

DESIGNER GENES

An analysis of a theoretical framework
for policy proposals in relation to genetic engineering
as a reproductive technology

by

Stacie Melissa Crain

A thesis submitted to the faculty of the Virginia Polytechnic Institute and State
University in partial fulfillment of the requirements for the degree of

Masters of Arts
in
Political Science

Dr. Timothy Luke, chair
Dr. William FitzPatrick
Dr. Richard Rich

May 16, 2003
Blacksburg, VA

Keywords: genetic engineering, public policy, biomedical technology, embryo research,
reproductive technology, cloning

Copyright 2003, Stacie Crain

**Designer Genes:
An analysis of a theoretical framework for policy proposals in relation to genetic
engineering as a reproductive technology**

Stacie Crain

ABSTRACT

With the new capabilities of genetic engineering and such biotechnologies, come added considerations for policy makers. If gene therapy (or even embryo selection) becomes common practice, we must look not only to creating policies that protect the interests of individuals in the legal and social realms, but consideration must also be given to the equality of opportunity in the genetic sense. This additional level brings with it much significance; one can argue that financial disparity is at least theoretically surmountable but it is difficult to account for intentional genetic alterations that would forever give certain individuals a physical advantage over non-enhanced persons.

It is with these new boundaries that genetic policy must find itself creating legislation; it is also with these new boundaries that policy will find its greatest hurdles. Given the ever-expanding field of biotechnology and gene therapy, one can hardly expect policy written today to be up-to-date ten, or even two years from now. Instead of focusing, therefore, on specific recommendations, I will center my discussion on a broad framework that outlines the arguments that should be considered when dealing with genetic engineering and public policy.

After creating a theoretical structure centered on historical experiences and the philosophical writings of John Rawls, we will delve deeper into the actual possibilities created by genetic engineering and embryo selection. I will further analyze the differences between positive and negative genetic interventions and discuss the consequences of these differences as they should (or should not) affect policy. This particular distinction and the implications of these differences on policy will serve as the bulk of my discussion.

TABLE OF CONTENTS

CHAPTER ONE: Introduction	1
CHAPTER TWO: Theoretical Analysis of Genetic Engineering	7
CHAPTER THREE: Negative Genetic Enhancements for Reproductive Purposes ...17	
CHAPTER FOUR: Positive Genetic Enhancements for Reproductive Purposes	31
CHAPTER FIVE: Genetic Engineering and Future Generations	40
BIBLIOGRAPHY:	49
VITA.....	52

CHAPTER ONE

“‘Stability,’ said the Controller, ‘stability. No civilization without social stability. No social stability without individual stability.’ His voice was a trumpet. Listening they felt larger, warmer.”

-Aldous Huxley, Brave New World

Not long ago, Aldous Huxley’s novel A Brave New World seemed purely science fiction; a time when it was unimaginable that, as humans, we could control the genetic outcome of our offspring. As we find ourselves in the early years of the twenty-first century, however, genetic engineering is becoming less fiction and more science. With this increasing technology, it is becoming more and more important to emphasize both the benefits and drawbacks of a community practicing any type of genetic engineering in the hopes of creating public policy that can encompass the many valid concerns of informed individuals as we enter into this brave new world of our own.

Does genetic engineering have a place in what might be defined as a ‘civilized’ society? How should we, as a community, approach the crossroads with which we are faced; should technological advancement take precedence over any ethical concerns, or should we work diligently to preserve human life as we know it today? The potential availability of genetic engineering for reproductive purposes forces the consideration of these questions; the urgency of initiating discussion now, rather than later, becomes clear with realization of the rapid pace at which science is developing.

Genetic engineering has many applications, and because of this, can be defined in several different manners. For the purposes of this thesis, however, I will be focusing on the use of genetic engineering for human reproductive purposes. Genetic engineering combines recombinant DNA technology with the application of natural selection theories. By picking and choosing the ‘best’ or most desired characteristics from the parents, scientists can genetically select which genes will be ‘turned on’ in the offspring’s genetic makeup. Often referred to as ‘passive’ genetic engineering, this type of selection does not create new traits for the offspring, but rather decides which of those characteristics of the parents will be expressed in the child.

Positive genetic enhancements, however, can be defined as that facet of genetic engineering that requires manipulation of the genetic makeup of an individual, either fixing those things that are considered defective, or improving on characteristics and thusly surpassing ‘natural’ abilities. By splicing genetic information from a gorilla, for example, into the genetic code of a human embryo, scientists might well be able to create a human child with the increased strength of a primate. Such positive enhancements are, today, untapped; but the scientific reality of a society in which nature is controlled in the laboratory lies not so far in the future. Assuming that the technology develops to the point that such advancements can be performed with little to no risk to those involved, the question remains: Will genetic engineering and genetic enhancements alter the ‘humanness’ of our world, and if so, is this an acceptable price to pay for increased abilities and scientific expression? In order to begin to answer this question, attention must be paid to how a ‘civilized’ society is, today, defined.

For the purposes of this paper, I will focus on the application of John Rawls’ principles of justice as fairness and equality of opportunity; I will make the argument that if both of these conditions are met, a given society meets the expectations of what we currently would consider a ‘good’ society. Once it has been outlined that the goodness of a society can be measured by its fairness in distribution of goods and its equality of opportunity for its members, the boundaries of these requirements must be specified. When dealing with genetic engineering, it is essential to include artificially obtained genetic advancements into the ‘fairness of distribution’ category since their marketability places them into the same classification as material commodities. If we are to reach the state in which we can label genetic characteristics as ‘commodities,’ does it also follow that individuals themselves will eventually be reduced to their value on the ‘social’ market? If it is decided that such a result would be unfavorable, what means can be taken to ensure that the commodification of humans will stop with the buying and selling of genetic characteristics and will not expand to social stratification based upon genetic traits? Within Rawls’ initial analysis, he took into consideration ‘natural inequalities,’ but with the introduction of genetic technologies, these inequalities can be magnified to an extent that would require ample compensation within a justly distributive society.

Such advancements at the genetic level must also be considered when questioning equality of opportunity since it seems quite likely that genetic qualities will inevitably be used in classification of individuals and their potentials. If genetic manipulations were used to enhance ‘natural’ human characteristics, some differences between the genetically modified humans and those without genetic tampering would be apparent upon physical inspection; those other traits such as mental capacity or immunity to diseases could be determined through genetic testing. In addition to the obstacles that non-genetically-engineered humans would face because of their ‘deficiencies,’ once they were labeled as inferior, discrimination could extend to include genetic differences and, for example, employment could be denied not on the basis of ability, but rather on the basis of genetic potential. This hypothetical situation would clearly not pass Rawls’ equality of opportunity within a just society.

Policy makers are faced with a challenging task; it is difficult to weigh the benefits of scientific technology that can help in producing ‘superior’ future individuals with the possibilities of what might happen if that technology is misused. In addition to these concerns, it must be recognized that policy adopted in one country will not necessarily be accepted in neighboring countries; without an international agreement on policy, individuals around the world may be affected no matter what. In approaching these issues, therefore, policy makers must lay out a basic ethical framework from which to derive legislation concerning these issues. They must look for both the intersection between policy and science and the intersection between individual choice and public interest, and they must do this in a manner that will create the most just situation possible. In this analysis, I will use Rawls’ philosophical perspectives as the basis for this theoretical framework and will demonstrate the potential for the reconciliation of genetic advancement and natural ‘humanness,’ if only on a theoretical level.

Although theory is an important element of determining the ‘goodness’ of different approaches and their consequences, it is essential to consider the practicality of these options. As we enter into an age in which technology will serve to reshape our perception of life and natural qualities, we must also reshape the approach taken when considering public policy reforms. No longer can we rely on multiple ethical constructs within this genetic revolution; due to the permanent nature of this genetic science, a

consensus must be reached and the regulations strictly obeyed. Not only should policy makers be wary of the repetition of state-sponsored programs that mirror the eugenics movement in this country, but it is important that policy be adopted that is in the best interest of the current population as well as in the predicted best interests of future generations.

Genetic engineering, cloning, and gene therapy have been hot topics in the public sphere and the publicity afforded to genetic research has not always been positive. Many people equate genetic research to cloning, and their ideas of cloning are based on media misconceptions, primarily movies such as Multiplicity or cartoons such as South Park. It is through these mediums that the general public concludes that cloning is replication of people, like carbon copies, and it is with this misconception that the parallel is drawn to any mention of genetic research or gene therapy. One would only need a basic understanding of genetics and reproduction to realize that this is a ‘Hollywoodization’ of the true science. In reality, cloning happens naturally on a regular basis: identical twins are ideal examples of clones. It is difficult, knowing this fact, to argue that all clones are little more than drones for those ‘real’ humans who decide they need another self. With public educational tools, perhaps these misconceptions can be rectified, and constructive conversations can ensue in the public sphere. While it is indeed important to consider the possible implications of certain practices, as are viewed in some popular media, it is quite different to let such future concerns serve as the sole basis for your decision-making. In other words, although the arguments put forth foretell of a future society based solely on genetic codes are not in themselves, implausible, with careful planning and policy making, they can remain where they belong: in our imaginations and in the movie theaters. If we are to assume that a society based solely on individuals’ genetic codes is undesirable, as is the assumption adopted within this paper, before such practices are implemented, ample restrictions must be in place.

With the new capabilities of genetic engineering and such biotechnologies, come added considerations for policy makers. If gene therapy (or even embryo selection) becomes common practice, we must look not only to creating policies that protect the interests of individuals in the legal and social realms, but consideration must also be given to the equality of opportunity in the genetic sense. In other words, “the prospect of

genetic interventions forces us to rethink the boundary that we have traditionally drawn between misfortune and injustice, and indeed between the natural and the social.”¹ This additional level brings with it much significance; one can argue that financial disparity is at least theoretically surmountable but it is difficult to account for intentional genetic alterations that would forever give certain individuals a physical advantage over non-enhanced persons.

It is with these new boundaries that genetic policy must find itself creating legislation; it is also with these new boundaries that policy will find its greatest hurdles. Given the ever-expanding field of biotechnology and gene therapy, one can hardly expect policy written today to be up-to-date ten, or even two years from now. Instead of focusing, therefore, on specific recommendations, I will center my discussion on a broad framework that outlines the arguments that should be considered when dealing with genetic engineering and public policy.

When examining those concerns that must be taken into account for policy frameworks, it would be helpful to rely on past experiences in order to draw parallels between similar genetic interventions. For this part of my discussion, I will briefly explore the history of eugenics, both in the United States and in Germany during World War Two. By uncovering the specific reasons that these programs were unethical, we can ensure that these injustices are not repeated when we are faced with technology that has the potential to travel down a similar discriminatory path. Once such mistakes have been explicitly revealed, a new framework can be laid out. Using John Rawls as my primary source, I hope to outline those ethical concerns that must be addressed by genetic policy, both in the United States and abroad.

After this theoretical structure has been created, we will delve deeper into the actual possibilities created by genetic engineering and embryo selection. Through the use of hypothetical situations, I hope to convey the controversial nature of this technology; it is only with consideration of such difficult cases, however, that policy can even hope to encompass the broad spectrum of the new genetic technology. In these chapters, I will further analyze the differences between positive and negative genetic interventions and discuss the consequences of these differences as they should (or should not) affect policy.

¹ From *Chance to Choice*, 18.

This particular distinction and the implications of these differences on policy will serve as the bulk of my discussion.

Public perception of embryo research and genetic engineering is limited to exaggerated storylines of moral decay and societal upheaval; the first step, therefore, must be public education of the current situation and of the possibilities of the future. Public support for policy proposals is essential for their success; we cannot expect support for regulations, however, unless adequate information is provided. By banning federal research, the government is creating a tendency towards fear of all types of genetic research by the public, but is also, simultaneously, allowing such research to continue outside of its realm of authority. Without compromise in this policy area, the results could be exactly what critics most deeply fear; without government regulations, private corporations, both in the United States and off-shore, will continue their research unhindered and will do so in the absence of standardized ethics committees. It becomes clear, then, the urgency of the situation; without swift action, we could find ourselves in a situation similar to that of the sorcerer's apprentice, albeit without a sorcerer to step in and save us before disaster strikes.

Government regulation is necessary and limits on genetic engineering must be imposed if we are to ensure the continuity of our societal expectations. The current lack of policy cannot remain for long; technological advancement is quickly surpassing the guidelines now in place. In order to ensure that we are able to retain our current perception of 'humanity,' questions surrounding genetic engineering must be addressed sooner, rather than later, lest we look back and speak of lost opportunities.

CHAPTER TWO

*“It is our choices, Harry, that show us what we truly are,
far more than our abilities.”*

-Albus Dumbledore, Harry Potter and the Chamber of Secrets

The extent to which our genes predetermine our futures has long been a topic of discussion. Extensive research has been conducted in attempts to discover the exact impact that particular genetic makeup has on the personality, ability, and general character of different individuals. Although no conclusive evidence has been presented that details the exact impact of genotype on the future of individuals, it can be said with high levels of certainty that a person’s character is dependent on a combination of genetic makeup and environment. Humans have long had the ability to alter one’s environment; with the use of genetic engineering, we are faced with the potential ability to greatly influence genetic makeup as well.²

This is not the first attempt of humans to use knowledge of genes and heredity to alter the makeup of future individuals; while it can be argued that the eugenics movement is nothing like the new genetic revolution, by examining the history of eugenics, we can analyze the reasons that this time period represents such a dark time in our history. The eugenics movement is generally agreed upon as exemplifying the violation of human rights by an organized government,³ in the context of genetic interventions, it would be beneficial to find the specific reasons that this particular movement was so unjust.

The ultimate goal of the eugenics movement was elimination of ‘inferior’ genes that began with encouragement of exceptional individuals to procreate in the hopes that their offspring would benefit society. The step following this positive eugenic movement was a government and privately-funded program that supported the sterilization of individuals deemed inferior because of physical or mental conditions; it can be argued that this forced sterilization program was the first step towards the murder of millions of

² I am referring, within this chapter, to the definite influence of a person’s specific genotype. Humans have always been able to influence the makeup of their offspring, most notably with the use of sexual selection of partners. For the purposes of this discussion, however, I am referring only to the intervention (either through eugenics or through genetic engineering) of humans on genetic makeup.

³ The organized governments included the United States, England, Russia, Brazil, and (most prominently) Nazi Germany.

humans with ‘second-rate’ genes during the Holocaust.⁴ Instead of focusing on the actual results of the eugenics movement however, it is helpful to examine the theory and the reasoning behind adopting such a program in the first place.

In the United States during the early 1900s, the eugenics movement found its roots; eugenicists set up displays in the Museum of Natural History and “Fitter Family” competitions were prevalent throughout the country. In these ‘competitions,’ families were judged on their how well they represented the ‘ideal American family.’⁵ Winners were therefore encouraged to pass along these ‘superior genes’ and create large families in order to increase the quality of the population. The philosophy behind this program was not based on science as we know it today, but rather on the idea that achievement was linked to inheritable genes; it was the goal of the eugenicists to promote the ‘healthiest’ of these individuals, and in turn discourage others from creating large families. In other words, at the beginning of the eugenics movement, the goal was based in a Nationalist ideal; the ‘more fit’ a country’s population, the greater that country’s chance for greatness in the future. In attempting to obtain this superior status, however, there was a conflict between the overall social good and individual rights, liberties, and interests. This tension remains today; if genetic interventions can be regulated so that this conflict is resolved, one of the primary problems associated with the eugenics movement would be eliminated.

Just as we cannot use the experiments at Tuskegee to rule out the possibility of human experimentation, we cannot justify anti-genetic intervention attitudes with the citation of the eugenics movement.⁶ While there are certainly parallels to be drawn between the two movements, current policy should take into account the mistakes of the past to ensure that they are avoided in the future; if, however, it is decided that such wrongs are inherent in any genetic interventions, policy makers must then act accordingly. In order to avoid the pitfalls of the eugenics movement, emphasis must be placed upon the ideas of fairness and social justice and a better balance must be created between the good of the individual and the good of the population. In addition to this over-reaching goal, there are four reasons, introduced by Buchanan et al, for which the

⁴ From Chance to Choice, 28.

⁵ From Chance to Choice, 31.

⁶ From Chance to Choice, 42.

eugenics movement as it was practiced in the United States should never be repeated; each of these must be avoided if a policy is created that allows genetic interventions as a reproductive option.

The eugenics movement, both in the United States and throughout the rest of the world, focused not on improving those individuals already existing, but instead, the program centered on replacing ‘substandard’ offspring through involuntary sterilization. If eugenicists truly wished to benefit society as a whole, measures would have been taken to encourage therapeutic resolution for those with existing health or social inadequacies.⁷ Gene therapy, in contrast to the eugenics movement, aims to improve the conditions of those who already exist as well as their future offspring.

Perhaps one of the most obvious wrongs associated with the eugenics movement within the United States was the violation of reproductive freedoms of so many individuals. In contrast to proposed reproductive technologies utilizing genetic interventions, the sterilization of the mentally and physically handicapped was involuntary, or forced.⁸ While one could argue that reproductive rights are so firmly established in this country that such violations could never be repeated, two things must be kept in mind. Despite the role of individual protection of rights in the United States, many countries do not experience a similar level of security; when debating the ethical issues with possible implications of genetic interventions, these countries must be considered. Additionally, while it is unlikely that adopted policy would support any type of sterilization against one’s will, policy makers must take into account the effect of social pressures on individual decisions. The possibility of a human-engineered genetic gap is a concept that will be examined in a later chapter.

In addition to the reproductive freedoms that were violated with the forced sterilization of individuals, the question that begs to be asked is, “who decides the standard for ‘good’ genes?” What might be viewed as a handicap to one person might be considered a benefit for another; additionally, who is to decide the value of individual advantages versus the benefits of a diverse society? These are questions that must be

⁷ Inadequacies, in this context, obviously refers to those conditions that were viewed as substandard during the eugenics movement.

⁸ There is, however, a difference between the involuntary sterilization of individuals associated with negative eugenics and the encouragement of procreation that is deemed positive eugenics. For the purposes of this argument, the violation of rights occurs only with the negative eugenics movement.

asked by policy makers, even if the answers continue to evade us. The eugenics movement failed to address these concerns; by adopting an ‘American’ or ‘Aryan’ unwavering standard, there was little to no room for disagreement. It could be argued, however, that future genetic interventions could bypass this problem due to the voluntary nature of ‘choosing’ which aspects of individuals should be altered. It seems difficult to propose any policy that supports either extreme, or one that neglects to address the plurality of views that are unavoidable when considering controversial issues of this magnitude.

Finally, the eugenics movement deliberately concluded that the social well-being of the community superseded individual freedoms.⁹ By allowing involuntary sterilization programs, the governments of countries associated with these movements clearly placed their emphasis on the utility of the many instead of the utility of the individual. It is here that the bulk of the ethical argument surrounding genetic interventions lies and it is with this conflict between social good and individual rights that policy makers should adopt a general rule of thumb when evaluating policy options. While the eugenics movement seemed to definitively choose in favor of the good of the ‘state’¹⁰ and not the freedom of individual choice, it is important for consideration to be given to both areas of those affected if there is any chance for successful adoption of genetic intervention regulation.

Before attempting to develop any kind of guidelines for the creation of policy in the area of genetic technologies, we must outline a basic framework with which we can measure justice, in the general sense. For this purpose, I turn to John Rawls and A Theory of Justice. In this writing, Rawls outlines a proposal for a plan of ‘justice as fairness;’ in this proposal, he summarizes:

“All social primary goods—liberty and opportunity, income and wealth, and the bases of self-respect—are to be distributed equally unless an unequal distribution of any of all of these goods is to the advantage of the least favored.”¹¹

In addition to Rawls’ principles of justice as fairness and equality of opportunity, he further suggests that those inequalities that are inherent by nature should be compensated

⁹ Freedoms, in this case, can be interpreted as both reproductive freedoms and freedom of choice.

¹⁰ Or, depending on the context, the good of society.

¹¹ Rawls, 303.

for within a society. With the development of genetic technologies, we must consider his arguments for this compensation of disadvantaged individuals¹² as well as his definition of ‘natural’ inequalities. Rawls’ principle of redress is stated as, “the principle that undeserved inequalities call for redress; and since inequalities of birth and natural endowment are undeserved, these inequalities are to be somehow compensated for.”¹³ Of course, when Rawls composed his theory in 1971, genetic technology had not developed to the point that humans had the ability to control their genetic makeup; these scientific advancements call for a re-evaluation of Rawls’ original principle of redress in today’s context.

Rawls briefly mentions the role of eugenic thinking as applied to his theories on equality; these ideas can be applied to the theoretical issues with which policy makers are faced today. Within his analysis of equality of opportunity and distribution of goods, Rawls emphasizes the importance of maximizing the situation of the least fortunate.¹⁴ This does not necessarily mean, however, that all advantages must *directly* apply to the least advantaged: “We should note, though, that it is not in general to the advantage of the less fortunate to propose policies which reduce the talents of others.”¹⁵ Specifically, Rawls claims that resources should not be distributed so that there are no ‘excellent’ members of society; well-endowed individuals have the ability to provide benefits to a society that would not be possible if every member of a community were merely mediocre. This argument seems to hold up well in cases that have a limited supply of ‘favorable conditions,’ but in considering genetic interventions, we must also think about those situations in which the number of ‘favorable conditions’ can be increased. In other words, with advances such as gene therapy and genetic engineering, it is possible to increase the supply of ‘good genes’ within a population. The question arises, therefore, as to how Rawls would view the use of genetic engineering, both for the removal of defects and for the enhancement of current characteristics, in respect to his difference principle.

If we are to imagine a circumstance in which the availability of reproductive genetic engineering is universal, it seems likely that Rawls’ principles would support the

¹² Again, ‘disadvantaged’ in this sense applies to a general concept of the term and should not be considered, for example, as a check-list of inequalities.

¹³ Rawls, 100.

¹⁴ Often referred to as the ‘maximin principle.’

¹⁵ Rawls, 107.

use of such measures, for both positive and negative therapy¹⁶. This is, in fact, addressed in his discussion of the difference principle: “We might conjecture that in the long run, if there is an upper bound on ability, we would eventually reach a society with the greatest equal liberty the members of which enjoy the greatest equal talent.”¹⁷ Technology focused on the enhancement of current conditions, however, would not have this ‘upper bound,’ but would continue to increase with the scientific advancements. It is difficult to imagine, however, a situation in which the distribution of availability of genetic technology is universal; one of the primary concerns of critics of genetic engineering is, in fact, the unequal distribution of such advancements.

The maximin principle, as introduced by Rawls, emphasizes the importance of increasing the situations of those less fortunate within a community; unequal distributions are favorable so long as they better the situation of those in the least desirable position. “One looks at the system from the standpoint of the least advantaged representative man. Inequalities are permissible when they maximize, or at least all contribute to, the long-term expectations of the least fortunate group in society.”¹⁸ In applying this concept to genetic engineering, we must decide how to define the ‘least fortunate group’ as well as to determine what would be considered beneficial for generations to come. Consider, for example, a society in which genetic engineering is unregulated and parents are able to genetically enhance their offspring. If this technology were available to all, Rawls, assuming there were no moral objections, would support this advancement. If, however, this genetic engineering technology were costly, the situation becomes more complicated. Given the inherently unequal distribution of wealth, there would undoubtedly be those individuals who could afford genetic enhancements and those who would be unable to utilize this technology; this would essentially create two groups of people who were initially divided along economic lines, but found these inequalities extending to a genetic gap as well. Unless it could be shown that those members of the ‘lesser’ group were better off because of the increased abilities of the genetically engineered group, this level

¹⁶ These terms are often used when distinguishing between levels of modifications to genetic makeup. While this will be discussed at length in a later chapter, negative therapy includes those changes that ‘fix problems’ to meet the established baseline minimum; positive therapy is defined as those changes that exceed this minimum and provide the individual with superior traits.

¹⁷ Rawls, 108.

¹⁸ Rawls, 151.

of genetic intervention would not pass the requirements of Rawls' maximin principle. It seems plausible to assert that not only would the position of the least fortunate not be increased, but that their position would be negatively affected. While it is at least theoretically possible for individuals to transcend their economic situations, genetic characteristics could brand them for life.

Consider, alternatively, a situation in which genetic engineering is limited to certain negative interventions, specifically, the elimination of debilitating diseases.¹⁹ In such a state, it becomes easier to reconcile Rawls' principles with the use of genetic engineering. Even if the technology were expensive so that it was not available to all, the maximin principle could allow for this type of intervention. With a decreased frequency of diseases within the 'privileged' class, less money would need to be spent on their care; this excess could theoretically be used to better the situation of the less advantaged. Even if no monetary benefits were present, one could argue that the situation of the least fortunate remained stable. If this were the case, utility would be gained by society as a whole, with nobody worse off because of the policy.

In considering the effects of genetic interventions, recognition must be given for the impact of social pressures and stigmas on individual freedom of choice. If, for example, genetic diseases are all but eliminated from the economically privileged upper class, the existence of genetic abnormalities could be equated with those in lower social circles. Just as the eugenics movement began as a program aimed at encouraging the procreation of 'superior' citizens, but ended with forced sterilization of 'tainted' individuals, it is possible that negative genetic interventions could follow the same path. While it is impossible to predict, without question, the eventual effect that genetic engineering will have in the future, all legitimate possibilities must be considered and their just or unjust nature decided. If, however, Rawls believes that inequalities that are a result of nature should be compensated for within society, would it not follow that he would support genetic engineering of all sorts?

"The natural distribution is neither just nor unjust; nor is it unjust that persons are born into society at some particular position. These are simply natural facts. What is just

¹⁹ I am not going to attempt to provide a list of those diseases that might be characterized as 'debilitating;' the distinction that is important here is that genetic interventions would be utilized only to eliminate suffering, instead of for either enhancing present human properties or for choosing desirable traits.

and unjust is the way that institutions deal with these facts.”²⁰ While Rawls does not support the adoption of policies of reparation and direct compensation for natural inadequacies, his principle of redress works in a similar fashion to, in a sense, level the playing field among members of a society. One can imagine, therefore, his theory supporting scientific advances that would raise the bar for natural assets. Consider another example: both positive and negative genetic interventions have been practiced within a single community for a number of years. The result is that the mental and physical capacities of individuals have increased with each subsequent generation. Unfortunately, only a small number of this specific population has been able to take advantage of this technology; the rest of the community has evolved at the slower, ‘natural’ pace.

We can view this situation in either of two lights. The first interpretation is that the non-genetically engineered group is worse off: their relative position to the rest of society has significantly decreased. Despite the fact that they are in the same absolute position in which they would find themselves in the absence of genetic interventions, the rapid progress of the other members of their society has negatively affected them in all aspects of their lives, such as employment, education, and social encounters. With this perspective, it seems probable that Rawls’ principle of redress would rule out the use of genetic engineering for enhancement (and perhaps even therapeutic) purposes: the position of the least fortunate members of society was not improved, but rather those individuals found themselves worse off as a direct result of genetic interventions.

Conversely, one could interpret a similar situation from an alternate perspective. Instead of placing the emphasis on the relative statuses of the two groups within society, imagine that the stress was placed on their absolute positions. In this case, the ‘unfortunate’ group would find themselves no better and no worse off than they would have been sans genetic intervention. The privileged group, however, would benefit from the use of genetic engineering, and would consider themselves at a higher utility level because of it. The net gain, therefore, could be viewed as positive: one group remained stable while the other group experienced increased fortune. Additionally, consider the increased mental capacity of the enhanced members of society; with this ‘suprahuman’

²⁰ Rawls, 102.

capability, one could imagine that benefits would eventually trickle down to the lower class. According to Rawls' theory, the advantages of the more fortunate should also benefit those who make up the least prosperous within a society.²¹ If we have the capabilities to harness the technology that allows us to better the situation of all members of a society, Rawls' principles of justice seem to encourage its use.

Despite the two interpretations available when considering Rawls' principles as they would apply to a community taking advantage of positive genetic enhancements, it is difficult to reconcile the interpretation focusing on the absolute positions of the more and less advantaged groups. In other words, even though the argument can be made that non-genetically engineered humans would not be any worse off if genetic enhancement were adopted as a reproductive technology, it is difficult to imagine a society in which this theory held true. Reality is bound by relative positions; it is for this reason that Rawls' principles must be applied so that we consider the relative position of the least advantaged to the most advantaged. By this interpretation, we can conclude that a society in which only privileged members are genetically advanced, is also a society that can be labeled as unjust and unequal.

By using Rawls' theory of equality of opportunity and the principle of redress, we can begin to closely examine the potential implications of acceptance of the different levels of genetic intervention as introduced in the previous chapter. While we cannot expect to accurately predict what specific repercussions might develop from alternate regulatory measures, we can utilize the general framework provided by Rawls to guide us in our approach to policy surrounding genetic interventions. As genetic engineering develops and we begin to realize its consequences (good and bad), it is the responsibility of policy makers to find the equilibrium between Rawls' principles, social well-being, and individual freedoms.

While I do not attempt to suggest methods by which this can be accomplished, I do mean to stress the importance of attention to this particular area. Unless it is decided that our definition of 'humanity' is disposable, until means can be found that can harness the negative outcomes of a genetically enhanced society, restrictions must be in place to ensure the continuity of our current philosophy of life. Perhaps it would be useful to

²¹ Rawls, 87.

consider Francis Fukuyama's definition of 'human dignity' when interpreting the importance of humanity as it is known today. Fukuyama, in his book, Our Posthuman Future: Consequences of the Biotechnology Revolution, emphasizes the importance of the human condition as a separate consideration from the scientific realm. He defines human dignity as "the idea that there is something unique about the human race that entitles every member of the species higher moral status than the rest of the natural world;"²² with this distinction also comes a responsibility, according to Fukuyama, to retain those characteristics that define our species. Without obstacles, it is difficult to truly achieve greatness as we know it today. No matter what regulations (or lack thereof) are created, we must be prepared to adapt them to fit the situation in which we find ourselves in the future; without this degree of flexibility, we could find ourselves in a downward spiral along the theoretical slippery slope, plummeting into a society that is as foreign to us as natural selection is to them.

²² Fukuyama, 160.

CHAPTER THREE

“This child is still you, simply the best of you.”
-GATTACA

Parents inevitably choose what they believe is best for their children, from picking out a partner with desirable traits to selecting the finest schools for their offspring; with the increased capabilities of genetic technology, parents may now be faced with one more opportunity to better the situation of their children: choosing the best embryos for implantation. The distinction is often made between negative and positive genetic interventions; while there are arguments against the moral significance of the difference between enhancement and treatment, this categorization serves as a convenient starting point for discussion of issues related to genetic engineering. By examining the practical differences between these two types of genetic interventions, we can then begin a discussion concerning the regulation of such reproductive technologies.

Negative genetic interventions can be equated with those interventions that have the aim of preventing disease or ‘fixing’ those genes that may be malfunctioning. Proponents of this type of genetic engineering envision a society in which debilitating diseases are eliminated and other ‘undesirable’ traits are controlled with treatment at the genetic level instead of with the use of medical treatment throughout one’s lifetime. Positive interventions are usually considered the next ‘level’ of genetic interventions; positive enhancements are associated with genetic engineering of embryos so that the baseline minimum is increased. Positive interventions include using gene therapy on a healthy individual, not to eliminate a disease, but to increase his capacity relative to the average person; an example of this could be using genetic technology to increase the height of an individual who is already of average stature. Critics of positive genetic interventions often focus on the future implications of changing the makeup of the human race and the dangers of engineering a ‘suprahuman’ race.

Inherent in this discussion of positive and negative genetic interventions are the definitions of therapy and enhancement; this often-overlapping distinction warrants an analysis with respect to genetic engineering. Therapeutic means are generally accepted

to mean those advancements that fix or repair some disadvantage so that the patient is able to function at a baseline ‘normal’ level. Enhancements, on the other hand are thought to be those interventions that ‘raise the bar’ in at least one area of human characteristic; the term ‘enhancement’ is usually reserved for use in discussions of genetic modification beyond the average or for those individuals already considered to be ‘average.’ According to the President’s Council on Bioethics, “therapy suggests bringing one up to the level of adequate human health, capacity, or performance; while enhancement suggests taking one up beyond one’s existing level of health, capacity, or performance.”²³ While these two concepts surely aid in producing necessary dialogue surrounding genetic engineering, the line between therapy and enhancement is easily blurred when intense examination is applied.

Although all enhancements are not therapeutic in nature, most (if not all) therapies can also be classified as enhancements.²⁴ The difference lies, therefore, not necessarily in the actual change itself, but rather in the starting position of the patient relative to his society’s norms. In other words, if the individual undergoing genetic intervention is considered handicapped in relation to the average individual within his community, any changes in his genetic makeup could be classified as therapy; if, however, the individual is already ‘normal’ by his society’s standards, any beneficial treatment is termed enhancement.

There are a few obvious questions and concerns raised by this division. The first of these can be explained by the ambiguity of the terms ‘normal’ and ‘average.’ How is this norm to be defined and by whom? Is there a means of differentiation between serious and cosmetic disadvantages? Related to the issue of the classification of the ‘average’ individual is the definition of one’s community or society. One can imagine the difficulty associated with creating a database of ‘normal’ traits based on the global community, but other options seem equally problematic. If, for example, one were to define his community as his country, it is assumed that there is some level of continuity between social classes that can be remedied with the definition of ‘average.’ In addition to the intra-nation diversity, would steps be taken to maintain the diversity between

²³ President’s Council on Bioethics, Distinguishing Therapy and Enhancement, 2.

²⁴ President’s Council on Bioethics, Distinguishing Therapy and Enhancement, 1.

populations, or would homogenization of cultures develop into a goal of creating the average global human? Finally, the notion of ‘average’ is ever-changing; advances that we take for granted in the twenty-first century were unheard of two hundred years ago. Advances in knowledge, science, and living conditions have helped us in our evolution into beings adept at living longer, healthier lives. As an even more robust generation is created with the use of genetic screening for diseases, it follows that the average will also increase at an even more rapid pace. “As the bottom end of the curve is raised up, the average, too, moves higher, leaving different people at the bottom.”²⁵ Therapy, whether in the medical sense as we know it today or at the genetic level, will inevitably lead to enhancement, though not necessarily taking the direct path that is often associated with gene therapy, for example.

Given the complicated nature of any discussion focusing on genetic engineering as a reproductive technology, it is helpful to examine the several different types of genetic intervention: those that are scientifically available today, and those that may be possible in either the near or distant future. Since 1978, reproductive technology has continued to progress at a rapid pace; it is this development that creates the need for a policy discussion as to the future of such reproductive developments.²⁶ The desire to have genetically related, healthy offspring is one that is imbedded in all creatures as part of their instinct. Human beings are no exception; the existence of reproductive technologies and the demand for such procedures are a testament to this idea. Many couples, however, are either infertile or are likely to produce genetically deficient children due to the combination of the parents genes. The advancement of reproductive technologies and the continuation of genetic research have already helped many couples produce their own offspring.

More than twenty-five years following the birth of the ‘first test tube’ baby in 1978, fertility clinics are today attempting to provide infertile couples with the chance to give birth to their biological children. While the advances in IVF technology have

²⁵ President’s Council on Bioethics, Distinguishing Therapy and Enhancement, 3.

²⁶ On July 25, 1978 Louise Brown was born in a hospital in the northern part of England. Her birth was far from ordinary as it sparked a debate that continues even today, over twenty-three years later. Louise Brown was the world’s first ‘test tube baby;’ her mother’s fallopian tubes were blocked so she was unable to naturally give birth to a biologically related child. Patrick Steptoe and Robert Edwards were able to offer her a solution as they attempted the first successful human in vitro fertilization (IVF).

evolved slowly and it remains an extremely inefficient method for inducing pregnancy²⁷, it is estimated that there will be at least 500,000 babies born from IVF technology in the United States alone by the year 2005.²⁸ It is true that the processes have improved in the past several years and the creation of fertility drugs has increased the number of embryos that can be removed from a female in a single treatment. Consequently, these fertility drugs have also increased the number of embryos that are left over after the couple is able to give birth to a child. The question remains, therefore, what is to be done with these 'spare' embryos? This is yet another issue that must be considered as policymakers approach the intersections between reproductive technologies and public policy.

It might help, in this instance, to compare and contrast currently accepted reproductive techniques with some possible proposed scientific advancements. It can be argued that there are possibly three types of couples who would opt for pre-implantation diagnosis: infertile couples using IVF who want to choose the embryo with the best chance of successfully coming to term, couples with known risk factors for transfer of genetic diseases wanting to ensure that the embryo implanted is healthy, and couples wishing to create a 'designer child.'²⁹

Consider the situation of a young couple, Michelle and David, who have recently found that they are both carriers of the gene that causes cystic fibrosis. They are currently planning to start a family; this new information, however, has complicated matters for the newlyweds. They could choose to let nature decide the fate of their child and reject any scientific intervention; besides, this is what they would have done had they never known their own genotypes. They could also choose to not have any genetically related offspring; they could look into adopting a child, or they might decide that the risk of having a child who suffers from cystic fibrosis is too great and they might change their minds about having children at all. Their options, however, do not stop there. Due to the rapid pace of advancements in reproductive technologies, the most important decisions affecting their child may in fact take place before he or she is even born.

Current technology and policy today would allow the new parents to undergo prenatal diagnosis to test their child for cystic fibrosis; if they chose to undergo

²⁷ In 1997, less than one in thirteen implanted embryos actually successfully resulted in live births.

²⁸ Silver, 80.

²⁹ Holm, 178.

amniocentesis a range of questions would arise. If it was found that the fetus was affected with the disease, should they terminate the pregnancy? What if there was no confirmation, but simply a 75% chance that the fetus would suffer from cystic fibrosis? What if the couple decided to undergo in vitro fertilization (IVF) and chose to implant only those embryos that tested negative for the disease? Finally, once the scientific technology is able, should Michelle and David be given the choice of ‘fixing’ a fetus affected with cystic fibrosis using gene therapy?

Consider now the situation of a similar couple, Susan and Fred. They currently have three children: all boys. Susan desperately wants a little girl, and she has decided that she will terminate any pregnancy if the fetus is male. Should this couple, then, have the opportunity to undergo in vitro fertilization to select for the gender of their unborn child? If so, what is the ethical framework that justifies sex selection at the stage of the embryo? If not, then what moral argument can support selective abortion, but refuse embryo selection?

Finally, consider the situation of Candace and Harold: while they are both of average mental capacity, both are significantly shorter than the average population. They have decided that they want a child that is related to them genetically, but they are concerned with the ridicule and suffering their offspring will go through on account of his or her height. They approach a doctor concerning in vitro fertilization and inquire into gene therapy to ensure that their child will be of normal height. How should policy makers approach this issue? What if the parents were of average stature and wished for a child six inches above the “normal” height? Is there a difference between positive enhancements that level the playing field to a standard and those enhancements that surpass this so-called ‘minimum’ level? How should these concerns be addressed by public policy?

Let us first examine the couple that is already using IVF to induce pregnancy. IVF patients are in a unique situation. While close to 90% of the population is fertile and can use natural methods of childbirth, those who undergo IVF treatment are faced with decisions riddled with ethical dilemmas. The process of genetic screening and pre-implantation diagnosis has given these couples the opportunity to select, from their own fertilized zygotes, those embryos that have the greatest chance of successfully producing

a healthy baby. Consider, then, a scenario in which an infertile couple has produced six healthy embryos from which they will choose one to implant via IVF; three of these embryos have male chromosomes and three have female chromosomes. This means that if the embryologist randomly chose one embryo to implant, the couple would have a fifty percent chance of having a child of either gender. Given that this couple could essentially choose the sex of their future child, and assuming that they have no ethical problems with making this choice, what are the arguments against allowing such selection? Perhaps one could even argue that it would be better for parents to choose the gender of their offspring if they so desired; the more appreciated the child, the better off he or she might be. This leaves, then, the argument that choosing your future child's sex is working against nature, against the normal gender distribution that is randomly generated naturally. This is a difficult argument to make in this situation, however, as the couple is, by nature, infertile. It almost seems as if one would have to reject both IVF and embryo selection or one would have to accept both, or at least accept the availability of both.

The second type of couple that would benefit from pre-implantation diagnosis and embryo selection would be one with a high chance of passing genetically defective genes onto their children. Today, embryologists are legally allowed, in Britain, to utilize sex selection of embryos in order to prevent diseases that are passed down only through one gender.³⁰ Embryos are screened and only those that possess female genetic information are implanted in cases in which there is significant concern that a life-threatening disease, passed along through the male chromosomes, is present.³¹ This idea of genetic selection presents an interesting situation; while many can easily argue against the use of genetic engineering to create 'perfect' embryos, the argument weakens when scientists are merely choosing the healthiest embryo out of a given set. Consider, for example, a case in which there are six embryos that could potentially be implanted for IVF. Three of these embryos are healthy, and three of them have genetic diseases. Most people would not argue against implanting the healthy embryos over the unhealthy ones; as a matter of fact, it could be argued that pre-implantation diagnosis is less invasive than pre-natal

³⁰ Mulkay, 140.

³¹ Mulkay, 140.

screening.³² Current medical practice today involves pre-natal diagnosis; with the presence of genetic disease, women are given the choice of performing chorionic villus biopsy (CVS) to terminate the pregnancy.³³ If we are willing to accept, in essence, fetal selection in cases in which there are significant genetic abnormalities, would it not follow that we would welcome the opportunity to diagnose embryos when they are nothing more than eight-celled zygotes?

This ethical dilemma seems to lead to what many critics of genetic selection fear: the slippery slope of social acceptance of scientific technologies that would lead to a reevaluation of the sanctity of life and the possible creation of a ‘suprahuman’ race. This brings us to our third couple, the couple wishing to create the perfect child either through genetic selection or gene therapy, despite their ability to naturally conceive. It is here that the ethical arguments become a bit more elusive; with conversations focused on the idea of creating a designer child with pre-selected characteristics, critics of genetic engineering and gene therapy find their strongest arguments in examples of possible outcomes of adoption of these techniques. Horror stories are easy to come by as images of parents engineering their genes to be the strongest, the smartest, and the most beautiful come to mind. But let us not jump at the chance to make a slippery slope argument. We must first examine genetic selection and its implications and consider the policy of such regulation following the introduction of a plausible ethical framework of considerations. Genetic selection for certain ‘frivolous characteristics’ such as eye color, hair color, or gender³⁴, for example, is illegal in Britain today. No couple can enter into a fertility clinic and choose the embryo that has the genetic makeup of a blue-eyed child, for instance. It is important to take a closer look at the reasons for this particular regulation; in his article “Rights and Reproductive Choice,” John Harris proposes an amendment to this restriction. If, he argues, gender is a morally neutral characteristic, then why should it matter if policy allows parents to make this choice? If, on the other hand, policy makers decide that gender is an important characteristic, then why should we leave such a decision up to chance?³⁵

³² Harris, 32.

³³ Holm, 180.

³⁴ In this particular instance, I am referring to gender selection for non-medical purposes.

³⁵ By ‘morally neutral,’ Harris means that it is not morally better for a person to be either male or female.

In summary, there are three ‘levels’ at which pre-implantation diagnosis can be used. The first, and least controversial, is the use of genetic screening to prevent genetically transmitted diseases. We already allow for the termination of pregnancies in which severe abnormalities are detected during pre-natal diagnoses; with the use of genetic screening, however, the decision is made at the embryo stage, so the pregnancy is never begun with an unhealthy embryo. The second level of genetic screening is one in which couples who are already using IVF for fertility reasons choose the gender of the embryo to be implanted. The third, and most controversial use of genetic screening is one in which fertile couples choose to have their embryos implanted by an embryologist so that they can choose the embryo with their desired characteristics; this level is often coupled with arguments concerning gene therapy. Arguments against legalization of this type of genetic intervention have strong roots in slippery slope predictions. Because genetic selection of this kind is closely related to genetic engineering of embryos, it seems plausible that the acceptance of one would lead to the legalization of the other. As a policy issue, this is also the most difficult to regulate; IVF is a costly procedure, and if offered to couples for the purpose of creating ‘designer children,’ the economic gap might actually widen to become a genetic gap as well.

Before delving into the issues that are inevitably raised with discussion of positive genetic interventions and gene therapy, it is helpful to examine negative interventions as compared to current reproductive practices. Current practices allow parents the option of prenatal screening of their developing fetus; once it has been determined that the fetus is either healthy or is suffering from some genetic disorder, the decision must be made as to whether or not the child will be brought to term. Such testing is not a required part of pregnancy, but rather is offered to those who request it. In developing policy, it is helpful to look at the similarities and differences between prenatal diagnosis and preimplantation diagnosis and their respective effects on prospective parents, future children, and, ultimately, society as a whole.

Proponents of genetic interventions often point to embryo selection as one of the main benefits that can be offered to prospective parents. The ability to choose those embryos with the greatest chance for successful implantation in the womb seems a welcome benefit for couples undergoing IVF. The ethical problem arises, however, when

genetic screening serves as the decision making step for the parents; by either eliminating embryos with genetic predisposition to disorders or by choosing those embryos with certain characteristics, some argue that science is overstepping its boundaries. According to Leon Kass, chair of the President's Council on Bioethics, "When a couple normally chooses to procreate, the partners are saying yes to the emergence of new life in its novelty—are saying yes not only to having a child, but also to having whatever child this child turns out to be."³⁶ By choosing one embryo over another, critics argue that parents are essentially rejecting a potential child in favor of one that conforms more towards their concept of the 'perfect child.' Their arguments strengthen as the discussion shifts from the prevention of disease to the screening of embryos for morally neutral characteristics such as eye and hair color. Those who support the availability of genetic screening upon request point to the alternatives offered by medicine today: without preimplantation genetic diagnosis, if a fetus is found to be the carrier of a disorder, then the choice faced by the parents is one of aborting the fetus or raising the child and accepting the condition. If, however, preimplantation diagnosis is practiced, this painful decision can be avoided by implanting only those embryos that tested negative for the condition in question. Bioethicist and philosophy professor Bonnie Steinbock supports this position: "If procreative liberty gives women the right to abort through the first two trimesters for any reason whatsoever, it is hard to see what justification there could be for putting limits on genetic screening and nontransfer of embryos."³⁷ The major concern, however, is not as much focused on the elimination of debilitating diseases such as Lesch-Nyhan syndrome as it is worry for what the future will hold as negative genetic intervention for diseases progresses to positive enhancements and cosmetic improvements. Current regulations allow at-risk couples to use prenatal diagnoses to screen the health of the fetus prior to birth, allowing the couple to either prepare for the arrival of a disabled child or to make the difficult decision to undergo an abortion.

Amniocentesis is commonly used today to screen fetuses for a number of diseases, including Down's syndrome and Tay-Sachs disease; this procedure has been

³⁶ Kass, Leon. Preventing a Brave New World, 8.

³⁷ As cited in Remaking Eden, Silver, 248.

widely used and accepted since the mid-1970s.³⁸ Proponents of genetic selection argue that embryo screening is not only a less invasive procedure for the mother, but they also claim that the moral issues surrounding the choice of desired embryos for implantation are greatly decreased from those of selective abortion. In other words, the difference between the current prenatal diagnoses and embryo screening seems to be the ease with which parents can handpick their ‘perfect’ child, given, of course, that the genetic screening processes will develop to the point that more traits can be tested in an efficient manner. Perhaps one of the most obvious ethical concerns that can arise from this testing is the question of what is to be done under the circumstances that a disorder is found in the fetus. While every couple will have their own personal reasons for either aborting the fetus or choosing to give birth to a child with a known disorder, we must ask ourselves if testing for these disorders is ethically acceptable in the first place. In allowing for the screening of fetuses for diseases, are we lessening the worth of those individuals who are less than perfect, at least in the genetic sense? Should parents and doctors have the capability (or the right) to decide when a disease makes living life a burden? Is there an ethical difference between selecting a desired embryo for implantation and aborting a fetus that has undesirable characteristics?

With the existence of prenatal diagnosis, these questions concerning the attitudes towards human disabilities have already been answered; parents have an option³⁹ to test for genetic disorders and once the health of the fetus has been determined, a value judgment must subsequently be made. With the acceptance of such options, it is implied that the existence of a child who is not affected by a disease can be of more value than another child who would be a carrier.⁴⁰ Some might argue that the mere existence of prenatal testing, in itself, reduces the value of any human life that is labeled as ‘defective.’ In order to lessen the burden to parents and society, genetic counselors were trained in the United States to aid the difficult decisions for prospective parents. The role of the genetic counselor is “to inform, to educate, to convey value-free facts and probabilities about genetic conditions, perhaps even to deal with psychologic problems,

³⁸ *Playing God?*, 256.

³⁹ In some cases, such as mothers over the age of 35, some may argue that prenatal diagnosis is not only an option, but it is the parents’ *responsibility* to test for genetic disorders before birth.

⁴⁰ This is assuming that the parents choose an embryo free from disorders; in some cases, parents might opt to implant an embryo that displays certain characteristics that would otherwise be deemed ‘disabilities.’

but never to advise and counsel.”⁴¹ In current practice, however, most women (and their partners) receive genetic counseling from their care providers⁴²; while obstetricians and gynecologists may indeed be knowledgeable on genetic disability, they are not trained to offer non-directive advice. On the contrary, with the profusion of lawsuits brought against doctors within the United States, physicians might even choose to err on the side of caution and advise their patients against taking a ‘risk’⁴³ by bringing a handicapped child to term.

The frequency with which genetic screening is used today is so small that it is impractical to think of repercussions on a larger scale; at the rate, however, that technology is advancing, it is difficult to believe that it will be long before preimplantation diagnosis will prove to be both a highly accurate and extremely efficient means of predicting the health of future children. Policy makers must, then, weigh the pros and cons of legalizing such reproductive technologies. Many disability-rights groups actively protest against any organized⁴⁴ attempts to select against diseases or disorders. Their argument is simple: any society that aggressively works to rid a community of some trait will inevitably lessen the worth of members who presently display that same trait. In other words, if couples consistently choose genetic screening against a disability, a value judgment is being made, and the status of any individual (current or future) who finds himself thusly disabled, will be significantly decreased. As Lee Silver points out in his book, Remaking Eden, this is a difficult conclusion to which these critics have come. “...one common...cause of disability in the past was the polio virus, which resulted in paralysis, muscular atrophy, and often physical deformity. Inoculation of children with the polio vaccine was not generally seen as discriminatory against those who were already disabled. Why should genetic inoculation against disability be viewed any differently?”⁴⁵ Attempts to eliminate future occurrences of diseases would not be discrimination against those carriers of the disease, just as vaccinations are not viewed as discriminatory acts against individuals today; care must be

⁴¹ Controlling Human Heredity, 130.

⁴² Controlling Human Heredity, 131.

⁴³ Risk, in this context, is meant to imply both the emotional risk of raising a child with a disabling disorder as well as the economic risk associated with the treatment and care for the disease.

⁴⁴ Or, more specifically, scientifically-oriented.

⁴⁵ Remaking Eden, 260.

taken, however, to ensure that attitudes towards those who suffer from any form of malady are not offensive in nature.

Once genetic screening is developed to the point that it is efficient and accurate, the availability of preimplantation diagnosis will increase and the market price for this service should be reduced. Unless it is decided that services such as genetic screening should be covered in some sort of governmental health care system, a very valid concern is the effect of genetic diagnosis on class structure within a society. Specifically, will a society of ‘haves’ and ‘have-nots’ develop into a society of those who are genetically able and those whose parents ‘took chances?’ The differences in opportunities are tremendous, both across the globe and throughout individual societies; many fear that the legalization of new reproductive technologies will increase this gap and will make permanent those differences that today are ‘merely’ social. While this is indeed a valid concern, we must remember that similar inequalities exist today, although not at the genetic level. Affluent parents are able not only to provide better healthcare for their children in the form of vaccinations and other treatments, but they also have the ability to give their offspring environmental advantages not available to those in lower economic classes. It is difficult, in today’s society, to argue that wealthier families should cease providing such opportunities; on the contrary, in today’s society it is the general consensus that every individual should strive to better his (and his children’s) position, not to meet at the lowest common denominator of opportunity. If we are to continue to allow parents to give their children the best possible advantages with respect to environmental factors, should it not be within their same rights⁴⁶ to provide similar advantages at the natural, or genetic, level?

It seems common to imagine a couple who hopes for a healthy child, free of diseases or disorders. It is equally as easy to imagine that society might look down upon a mother who refuses to, for example, refrain from drinking alcohol while she is pregnant, knowing that her child will suffer because of her selfish decisions. Some compromise must be found that protects the individual freedoms of the parents to raise their children in the manner they choose while also ensuring that the child will not be harmed in the process. It is assumed that parents will not only hope for the best possible

⁴⁶ And, some may argue, their responsibilities.

situation for their offspring, but it is also expected that the same parents will do everything in their capacities to provide such an environment. The controversy does not lie, therefore, in the intentions of the parents, but rather the focus should shift to the definitions of ‘disability’ and ‘advantage’ and the social implications of using these terms. While specific interpretations of different characteristics may differ slightly, the overall attitude towards certain traits will, more likely than not, be almost universally agreed upon. In his discussion of ‘disability,’ John Harris gives us this explanation. “I have in mind the sort of condition in which if a patient presented with it unconscious in the casualty department of a hospital and the condition could be easily and immediately reversed, but not reversed unless the doctor acts without delay, a doctor would be negligent were she not to attempt reversal.”⁴⁷

This definition of disability is not meant, in any way, to discount the experiences of individuals who have overcome any sort of handicap; on the contrary, it defines the human spirit to live with a disadvantage and to become a better person because of it. Individual accounts of inspirational stories are countless and oftentimes the protagonist would refuse a ‘normal’ existence if given the option to relive a particular situation. It is with the use of these testimonials that critics of genetic selection against disabilities draw their strongest arguments. While it is nearly impossible to argue against personal experience, policy makers must consider not only the good of the individual, but also the betterment of the whole of society. In considering the interests of the individual, one could advocate individual choice; given this option, some could opt to screen against disease, while others who disagreed with this genetic intervention could refuse such testing. From the perspective of the community as a whole, it could be argued that society would benefit from the healthiest population; the healthier its citizens, the more productive a country and the less cost per individual for health care.

Let us imagine that scientific technology has increased to the point that genetic screening is both accurate and noninvasive. Imagine, too, that the number of genetic characteristics that can be predicted by preimplantation diagnosis has increased significantly; no longer is the screening limited to diseases such as Tay-Sachs, cystic fibrosis, and Huntington disease, but now doctors can provide parents with an entire map

⁴⁷ Is Gene Therapy a Form of Eugenics?, 166.

of genetic characteristics carried by each embryo.⁴⁸ Given the availability of comprehensive screening, where should policy makers look to draw the line? If one is to decide that genetic screening should only be used to rule out the possibility of genetic diseases, how is it decided which diseases should be tested for? Would diabetes be considered a disability, but not obesity? How would regulations handle diseases that do not express themselves until later in life, like Huntington disease? If it were found that one embryo had a twelve percent chance of expressing the genotype that caused breast cancer while another embryo had less than a one percent chance of developing the same disease, would parents be justified in choosing the lower-risk embryo?⁴⁹ Would the answer to this question change if it were revealed that the average chance for humans to contract breast cancer is in fact twelve percent? Should it make a difference? If the key to utilizing genetic screening is to reduce the risk and the expression of disease and disability, should parents not be encouraged to select the embryo that has the highest chance for a completely healthy life? If this is true, then how would policy deal with the removal or the ‘fixing’ of genes that could develop into disease-causing agents?

Because of the emphasis on individual freedom of choice within the United States, it is difficult to imagine, given the availability of technology, the adoption of policy that restricts the use of such genetic advancements. It is in this idea that the problems surface. The decisions made today will inevitably affect future generations and will most likely change the way our descendents view the human condition. Within this chapter I have focused on negative genetic interventions and their uses; critics of any sort of genetic intervention often discuss the slippery slope and the unavoidable downfall of society because of it. If, they argue, we, as a society, accept the screening of embryos against disease, what is to stop us from creating disease-resistant embryos? And if we are to create disease-resistant embryos, why would we not alter our genome so that we can overcome other limitations with which we are faced? And so begins the descent down the theoretical slippery slope; in the following chapter I will examine some of the positive genetic interventions with which these critics are concerned.

⁴⁸ While genetic screening has not advanced to this point yet, with the completion of the human genome project, scientists will be developing tests in the near future.

⁴⁹ This is an example borrowed from Lee Silver in Remaking Eden, 252.

CHAPTER FOUR

“Why do some people feel that designing children to be healthy, talented or to possess some beneficial feature might be wrong? If it’s not wrong for a prospective parent to wish to have a bonny, bouncing brown-haired baby boy, how does it become wrong if we have the technology to grant our wish?”

-John Harris, University of Manchester

The line between gene therapy and genetic enhancements is a blurry one, as was shown in previous discussions; the prospect of using gene technology to improve upon existing human characteristics presents a plethora of ethical, social, and regulatory concerns. In addition to the concerns of unequal distribution that also surround negative genetic interventions, positive enhancement brings into question the justification for redefining the human race in terms of current physical and mental abilities. With the artificial increase of human capacities, coupled with the unequal economic situations throughout the world, the potential for division of the human species along genetic lines is not as unlikely as it at first seems. Additionally, despite the emphasis that proponents of genetic interventions place on the autonomy of individuals to choose the fate of their offspring, with the adoption of positive genetic therapy as a reproductive option, critics argue that the availability of enhancements will put tremendous pressure on parents to take advantage of such technologies; that children born without screening and improvement will be seen as inferior and their parents as inadequate providers for their families. Finally, genetic enhancements also bring into question the difference between individual accomplishment and innate ability; without the challenge presented when faced with obstacles, will the human condition prevail or fall short?

Robert Nozick introduced the idea of the creation of a ‘genetic supermarket’ in his 1974 work, Anarchy, State, and Utopia.⁵⁰ In his discussion, Nozick outlines the basis for a liberal market economic approach to the regulation of genetic enhancements within a society. Leaving the market to regulate, he argues, will ensure that individual freedom is protected; with only minimal intervention from the government, each family can

⁵⁰ Nozick, Anarchy, State, and Utopia, 315.

choose those characteristics that would most benefit their particular family structure. In order to maintain diversity within a community, Nozick discusses the need for some form of central regulating body; instead of leaving this responsibility solely to governing bodies, he proposes the use of market forces to provide incentives for people that would result in a particular ratio within a society. For example, he recognizes the importance of maintaining some sort of balance between males and females; in order to make sure that this equilibrium is preserved, hospitals would be made to keep records of their births and would not be able to begin treating a couple desiring a male child until another couple that desired a female child was found. If there were greater desire for one sex over the other, market forces would take over as couples that were neutral as to the gender of the child could be paid to pair up with other couples.⁵¹ In introducing this scenario, Nozick appeals to the notion of freedom of choice as well as attempting to curb the fear of a homogenous society because of genetic technologies. Before attempting to develop a means of controlling the use of positive genetic interventions, such as controlling for non-medical tendencies and enhancement of current capabilities, it is necessary to examine the arguments both for and against the adoption of such techniques.

“Even an elite can be dehumanized, can dehumanize itself. The central matter is not equality of access, but the goodness or badness of the thing being offered.”⁵² In Aldous Huxley’s Brave New World, a genetically based caste system is created; reproductive specialists engineer future persons in accordance to the demand within society to fill certain positions. The more intelligent are engineered to have the capability to use their genetic traits to advance their society, while those needed for menial labor related tasks are created so that they desire nothing higher than their current position in society. In order to prevent feelings of discontent within the lower classes, in Huxley’s world, individuals simply are not given the opportunity to question their position within society because of their inferior genetic makeup. In this world, genetic engineering is taken to its culmination; reproduction is removed from the private sector of society, freedom of choice is no longer applicable, and ‘natural children’ are considered savages within the society. In 1932, when Huxley published his novel, the advances seemed far-

⁵¹ Nozick, Anarchy, State, and Utopia, 315.

⁵² Kass, Leon. Beyond Therapy: Biotechnology and the Pursuit of Human Improvement, 6.

fetched, but policy makers today must consider the possibility of scenarios similar to Huxley's as genetic interventions continue to advance at a rapid pace. While there is no guarantee that a society that uses genetic selections and enhancements will reach such extremes as presented in science fiction, perhaps more disturbing, there is no guarantee that they will not.

Close to half of all Americans reject the proposal to use genetic engineering to 'fix' diseases, on both existing individuals and those future children.⁵³ Despite this hesitation to accept genetic interventions to prevent diseases, with few exceptions, the majority of Americans accept medical treatment to either cure disorders or allow affected individuals to lead 'normal' lives. DNA is viewed by the public as the "secret of life;"⁵⁴ for this reason, the idea of scientists tampering with disorders at this genetic level seems much more difficult to accept than using medical technologies to therapeutically fix disorders. If the aim is to 'cure' a patient with diabetes, for example, is there a difference between prescribing daily insulin injections in a hospital versus changing the defective gene at the genetic level and therefore bypassing this daily medical treatment? Some would argue that no, there is no significant difference; in fact, genetic intervention is a preferred choice because there is less responsibility of the patient to remember to take his shots and the doctors will no longer need to regulate the amount of insulin on a regular basis. Others, however, could recognize the differences resulting from treating a disease through medicinal means and eliminating the disease from ever existing at the genetic level.

There are two additional consequences of removing affected genes within an individual of any age. The first of these focuses on the fact that gene therapy is permanent and unlike medical therapy cannot be discontinued when deemed beneficial; once the individual is treated at the genetic level, replication of DNA within the cells will guarantee that the change will remain a lasting fixture of his person. The second difference is one that generates feelings of both hope and anxiety for the future; unlike therapeutic medicine, genetic interventions have the capability of not only fixing those problems that are inherent in nature, but also eliminating the existence of genetic

⁵³ Remaking Eden, Silver, 275.

⁵⁴ President's Council on Bioethics, Human Genetic Intervention, 1.

disorders completely. Once scientists have the means to eliminate serious medical conditions, the likelihood of creating a market for gene therapy for cosmetic reasons increases and scenarios fueled by science fiction become closer to reality.

As discussed in the previous chapter, a major concern that surrounds the use of any type of genetic engineering for reproductive purposes is that the use of genetic technologies will fuel an increase in the already unequal distribution of advantages within a society. Even without the option of engineering the ‘perfect’ child, financially stable couples are most likely to provide environmental advantages for their children within the United States.⁵⁵ Additionally, more developed countries are most likely to provide similar advantages to their citizens; without the immediate demands of providing basic necessities to the country, governments of stable countries can focus on improvements to the relative situation of their citizens. This economic gap prompts many to argue that there is little to no equality of opportunity that is so central to Rawls’ principles of justice. Will the advancement of genetic technology help to close this gap, or will it hinder any progress by extending the inequality from one that is based on social opportunities to an inequality inherent in the genetic makeup of all individuals?

“We mold and shape our children according to environmental factors. We give them piano lessons and every other type of lesson imaginable. I’m not sure there is anything wrong with using genetics....as long as it is not hurting anyone or...ideas of perfection (are not being imposed) on anybody.”⁵⁶ Arthur Caplan, Director of the Center for Bioethics at the University of Pennsylvania cites those potential problems that policy makers and the public must consider when analyzing genetic engineering: the principle of inclusion (and, conversely, exclusion) and freedom of choice. Few would argue that there is a fair equality of opportunity within today’s global society, or even within the United States. If legislators were to decide that genetic technologies should be used in reproductive situations, there is the chance (or, perhaps the likelihood) that these inequalities would be exacerbated and a definitive class system would develop.

Consider a society in which parents are able, and even encouraged, to screen their embryos prior to implantation to ensure that they are free from debilitating diseases.

⁵⁵ By ‘environmental’ factors, I am referring to advances that can be purchased at a monetary cost, such as private schooling, individual tutoring, personal trainers, musical lessons, etc.

⁵⁶ Arthur Caplan, as quoted in Remaking Eden, 249.

Chances are, when the technology is first introduced, only a few will have the resources to take advantage of this innovation and the overall effect on society will be minimal. As the efficiency of screening increases and as embryologists are able to test for more genetic traits, the cost of the procedure will decrease. Those who could not initially afford the treatment might now be able to screen their embryos to ensure that their children are not afflicted with the genetic diseases that society has agreed diminish quality of life significantly. In addition to screening for these diseases, imagine that doctors now have the ability to tell prospective parents considerably more about the embryo's genetic traits. Imagine, too, that the treatment has advanced to the point that parents can choose the most desirable embryo for implantation and that they can alter those genetic traits that they deem necessary in order to create their own perfect child. Finally, once society has become comfortable with genetic screening for diseases and secondary characteristics, suppose the technology for genetic enhancement is introduced into reproductive options for parents. Now consider the economic gap that is present today; as this technology begins to trickle down to the lesser-developed areas of the world, a game of 'catch-up' will begin. The rate at which science is evolving is exponential and countries (or individuals) lagging a few generations behind in the genetic race for perfection might find themselves permanently at a disadvantage. With genetically enhanced mental capacity would come an even greater technological increase; unless these potential benefits were somehow redistributed according to Rawls' difference principle, it becomes difficult to imagine a situation in which equality of opportunity would ever exist. This stepwise progression that begins with simple transitions between what is currently accepted to something a bit more controversial to, eventually, a final step that was originally deemed unacceptable, is often referred to as the 'slippery slope' argument.

While there are countless predictions of exactly how the slippery slope of genetic interventions could play out, one particular interpretation tells a chilling tale of a society reduced solely to the genetic makeup of their members. GATTACA served to initiate discussion among members of the public with its release into movie theaters in 1997. In this society, predestination, based on genetic makeup, is the sole predictor of an individual's placement within society. Children born of natural means were referred to as

‘in-valids’ and were restricted to performing menial labor tasks because of their inferior DNA. If parents were to give their offspring the best opportunities for success, they were forced to initiate their pregnancy in a fertility clinic, complete with tools used to screen embryos for health and greatest potential: both physical and mental. In this fictional society, a drop of blood was obtained from children upon birth and a computer printout outlined their potential in every aspect of life: propensity towards violence, chances of developing heart disease, exact life expectancy. Prospective employers conducted interviews by taking blood samples and it was unheard of for individuals to better their position in society. It is a society such as this one that critics of genetic engineering often cite; it is difficult to accept a situation in which human potential is eliminated and one’s future is dictated by circumstances behind his control. It is a society such as this one that policy makers and scientists alike must guard against; if we are truly to support a principle of equality of opportunity, predestination cannot be a means of evaluation of individuals and we must tread carefully when dealing with the potential separation of ‘genetically enhanced’ children and ‘naturally-born’ offspring.

GATTACA can serve as a fictional case study in respects to the expansion of the gap between classes and the potential caste-society that could be created with the use of genetic enhancements, but it also brings up the issue of reproductive freedoms and the use of genetic interventions. While some of the strongest arguments supporting genetic interventions are based upon increasing individual freedom of choice with regards to reproduction, the potential for coercion and lack of freedom of choice also arises. If, for example, the baseline minimum for human characteristics is raised to a level unattainable without genetic enhancements, any parent refusing gene therapy would be, in essence, depriving her child of equal opportunity for success. It could even be argued that if a parent refuses to provide her child with these ‘necessary’ enhancements, she is putting her offspring at a disadvantage; one could imagine a situation in which this could be termed neglect, provided the means for genetic testing were available within the family funds. Leon Kass refers to this restriction of freedom as the “problem of conformity or homogenization.”⁵⁷ Despite the attempt of genetic engineering to increase the level of choice for prospective parents, he warns that coercive forces will eventually dictate the

⁵⁷ Kass, Leon. Beyond Therapy: Biotechnology and the Pursuit of Human Improvement, 7.

level to which embryos must be screened and improved upon if parents are to meet the standards that will be imposed upon them by a genetically-enhanced society. Kass writes, “we are right to worry that the self-selected non-therapeutic uses of the new powers, especially where they become widespread, will be put in the service of the most common human desires, moving us toward still greater homogenization of human society – perhaps raising the floor but greatly lowering the ceiling of human possibility, and reducing the likelihood of genuine freedom, individuality, and greatness.”⁵⁸ He continues to give an example of this restriction of freedom: if one were to be given the opportunity to undergo noninvasive treatment that would succeed in ‘brightening his mood’ so that he was less bothered by the troubles around him, it seems difficult to see the ‘choice’ involved. Those who would have access to such opportunities, therefore, would most certainly be swayed by their potential for providing greater quality of life, but those without such ‘choices’ would be left behind.

Assuming that we accept Kass’ argument that genetic enhancements will ultimately leave individuals with such fantastic opportunities that they have no choice but to accept them, we will soon find ourselves facing the “Tragedy of the Commons”.⁵⁹ On an individual level, parents would opt for their children to have the best opportunities in life; they would, at the genetic level, insert those genes that would make their offspring healthier, stronger, and more intelligent. If, however, every family is ‘forced’ into making these same choices, society as a whole may be harmed. If, for example, genetic technology were able to extend the healthy life span of individuals by two or three decades, we can assume that, given the option, individuals would agree that this would be a benefit of which they would want to take advantage. Once everyone in a community capitalized on this genetic enhancement and benefited on an individual level, the society would begin to see negative repercussions, such as overpopulation, for example. It is essential that choices made by individuals do not trade off future sustainability of the whole in favor of immediate benefits for the individuals.

Up until this point, we have assumed that, at least on an individual level, enhancement of human capabilities is a positive thing; it presented with the opportunity

⁵⁸ Kass, Leon. Beyond Therapy: Biotechnology and the Pursuit of Human Improvement, 7.

⁵⁹ Based on the analysis made famous by biology professor Dr. Garrett Hardin in 1967.

of, for example, an increase in athletic prowess with no long-term negative repercussions, one would imagine a rational decision maker to accept the enhancement. This is a presupposition, however, that must be more closely evaluated. Philosopher Michael Sandel introduces a dichotomy that could result with the incorporation of genetic enhancements into everyday life: the relationship between human agency and the individual's creator.⁶⁰ In other words, the more interrelated human accomplishment and genetic enhancements, the less impressed we should be with individual achievement. As the agent deviates from his achievements, he becomes less of an autonomous being and more of a means of serving a purpose chosen by his genetic makeup. He argues that as we control the genetic makeup and, consequently, the innate ability, of an individual, we lose an aspect of humanity that, today, we take to be a defining characteristic of our species. "The more the athlete relies on drugs or genetic fixes, the less his performance represents *his* achievement...The bionic athlete would not be an agent at all; 'his' achievements would be those of his inventor."⁶¹ Without the challenge of adversity, accomplishment is expected and the level of admiration for unparalleled success is greatly reduced.

The human condition is one that thrives on experience in shaping individual success; the experiences that usually define one's character the most are those that are not necessarily chosen or foreseen. By creating 'perfect' individuals and eliminating the 'learning' phases of human development, will we be, in fact, creating the best possible individuals? The President's Council on Bioethics examined this question and the effect that extreme genetic enhancements might have on future persons and their capacity for 'humanness.' "Human life is an ongoing experience, not a static condition, and so the way that ends are reached – the experience of change – often matters at least as much as the ends themselves. Separating improvement from the experience of effort and exertion could tend to undermine the meaning and importance of improvement...artificial enhancement may well prove to be a barrier to genuine self-improvement."⁶² As we attempt to improve the human condition, therefore, we might in fact be losing that which

⁶⁰ Sandel, Michael, What's Wrong with Enhancement?, 2.

⁶¹ Sandel, Michael, What's Wrong with Enhancement?, 2.

⁶² President's Council on Bioethics, Distinguishing Therapy and Enhancement, 3.

we value most. Today, we may wish for perfection, but in a genetically engineered tomorrow, we may instead desire the journey towards excellence instead.

In addition to these central potential problems surrounding positive genetic interventions, we must evaluate specific social implications that could arise because of the incorporation (or lack thereof) of policy restrictions within the United States. How probable is the evolution of a suprahuman race and how much are we willing to risk to find out? Does the fact that we will soon have the ability to redefine human capabilities mean that we should capitalize on this technology? Is it possible to accept negative genetic interventions without while successfully resisting the temptations to travel down the theoretical slippery slope? No matter what the answers, it is clear that it is the responsibility of policy makers to ask these difficult questions and to adopt policy that will reflect the desires and concerns of both individuals and of society as a whole; without proper consideration and sufficient regulations, these important decisions will be made without the necessary precautions and we might find ourselves in a situation in which we are unable to remedy the damage already done.

CHAPTER FIVE

“With great power comes great responsibility.”

-Uncle Ben Parker, Spiderman

The advancements offered by genetic interventions are presenting themselves at a pace more rapid than most would have imagined. This increase in reproductive options is proving to change the way we look at nature, human beings, and future generations; without guidance provided through regulations and legislation, this biotechnological science will continue to develop outside the watch of a standardized ethics committee. Discussion about tomorrow must begin today; science has continued to offer more options for us to improve our lives and the lives of our children, it is now time to evaluate those options and determine whether or not they truly constitute ‘improvements.’ While the technology to enhance genes so that they exceed ‘normal’ human capacity is not available today, geneticists today are able to screen embryos and genes for mutations and therefore have the capability of practicing negative genetic interventions.

In 1994, Lisa and Jack Nash gave birth to Molly, their first child, and found that she suffered from Fanconi anemia, a disease that causes bone marrow failure and ultimately results in leukemia. Children who suffer from this severe disorder rarely survive past six years old; immediately following her birth, Molly’s parents began researching the disease and prayed for options that might save their daughter’s life. The answer came when they were contacted by Dr. John Wagner and given the opportunity to participate in an experimental procedure that might give their daughter a chance to fight the leukemia that was imminent as a result of her disease. The Nashes accepted his proposal immediately; Wagner’s idea was to use genetic screening on the Nash’s second child to ensure that their next offspring could serve as a bone marrow donor for Molly. In other words, since the Nashes had already wanted a second child, Wagner wanted to use genetic technology to make sure that the child was ‘the best’ child for this family. In this case, ‘best’ meant a child who not only did not suffer from Franconi anemia, but also a child who was a compatible human leukocyte antigen (HLA) donor for their existing child. The probability of success of transplants between siblings was 85 percent; bone

marrow transplants from nonrelatives were only successfully completed 30 percent of the time, but because of the severity of Molly's condition, this percentage dropped close to zero. Given the comparative statistics of success, the Nashes did not hesitate to accept the genetic screening offered by Wagner. "Though society may ask 'How could you?' the only question patients and families ask is, 'How could we not?'"⁶³

The road to ensuring that their second child was both healthy and a donor for Molly was a rocky one. After dozens of attempts to successfully use IVF to implant an embryo that matched Molly's HLA and following Wagner's forced resignation from his research facility and from the National Institute of Health, the pregnancy was successful and Adam was born in August of 2000. Molly's transplant was a triumph and she is living a healthy life today; while the operation did not cure her disease, it prevented the onset of leukemia which would have proven fatal without the transplant.

This story had a happy ending for the Nashes, but it is easy to see where society, ethicists, and policy makers have room for concern. Some may argue that the Nash's case was morally acceptable because they had already made the decision to have a second child, but by what means could this intent be determined for couples in the future? Would allowing situations like the Nash's to occur again be violating Kant's principles by creating children as a means to save others, instead of ends in themselves? "Is the potential for abuse in some circumstances reason not to pursue research that can be lifesaving under the right circumstances?"⁶⁴ Regulation of genetic interventions will be a difficult task, especially given the ever-evolving possibilities and discoveries made every day. As this research will inevitably continue, whether it be within federal guidelines, in the private sector, or off-shore, policy makers must look at the arguments for and against embryo research as scientists work to develop new advancements within the genetic realm.

Many critics of genetic engineering disagree with all aspects of this biological science and reject it at the level of embryo research; without the continuation of such study, the developments (both negative and positive) will be halted. Policy makers must ask, then, should regulatory measures be put in place to control, or eliminate, such

⁶³ Belkin, Lisa. The Made-to-Order Savior, 2.

⁶⁴ Belkin, Lisa. The Made-to-Order Savior, 5.

research? In order for the State to have a legitimate claim to restrict the freedom of an individual, it must be shown that the individual's practice is harming another. "Each should be bound to observe a certain line of conduct towards the rest. This conduct consists first, in not injuring the interests of one another; or rather certain interests, which, either by express legal provision or by tacit understanding, ought to be considered as rights....These conditions society is justified in enforcing at all costs to those who endeavor to withhold fulfillment."⁶⁵ The question remains, therefore, as to where the harm is taking place. There are three areas to which we should give attention: society, the embryos as a collective group, and those who would be directly affected by research and technology growth in this area.

In an attempt to avoid delving into the issue of moral status of the embryo as it develops from an eight-celled entity into a fetus with limited human rights,⁶⁶ I will focus only on the embryo before the onset of the primitive streak. In this situation, unjust harm is a difficult concept to define; the fact that we are dealing with cells that only have the potential to turn into humans makes the idea of unjustly harming them a bit elusive. Take, for example, an embryo left over from an IVF procedure. If the embryo is no longer to be implanted into the female, then its fate is one of either disposal by incineration or donation to scientific research. If one were to argue that embryos should not be either destroyed or be the subjects of research on the basis of their moral status, then the road ahead may be rocky. Take, for instance, the fact that up to 75% of embryos, during the natural reproductive cycle, fail to implant into the woman's womb.⁶⁷ If we are to grant the embryo full moral status or even limited legal rights, would it not follow that we would have a responsibility to save even those embryos that were 'discarded' naturally?

It is possible to differentiate between the use of 'discarded' embryos for research and the creation of new embryos for the sole purpose of scientific experimentation. In cases focusing on spare embryos left over from IVF procedures, the intentions of the parents were not to create research subjects; the choice is not between creation and non-creation, but rather whether the embryo will be destroyed before or after scientific

⁶⁵ Mill, 75.

⁶⁶ As far as the law is concerned.

⁶⁷ Green, 37.

research. It is difficult, however, to reconcile the case of embryos being created for the purpose of research with Kant's claim that beings with moral status must be used as ends in themselves, and not as means. Using this distinction between intentions is a risky undertaking, especially in situations that are inevitably regulated by their outcomes. In other words, if we are to agree that the embryo has some level of moral status, albeit not full moral status, we must work to ensure that embryos are not created as one would create material commodities for the market. Is it permissible, then, to use discarded embryos for research if it is unacceptable to create embryos for that same purpose?

In the case of using discarded IVF embryos, the scientists doing the research are not deciding whether or not the embryo will be implanted to develop into a person or whether the embryo will be discarded; the embryo is already being destroyed, but it is the method by which it is destroyed that embryo research influences. Given that the embryos in question are either going to be incinerated or used in the laboratory, pro-researchers would advocate the idea that "doing something good is better than doing nothing at all."⁶⁸ In other words, if the embryos in question are already tagged for destruction, why should scientists not use them to further their research?⁶⁹ It seems to follow that if one is to oppose embryo research on discarded IVF embryos, then that argument should have its basis in the opposition to the destruction of the unused embryos in the first place. If, however, we grant even partial moral status to embryos, the use of discarded embryos to achieve some end would violate their interests to be ends in themselves.

Before determining the level of unjust harm upon the embryos used for research, therefore, the manner in which they will be assigned status must first be decided. This decision is one that could indeed shape the attitude of the society towards any humans deemed 'less-than perfect,' and so should be handled by both academics and the general public. If it is determined that embryos should be afforded full moral status, the sanctity of life principles will be held intact and immovable; if embryos are instead classified as non-human entities without moral status, we must be hesitant to expand such analysis to less fortunate members of society. Perhaps the most intuitively appealing and the most practical solution would be to afford embryos limited moral status, but not in the sense

⁶⁸ Harris, 12.

⁶⁹ This is, of course, assuming that their research goals are deemed advantageous to society.

that we afford moral status to humans; by delineating embryos from skin cells, for example, we would be recognizing their potential to create human life, but we would be able to reconcile their limited status with the possible benefits toward future members of society resulting from the suspension of their moral statuses. Such an approach would prevent scientists from creating embryos in a research facility, but would allow parents to relinquish discarded embryos to genetic researchers for study and experimentation.

The second group that must be considered when assessing the impact of embryo research is that of the future generations of children whose genetic diseases could be cured as a result of scientific research. While it becomes difficult to weigh the interests of one group against the interests of a future group, if we accept that embryos are not afforded the same status as humans, it seems unlikely that their ‘interests’ not to be harmed would outweigh the interests of future children to be advantaged. We are considering, therefore, any interests satisfied in the future as almost a total net gain due to advances in genetic engineering. If we are to imagine a society that has harnessed the capability of reducing suffering within the population with the genetic elimination of diseases, it seems as if the interests of future generations would indeed be significant. With the help of embryo research, the possibilities of controlling genetic disorders with the use of somatic gene therapy are quite high; this being said, it becomes difficult to imagine that the interests of an embryo could outweigh those of current and future generations, given that we can consider such advances as positive changes. We must, therefore, examine the impact of genetic engineering on future individuals as a collective society.

The third group that will most definitely be affected by embryo research is society as a whole. The topic of embryo research is, understandably, a very controversial one; it questions the basic premise of moral philosophy and does so with the promise of a ‘better’ future. With successful embryo research, the likelihood of developing a lucrative market for positive genetic interventions increases. If embryo research is permitted to continue without government-approved guidelines, however, the chances of creating a society in which one’s status is determined not only by economic stability, but also by genetic makeup, are much higher. Tales of the slippery slope in which the moral backbone of society diminishes to the idea of pre-destination as prescribed by DNA are

indeed possible; it is with government regulations, however, that the possible will not become the probable.

When approaching policy issues, it is important to consider not only the moral and ethical aspects of genetic engineering and embryo selection, but policy makers must look at the possible implications of adoption of policies of all sorts. It is essential to reach equilibrium between social justice and individual freedom; this difficulty of creating this balance, however, is clear upon close inspection of the possibilities of genetic interventions. By following the general guidelines laid out by John Rawls, we can expect to emphasize equality of opportunity as well as adoption of policies that present the greatest benefits to the least fortunate within a society. The means of attaining these goals will not be static; with the constant development of new techniques and advancements on technology, policy makers will find themselves continuously reestablishing the equilibrium in order to achieve their goals.

Genetic engineering is not an issue unique to the United States; this is a policy issue that must be given international attention and priority, for the actions of one area of the world will ultimately affect the rest of the international community. Genetic interventions provide the ultimate example of peer pressure: if everyone else is using genetic technologies to improve their position within society, the choices left to others is to also take advantage of the technology, or to get lost in the evolutionary scheme of things.

In the end of his book, Remaking Eden, Professor Lee Silver jumps ahead to the year 2350. He narrates the history of a world that has embraced the technologies of the genetic revolution; limitations were not placed on positive genetic enhancements within the private realm, and the liberal market economy encouraged research into such enhancements. When Silver begins his epilogue, the members of Congress are holding a meeting concerning the future of the human races. Because of genetic technology, human beings developed into two separate species, incapable of reproduction between the “GenRich-humans” and the “Natural-humans.”⁷⁰ The GenRich-humans were those endowed with enhanced genetic codes and they were the leaders of the countries, the presidents of the corporations, and the athletes competing in the sports arenas. This

⁷⁰ Silver, Lee. Remaking Eden, 282.

separation took only twelve generations of reproduction; the first enhanced GenRich-humans bore offspring that were further genetically enhanced, their children's genes could be manipulated to be even more improved, and so forth. Government took a 'hands-off' approach to the development of technology. This was not surprising, considering all members of the leadership were, themselves, products of the GenRich class.

Silver claims to make no value judgments in his interpretation of what the future can hold, but rather his attempt was to inform the public of potential repercussions of quick acceptance of genetic technology void of sufficient ethical analysis. "Being a scientist, by temperament as well as profession, I am more interested in explaining things as they are – or as I think they will become – than in imagining a utopian future that seems to me based on wishful thinking....I leave it to the philosophers and bioethicists to figure out how these ethical dilemmas might be resolved."⁷¹

Perhaps the most terrifying aspects of Silver's hypothetical culture are not specifically those that focus on the physical differences between the genetically engineered humans; the nervous feeling that is emitted from his tales are most likely centered around a realization that our current philosophy on 'humanness' is one created by us. It is also a philosophy that can be altered, or even discarded, by us as well. The prospect of using genetic engineering is one that has countless possibilities of harnessing the human greatness that is sporadically found within the population. If we 'create' this greatness, however, we must consider the impact that this will have on our perception of humanity. Midas once wished for everything that he touched to turn gold; it was only upon receiving his wish that he found that the objects he truly desired were those that he was unable to obtain. We must be wary of taking things for granted as we capitalize on opportunities for supposed greatness.

Today, we view 'humanness' as something intangible, our greatness is something that is, in essence, found only in nature. If we are to utilize this greatness to control nature, down to our genetic makeup, we will inevitably lose the value of those characteristics that we label as amazing today. Efficiency of creation is something to which manufacturers strive, it is not the manner in which we view human reproduction;

⁷¹ Silver, Lee. Remaking Eden, 294.

as demonstrated in Silver's hypothetical, however, it could very well be a foreseen consequence of scientific genetic control.

We must not ignore the potential complications associated with the use of genetic engineering for reproductive purposes; being capable of manipulating the human genetic code does not immediately justify the use of such technology. Using principles of equality of opportunity and distribution as introduced by Rawls, we can see several possible negative consequences of unhindered human genetic engineering. If we essentially translate material advantages to genetic superiority, we, in essence, eliminate even the appearance of equality between humans.

Arguments can be made that claim that such advancements of human ability are, in fact, beneficial for future humans, but, as Fukuyama asserts, there are conditions other than physical and mental capacities that must be considered. He argues that we must strive to maintain our 'humanness' within our species; this human dignity will be lost with the elimination of any need to overcome obstacles that are presented us in everyday life. As mentioned in Our Posthuman Future, before embarking on this engineering journey, we must be able to contain our manipulations to therapeutic changes, instead of enhancements.

This difference between negative and positive therapy, however, is not separated by a clear dividing line; as discussed in prior chapters, what is considered therapy for one could also be labeled enhancement for another. This difficulty in distinguishing between the two forces us to adopt the strictest regulations surrounding genetic engineering; until it is found that we can clearly define these two categories, the acceptance of one will ultimately lead to the use of the other. If we are to agree that the preservation of an equal society that retains the qualities of 'humanness' is our goal, the science of genetic engineering must take a back seat to evaluation of the ethical and moral issues surrounding such technology. Decisions made today will affect generations to come and we must not accept such technology simply on the basis of its availability.

Genetic engineering offers the human race some fantastic improvements on our current condition: it promises relief from suffering, extension on our present lifespan, and elimination of those conditions that cause us the greatest sadness. Along with these advantages, however, come tremendous risks: creation of a society that bases all social

structure solely on genetic makeup, coercive pressure to accept genetic enhancements in order to survive, and even the eventual division of the human race into multiple species. If we are to decide that our perception of 'humanness' is sacred enough to maintain, until it is shown that parameters can be placed to ensure the survival of such a perception, genetic engineering research, for positive enhancements, should be put on hold. Genetic interventions that could eliminate diseases for future generations, however, could theoretically be offered with specific restrictions. If such measures are adopted, the risks and benefits must be reviewed in a public manner and experts should open discussion to members of the community; this will not only foster much-needed comprehension of the current situation by the public, but it will involve those who will ultimately be most affected by decisions made by the governments. With intellectual conversation, we can hope to harness the beneficial potential of this new technology while avoiding the loss of our sense of humanity that seems as if it will almost inevitably follow a blind acceptance of this genetic revolution.

BIBLIOGRAPHY

- Belkin, Lisa. "The Made-to-Order Savior," *New York Times Magazine*, 1 July 2001, 1.
- Buchanan, Allen, Dan Brock, Norman Daniels, and Daniel Wilker. *From Chance to Choice*. New York: Cambridge University Press, 2000.
- Caplan, Arthur, Glenn McGee, and David Magnus, "What is immoral about eugenics?," *The Western Journal of Medicine* (November 1999): 335.
- Caulfield, Timothy. *Clones, Controversy, and Criminal Law: A Comment on the Proposal for Legislation Governing Assisted Human Reproduction*. The Alberta Law Review. September, 2001. 39 Alberta L. Rev. 335.
- Charlesworth, Max. "Community Control of IVF and Embryo Experimentation." *Embryo Experimentation*, Peter Singer et al. eds. Cambridge: Cambridge University Press, 1990. 147-152.
- Columbus, Chris, dir. *Harry Potter and the Chamber of Secrets*. New York: Warner Bros Pictures, 2002.
- Davis, Dena. *Genetic Dilemmas: Reproductive Technology, Parental Choices, and Children's Futures*. New York: Routledge, 2001.
- Dawson, Karen. "Fertilization and Moral Status: A Scientific Perspective." *Embryo Experimentation*, Peter Singer et al. eds. Cambridge: Cambridge University Press, 1990. 43-52.
- Dawson, Karen. "Segmentation and Moral Status: A Scientific Perspective." *Embryo Experimentation*, Peter Singer et al. eds. Cambridge: Cambridge University Press, 1990. 53-64.
- Evans, John. *Playing God?: Human Genetic Engineering and the Rationalization of Public Bioethical Debate*. Chicago: The University of Chicago Press, 2002.
- Fukuyama, Francis. *Our Posthuman Future: Consequences of the Biotechnology Revolution*. Chicago: The University of Chicago Press, 2003.
- Glannon, Walter. *Genes and Future People*. Cambridge: Westview Press, 2001.
- Green, Ronald. *The Human Embryo Research Debates*. Oxford: Oxford University Press, 2001.
- Hare, R.M. "Public Policy in a Pluralistic Society." *Embryo Experimentation*, Peter Singer et al. eds. Cambridge: Cambridge University Press, 1990. 183-194.

- Harris, John. "Rights and Reproductive Choice." *The Future of Human Reproduction*, John Harris and Soren Holm, Eds. Oxford: Clarendon Press, 1998. 5-37.
- Holm, Soren. "Ethical Issues in Pre-Implantation Diagnosis." *The Future of Human Reproduction*, John Harris and Soren Holm, Eds. Oxford: Clarendon Press, 1998. 176-190.
- Hubbard, Ruth, and Elijah Wald. *Exploding the Gene Myth*. Boston: Beacon Press, 1993.
- Huxley, Aldous. *Brave New World*. New York: Harper & Row Publishers, Inc, 1965.
- Kasimba, Pascal. "IVF Regulation: The Search for a Legal Basis." *Embryo Experimentation*, Peter Singer et al. eds. Cambridge: Cambridge University Press, 1990. 153-167.
- Kass, Leon R. "Beyond Therapy: Biotechnology and the Pursuit of Human Improvement," January 2003.
<http://bioethicsprint.bioethics.gov/background/kasspaper.html>
- Kass, Leon R. "Preventing a Brave New World," *The Human Life Review* (Summer 2001): 14.
- Kass, Leon R. "The Moral Meaning of Genetic Technology," *The Human Life Review* (Winter 2000): 76.
- Lauritzen, Paul. "What price parenthood?" *The Hastings Center Report* (March-April 1990): 38.
- Liew, Julian, and Walter von Wartburg. *Gene Technology and Social Acceptance*. New York: University Press of America, 1999.
- McGee, Glenn. *The Perfect Baby*. Lanham, MD: Rowman & Littlefield Publishers, Inc, 2000.
- Mill, John Stuart. *On Liberty*. Cambridge: Cambridge University Press, 1989.
- Mulkay, Michael. *The Embryo Research Debate: Science and the Politics of Reproduction*. Cambridge: Cambridge University Press, 1997.
- Niccol, Andrew, dir. *GATTACA*. New York: Sony Pictures, 1997.
- Nozick, Robert. *Anarchy, State, and Utopia*. United States: Basic Books, Inc, 1974.

- Parens, Erik, "The Goodness of Fragility: On the Prospect of Genetic Technologies Aimed at the Enhancement of Human Capacities," in *Contemporary Issues in Bioethics*, Tom Beauchamp, ed. Boston: Wadsworth Publishing Company, 1999.
- Pattison, Shaun D. *Influencing Traits Before Birth*. Burlington, VT: Ashgate Publishing Company, 2002.
- Paul, Diane B. *Controlling Human Heredity: 1865 to the Present*. New Jersey: Humanities Press, 1995.
- Raimi, Sam., dir. *Spiderman*. New York: Columbia Tristar, 2002.
- Ramis, Harold, dir. *Multiplicity*. New York: Columbia Tristar, 1996.
- Rawls, John. *A Theory of Justice*. Cambridge: Harvard University Press, 1971.
- Sandel, Michael. "What's Wrong with Enhancement," December 2002. <http://bioethicsprint.bioethics.gov/background/sandelpaper.html>
- Silver, Lee. *Remaking Eden*. New York: Avon Books, Inc, 1997.
- Singer, Peter, and Helga Kuhse. "Individuals, Humans and Persons: The Issue of Moral Status." *Embryo Experimentation*, Peter Singer et al. eds. Cambridge: Cambridge University Press, 1990. 65-75.
- Singer, Peter. "Technology and Procreation: how far should we go?," *Technology Review* (Feb-March 1985): 22.
- Strong, Carson. *Ethics in Reproductive and Perinatal Medicine*. New Haven: Yale University Press, 1997.
- The President's Council on Bioethics, "Distinguishing Therapy and Enhancement," April 2002. <http://bioethicsprint.bioethics.gov/background/workpaper7.html>
- The President's Council on Bioethics, "Human Genetic Engineering," December 2002. <http://bioethicsprint.bioethics.gov/background/humangenetic.html>
- Watson, James. *A Passion for DNA: Genes, Genomes, and Society*. New York: Cold Spring Harbor Laboratory Press, 2000.

Virginia Polytechnic Institute

Blacksburg, VA
2001-current

MA in Political Science, May 2003

Thesis Topic: Reproductive Genetic Engineering and Public Policy

Teaching Assistant (GTA); Professor Scott Nelson:

- PSCI 2056 World Politics and Economy (Spring 2003)
- Teach Weekly recitation sessions

Teaching Assistant (GTA); Professor Edward Weisband:

- PSCI 1004 Nations and Nationalities (Fall 2001, Fall 2002)
- PSCI 2056 World Politics and Economy (Spring 2003)
- Responsible for administration, lecture organization, and grading
- Teach Weekly recitation sessions

Graduate Representative in Political Science Department:

- Liaison between faculty and graduate students (2001-2002)
- Attend faculty meetings

Graduate Student Assembly (GSA) Student Representative (2001-2002)

Virginia Tech Women's Rugby Head Coach (2002-current)

- Responsible for organizing and running daily practices
- Representing Virginia Tech during games and tournaments

Princeton University

Princeton, NJ
1997-2001

A.B. in Politics, Certificate in Political Theory, 2001

Odyssey of the Mind; President; (*Creative Problem Solving Competition*):

- Founder of program at Princeton University; organize student teams
- Develop and present budget to President Shapiro; bylaws to Princeton University Development Office

Princeton Club Sports Executive Council; President

- Conduct meetings of the Executive Council
- Preside over meetings held by all Club Sports Presidents
- Organize Princeton University Club Sports Program schedules and fundraising for 1300 students
- Liaison between athletes and Athletic Directors

Princeton Women's Rugby Team; 2000-2001 President

- Responsible for financial and administrative tasks including hiring and payment of coaches
- Representative for Alumni Graduate Board meetings
- Organize lodging, travel and fundraising for National Competition

Princeton Women's Rugby Team; Tour Chairman; 2000; 2001

- Set up games, order uniforms, organize on/off campus fundraising for off-season tour
- Plan and organize weeklong, off-season winter tour; England, 2000; Florida, 2001

Awards and Distinctions

- First Team Selection Division I Women's Collegiate Rugby; All-Ivy Conference
- National Women's Rugby Division I Final Four Game 2001; Rockford, IL
- National Women's Rugby Division I Championship Game 2000; Tampa, FL
- National Women's Rugby Division I Championship Game 1999; State College, PA
- Second Place 1999 Odyssey of the Mind World Finals Classical Problem; Orlando, FL
Third Place 1999 Odyssey of the Mind World Finals Structure Problem; Orlando, FL

Cape Henry Collegiate School

Virginia Beach, VA
1994 -1997

Leadership Workshops (selected):

- Virginia Girls State Ambassador; Lieutenant Governor Candidate
- Hugh O'Brien Youth Leadership Foundation Delegate (HOBY); Virginia
- United States Naval Academy Summer Scholars Program for Science and Engineering

Offices Held (selected):

- Class President, 9; Class Vice-President, 12
- Yearbook Editor; 11-12
- Key Club President; 11-12
- International Club President; 11-12

Awards and Distinctions (selected):

- Discover Card Tribute Award for academics, community service, athletics, and leadership
- Randolph-Macon College Book Award
- 1997 Maryann Jacobson Award (Female Athlete of the Year)