disabilities. His belief that it will be certain types of people who provide support rather than public policies leads him to a vision of shared life between those with disabilities and those without:

> If anything, adequate moral support for disabled persons will depend on a particular kind of moral life rather than on public policies installed by liberal democracy. That is to say, the democratic state will be able to sustain adequate support for the disabled and their families to the extent that its citizens are the kind of people who are prepared to share their lives with them and who have the character and skill to do so.[17]

Not hopeful that liberal society will prevent discrimination against those with disabilities (i.e., by allowing the continuance of prenatal tests and selective abortion for the sake of

---

[15] Ibid.

[16] Ibid.

[17] Hans S. Reinders, *The Future of the Disabled in Liberal Society: An Ethical Analysis*, Revisions (Notre Dame, IN: University of Notre Dame Press, 2000), x-xi.

personal freedom and choice), Reinders appeals to those who compose society. Reinders also appeals to the idea of life as gift. He takes a slightly different approach than others, however, by focusing first on those already born. Reinders emphasizes that those who exist with the cognitive ability to think about ethical and moral issues are themselves recipients of the gift of life rather than controllers or producers of it. Drawing from the work of Knud E. Løgstrup, Reinders explicates the concept of caring for the dependent because no person is truly sovereign over his own life.[18]

To the Christian, a lack of sovereignty over one's life is evident. A Christian knows his life is sustained by Someone other than himself. Christians believe that Christ "is before all things, and in him all things hold together" and that He is "sustaining all things by his powerful word (Colossians 1:17; Hebrews 1:3, NIV). The difference between the perspective of receiving life as gift and that of being sovereign over it produces drastically different outcomes. Those who act as though sovereign over their lives will interact with people based on a "contractualist posture" in which each party makes claims of the other.[19] Those who do not claim sovereignty over their lives and recognize their own dependence can make sense of the demand to care for others who are dependent in the ways that differ from their own dependency in certain regards. Reinders writes:

> The demand that we care for the other person's life is rooted in the fact of our indebtedness for all the things we have received: intelligence, speech, love, and much more. These are things that both enable and oblige us to respond to the needs of others.[20]

---

[18] Ibid., 146-147.

[19] Ibid., 147.

[20] Ibid.

Reinders claims that caring for others is not an option, something in which the kind-hearted will be involved and from which others will refrain. Rather, he says caring for others is a demand made upon those with the ability to do so; however, it is only those who see their own lives as a gift who will acknowledge and accept this demand. Thus, recognizing that both those who provide care and those who receive it are recipients of the gift of life is requisite for the proper care of those gifts which are the lives of people with disabilities.

It would be easy to say that Reinders' account of caring for those who are largely dependent upon others for their survival and well-being does not bear on the question of whether those who have disabilities should be prevented from existing or not. Some may agree that there is a demand to care for those with disabilities who exist currently without concluding that they must also oppose the prevention of those with similar disabilities or the genetic enhancement of future generations. This way of thinking stands in contrast to one of the qualifications of the demand to care for others as explained by Løgstrup. The qualification in question is that of following the demand "for the sake of the other."[21] The care provided for others must be motivated by unselfishness. Taking from Kees van Kooten Niekerk's work on Løgstrup, Reinders notes that with selfish motivations, there is the risk of "denying the *otherness* of the other" and of being tempted to gratify the self by "denying responsibility for the other or by determining what is good for the other in a egocentric way."[22] A denial of responsibility for the other may manifest itself in denying the birth of a certain other in the first place, be it via screening and abortion,

[21] Ibid., 144

[22] Ibid.

preimplantation genetic diagnosis (PGD), or germline therapy. Preventing these births from taking place may not, *prima facie*, be a selfish undertaking. Prevention in the name of preventing suffering for the other or preventing a difficult life for the other are reasons which may be given in this vein. However, this may also be an attempt to prevent suffering or difficulty on the part of the person preventing the birth. If it is not, it is still approaching the issue from an egocentric perspective without an imagination which provides the ability to see the lives of those with disabilities as a good thing. It is helpful to return to Hall's coverage of Jepson at this point.

Jepson has a unique perspective regarding those with cognitive disabilities. Her brother, Alastair (born with Down syndrome), has an extraordinary perspective of the world. His perspective is manifested in the photographs he enjoys taking. The subjects of his photographs consist of dustbin men, the postman, and workers in the street, none of whom his sister would have seen had it not been for sharing life with Alastair.[23] Joanna Jepson views Alastair's life as a gift. In regards to suffering, a brief response in one of Jepson's interviews is telling. She points out that "we pursue happiness to the extent of making pain and suffering taboo. There needs to be maturity in accepting there will be suffering in this life."[24] Her responses indicate that suffering and difficulties faced throughout life are not sufficient causes for the prevention of those born with disabilities. Instead, sharing life with these people can provide immense benefits. Even if these benefits are never manifested, their lives have "value [that] is unconditional."[25]

---

[23] Hall, "Public Bioethics and the Gratuity of Life," 25.

[24] Ibid., 24.

[25] Ibid.

Justice

Related to the idea of caring for those who are extremely dependent are ideas concerning social justice. Christopher Tollefsen, in "Disability and Social Justice,"[26] writes on the relation of the state to those who have disabilities. Like Reinders' *Future of the Disabled in a Liberal Society*, Tollefsen's chapter hones in on the makeup of a liberal state and the difficulties this poses to those who have disabilities. The recognition of humans as free and equal is a key component to liberalism. A third trait, independence, is "frequently lauded by liberalism" and is perceived through the lenses of freedom and equality.[27] Tollefsen notes that what liberalism seems to be saying is that those capable of asserting moral claims and who have the ability to act may engage reciprocally with one another, but those outside that realm are devoid of meaningful engagement with the liberal society.[28] Tollefsen argues that those who are dependent are on the outside of the social contract, and the world of disability is "extra to justice" in a liberal society.[29] He argues that the state is teleological in its purposes, that it exists to serve the needs of humans according to a particular account of human flourishing.[30]

Tollefsen argues for the development of a moral ecology in which those with disabilities are unquestionably considered to be of worth. Genetic testing followed by abortion of those with disabilities produces a world in which those with disabilities have

---

[26] Christopher Tollefsen, "Disability and Social Justice," in *Philosophical Reflections on Disability*, ed. D. Christopher Ralston and Justin Ho, Philosophy and Medicine, v. 104 (Dordrecht ; New York: Springer Verlag, 2010).

[27] Ibid., 211.

[28] Ibid.

[29] Ibid., 212, 214.

[30] Ibid., 213.

"their sense of worth and ability to flourish jeopardized."[31] Tollefsen thinks that the promotion of a different moral ecology, one in which the worth and flourishing of those with disabilities is promoted, is a possibility for the state to create. He writes:

> [the state can] take steps to clear up the array of hostile attitudes towards the disabled, not merely by changing structural features of the environment that are a result of those attitudes (like non-ramped buildings) but also by eliminating some avenues of expression of those attitudes, such as Prenatal Genetic Diagnosis (PGD) for the purposes of abortion, more permissive conditions for the abortion of the disabled, wrongful birth suits, and the de facto immunity of medical practitioners from prosecution for failing to treat "defectives."[32]

Tristram Engelhardt, in "The Unfair and the Unfortunate,"[33] notes the difficulty with which the state can justifiably act in ways that Tollefsen has suggested when lacking moral justification. In the past, religious justification may have allowed the state to act with moral authority. Currently, there is a "loss of general moral authority for social programs [which] is a function of the difficulty of providing a secular surrogate for the religious justification of secular state authority."[34] Engelhardt argues that in the absence of the authority to make moral claims, the state finds itself unable to justify compulsory actions of its citizens in order to remedy or create a better situation for those whom they have not personally harmed. Engelhardt finds moral authority and warrants for the claim-rights of those with disabilities to be lacking in the post-Christian West, a situation in which far more than the plight of those with disabilities could be greatly affected.

---

[31] Ibid., 220.

[32] Ibid.

[33] H. Tristram Engelhardt, "The Unfair and the Unfortunate: Some Brief Critical Reflections on Secular Moral Claim Rights for the Disabled," in *Philosophical Reflections on Disability*, ed. D. Christopher Ralston and Justin Ho, Philosophy and Medicine, v. 104 (Dordrecht ; New York: Springer Verlag, 2010).

[34] Ibid., 236.

From a Christian perspective, however, there is reason to believe that natural human rights exist for any person simply because he is a person. Nicholas Wolterstorff argues that it is humanity's relationship with God that grants every human inherent rights. Capacity and ability have no bearing on a person's rights under his conception of God's relationship to humanity. According to Wolterstorff, it is God's love for each who bears his image that gives that person "the worth in which natural human rights inhere."[35] God loves His human creatures with a love that bestows worth upon them. Wolterstorff describes humanly bestowed worth in order to provide a better picture of that to which divinely bestowed human worth amounts. One example he uses is that of Mount Vernon's historical importance.[36] Mount Vernon's physical and architectural characteristics alone would likely fail to make it of great national importance and admiration. However, worth has been bestowed upon Mount Vernon because of who it housed, George Washington. Wolterstorff couples the idea of bestowed worth with attachment love in order to explain the consequences of God's relationship with humans.

Attachment love, on a human-scale, looks like a child who loves a particular stuffed animal because it is his and it is the one he has chosen to love.[37] Wolterstorff notes that a child may choose to love a particular stuffed animal that is utterly ugly. However, even if the child recognizes that stuffed animal is not as pretty as others, he chooses to love it regardless. The child's love for the stuffed animal confers worth upon it that it would not otherwise have if worth were conferred on the basis of beauty or some

---

[35] Nicholas Wolterstorff, *Justice Rights and Wrongs* (Princeton: Princeton University Press, 2008), 353, http://public.eblib.com/choice/publicfullrecord.aspx?p=457944.

[36] Ibid., 357.

[37] Ibid., 359.

other measure. Wolterstorff goes on to say that if God has an attachment type of love with humans, which he believes God does, then that love bestows great worth upon those humans, and natural human rights "inhere in the worth bestowed on human beings by that love."[38] This theological grounding of human rights makes necessary the deliverance of justice for every single person. Regardless of that person's ability or disability, because he has been loved by God, he has been given great worth. An acknowledgment of that worth manifests itself in acting justly toward all human beings, acknowledging that each one is of immeasurable worth.

Conclusion

Navigating the tension between what genetic reproductive technology can offer and whether it should be used or not is a complex task. There are benefits made available via genetic reproductive technology that would not otherwise exist. However, there are also ethical issues and potential misuses that accompany the technology. The power to prevent certain types of people from being born is a massive one. Genetic reproductive technology grants humans the ability to make preventative decisions based upon traits made known prenatally. Should germline genetic engineering develop, humans would be granted yet greater control over the reproductive process. Germline gene technology would go a step beyond the prevention of certain types of people; it would allow the promotion of certain types of people in ways that are currently impossible.

The prevention and promotion of certain births, as noted in chapter five, is not new. Eugenic practices have resulted in abominable consequences in the past, but they are seen to be resurfacing today in the era of new genetic reproductive technology. These

[38] Ibid., 360.

technologies are making it increasingly easy to prevent the births of some and promote the births of others. With the ability to make choices regarding who comes into being and who does not, parents are granted a choice of enormous magnitude.

Jepson says that every life is valuable in a way that humans do not have the ability to calculate.[39] How a person wrestles with ideas like Jepson's and concepts relating to the use of genetic reproductive technology bears significantly on the world in which he finds himself and in which future people will find themselves. As this final chapter has shown, the continued employment of genetic reproductive technology in certain ways has the ability to produce results that would make a Christian wary of or opposed to its uses. For those who know they lack sovereignty over their lives, recognize their utter dependence upon God and others, and are commanded to seek justice, considering the ethical issues surrounding the use of genetic reproductive technology is of great importance.

[39] Hall, "Public Bioethics and the Gratuity of Life."

BIBLIOGRAPHY

"Abortion Act 1967," accessed April 2, 2016, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215147/dh_132849.pdf.

"ACOG Practice Bulletin No. 77: Screening for Fetal Chromosomal Abnormalities." *Obstetrics & Gynecology* 109, no. 1 (January 2007): 217–28.

Agar, Nicholas. "Liberal Eugenics." *Public Affairs Quarterly* 12, no. 2 (1998): 137–55.

Akolekar, R., J. Beta, G. Picciarelli, C. Ogilvie, and F. D'Antonio. "Procedure-Related Risk of Miscarriage Following Amniocentesis and Chorionic Villus Sampling: A Systematic Review and Meta-Analysis." *Ultrasound in Obstetrics & Gynecology* 45, no. 1 (January 1, 2015): 16–26. doi:10.1002/uog.14636.

Berger, Abi. "HLA Typing." *British Medical Journal* 322, no. 7280 (January 2001): 218.

Buchanan, Allen E., Dan W. Brock, Norman Daniels, and Daniel Wikler. *From Chance to Choice: Genetics and Justice*. Cambridge, U.K. ; New York: Cambridge University Press, 2000.

Calda, Pavel, and Miroslav Brestak. "Amniovacucentesis vs Standard Syringe Technique for Amniocentesis: Experience with 1219 Cases." *American Journal of Obstetrics and Gynecology* 201, no. 6 (December 2009): 593.e1–593.e3. doi:10.1016/j.ajog.2009.06.023.

"California Cryobank." Accessed March 14, 2016. https://www.cryobank.com/search?listview=0#.

"Conditions Screened By State." Accessed March 4, 2016. http://www.babysfirsttest.org/newborn-screening/states.

Council of Europe. "Convention for Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Biomedicine: Convention on Human Rights and Biomedicine." *Kennedy Institute of Ethics Journal* 7, no. 3 (1997): 277–90. doi:10.1353/ken.1997.0021.

Cyranoski, David, and Sara Reardon. "Chinese Scientists Genetically Modify Human Embryos." *Nature*, April 22, 2015. doi:10.1038/nature.2015.17378.

David, Henry P., Jochen Fleischhacker, and Charlotte Hohn. "Abortion and Eugenics in Nazi Germany." *Population and Development Review* 14, no. 1 (1988): 81–112. doi:10.2307/1972501.

De Graaf, Gert, Frank Buckley, and Brian G. Skotko. "Estimates of the Live Births, Natural Losses, and Elective Terminations with Down Syndrome in the United

States." *American Journal of Medical Genetics Part A* 167, no. 4 (April 1, 2015): 756–67. doi:10.1002/ajmg.a.37001.

De Jong, Antina, Idit Maya, and Jan M.M. van Lith. "Prenatal Screening: Current Practice, New Developments, Ethical Challenges." *Bioethics* 29, no. 1 (January 1, 2015): 1–8. doi:10.1111/bioe.12123.

Dyer, Charissa A. "Pathophysiology of Phenylketonuria." *Mental Retardation and Developmental Disabilities Research Reviews* 5, no. 2 (January 1, 1999): 104–12. doi:10.1002/(SICI)1098-2779(1999)5:2<104::AID-MRDD2>3.0.CO;2-7.

Edwards, S. D. "Disability, Identity and the 'Expressivist Objection.'" *Journal of Medical Ethics* 30, no. 4 (August 1, 2004): 418–20. doi:10.1136/jme.2002.002634.

Engelhardt, H. Tristram. "The Unfair and the Unfortunate: Some Brief Critical Reflections on Secular Moral Claim Rights for the Disabled." In *Philosophical Reflections on Disability*, edited by D. Christopher Ralston and Justin Ho. Philosophy and Medicine, v. 104. Dordrecht ; New York: Springer Verlag, 2010.

"Eugenics | Define Eugenics at Dictionary.com." Accessed March 9, 2016. http://www.dictionary.com/browse/eugenics.

Furman, Boris, and Zvi Appelman. "Genetic Diagnosis in Multiple Pregnancies: Amniocentesis versus Chorionic Villus Sampling." *Ultrasound Review of Obstetrics & Gynecology* 5, no. 1 (March 2005): 69–74. doi:10.1080/14722240500074281.

Galton, Francis. *Hereditary Genius: An Inquiry into Its Laws and Consequences,*. [2d ed.]. London, 1914. http://hdl.handle.net/2027/mdp.39015002147646.

Gammon, Katharine. "Gene Therapy: Editorial Control." *Nature* 515, no. 7526 (November 13, 2014): S11–13. doi:10.1038/515S11a.

Gardner, R. L., and R. G. Edwards. "Control of the Sex Ratio at Full Term in the Rabbit by Transferring Sexed Blastocysts." *Nature* 218, no. 5139 (April 27, 1968): 346–48. doi:10.1038/218346a0.

Gavaghan, Colin. "Right Problem, Wrong Solution: A Pro-Choice Response to 'Expressivist' Concerns about Preimplantation Genetic Diagnosis." *Cambridge Quarterly of Healthcare Ethics* 16, no. 01 (January 2007). doi:10.1017/S096318010707003X.

Geraedts, JPM and GMWR de Wert. "Preimplantation Genetic Diagnosis." *Clinical Genetics* 76, no. 4 (October 1, 2009): 315–25. doi:10.1111/j.1399-0004.2009.01273.x.

Goddard, Henry Herbert. *The Kallikak Family;a Study in the Heredity of Feeble-Mindedness,*. New York, 1912. http://hdl.handle.net/2027/uc1.b3972985.

Graves, J. Christopher and Karl E. Miller."Maternal Serum Triple Analyte Screening in Pregnancy." *American Family Physician* 65, no. 5 (March 2002): 915-920.

Habermas, Jürgen. *The Future of Human Nature*. Cambridge, UK: Polity, 2003.

Hall, Amy L. "Public Bioethics and the Gratuity of Life: Joanna Jepson's Witness Against Negative Eugenics." *Studies in Christian Ethics* 18, no. 1 (April 1, 2005): 15–31. doi:10.1177/0953946805052114.

———. "Good Breeding: The Eugenics Temptation." *The Christian Century Foundation* 121 (2004): 24–29.

Handyside, A. H., E. H. Kontogianni, K. Hardy, and R. M. L. Winston. "Pregnancies from Biopsied Human Preimplantation Embryos Sexed by Y-Specific DNA Amplification." *Nature* 344, no. 6268 (April 19, 1990): 768–70. doi:10.1038/344768a0.

"Henry I. Miller." *Hoover Institution*. Accessed February 21, 2016. http://www.hoover.org/profiles/henry-i-miller.

Herissone-Kelly, Peter. "Habermas, Human Agency, and Human Genetic Enhancement: The Grown, the Made, and Responsibility for Actions." *Cambridge Quarterly of Healthcare Ethics* 21 (2012): 200-210.

Kenner, Carole and Maribeth Moran. "Newborn Screening and Genetic Testing." *Journal of Midwifery Women's Health* 50, no. 3 (May 2005): 219-226. doi:10.1016/j.jmwh.2005.01.002.

Kent, Deborah. "Somewhere a Mockingbird." In *Prenatal Testing and Disability Rights*, edited by Erik Parens and Adrienne Asch. Hastings Center Studies in Ethics. Washington, D.C: Georgetown University Press, 2000.

Kevles, Daniel J. *In the Name of Eugenics: Genetics and the Uses of Human Heredity*. 1st ed. New York: Knopf, 1985.

Lagay, Faith. "Gene Therapy or Genetic Enhancement: Does It Make a Difference?" *Virtual Mentor* 3, no. 2 (February 1, 2001). doi:10.1001/virtualmentor.2001.3.2.gnth1-0102.

Latendresse, Gwen, and Angela Deneris. "An Update on Current Prenatal Testing Options: First Trimester and Noninvasive Prenatal Testing." *Journal of Midwifery & Women's Health* 60, no. 1 (January 1, 2015): 24–36. doi:10.1111/jmwh.12228.

Liang, Puping, Yanwen Xu, Xiya Zhang, Chenhui Ding, Rui Huang, Zhen Zhang, Jie Lv, et al. "CRISPR/Cas9-Mediated Gene Editing in Human Tripronuclear Zygotes."

Protein & Cell 6, no. 5 (April 18, 2015): 363–72. doi:10.1007/s13238-015-0153-5.

Malek, Janet. "Deciding against Disability: Does the Use of Reproductive Genetic Technologies Express Disvalue for People with Disabilities?" *Journal of Medical Ethics* 36, no. 4 (2010): 217–21.

Mansfield, Caroline, Suellen Hopfer, and Theresa M. Marteau. "Termination Rates after Prenatal Diagnosis of Down Syndrome, Spina Bifida, Anencephaly, and Turner and Klinefelter Syndromes: A Systematic Literature Review." *Prenatal Diagnosis* 19, no. 9 (September 1, 1999): 808–12. doi:10.1002/(SICI)1097-0223(199909)19:9<808::AID-PD637>3.0.CO;2-B.

Steinberg, Martin H., Bernard G. Forget, Douglas R. Higgs, and David J. Weatherall, eds. *Disorders of Hemoglobin: Genetics, Pathophysiology, and Clinical Management*. 2nd ed. Cambridge University Press, 2009.

Meehan, Mary. "The Triumph of Eugenics in Prenatal Testing." *Human Life Review* 35, no. 3 (Summer 2009): 28–40.

"Mein Kampf: Nation and Race." Accessed March 10, 2016. http://www.hitler.org/writings/Mein_Kampf/mkv1ch11.html.

Miller, Henry I. "Germline Gene Therapy: We're Ready." *Science* 348, no. 6241 (June 19, 2015): 1325–1325. doi:10.1126/science.348.6241.1325-a.

Natoli, Jaime L., Deborah L. Ackerman, Suzanne McDermott, and Janice G. Edwards. "Prenatal Diagnosis of Down Syndrome: A Systematic Review of Termination Rates (1995–2011)." *Prenatal Diagnosis* 32, no. 2 (February 1, 2012): 142–53. doi:10.1002/pd.2910.

"Newborn Screening." *Genetics Home Reference*, February 29, 2016. https://ghr.nlm.nih.gov/nbs.

"News Around the World: Tenth Anniversary of Preimplantation Genetic Diagnosis." *Journal of Assisted Reproduction and Genetics* 18, no. 2 (February 2001): 64–70. doi:10.1023/A:1026522422757.

Nourse, Victoria. "History of Science: When Eugenics Became Law." *Nature* 530, no. 7591 (February 25, 2016): 418. doi:10.1038/530418a.

Olivieri, Nancy F. "The B-Thalassemias." *New England Journal of Medicine* 341, no. 2 (July 8, 1999): 99–109. doi:10.1056/NEJM199907083410207.

Parens, Erik, and Adrienne Asch, eds. "The Disability Rights Critique of Prenatal Genetic Testing: Reflection and Recommendations." In *Prenatal Testing and Disability Rights*. Hastings Center Studies in Ethics. Washington, D.C: Georgetown University Press, 2000.

Pourfarzam, Morteza, and Fouzieh Zadhoush. "Newborn Screening for Inherited Metabolic Disorders; News and Views." *Journal of Research in Medical Sciences : The Official Journal of Isfahan University of Medical Sciences* 18, no. 9 (September 2013): 801–8.

President's Council on Bioethics (U.S.), and Leon Kass, eds. *Beyond Therapy: Biotechnology and the Pursuit of Happiness*. Washington, D.C: President's Council on Bioethics, 2004.

Reinders, Hans S. *The Future of the Disabled in Liberal Society: An Ethical Analysis*. Revisions. Notre Dame, IN: University of Notre Dame Press, 2000.

International Bioethics Committee. "Report of the IBC on PGD and Germ-Line Intervention." (2003)

Reynolds, Thomas E. *Vulnerable Communion: A Theology of Disability and Hospitality*. Grand Rapids, Mich: Brazos Press, 2008.

Sandel, Michael J. *The Case Against Perfection : Ethics in the Age of Genetic Engineering*. Cambridge, Mass: Harvard University Press, 2007. http://ezproxy.baylor.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=nlebk&AN=282827&site=ehost-live&scope=site.

Schwartz Cowan, Ruth. "Aspects of the History of Prenatal Diagnosis." *Fetal Diagnosis and Therapy* 8, no. 1 (1993): 10-17, doi:10.1159/000263869.

Selgelid, Michael J. "Moderate Eugenics and Human Enhancement." *Medicine, Health Care and Philosophy* 17, no. 1 (June 1, 2013): 3–12. doi:10.1007/s11019-013-9485-1.

Sermon, Karen, André Van Steirteghem, and Inge Liebaers. "Preimplantation Genetic Diagnosis." *The Lancet* 363, no. 9421 (May 15, 2004): 1633–41. doi:10.1016/S0140-6736(04)16209-0.

Singer, Peter. "Shopping at the Genetic Supermarket." In *Disability: The Social, Political, and Ethical Debate*, edited by Robert M. Baird, Stuart E. Rosenbaum, and S. Kay Toombs. Amherst, N.Y: Prometheus Books, 2009.

Steendam, Guido Van, András Dinnyés, Jacques Mallet, Rolando Meloni, Carlos Romeo Casabona, Jorge Guerra González, Josef Kuře, et al. "The Budapest Meeting 2005 Intensified Networking on Ethics of Science." *Science and Engineering Ethics* 12, no. 4 (December 2006): 731–93. doi:10.1007/s11948-006-0067-y.

Strong, Kimberly, Ian Kerridge, and Miles Little. "Savior Siblings, Parenting and the Moral Valorization of Children." *Bioethics* 28, no. 4 (May 1, 2014): 187–93. doi:10.1111/j.1467-8519.2012.02001.x.

Sutton, Agneta. “A Case against Germ-Line Gene Therapy.” *Ethics & Medicine: An International Journal of Bioethics* 29, no. 1 (2013): 17.

Swinton, John, and Brian Brock. “Being Disabled in the New World of Genetic Testing: A Snapshot of Shifting Landscapes.” In *Theology, Disability, and the New Genetics: Why Science Needs the Church*. New York; London: T&T Clark, 2007.

Tollefsen, Christopher. “Disability and Social Justice.” In *Philosophical Reflections on Disability*, edited by D. Christopher Ralston and Justin Ho. Philosophy and Medicine, v. 104. Dordrecht ; New York: Springer Verlag, 2010.

Valentine, Alex J, Aleysia Kleinert, and Jerome Verdier. “The ‘Atom-Splitting’ Moment of Synthetic Biology.” *EMBO Reports* 13, no. 8 (August 2012): 677–79. doi:10.1038/embor.2012.95.

Verlinsky, Yury, Svetlana Rechitsky, William Schoolcraft, Charles Strom, and Anver Kuliev. “Preimplantation Diagnosis for Fanconi Anemia Combined with Hla Matching.” *JAMA* 285, no. 24 (June 27, 2001): 3130–33. doi:10.1001/jama.285.24.3130.

Verma, Inder M., and Matthew D. Weitzman. “GENE THERAPY: Twenty-First Century Medicine.” *Annual Review of Biochemistry* 74, no. 1 (2005): 711–38. doi:10.1146/annurev.biochem.74.050304.091637.

Wang, Dan and Guangping Gao. "State of the Art Human Gene Therapy: Part II. Gene Therapy Strategies and Clinical Applications." *Discovery Medicine* 18, no. 98 (2014): 151-161.

Wilkinson, Stephen. *Choosing Tomorrow’s Children: The Ethics of Selective Reproduction*. Issues in Biomedical Ethics. Oxford: Clarendon Press, 2010.

Winter, Stefan F. “Our Societal Obligation for Keeping Human Nature Untouched.” In *Engineering the Human Germline: An Exploration of the Science and Ethics of Altering the Genes We Pass to Our Children*, edited by Gregory Stock and John H. Campbell. New York: Oxford University Press, 2000.

Wolterstorff, Nicholas. *Justice Rights and Wrongs*. Princeton: Princeton University Press, 2008. http://public.eblib.com/choice/publicfullrecord.aspx?p=457944.

Young, Carmen, Peter von Dadelszen, and Zarko Alfirevic. “Instruments for Chorionic Villus Sampling for Prenatal Diagnosis.” In *Cochrane Database of Systematic Reviews*. John Wiley & Sons, Ltd, 2013. http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD000114.pub2/abstract.