

Respect For Persons As A Guide To Genetic Enhancement

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I. Introduction

Is it possible that someday it will be considered unethical for parents not to enhance their unborn child with the best characteristics modern genetics can make possible? With the approach of genetic enhancement, what will happen to individuality and diversity? Will those who are considered imperfect individuals become less valuable in society than those with optimal characteristics? And, if we rid humanity of all our imperfect characteristics, thus taking away the struggles and difficulties of normal functioning, what will happen to the work ethic and determination of persons?

The goal of the Human Genome Project, as stated by Dr. Louis Sullivan, is "to locate and describe the activity of human genes, to dispose for new treatments and cures for diseases, as well as to develop a deeper understanding of all biological processes."¹ But it follows that along with the illness-treating technologies of the Genome Project, other kinds of applications also will occur. Understanding the biological processes more thoroughly does not necessarily mean that this knowledge will be used solely for the ethical well-being of persons. In some cases, the knowledge gained concerning an individual's genetic makeup could be used to that person's detriment. Consider the case of those individuals who have preexisting diseases resulting from their genetic abnormalities. These examples raise many ethical questions regarding the potential benefit or harm of genetic enhancement.

1. French Anderson, "Human Gene Therapy," *Science*, 8 May 1992, p. 810.

The concept of eugenics, however, is at the forefront of these issues, particularly when many physicians and medical professionals throughout the world hold the notion of health as a state of optimal physical or cognitive functioning.² The difficulty arises when we try to distinguish between defective gene repair and the enhancement of normally functioning genes. The repair of abnormal genes may restore health and thus help to restore equal opportunity to unequal individuals within the natural limits of humanity. On the other hand, genetic enhancement may be used to increase the ability of normally functioning genes or to change the genetic makeup of individuals in order to enhance their skill to an elite level.

Numerous ethical problems arise regarding the science of genetic enhancement when we seek to understand what separates it from outright eugenics. Where does one draw the line between what procedures are and are not morally acceptable? It is clear that enhancement can help to create a better physical being, but this does not necessarily mean that a better person will result. As Jacques Maritain notes in his book, *The Person and the Common Good*:

Because it is ordained to the absolute and is summoned to a destiny beyond time, or, in other words, because of the highest requirements of personality as such, the human person, as a spiritual totality referred to the transcendent whole, surpasses and is superior to all temporal societies.³

Maritain emphasizes the important intrinsic value of each individual human person, not merely as a being with certain "good" qualities that will increase his or her usefulness in society. The affirmation of this intrinsic value encourages an ethics that focuses on respect for persons as its fundamental principle. Since respect for persons involves the avoidance of harm to human beings, as well as the active promotion of their well-being, genetic enhancement should only be used if the enhancement benefits the whole person. Moreover, respect for persons demands that all human beings are treated justly. And so if genetic enhancement is made possible to only those who have adequate health care, then they will have an unfair advantage over others who could not afford to endow their children with such improvements.⁴ Some would say that society already encourages en-

2. Phillip Sloan, ed., *Controlling Our Destinies: Historical, Philosophical, Ethical, and Theological Perspectives on the Human Genome Project* (Notre Dame, Indiana: University of Notre Dame Press, 2000), p. 217.

3. Jacques Maritain, *The Person and The Common Good* (Notre Dame, Indiana: University of Notre Dame Press, 1966), p. 61.

4. Sloan, *Controlling Our Destinies*, p. 221.

hancement through activities such as private schools, athletic camps, or music lessons. This form of natural enhancement, however, does not drastically alter the genetic makeup of the individual. These improvements seem tame in relation to changing the genetic code of the unborn to enhance their skill, ability, or beauty.

Beyond these concerns, two additional problems arise. First, it is obvious that certain physical changes will allow individuals to feel healthier and better about themselves, such as reduced weight, lowered blood pressure, and increased beauty. However, these individuals may overlook the emotional changes or stresses that might occur as they seek to approach perfection. Secondly, environmental influences remain regardless of any genetic changes that take place. Whether or not children are genetically enhanced, they will still be influenced by the values and moral principles instilled in them by their social environment. If one's environment is negative, it is unlikely that genetic enhancement alone would be able to take the place of the love and nurturing needed for that child to grow within his or her community. These examples raise many ethical questions regarding the benefit of enhancement and its potential for harm.

II. Eugenics and Genetic Enhancement

The direction of genetic enhancement today is challenged by the concept of eugenics. Is it aimed solely at helping those who seem to be lacking optimal functioning, or is its goal that of creating vain perfection? Traditionally, eugenics concerned races and societies, not individuals only. Within the eugenics movement, there are two distinct approaches: positive and negative. Positive eugenics encourages reproduction, but only among those who are fit. This movement encourages "fit" people to have more children so as to create a better genetic society. Negative eugenics, on the other hand, promotes the sterilization or elimination of any person thought to have undesirable genes. This would stop reproduction of the unfit genes by simple extermination.

In Germany during World War II, the world saw attempts at both types of eugenics. Negative eugenics programs were occurring throughout concentration camps, with the goal of developing "racial hygiene" within the country.⁵ But the attitude of Hitler did not stop at the Jewish prisoners. Rather, Hitler wanted to purify all of Germany. Thus, the Germans wanted to control

5. Arthur Caplan, "What's Morally Wrong With Eugenics?" in *Controlling Our Destinies*, p. 211.

the offspring of the citizens and eventually wipe out the characteristics viewed as undesirable within the Nazi state. Negative eugenics programs such as these were aimed at eliminating the undesirable genes through strictly enforced prohibitions in the areas of sexual relationships, marriages, and sterilization of "unfit" women. At the same time, however, positive eugenic programs were also in full effect throughout Germany. Those who satisfied the specific characteristics desired by the government were urged to have more children. If they were successful, rewards and benefits were offered for ideal gene pool reproduction.⁶

And so, in theory, both positive and negative eugenics can enhance the genetic makeup of a specific population. However, we must be cautious; the idea of population enhancement is often presented as having only positive results because of the apparent good that it will provide society in the future. Eugenacists generally share a common belief: "Concern for human betterment through selection - - that is, by taking measures to ensure that the humans who do come into existence will be capable of enjoying better lives and of contributing to the betterment of the lives of others;"⁷ such is their motivation for enhancing individuals. Allen Buchanan points to this and several other dangers in his book *From Chance to Choice: Genetics and Justice*, which explains very clearly the dangers of the appeal of the genetic enhancement movement. One example is that many eugenacists tend to believe that a person's rank in society is solely a reflection of his or her capabilities, meaning that social standing is one factor that could be used as an indication of the genes which should be passed down to later generations. Another danger is that acceptance of the eugenics ideology diminishes the ability of members within a society to recognize the originality and uniqueness of others. For example, with instruction in eugenics introduced into Nazi-era German medical schools and practices, physicians became numb to the idea of individuality and genetic differences in their treatment of patients and family members.⁸ Instead, they began to revel in their new discoveries and continued to perform disastrous surgeries and medical procedures, paying no attention to the consequences or ethics of experimenting on human persons. Thus, the focus of eugenics on population enhancement is fraught with danger. It violates the ethical norm of respect for persons by ignoring the importance of individuality and the unique characteristics and inherent value of the person.

6. Ibid, p. 210.

7. Allan Buchanan et al, *From Chance to Choice: Genetics and Justice* (New York: Cambridge University Press, 2000), p. 33.

8. Ibid.

III. Individual Enhancement

What is sometimes overlooked however, is that both positive and negative eugenics also can be performed at an individual level, influencing the direct offspring of the parent.⁹ Those who desire genetic enhancement for their children are not aiming for the good of a race or society, but rather for the betterment of their progeny concerning specific characteristics they deem important. This idea of enhancing specific traits in an individual seems to be more controversial in the current debate over genetic engineering, because it is a revised form of eugenics, though now on an individual basis.

It is important to reflect on the implications of this contrast between racial and social eugenics versus individual enhancement. When enhancing a trait for the betterment of society by attempting to rid the population of a defective gene, the goal is less focused on the good of the few, and aimed more directly at helping society as a whole. Efforts to enhance certain properties of large-scale populations look, at first glance, to be beneficial for all persons involved. The treatment is not harming anyone physically, but actually embodies the opposite aim: to make the lives of future generations better. Today, governments tend to avoid direct involvement in genetic enhancement efforts, because of the moral repugnance directed towards the memory of Hitlerian eugenics. If this is so, why does it now seem to be acceptable, even noble, for individual couples to desire the same thing for their unborn children? If the world has rejected racial eugenics as immoral, why are similar choices, made at the individual level, viewed so differently?

The difference in attitude between eugenics and individual enhancement among geneticists is coupled with a shift in focus on the contemporary scene. What once aimed at the removal of harmful genes causing defects and abnormalities in children has now turned towards improving the characteristics inherent in every person that may not be deemed "desirable." Symbols of beauty such as attaining a certain height now have the chance to become one of the many alterable characteristics available to every person. This new form of enhancement is not merely for the purpose of treating disease; the goal is to take seemingly normal persons and attempt to improve both the mental and physical traits with which they were born.

9. Caplan, "What's Morally Wrong with Eugenics," p. 213.

There is a long list of problems regarding this type of individual enhancement, but a few are especially notable. The first is the problem of having the capability of knowing in advance your probable genetic future. As Leon Kass asks in his article, "The Moral Meaning of Genetic Technology," "will and should we welcome knowledge ... that genes will definitely produce at an unknown future time a serious but untreatable disease?"¹⁰ If a patient discovers that he carries the gene for Huntington's disease, will he live the rest of his life in fear and unhappiness, not knowing when it will become active? It is possible that foreknowledge of your condition will be helpful in determining treatment or prevention? And finally, what if the condition is untreatable? Tensions arise when we are faced with difficult questions such as these, because previously they did not exist. At some point, it may have been better to consider the opinion that ignorance is bliss, and that we should continue living our lives the way we would even if these options were not available at all. The psychological and social implications of this issue lead to many more problems than solutions, and they lead one to question whether or not this is responsible medicine and science.¹¹ This problem is heightened by the fact that we know about many more diseases than we can treat. Is such knowledge "beneficial" or "harmful?"

A second problem concerns the payment and cost of determining the specific characteristics of a person's genome. It is probable that the average person will not be able to pay for genetic testing on his or her own, but, with the help of insurance companies, everyone may be eligible. There are serious implications that follow from this, however. If the insurance company pays for the procedure, it should have access to the results as well. With this information, the company could discontinue providing medical coverage for a person found to have a serious condition (or the predisposing gene) that could require future expensive medical attention. This hardly seems ethical, as this type of situation challenges our normal sense of privacy and justice. It defies the purpose of insurance as a support system that helps those in need, and takes away our rights to receive treatment even while we continue to pay for coverage.

A third problem regarding genetic enhancement is the ability of the individual or geneticist to "play God." Some critics dismiss this concern as a theological matter, but the issue is valid whether or not the interpreter has a religious orientation. Geneticists play the role of "creator" when they

10. Leon Kass, "The Moral Meaning of Genetic Technology," *Human Life Review* (Winter 2000): p. 79.

11. *Ibid*, p. 80.

determine, through their own beliefs, who and what characteristics are worthy of existence in this world. Kass notes, "Not only are they [geneticists] creating life, but they stand in judgment of each being's worthiness to live or die."¹² The problem arises because these scientists are judging worthiness not on moral grounds, set by each individual and his or her beliefs, but rather on genetic ones, given inherently to each person. Although we are only capable of "playing" the role, the implications are still the same: we are using our human reason and limited capabilities to determine the worth of another individual. In the future, the power we have over one another will only grow and this may increase our willingness to make decisions for people without their input.¹³

A final problem worth noting is the depersonalization of bringing children into the world that have been genetically enhanced before birth. Moreover, if the characteristics of the unborn may be more desirable after enhancement, many will have less chance of being born with a defect or abnormality. But doesn't this strike at the heart of what it means to be human, with true flaws and individual characteristics that were given to us naturally? In Pope John Paul II's Apostolic Exhortation "On the Family," he explains the need for compassion towards children in our society. "Concern for the child, even before birth, from the first moment of conception and then throughout the years of infancy and youth, is the primary and fundamental test of the relationship of one human being to another."¹⁴ This increasing control over our offspring runs the risk of making the process of having a child become similar to a mere manufacturing operation.¹⁵

On the other hand, after explaining the negative aspects of genetic enhancement and the ethical implications surrounding it, some would argue that we also should acknowledge the positive aspects of enhancement for all members of society. Not all instances of enhancement raise ethical questions. On the contrary, some geneticists are working diligently to map the human genome and determine which genes carry specific defects and abnormalities that create lifelong problems for their carriers. As a society, we have an obligation to give our children the best possible care and opportunities available to them at the time. This has always been a primary goal of medicine, one that respects persons. Beyond simply working to remove harmful defects, however, the concept of enhancement also allows for

12. *Ibid.*, p. 82.

13. *Ibid.*

14. John Paul II, Apostolic Exhortation, "On The Family," (Washington, D.C.: United States Catholic Conference, 1982), p. 24.

15. Kass, "The Moral Meaning of Genetic Technology," p. 82.

creating new capacities and standards of goodness for humanity as a whole.¹⁶ This includes such possibilities as improving our children's memory capacity, intelligence level, and physical characteristics - - the list is truly endless. Some would even say that if we were all given the chance to enhance the characteristics of our offspring, diversity would increase because not everyone will want the same characteristics for his or her child.¹⁷ The argument is that different people with different values and beliefs will not all want the same characteristics for their children, and thus it will depend solely on what each parent values. This could be viewed as beneficial to the future well being of humanity.

IV. Respect For Persons As A Guide To Genetic Enhancement

The moral problem arises when we face this question: what lines do we draw regarding ethics and enhancement, and how do we protect ourselves from losing personhood and inherent dignity? These are key issues surrounding the controversy.

To resolve the problem of where the line may be drawn, it is necessary to explain "personhood." The concept of "personhood," especially as it is used on the contemporary scene, is lacking. It does not give us any concrete indication as to how we should follow through with the dilemmas that genetic enhancement has presented to society. This does not mean that we can ignore the moral obligations that are attached to the concept of "personhood." Instead, it is helpful to once again turn to Maritain for insight:

Because each soul is intended to animate a particular body, which receives its matter from the germinal cells, with all their hereditary content, from which it develops, and because, further, each soul has or is a substantial relation to a particular body, it has within its very substance the individual characteristics which differentiate it from every other human soul.¹⁸

This explains precisely what it means to be an individual person; not only does it include the importance of unique physical characteristics, but also a reference to the "soul" of the individual, which encompasses personhood in a spiritual way. Thus, when dealing with the notion of "personhood" in relation to each individual, it is necessary to make a simple transition. Whatever our notion of personhood, we must shift our under-

16. *Ibid*, p. 77.

17. Matt Ridley, "The New Eugenics," *National Review* 31 (July 2000), p. 14.

18. Maritain, *Common Good*, p. 36.

standing of respect for persons from that of the abstract notion regarding personhood as a concept, to that of respect for persons on an individual level for each human being. The general idea of "respect for persons" is embodied in concrete acts of respect for each individual human being.

This relates directly to the question of genetic enhancement because it challenges the motives behind developing medical technology. The reasoning behind genetic enhancement, particularly the Human Genome Project, is to improve the physical characteristics of human beings by altering their genetic makeup. This goal seems to aim at the good of society, particularly by aiding those who carry genes that are prone to disease or illness that would have been previously untreatable. Leon Kass highlights another important point in his article when he explains the danger of these procedures: "Enhancement is a soft euphemism for 'improvement,' and the idea of improvement necessarily implies a good, a better, and perhaps even a best."¹⁹ From this explanation comes a glimpse into just how far genetic enhancement can extend: that although its first goal is preventing disease and helping individuals, there is also the ability to "improve" those who are not prone to disease and have normal functioning.

It is a part of human nature and modern society to want to improve individual characteristics, which is shown through such trends as dieting and plastic surgery. What makes us think that this will be any different with the availability of genetic enhancement? With the capabilities of genetic enhancement, why would people deny themselves and their children the hope for an easier, happier life? This kind of thinking is the main part of the problem. Many people do not realize that if we are not careful, this altering of genetic makeup could be the beginning of a downward spiral leading to the destruction of individuality and uniqueness. This is not to say that all genetic enhancement is bad. Using genetic enhancement as reparation to rid individuals of defective genes is a noble cause. Enhancement as an extension of medical practices or as a part of medical therapy is both moral and ethical because it follows the principle of respect for persons. But unless enhancement stays within the confines of medicine as a way of correcting abnormal genes, problems are sure to arise.

It is also necessary to realize the risks involved with genetic enhancement because of unknown future repercussions. "Until certain knowledge of the real risks and benefits associated with human genetic engineering has been obtained, the potential risks to all of the future descendants of the patient outweigh any benefit to a very small number of persons who might

19. Kass, "The Moral Meaning of Genetic Technology," p. 79.

benefit.”²⁰ The notion that parents today are choosing the fate of their descendants is a frightening one, not to mention that we are still unsure what consequences these alterations will have on future generations. With these concerns looming over such a controversial issue, it is necessary to step back and evaluate the real benefit that will come out of such procedures.

The time to consider the ethical issues of enhancement is now, while we are still on the doorstep of such monumental changes that have the potential to alter human society dramatically. Returning to Jacques Maritain, he states:

Historical conditions and the still inferior development of humanity make difficult the full achievement of the end of social life. But the end to which it tends is to procure the common good of the multitude in such a way that the concrete person gains the greatest possible measure, compatible with the good of the whole, of real independence from the servitudes of nature.²¹

To the extent that genetic enhancement can further our “independence from the servitudes of nature,” it would seem worthwhile; to the extent that genetic enhancement would seek to further our own individual (or our children’s) variety, it does not. True respect for the human person transcends mere physical enhancement and affirms the intrinsic dignity and sanctity of the whole person, body and spirit.

20. Bernard Gert, “Genetic Engineering: Is It Morally Acceptable?” *USA Today*, January 1999, national ed., p. 30.

21. Maritain, *Common Good*, p. 54.

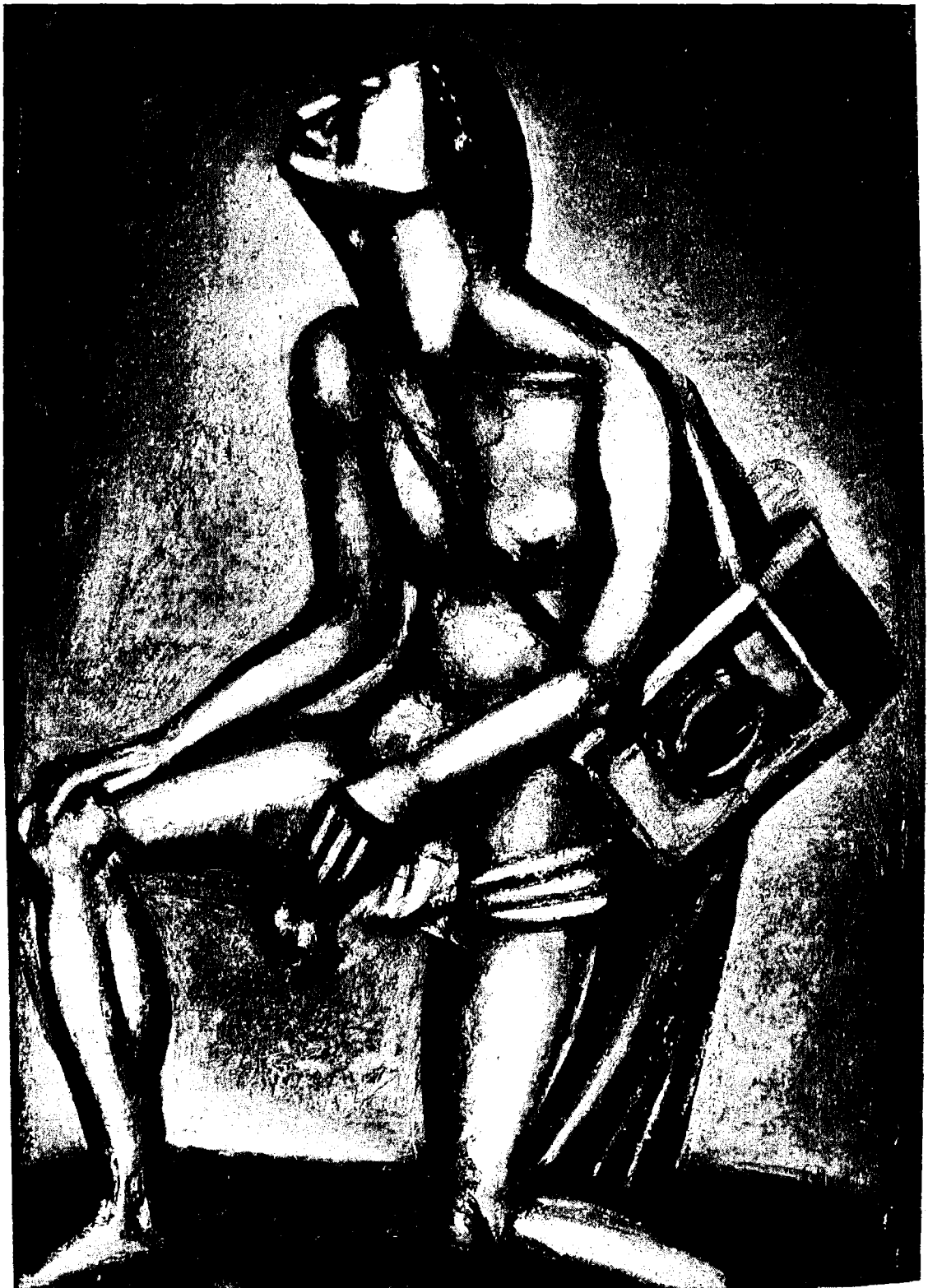


Plate XXVII Sunt lacrimae rerum...