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Sample Research Position Paper

#### Unit IV Essay: The Ethical Dilemma of Designer Babies

The death of a child at an early age due to disease is a heart wrenching event. I experienced this first hand when my cousin's newborn baby perished after only 2 weeks of life, because of a disease that could have been prevented through new medical technology known as designer babies. This method is a very controversial topic today, because many people question the ethical nature of the procedures involved and their possible outcomes. Designer babies are defined as "babies who have been genetically modified to eradicate certain diseases or defects, or to ensure a certain gene is present" (Oxford Dictionary). Many people believe that genetically engineering a child is an unethical practice that will only serve to divide our society even more and magnify the current inequalities we experience today. Others believe that this development in medical technology is an ethical practice that will only benefit our lives and more importantly, the lives of our children.

The majority of this medical technology is still being developed and tested and is nearing completion, but we are beginning to use processes that are only the tip of the iceberg when it comes to the potential that this procedure could provide. One of the methods used to genetically engineer children today is preimplantation genetic diagnosis otherwise known as PGD. In this form of genetic engineering, embryos are examined and are analyzed for genetic abnormalities associated with certain diseases such as Huntington's or Tay Sachs. They are then modified to eliminate the disease or an embryo without the genetic coding for these diseases is chosen

(Walker 349). Many ethical qualms arise from this technique alone, because many people are concerned with what happens to the embryos that are not chosen for implantation. This line of thinking leads into the abortion debate which is a topic of discussion that many people will never agree on. I recognize this is an important consideration for many people, but my argument will not be centered on this point of contention. Instead, I will focus on the ethical nature that surrounds the consequences of the engineering process. The main difference between the genetic intervention that is currently used and the methods that are being developed is how long the engineered genes would be present. Currently, Somatic Cell Therapy is used which fixes/changes/replaces the genes in just the person being engineered whereas, in Germ-Line therapy the genetic modification that is made is passed on to future offspring. The concept of genetic engineering was brought to the forefront of people's minds through the Human Genome Project which aimed to "produce a detailed genetic and physical mapping of the human genome contained within the DNA of the twenty-three pairs of chromosomes of the human cell" (Rettig, Tumpyte, Rosano 127). Advancements in this field are being made swiftly and this technology needs to be analyzed, so that decisions regarding the ethics and consequences of this development can be weighed appropriately, because this technique has the potential to change the lives of many children. Genetically modifying a child should be considered unethical when used to choose physical features such as hair color, height, and athletic ability, but considered an ethical practice when used to prevent disease or to restore a child to a healthy state.

Designer baby technology has the potential to benefit many lives, but it also has the potential to inflict a lot of damage if misused, such as in the case of genetically engineering children for the sole purpose of selecting physical attributes or physical enhancements. In this debate, the term "enhancement" can be classified into two different categories, pure

enhancement and prevention enhancement. According to Ronald Green, author of *Babies by Design: The Ethics of Genetic Choice*, “pure enhancements aim at gratifying the wishes of normal and healthy people for improved performance or superior capabilities” whereas, “preventions are a kind of enhancement aimed at maintaining normalcy” (61). This distinction is important when considering what type of enhancements should be deemed ethical or permissible and which ones should be avoided. In Rettig, Tumpyte, and Rosano’s argument “Designer Babies: A Discursive Justification of a Moral Dilemma,” the authors conclude that the genetic engineering of genes in an embryo should not be permitted for the sole purpose of choosing traits that you like, or engineering the child to have an advantage in intelligence or athletic ability. Thus, these authors deem pure enhancement an unethical practice. Some of the reasons they came to this conclusion was that it could potentially damage the child’s ability to be autonomous, this practice would contradict a natural process and would limit the diversity of the human species, and it could create a “master class” of children that could further exacerbate class divisions (Rettig, Tumpyte, Rosano 140). These reasons illustrate that it is all too easy for the concept of “build-a-child” to be exploited and misused by those who could afford this type of technology. Using the technology in this way could end up only damaging the child instead of benefitting them as the parents had intended. An example of this phenomenon is used in Rosemarie Tong’s essay “Genetic Screening: Should Parents Seek to Perfect Their Children Genetically?” when she references a man by the name of John Stuart Mills who through his child rearing practices ends up overdeveloping his son’s analytical side of the brain and under developing the more emotional side of the brain. This imbalance lead the son to having a mental breakdown at a young age (Tong 91). This emphasizes that trying to genetically engineer children to provide them with mental or physical enhancements might ultimately harm the child

in question. The parent in this situation thought they were bettering their child, but in reality, they were only cultivating a damaging experience that had a negative outcome rather than the intended positive one.

Genetically engineering children for the sole purpose of selecting their physical traits or providing them with physical enhancements has the potential to heighten the disparity between the different classes and lead to the creation of a master or elite class. This class division would be made up of children whose parents decided to genetically modify them to give them an advantage over others. This would result in the creation of the “genetic aristocracy” and the “genetic underclass” which would undermine social equality in different ways (as quoted by Tong 97). First, it would increase the inequality between the genetic aristocracy and the genetic underclass, because the former would have access to better genetic talent and health. Secondly, the belief of equality of opportunity would be destroyed, because the genetic aristocracy could simply engineer themselves and their children to be the *crème de la crème* of society. Thirdly, it would eliminate the ability to be socially mobile and will lead those in the genetic underclass to become increasingly resentful about their lack of enhancements (Tong, 97). The author’s points are valid because, the creation of this situation would not only affect a child’s opportunities in life, it would have a psychological impact as well. Children might think negatively of themselves if they know their parents did not choose to genetically modify their genes and provide them with enhancements. The reversal of this could also be true. A child could think negatively of themselves if they knew their parent chose to modify their genes. They could potentially feel as if they were no longer their own person free to develop and change as they got older, but constricted to pre-conceived notions of themselves put in place by their parents.

Genetically engineering children to prevent disease or return them to a normal state is considered prevention enhancement. A form of this augmentation that we currently use today is vaccinations. This method to prevent disease and increase immunity has been mainstreamed and accepted by most people as an ethical practice. It is almost considered a parent's obligation to have their child vaccinated at an early age, so they are protected against certain diseases that would disrupt their fulfillment of a long and healthy life. In John Harris's book *Enhancing Evolution: The Ethical Case for Making Better People*, he mentions a study being conducted at Caltech that is focused on figuring out a way to engineer resistance or even complete immunity to debilitating diseases such as HIV/AIDS and cancer. Harris makes the point that a medical breakthrough such as this would be viewed in the same light as vaccinations are, a medical method that would save countless lives (22). These genetic modifications would revolutionize the medical community. This type of genetic enhancement to any child isn't seen as unethical, because it is preventing a disease that many scientists today are struggling to find the cure for. Having genes that are resistant to diseases such as cancer is not a natural or a normal function of humans genetic makeup, but will nevertheless save countless lives and could even become a mainstream medical technology that is available to all (Harris 22). This suggests that genetically engineering babies to prevent disease, or to return a child to a normal state is ethical, since it is not causing the child harm and is considered an overall beneficial process.

An argument that has arisen over the ethics of genetically engineering an embryo to prevent diseases is that this technology would improve this child's position in life relative to others. This is possibly an incorrect assumption, because really the technology is being used to give the child the best chance at a long and healthy life. The child isn't being changed to take advantage of others as in the case of engineering for pure enhancement, but rather for the child's

own good since it is a form of prevention enhancement (Harris 28). This is a fair and ethical argument, because according to Harris “fairness does not require that I should not try to protect myself because others cannot” (Harris 28). He also claims that “fairness might require that we make all reasonable attempts to achieve universal provision” (Harris 28). Therefore, this technology would not be used to try to “one up” all the other children. Rather it would act in the child’s own best interest giving the child a chance at a long healthy life-a life they otherwise might never had had, as in the case of my cousin’s baby.

As mentioned above, PDG technology is the main form of genetic engineering that is employed today. The main purpose of this medical technique is for couples who have a high risk of transmitting genetic diseases and disorders to their potential offspring. This process is accomplished through in-vitro fertilization, also known as IVF, in which potential embryo’s genetic makeup is examined and analyzed for abnormalities and disease causing DNA sequences. The couple can then select embryos that are and deemed healthy to be used for pregnancy (LiYing et al. 666). This is a life changing procedure for couples who are carriers for certain debilitating diseases or are themselves afflicted. This gives them the opportunity to bring a child into the world who has the full potential for a healthy and long life that otherwise might have been denied to them. Continued progress in this area may even lead to eradication of some diseases in children before they are even born eliminating much pain and suffering from their lives. With continued research this technology will become increasingly safer and readily available to all who wish to take advantage of its benefits. Thus, it should be considered ethical to genetically modify children to prevent disease or return them to a normal state since, it enables these children the opportunity to live a full life that would have otherwise been out of reach.

There are many definitions of what it means to be classified as “healthy.” This term means different things to different people, so a standard for what is deemed healthy needs to be clarified when determining policies and arguments for the ethical nature of this technology. The basic approach when considering what type of genetic engineering is considered to make someone healthy is the health intervention principle. This principle states that “a genetic intervention on a future person should be permitted in medicine if it promotes the person’s health and prohibited if it compromises it” (Malmqvist 183). This line of thinking focuses on health when thought of in the context of medicine and relies on the thought that being healthy is something that is highly valued by humans. Thus, the healthier a person is, the better for that person (Malmqvist 184). Elaborating on the principle even further is Lennart Nordenfelt’s welfare theory of health. Nordenfelt’s theory states that “being healthy is being able to perform certain actions or realize certain goals” (Malmqvist 187). These definitions of health can be used in determining a framework for what is constituted as healthy when applied to the topic of genetic intervention/engineering. Both theories recognize that being healthy entails meeting ones vital goals that can be considered universal such as, survival. But, they also account for the variability that is inherent in any definition of health. That being, some vital goals are set by the person as pertains to their situation. Three legitimate reasons for interventions that are focused on promoting someone’s health and not compromising it are treating for disease, improving of the immune system, and increasing defense against certain environmental phenomena that cause bodily harm.

In some cases, designer baby techniques are desired by parents to insure that their child is born into the same genetic heritage as they are, or into a culture that reflects the parent’s disability. An instance of this is when a deaf couple wants to deliberately engineer their child to

be deaf as well, since deafness is not always inherited by offspring. Those who are deaf argue that their deafness is not a disability, but instead a linguistic and cultural identity (Davis 52). In fact, many deaf people who identify with this deaf cultural movement, when asked, would not make the choice to become hearing if given the opportunity (Davis 57). While it is true that there is a certain cultural identity associated with those of the deaf community, it is also true that deaf people have incomes that are 30-40% less than the national average. Their education is also severely limited. It has been found that many deaf individuals who graduate from high school cannot even read a newspaper. It has been found that deaf people have a lower standard of living and limited vocational options as well (Davis 58). When all this information is taken into account, deliberately choosing for disability should be seen as a moral harm since a child is neither being modified to prevent disease or restore a child to a healthy state. It is in fact, quite the opposite. Choosing for disability forever confines a child to a life of limited opportunities. Their choice of vocation is limited, they are bound to a narrow group of people and most importantly it violates a child's right to an open future full of a variety of life choices as they become adults. This is also true in cases of achondroplasia or more commonly known as dwarfism. Many "little couples" wish to have children who are dwarfs as well, but this confines a child to a life where they must deal with a disability or disease they might not have been born with in the first place. Ultimately, selecting for disability should be seen as unethical since it is neither preventing disease nor restoring a child to what should be considered a healthy state as explored previously, but instead, depriving a child of the opportunities they could potentially have in life.

Designer baby technology has the potential to benefit many people's lives and the lives of their children. It would be a shame to see this potential unrealized, because people are

afraid it is an unethical practice, since it has never been seen before. The technology of designer babies is relatively new and still in the works as of now. Humans inherently fear the unknown and this fear is seen especially in an issue such as genetically modifying children, since there is no precedent to compare it to. By bringing this conversation to the forefront we are giving children, such as my cousin's baby, the opportunity to achieve a long and healthy life that would otherwise be denied to them. By looking at different possibilities and situations, we will be able to identify what could be considered an ethical procedure and would should maybe be restricted due to possible unethical grounds. A possible solution could be the following. Genetically modifying a child should be considered an ethical practice when used to prevent disease or to restore a child to a healthy state, but considered an unethical practice when used to choose physical features such as hair color, height, and athletic ability.

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