Expanding the Child's Range of Open Futures: A Proposed Basis for the Ethical Assessment of Parental Genetic Trait Selections

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Abstract

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This dissertation considers the bases upon which ethical assessments of parental genetic trait selections for their children can be made. It argues that if parents engage in genetic trait selections, they must act to expand their child's range of open futures, not to constrict their child's range of open futures or to differentially shift their child's range of open futures. It contends that other proposed distinctions, including distinctions between normal and diseased states and between treatment selections and enhancement selections, do not provide a sound basis for making ethical assessments of parental genetic trait selections. It contends that children have a right to an open future that parents hold in trust for their children and that parents must respect in making genetic trait selections. It considers examples of possible parental genetic trait selections regarding children's hearing, height and visual acuity. Finally, it addresses a number of concerns about and objections to this proposed basis for ethical assessment and to parental genetic trait selection generally but concludes that none of these concerns or objections are fatal the approach that if parents use

parental genetic trait selection, they must do so in ways that expand their child's range of open futures.

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DEDICATION

I dedicate this dissertation to my parents, Bernard and Gwen Schmidt, without whom I would not have had the open future that led to this dissertation, and to my wife, Kristin Henderson, without whose support and patience this dissertation would not have been possible.

CHAPTER ONE: SETTING THE STAGE

1. Introduction

With developments in genetic technologies come new, or at least newly emphasized, issues regarding the ethical assessments of the use of those technologies to select for specific genetic traits. We can address the results of some genetic traits with current technologies, such as dietary restrictions for children born with phenylketonuria (PKU) and cochlear implants for some children born with genetically caused deafness. We can also elect whether to allow children to be born with some genetic traits through post-implantation genetic diagnosis, followed by selective abortion, or through pre-implantation genetic diagnosis, followed by selective implantation.

But we near the threshold of being able to select directly certain genetic traits. Rather than waiting to address a child's genetically caused deafness through cochlear implants, we may soon be able to modify the child's genes to eliminate the gene's expression that results in deafness. Rather than selectively aborting, or electing not to implant, those embryos whose genes will result in the expression of deafness, we may soon be able to modify an embryo's genes to eliminate the gene's expression of deafness.

Further in the future, we may be able to modify the genes in the reproductive cells of an embryo in order to select the genetic traits of not just that embryo, but of future embryos to whom the modified gene is passed. Through this "germ-line" genetic trait selection, we may be able to modify an embryo's genes, such that genetic traits like sickle cell trait (and sickle cell anemia) are eliminated not only from that embryo, but also from all future generations to whom the modified gene is passed.

These current and future abilities to select or modify genetic traits raise a number of ethical issues. For example, if we can selectively implant embryos whose genetic trait is hearing capability (or selectively abort embryos whose genetic trait is deafness), then we can, if we wish, selectively implant embryos whose genetic trait is deafness (or selectively abort embryos whose genetic trait is hearing capability). If we can modify an embryo's genes, such that the embryo's genetic trait will be hearing capability instead of deafness, we will likely be able to modify another embryo's genes, such that the embryo's genetic trait will be deafness instead of hearing capability. The intuitions of most people, particularly those who are hearing capable, is that in each pair of actions, the former is ethically acceptable but the latter is ethically unacceptable. But intuition is not enough. On what grounds should we assess the ethical acceptability of these genetic trait selections? The selections would use the same technology, so there must be some other reason that distinguishes them.

We may be inclined to say that selectively implanting an embryo that will become a hearing capable child, instead of an embryo that will become a deaf child, or that modifying an embryo's genes to change its genetic trait from deafness to hearing capability, would be changing the embryo from diseased to normal, and thereby would be ethically acceptable. We may be similarly inclined to say that selectively implanting an embryo that will become a deaf child, instead of an embryo that will become a hearing capable child, or that modifying an embryo's genes to change its genetic trait from hearing capability to deafness, would be changing the embryo from normal to diseased, and is thereby ethically unacceptable. But how do we distinguish between normal and diseased in these situations? What if the parents, who wish to select for a deaf child instead of a hearing capable child, or who wish to change their embryo from hearing capable to deaf, not only have genetically caused deafness themselves but are enthusiastic participants in the Deaf culture, in which deafness is not considered a disability but rather considered a different way of interacting with the world? Can those parents assert that deafness is normal <u>for them</u> and thereby make their selection of embryos with genetically caused deafness ethically acceptable? This issue has a current, non-genetic analog -- whether parents act ethically if they refuse to have cochlear implants placed in their deaf children.

Thus, the first question that I will address is whether the normal/diseased distinction can assist us in determining what parental genetic trait selections are ethically acceptable and what parental genetic trait selections are ethically unacceptable. "Naturalists" contend that diseases can be defined through statistical distributions of species-typical function, without any normative implications. "Normativists," on the other hand, contend that diseases are those that are somehow normatively bad, in that they are painful, limiting or otherwise disadvantageous. One strength of a naturalistic, non-normative definition of disease would be to avoid issues of subjectivity, regarding what is bad, that may arise in a normative definition of disease. If we had such a non-normative definition of disease, then we might be able to use the normal/diseased distinction for assessing parental genetic trait selections. But I will argue that the proposed non-normative definitions of disease are not truly non-normative, so the suggested normal/diseased distinction does not provide us with a non-normative distinction between ethically acceptable and ethically unacceptable parental genetic trait selections. Thus I will argue that we must look to other distinctions.

As a second example, in the future we may be able to modify an embryo's genes to eliminate the genetic trait of deficient growth hormone production, which results in extreme shortness of stature. We would thereby be making the child taller than she otherwise would have been. But we may also be able to modify an embryo's genes to make a child who will be of average adult height taller than she otherwise would have been in order to improve her chances to become a basketball player. Again, the intuitions of most people, particularly people who are of average height, are that the first modification is ethically acceptable but that the second modification is ethically unacceptable. But again, intuition is not enough. On what grounds should we assess the ethical acceptability of these two genetic trait modifications?

We may be inclined to say that modifying the genes of an embryo to eliminate the deficiency in growth hormone production, thereby allowing the child to reach a more typical height, would be an ethically acceptable genetic treatment of a disease, but that modifying the genes of an embryo to allow the child to reach a height significantly greater that average height would be an ethically unacceptable genetic enhancement of a normal state. Thus, the second question that I will address is whether the treatment/enhancement distinction is sufficient to determine what parental genetic trait selections are ethically acceptable and what selections are ethically unacceptable. This question has a current, non-genetic analog -- whether it is ethically acceptable for parents to give human growth hormone to their children whose projected adult height is much shorter than average but who do not have any diagnosed genetic or hormonal disease that results in short stature.

But even if a genetic trait selection plainly resulted in an enhanced condition, would that selection necessarily be ethically unacceptable? If we could modify an embryo's genes to give that person 20/10 visual acuity, and that modification made no other changes to the person, would that modification be ethically unacceptable, and if so, why? The modification would seem to confer advantages to the person without any concomitant disadvantages. Would it be ethically unacceptable because it would confer advantages over other, non-modified persons in athletic performance or military prowess? We allow, and often encourage, parents to engage in a wide range of actions to confer advantages to their children over other children, such as nutritional supplementation, additional educational opportunities, and athletic, artistic and musical training. How is conferring advantage through genetic trait modification different from these means of conferring advantage? Are societal interests in maintaining "genetic parity" among members of the society enough to overcome the parental rights to confer advantages when the parents wish to employ genetic trait selection?

I will argue that the treatment/enhancement distinction is not sufficient to provide us with a distinction between ethically acceptable and ethically unacceptable genetic trait selections. But if neither the normal/diseased distinction nor the treatment/enhancement distinction is sufficient to determine what parental genetic trait selections are ethically acceptable and what selections are ethically unacceptable, then are all parental genetic trait selections ethically acceptable? Most people have the sense that there is some boundary on what parental genetic trait selections are ethically acceptable.

I will use the term "ethically acceptable" to mean actions that satisfy the duties and obligations that parents owe to their children, and "ethically unacceptable" to mean actions that do not satisfy those duties and obligations. While our intuitions about the ethically acceptability of parental actions may coincide with the extent to which those parental actions satisfy the duties and obligations that parents owe to their children, that coincidence is not sufficient to make the actions ethically acceptable. I will try to develop a standard for ethical acceptability, or ethical unacceptability, based on those parental duties and obligations.

Instead of trying to distinguish between ethically acceptable and ethically unacceptable parental genetic trait selections based on the treatment/enhancement distinction, I will argue that parents have a duty to respect "a child's right to an open future" when making genetic trait selections. Joel Feinberg proposed such a right in 1980, and Dena Davis and Dan Brock have recently proposed observance of a child's right to an open future as a distinction between ethically acceptable and ethically unacceptable parental genetic trait selections. Under this view, if a selection preserves the child's right to an open future regarding actions and desires in his or her life, then the selection is ethically acceptable. But if a selection interferes with such a right, by deliberately and substantively limiting the child's futures, then the selection is ethically unacceptable.[1]

I will build upon Feinberg's, Davis's and Brock's "right to an open future" to argue for a distinction between ethically acceptable and ethically unacceptable parental genetic trait selections, in lieu of the normal/diseased distinction or the treatment/enhancement distinction. Feinberg's original claim of a child's "right to an open future" argues, in significant part, that a child has the right to the future that his or her heredity would allow him or her to pursue. Part of that heredity is the child's genes. However, in the case of genetic trait selection, we are not simply allowing a child to develop as his or her genes would allow. We are changing those genes upon which development of the right to an open future rests.

By changing those genes, though, we may also be changing the child's identity. If the genetic trait selection were such that the child's identity is changed, then the issue would no longer be whether the genetic trait selection respected that particular child's right to an open future. The issue would be whether the genetic trait selection would result in a child whose right to an open future the parents respected in making that genetic trait selection.

Therefore, I will argue that in assessing whether a genetic trait selection is ethically permissible or ethically impermissible, children have a range of open futures, the rights to which parents must respect in making genetic trait selections. Before deciding whether to engage in a genetic trait selection, parents would need to compare

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[1] Dena S. Davis, *Genetic Dilemmas: Reproductive Technology, Parental Choices, and Children's Futures* (New York: Routledge, 2001), 65-66.

two possible ranges of open futures: (1) the range of open futures the child would have without the genetic trait selection and (2) the range of open futures the child would have with the genetic trait selection.

I will argue further, that once we have established the ranges of open futures with and without the genetic trait selection, we can distinguish between those parental genetic trait selections that expand the child's range of open futures and those parental genetic trait selections that constrict the child's range of open futures. I will argue that in order to respect the child's right to an open future, parents have a duty to consider the child's range of open futures in making parental genetic trait selections. Davis and Brock contend that parents violate their child's right to an open future if their genetic trait selections significantly constrict the range of futures open to that child. I will extend Davis's and Brock's positions to argue that not only must parents not significantly constrict their child's range of open futures, they may not ethically use genetic trait selection to favor some futures, while concomitantly disfavoring a significant number other futures. Such genetic trait selections would violate the child's right to an open future, which the parents hold in trust, because they are made based on the parents', not the child's, opinions of what futures are desirable and what futures are undesirable. In order to maximize the child's right to self-determination as to her futures, parental genetic trait selections should be made in ways that increase the range of open futures available for the child to pursue. Accordingly, I will argue that if parents choose to engage in parental genetic trait selection, they respect their child's right to an open future, which they hold in trust for the child, only if the selection expands the child's range of open futures.

I will argue that this constraint, under which parents should use genetic trait selection only to expand the range of open futures available to the child, serves as an adequate distinction between ethically acceptable and ethically unacceptable genetic trait selections and maps onto our intuitions about the acceptability of those genetic trait selections. As I will explore further, in the case of Deaf parents wishing to employ genetic trait selection to cause their child to be deaf as well, the genetic trait selection would not expand the range of open futures available to the child. The selection would instead constrict the range of open futures available to the child. Therefore, that genetic trait selection would be ethically unacceptable. In contrast, parents who wish to employ genetic trait selection to cause their child to be hearing capable rather than deaf would be expanding the range of open futures available to the child. Accordingly, that genetic trait selection would be ethically acceptable. The issue of whether deafness is a disease, or whether hearing capability is normal, need not be resolved under this approach. But as I will address later, some would dispute my contention that deafness constricts the range of open futures.

This distinction would further address issues of genetic "enhancement." Parents wishing to employ genetic trait selection to increase the child's projected adult height might or might not be acting to expand the range of open futures available to the child. If the parents wish to employ genetic trait selection to expand the range of open futures available to a child who otherwise would be extremely short (whether that shortness is caused by a diagnosed genetic condition or not), then the genetic trait selection would be ethically acceptable. However, if the parents wish to employ genetic trait selection to make their child taller without expanding the range of open futures, the parents are not acting to expand the range of open futures available to the child. Instead, they are acting to favor, and concomitantly disfavor, certain futures among the open futures available to the child based on their opinions as to which of the futures are more and less desirable. For example, making a child taller would enhance the possibility of her becoming a professional basketball player, but it would concomitantly diminish the possibility of her becoming a fighter pilot. Such a genetic trait selection would not expand the range of open futures available to the child, and I will argue that such a genetic trait selection would be ethically impermissible.

But under this distinction, some genetic "enhancements" would expand the range of open futures available to the child, not just favor certain futures among the open futures available to the child. Parents wishing to employ genetic trait selection to improve visual acuity to 20/10, or to give a child perfect pitch, with no other modifications to the child's genetic expression, would be acting to expand the range of open futures available to the child. Enhanced visual or auditory acuity would expand the range of open futures by adding those futures in which a high degree of visual or auditory acuity is useful, such as some athletic or artistic endeavors. And enhanced visual or auditory acuity would not significantly diminish the possibility of pursuing any futures within the range of open futures. Therefore, even if we consider these types of genetic trait selection as genetic "enhancements," they would be ethically acceptable genetic trait selections.

Finally, I will address a number of concerns and objections to my proposed distinction and to parental genetic trait selection in general. These concerns and objections include obligatory parental action, eugenics, disability rights, justice, inauthenticity, shortcutting, variability, "playing God," effects on identity, the "genetic supermarket" and multi-generational trait selections. While those objections and concerns raise issues that parents should consider when deciding whether to engage in parental genetic trait selection, and in deciding what traits they should select for, none of them demonstrates that parental genetic trait selections, made to expand the child's range of open futures, are necessarily ethically unacceptable.

In conclusion, I will contend that the distinction between those parental genetic trait selections that are ethically acceptable and those that are ethically unacceptable can be made based on whether the parental genetic trait selection observes the parents' duty to use genetic trait selection only to expand the range of open futures available to the child. If the genetic trait selection expands the range of open futures available to the child who results from the selection, then the selection is ethically acceptable. But if the genetic trait selection constricts the range of open futures available to the child who results from the selection, then the selection is ethically unacceptable. And if the genetic trait selection merely favors some of the futures available to the child, from among the range of futures, while reducing the possibility of the child pursuing a significant number of other futures that would otherwise be available to the child, then that selection is also ethically unacceptable.

2. Definitions

This work addresses parental genetic trait selections. Thus, I must define "parent" and "genetic trait selection." By parent, I mean any person who (1) participates in making (or declining to make) genetic trait selections and (2) becomes responsible for the care and raising of the child whose genetic traits have been selected. Most often, this definition of parent will coincide with the traditional definitions of parent as a father, who has contributed his sperm and is legally and morally responsible for the child, or a mother, who has contributed her ovum and is legally and morally responsible for the child.

But with the growth of reproductive technologies, those roles and functions no longer necessarily coincide. The man who contributes his sperm may have no role in creating the child, or even knowledge of the child created thereby. Under my definition, that man would not be a parent so long he does not participate in making the genetic trait selection or otherwise make himself legally or morally responsible for the resulting child. Similarly, the woman who contributes the ovum, and even the woman in whom the child gestates, may not necessarily be a parent under my definition. The woman may contribute the ovum just as a man may contribute the sperm, without subsequent participation and without making herself legally or morally responsible for the raising of the child. And a woman may contribute her ability to have an embryo implanted in her but not participate in the genetic trait selection and have no legal or moral responsibility for the raising of the child after he or she is born.

Conversely, those who are "genetic strangers" to a child, in that they do not contribute either the ovum or the sperm from which the child is created, may be parents under my definition. As individuals or as a couple, people can become parents whether or not they contribute ova or sperm to the creation of the child, so long as they participate in making genetic trait selections regarding the child and are legally and morally responsible for the care of the child. Thus, a single man or a gay couple may become a parent or parents by arranging for the contribution of an ovum and a womb, by the same woman or different women, and by contributing either their own sperm or the sperm of another man, so long as he is or they are legally and morally responsible for the care of the resulting child. Similarly, a single woman or lesbian couple may become a parent or parents by arranging for the contribution of sperm from a man and by contributing an ovum and a womb, whether their own or those of other women, so long as she is or they are legally and morally responsible for the care of the resulting child. And heterosexual couples, who cannot or choose not to create a child with their own sperm and ovum, may arrange for the contribution of sperm, an ovum, or a womb, from others, so long as they are legally and morally responsible for the care of the resulting child. This definition of parent, as used in parental genetic trait selection, focuses on the people participating in making the genetic trait selections and responsible for raising the resulting child, not necessarily on those who were the genetic or gestational contributors to the creation of the child.

The other term I need to define is "genetic trait selection." By genetic trait selection, I mean any intervention, other than mate selection, through which a parent attempts to influence the child's genotype. The particular mechanism of the intervention is often not relevant to the ethical considerations of parental genetic trait selection. But before delineating the different forms of parental genetic trait selection, I pause to exclude one form of parental action from the definition of genetic trait selection: mate selection with subsequent reliance on the genetic lottery.

Even before we knew of genes or genetic trait expression, we attempted to influence our children's genotypes through selection of a reproductive partner. A person who wishes to have a tall child can try to increase that possibility by selecting a taller, rather than a shorter, reproductive partner, and a person who wishes to have a short child can do the opposite. The same is true of other physical characteristics, such as hair color, eye color, facial characteristics and skin color. It may also be true of more controversial characteristics, such as intelligence, athletic prowess and other performance abilities.

But as many parents have discovered, tall parents sometimes have short children, and vice versa. Blond parents sometimes have black-haired children, and vice versa. Mate selection, without pre-conception genetic analysis of the potential parents' genotypes, is generally too unreliable a form of influencing a child's genotype to be considered an intervention into the reproductive process. Further, if we include this form of mate selection as a form of genetic trait selection, then we may be placed in a position of arguing that people with certain genotypes should not have children with people with other certain genotypes. For example, if both potential parents have genetically caused deafness, they have a greater risk of having a deaf child than if only one of the potential parents has genetically caused deafness. If we say that their selection of each other as mates constitutes genetic trait selection, then we are suggesting that they should not have any children because they would have a greater likelihood of creating a deaf child instead of a hearing child. This is a result that I wish to avoid, for reasons upon which I will elaborate later. Therefore, I exempt mate selection, in which the parents do not undergo pre-conception genetic analysis and rely simply upon the genetic lottery to determine their children's genotypes, from the term "genetic trait selection."[2]

But mate selection, following pre-conception genetic analysis of the potential parents' genotypes, would constitute "genetic trait selection." As an example, in an effort to reduce the instances of children born with Tay-Sachs disease, which occurs more often in the Ashkenazi Jewish population than in the general population, a rabbi created the Dor Yeshorim organization. Dor Yeshorim offers tests for Tay-Sachs (and Canavan's disease and other similar profound genetic conditions) to Orthodox Jewish young people. Dor Yeshorim, through the use of matchmakers, then discourages relationships between those whose genetic testing indicates a possibility of creating a child with one of the

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[2] While this form of trait selection most often arises out of selecting a sexual partner, it can occur through selections of sperm or ova. Sperm banks categorize the donors of the sperm by various characteristics, including skin color, eye color, hair color, height, weight, and other characteristics, both physical and behavioral. See, for example, www.thespermbankofca.org, www.cryobank.com, or many others. William Shockley, an inventor of the transistor, supported and publicized the Repository for Germinal Choice, a so-called "genius" sperm bank in which sperm donors had to meet particular criteria of intelligence, with the notion that children conceived of such sperm would be more intelligent than those conceived of sperm donated from the general population. See slate.msn.com/id/101318 for a history of the Repository for Germinal Choice and Shockley's involvement. Similarly, women who donate ova are characterized by their physical and behavioral characteristics. See, for example, www.eggdonor.com. Some prospective parents are willing to pay greater "compensation" to ovum donors who have certain characteristics, typically involving height (tall), hair color (blond), intelligence (high academic performance), and behaviors (athletically or artistically accomplished), than to other ovum donors, with the desire that the child created of ova from such women will have those characteristics as well.

genetic conditions.[3] Thus, with the assistance of matchmakers, those participating in Dor Yeshorim are making genetic trait selections, against Tay-Sachs and similar genetic conditions, even before creation of a child begins.[4] I will refer to mate selection, which follows pre-conception genetic analysis of the potential parents' genotype, as "indirect pre-conception genetic trait selection."

Although the technology does not exist at present, it may become possible to modify the genes of sperm or ova before conception. This "germ-line" modification would have the advantage, and the potential risk, of selecting the genetic traits of not only the child being conceived, but of selecting the genetic traits of the genetic descendents of the child being conceived. I address such "germ-line" modifications later in this work. In general, I will refer to such modifications of the sperm or ova as "direct pre-conception genetic trait selection."

Until the development of *in vitro* fertilization in the 1970's and 1980's, pre-natal diagnosis, followed by selective abortion for fetuses with certain genetic traits, was all that was available to parents. But with *in vitro* fertilization, and the subsequent development of pre-implantation genetic diagnosis, parents can engage in more direct, and more certain, forms of genetic trait selection. Take cystic fibrosis as an example. If both parents are heterozygotic carriers of the gene that can cause cystic fibrosis, meaning that they do not have cystic fibrosis but have one copy of the mutated gene that results in

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[3] See www.jewishgeneticscenter.org/rabbis/issues.

[4] Whether programs such as Dor Yeshorim would be successful outside of cultures in which matchmakers are used, and in which sensitive information such as genetic test results are conveyed to such matchmakers, is questionable at best.

cystic fibrosis, then they have a 1 in 4 chance that each child they conceive will have cystic fibrosis.

In the past, such parents had but three options: to forgo conceiving, to take the 25% risk that their child would have cystic fibrosis, or to test each fetus for cystic fibrosis and abort those fetuses who tested positive. None of these options is particularly attractive. With the development of *in vitro* fertilization, however, parents could obtain sperm or ova from persons known not to carry the cystic fibrosis mutation and use that sperm or ova instead of their own to avoid the risk of cystic fibrosis. And with the development of fetal genetic testing, through amniocentesis or chorionic vilii sampling, parents could learn whether the fetus had cystic fibrosis and if so, could elect to terminate the pregnancy to avoid the risk of cystic fibrosis.

With the combination of *in vitro* fertilization and pre-implantation genetic diagnosis, parents can engage in genetic trait selection before the embryo is implanted. Multiple embryos can be created of ova and sperm contributed or acquired by the parents. Those embryos can be tested for some genetic conditions, such as Tay-Sachs, Canavan's disease and cystic fibrosis. The embryos can also be tested for some genetic characteristics, such as sex. Armed with information as to which embryos do or do not have certain genetic conditions or characteristics, parents may elect which embryos to implant in the hopes that a pregnancy will develop and which embryos not to implant. Thus, parents wishing to avoid the risk of their child having cystic fibrosis can elect to implant only those embryos that do not have cystic fibrosis. They could also elect to implant only those embryos that neither have cystic fibrosis nor carry the mutated gene for cystic fibrosis, such that no child of the child born of such an embryo would run the risk of having cystic fibrosis.

Thus, through the use of such pre-implantation genetic trait selection, parents have greater control over the genetic traits that they wish to select for, or against, in their children. But such pre-implantation genetic trait selection requires intrusive and expensive medical intervention. And it allows only for the decision of whether or not to implant a given embryo. It does not allow for "direct" genetic trait selection, wherein a specific gene, such as the mutated gene that expresses itself as cystic fibrosis, could be removed and replaced by an unmutated gene, and so eliminate the genetic condition. I will refer to such selections as "indirect pre-implantation genetic trait selection." But it is possible that we will develop the technical ability to engage in genetic trait selection through direct modification of an embryo's genes. Thus, in the future we may also have "direct pre-implantation genetic trait selection," in which embryos are tested, undergo modification or replacement of undesired genes, and then are implanted.

Finally, as noted above, parents now have only one option to engage in genetic trait selection after their embryo is implanted in the gestational mother's womb. Parents can use fetal testing to determine whether the fetus has certain genetic conditions or characteristics. If parents do not wish to have such a child, their only option is to terminate the pregnancy. I will refer to this option as "indirect post-implantation genetic trait selection." But many parents would prefer an option in which the genetic condition or characteristic of a fetus could be modified after implantation, so they could avoid the option of terminating the pregnancy. And parents might prefer an option in which an embryo conceived through means other than *in vitro* fertilization could undergo modification of undesired genetic traits or conditions while *in utero*. Such "direct post-implantation genetic trait selection" is not yet available, but may be on the horizon.

Thus, I subdivide "genetic trait selection" into six forms:

> (1) Indirect pre-conception genetic trait selection, accomplished through genetic counseling;
> (2) Direct pre-conception genetic trait selection, to be accomplished through direct genetic modification of sperm or ova, but not presently available;
> (3) Indirect pre-implantation genetic trait selection, accomplished through *in vitro* fertilization, pre-implantation genetic diagnosis and selective implantation;
> (4) Direct pre-implantation genetic trait selection, to be accomplished through *in vitro* fertilization, pre-implantation genetic diagnosis and direct genetic modification of the embryo, but not presently available;
> (5) Indirect post-implantation genetic trait selection, accomplished through fetal testing and selective termination of pregnancy; and
> (6) Direct post-implantation genetic trait selection, to be accomplished through fetal testing and direct genetic modification of the fetus, but not presently available.

3. Assumptions

As I have often noted above, the direct forms of genetic trait selection, in which an undesired gene of a sperm cell, ovum, embryo or fetus is replaced with a desired gene, do not yet exist. Although it seems likely, given the trajectory of genetic technologies, that techniques to engage in the direct forms of genetic trait selections will be developed, it may be that such technologies are never developed or are not possible. I will assume in this work that the direct forms of genetic trait selections are possible and will be developed, and I ask the reader's indulgence to consider the arguments to follow as thought experiments.

I make a second assumption regarding the genetic traits that parents may be able to select. Geneticists have located a number of genetic mutations that are expressed as conditions and traits, such as Tay-Sachs, cystic fibrosis, forms of deafness, and many others. They will locate many more in the future. But it may be the case that some of the genetic traits discussed here, such as height, visual acuity and auditory ability, cannot be modified through genetic trait selection.[5] I will assume in this work that such genetic traits will be capable of modification, and will argue accordingly.

Third, I will assume in the following arguments that direct genetic trait selection can be accomplished safely and accurately. Much of the criticism of genetic trait selection, reasonably so, is that attempting to modify certain genetic traits will result in undesired and unwanted modifications to other genetic traits. Until developments in the technology demonstrate that direct genetic trait selection can be accomplished safely and accurately, few parents will elect to use it.

Thus, in what follows, I will assume that direct genetic trait selection is possible, safe and accurate, and can modify the genetic traits I discuss.

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[5] For a discussion of the difficulties in selecting specific traits, especially "polygenic" traits that are influenced by more than one gene, see Dan Bradley, "Designing Life: The Role of Inheritance," in Maureen Junker-Kenny, ed., *Designing Life? Genetics, Procreation and Ethics* (Aldershot, England: Ashgate Publishing Ltd., 1999), 70-78.

4. A Caveat

Last, I wish to make clear that I do not subscribe to genetic determinism in this work. Many human traits, including intelligence, courage, compassion, aggression and other behaviors, result from both genetic contributions and environmental contributions. So too are physical traits, such as height, vision and hearing, influenced by both genetic traits and environmental conditions. Genes are important, and some traits are substantially controlled by genetic contributions. But to say that one's genes determine entirely one's behavioral or physical traits would be to commit the error of genetic determinism.[6] In order to reduce such errors, I avoid examples of behavioral traits, such as genetic trait selections for intelligence or courage or compassion. I will focus on physical traits such as height, vision and hearing, which, in the absence of negative environmental influences such as malnutrition, trauma or disease, are largely determined by genotype.

5. Meet the Parents

Imagine yourself a member of a genetic counseling and treatment clinic. On your first day, two sets of parents come to the clinic. The first set, the Alphas, are hearing capable but have family histories including hereditary deafness. The Alphas want to use genetic trait selection to make sure that the child they intend to create will be hearing

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[6] For an excellent discussion of how genetic determinism is an error, see Appendix A to Allen E. Buchanan, Dan W. Brock, Norman Daniels and Daniel Wikler, *From Chance to Choice: Genetics and Justice* (Cambridge, England: Cambridge University Press, 2000). See also Richard Lewontin, *It Ain't Necessarily So: The Dream of the Human Genome and Other Illusions* (New York: New York Review of Books, 2000), 141-61.

capable. The second set of parents, the Betas, both have hereditary deafness, as do many in their families. They are active participants in the Deaf culture, in which deafness is viewed as a different means of interacting with others and the world, not as a disease or disability. The Betas want to use genetic trait selection to make sure that the child they intend to create will have hereditary deafness, so their child can become a member of the Deaf culture as well.

Are the requests of the Alphas and the Betas ethically equivalent? Many people would think not. The intuition of most people, especially hearing capable people, is that the request of the Alphas is an ethically acceptable use of genetic trait selection because it assures that their child will born hearing capable and not be born with hereditary deafness. But the intuition of most people, again especially hearing capable people, is that the request of the Betas is not an ethically acceptable use of genetic trait selection because it assures that their child is born with hereditary deafness. The Betas could use the same genetic trait selection process to create a hearing capable child. So their act of intentionally creating a child with a disability, deafness, when they could have created a child without that disability, would be unethical. But at most levels, the requests of the Alphas and the Betas are the same. Both are sets of parents wanting to create children who are similar to them, particularly regarding their hearing capacities. We generally have little objection to parents wanting to have children who are like them in various capacities. What is it about hearing and deafness that differentiates the Alphas and the Betas?

Imagine that three sets of parents come to the clinic the next day. The first set, the Gammas, are both 4'6" tall because of a hereditary condition that inhibits their secretion of growth hormone. They want to use genetic trait selection to assure that the child they intend to create will have an adult height of 5'10". The second set of parents, the Deltas, are both 4'6" tall. But they do not have any recognized hereditary condition that inhibits their secretion of growth hormone. The Deltas are "normal short" parents. They, too, want to use genetic trait selection to assure that the child they intend to create will have an adult height of 5'10".[7] The third set of parents, the Epsilons, are both 5'10" tall. They want to use genetic trait selection to assure that the child they intend to create will have an adult height of 6'10".

Are the requests of the Gammas, the Deltas and the Epsilons ethically equivalent? Again, many people would think not. The intuition of most people, especially those of typical height, is that the request of the Gammas is an ethically acceptable use of genetic trait selection because it assures that their child will not have a hereditary insufficiency of human growth hormone and so will have typical adult height. And the intuition of most people, whether of typical height or not, is that the request of the Epsilons is not an ethically acceptable use of genetic trait selection because they would be creating a child who is atypically tall instead of creating a child who is of typical height. The Epsilons would not be preventing their child from having a disability in the way the Gammas are.

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[7] The Gammas' and the Deltas' situations are adapted from Norman Daniels, "The Genome Project, Individual Differences, and Just Health Care" in Timothy F. Murphy and Marc A. Lappé, eds., *Justice and the Human Genome Project* (Berkeley: University of California Press, 1994), 123, citing David B. Allen and Norman C. Fost, "Growth Hormone Therapy for Short Stature: Panacea or Pandora's Box?" *Journal of Pediatrics* 117: 16-21 (1990).

They would be making a typical child atypically tall, and so seem to be acting unethically. But many people do not have a clear intuition about the request of the Deltas. They want to use genetic trait selection to assure that their child will be 5'10" tall rather than 4'6" tall, just as the Gammas do. So the Deltas' request would seem to be as ethically acceptable as that of the Gammas. But the Deltas do not suffer from a hereditary condition inhibiting their human growth hormone secretion, and neither would their child. The height that is typical *for the Deltas* is 4'6". In using genetic trait selection, they would not be preventing their child from having a hereditary insufficiency of human growth hormone secretion. They would be making a child, in terms of what is typical for them, atypically tall, just as the Epsilons would be making their child atypically tall. So the Deltas' request would seem to be as ethically unacceptable as that of the Epsilons. But the Deltas' request cannot be both ethically acceptable and ethically unacceptable. Is the Deltas' request more like the Gammas' request, and thus ethically acceptable, or more like the Epsilons' request, and thus ethically unacceptable? What is it about height, and the reasons for it, that differentiates the Gammas, the Deltas and the Epsilons?

Finally, imagine that on your third day, two sets of parents come to the clinic. The first set, the Kappas, have visual acuity of 20/200 and are "tone deaf," both as a result of hereditary conditions. They want to use genetic trait selection to assure that the child they intend to create will have visual acuity of 20/20 and will have typical tone sensibility. The second set of parents, the Lambdas, have visual acuity of 20/20 and have typical tone sensibility. They want to use genetic trait selection to assure that the child they intend to create will have visual acuity of 20/10 and will have perfect pitch.

Are the requests of the Kappas and the Lambdas ethically equivalent? Again, the intuitions of many people are unclear. The Kappas seek to use genetic trait selection to assure that their child would have typical vision and hearing, rather than deficient vision and hearing, and so their use of genetic trait selection would seem ethically acceptable. And the Lambdas seek to use genetic trait selection to assure that their child would have atypically good vision and hearing, rather than typical vision and hearing. So their use of genetic trait selection would seem ethically unacceptable. But why should the Lambdas be criticized ethically for wanting to improve their child? Would their use of genetic trait selection to improve their child's visual acuity be any different from using training techniques, special lenses and even surgery to improve their child's visual acuity after birth? What, if anything, is lost in a child having 20/10 visual acuity and perfect pitch instead of 20/20 visual acuity and typical tone sensibility? What, if anything, differentiates the requests of the Kappas and the Lambdas? And what differentiates the requests of the Lambdas and the Epsilons?

6. Summary

In the remainder of this work, I will use these hypothetical parents to explore the possible distinctions that might assist us in assessing which, if any, of the parents' proposed uses of genetic trait selection are ethically acceptable and which, if any, are ethically unacceptable.

CHAPTER TWO: THE NORMAL/DISEASED DISTINCTION AND THE TREATMENT/ENHANCEMENT DISTINCTION

1. Introduction

Almost as soon as genetic intervention became technically feasible, commentators began discussing the ends to which such intervention should be put. W. French Anderson, an early writer on genetic ethics issues, noted that genetic intervention "opens the door for enhancement genetic engineering."[8] Anderson opposed enhancement engineering on two grounds: that it could be medically hazardous and would be morally precarious. He suggested that a line should be drawn at the point of "treatment of serious disease," under which genetic interventions intended to treat serious disease would be ethically acceptable but genetic interventions for other purposes would be ethically unacceptable.[9] He contended that until human society had greater wisdom than it now has, genetic intervention "should never be used in an attempt to make a good body better."[10]

Anderson's dividing line raises two questions: (1) what differentiates between serious disease and non-serious disease; and (2) more fundamentally, what is a disease? Anderson suggests that a serious disease, for the purposes of genetic intervention, is a

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[8] W. French Anderson, "Human Gene Therapy: Why Draw a Line?" *Journal of Medicine and Philosophy* 14: 681-93 (1989), 682.

[9] Anderson 1989, 687-88. See also W. French Anderson, "Genetics and Human Malleability," *The Hastings Center Report* 20: 21-24 (January/February 1990), 23-24

[10] W. French Anderson, "The First Signs of Danger." *Human Gene Therapy* 3: 359-360 (1992), 360.

condition that produces “significant suffering and premature death.”[11] But why should genetic interventions be limited to such conditions? Anderson suggested such a high standard because of the medical hazard of genetic interventions. But as the risks of genetic interventions diminish, the need for such a high standard diminishes as well. In the scenarios I have suggested, medical risk is no longer an objection to genetic intervention. So the distinction between serious disease and non-serious disease is of less value in assessing the ethical status of a genetic intervention.[12]

Further, Anderson’s proposed distinction between genetic treatment and genetic enhancement requires a definition of disease, so that we can separate those genetic traits that are diseases to be treated from those genetic traits that are not diseases and are not to be enhanced. The question of what is a disease is a long-standing and controversial one within the philosophy of medicine. Many define disease in normative terms.[13] But others suggest that a non-normative definition of disease is possible. Such a non-normative definition would avoid the introduction of normative elements to the assessment of the ethical acceptability of genetic trait selections — a feature that some would find desirable because it would avoid resting the ethical assessment of parental genetic trait selection on another ethical assessment, that of whether a condition is a disease.

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[11] Anderson 1989, 688.

[12] The seriousness of the disease may re-enter the issue in assessing whether the child’s range of open futures is constricted by the disease.

[13] See W. Miller Brown, “On Defining ‘Disease,’” *Journal of Medicine and Philosophy* 10: 311-328 (1985), 318; Joseph Margolis, “The Concept of Disease” in A.L. Caplan, H.T. Engelhardt, Jr., and J.J. McCartney (eds.), *Concepts of Health and Disease: Interdisciplinary Perspectives.* (Reading, Massachusetts: Addison-Wesley, 1981), 561-577; R.M. Hare, “Health,” *Journal of Medical Ethics* 12: 174-181 (1986); and H. Tristan Engelhardt, Jr., “Ideology and Etiology,” Journal *of Medicine and Philosophy* 1: 256-268 (1976).

2. A Non-Normative Definition of Disease

Christopher Boorse has proposed a non-normative "naturalistic" definition of disease. Through a series of articles,[14] Boorse has developed the following definition of disease:

> 1. The *reference class* is a natural class of organisms of uniform functional design; specifically, an age group of a sex of a species.[15]
> 2. A *normal function* of a part or process within members of the reference class is a statistically typical contribution by it to their individual survival and reproduction.
> 3. A *disease* is a type of internal state which is either an impairment of normal functional ability, i.e., a reduction of one or more functional abilities below typical efficiency, or a limitation on functional ability caused by environmental agents.

Boorse defines "normal functional ability" as the "readiness of an internal part to perform all its normal functions on typical occasions with at least typical efficiency." In turn, he defines "typical efficiency" as "efficiency above some arbitrarily chosen minimum in its species distribution."[16] Thus, he suggests that the "basic idea" of his

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[14] Boorse first presented his theories of disease and health in a series of four articles: "On the Distinction Between Disease and Illness," *Philosophy and Public Affairs* 5: 49-68 (1975) (hereinafter DDI); "What a Theory of Mental Health Should Be," *Journal of Theory Social Behavior* 6: 61-84 (1976) (TMH); "Wright on Functions," *Philosophical Review* 85: 70-86 (1976) (WF); and "Health as a Theoretical Concept," Philosophy *of Science* 44: 542-573 (1977) (HTC). He refined his theories in "Concepts of Health" in D. VanDeVeer and T. Regan (eds.), *Health Care Ethics: An Introduction* (Philadelphia: Temple University Press, 1987) (CH), 359-393, and has recently defended his theories against his critics in "A Rebuttal on Health" in J.M. Humber and R.F. Almeder (eds.), *What is Disease?* (Totowa, New Jersey: Humana Press, 1997) (RH), 3-134.

[15] Boorse defends using age and sex to distinguish reference classes "because of differences in normal physiology between males and females, young and old." Boorse (RH), 8. But he could be accused of smuggling in some measure of normativity by using age and sex to separate reference classes. While there are a number of areas where physiological function may differ structurally between the sexes, particularly regarding reproduction, there are also many areas where physiological function does not differ structurally between the sexes. And while there may be structural distinctions between childhood, adolescence and adulthood, the grounds for otherwise separating reference classes based on age groups are not clear. Chronological age and physiological age do not always coincide. Thus, using sex and age to distinguish reference classes may sometimes unwittingly introduce normativity into the BST.

[16] Boorse (RH), 8.

theory, for which he adopts the term "biostatistical theory" (BST), can be shown by a distribution curve.[17]

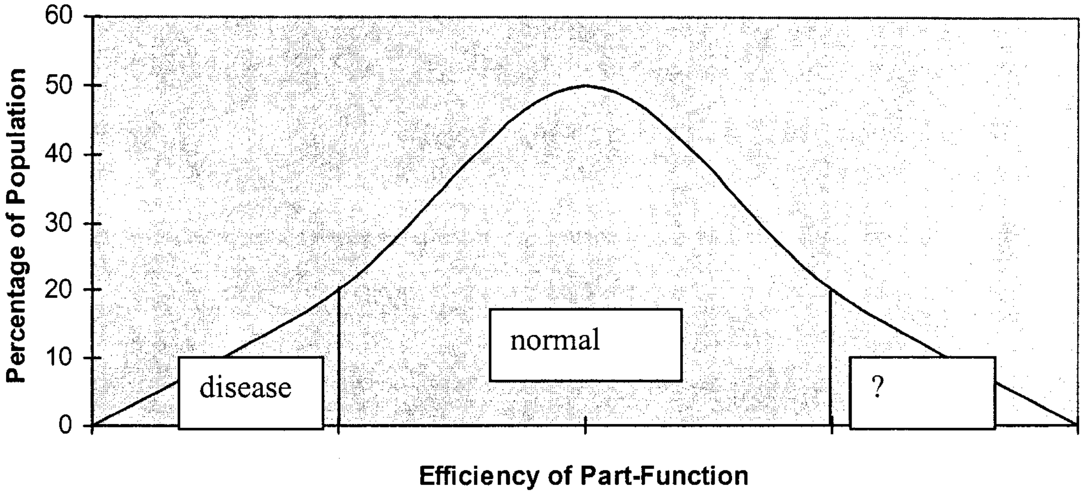

Figure 1 - Boorse's Biostatistical Theory

In short, the BST claims that the distinction between health and disease is the efficiency of the function of a part or process (the "part-function") of a member of the reference class. If the efficiency of the part-function falls outside the normal range of the statistical distribution for that function, then it is statistically abnormal. If the part-function is statistically abnormal, then the member of the reference class is said to have a disease with respect to that abnormality.

Figure 1 raises two concerns about Boorse's BST, which I will note but will not attempt to resolve here. First, the mechanism for establishing the dividing lines between the normal section of the distribution curve from the right and left tails of the distribution

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[17] Boorse (CH), 370 and Boorse (RH), 8.

curve is not clear. In some part-functions, such as stature, the dividing lines may be determined from calculating standard deviations, although those standard deviations may not correspond with insufficient part-function. In others, such as basal body temperature, the dividing lines may be determined by the onset of bodily dysfunctions. But for some part-functions, such as weight and auditory acuity, the inefficiency of part-functions such as weight and auditory acuity cannot be determined solely by the onset of bodily dysfunctions. Some elements of normativity, such as the perceived societal desirability of certain weights or the amount of hearing loss perceived as being undesirable, may influence where the dividing lines for such part-functions are set.[18] This injection of normative elements into Boorse's definition of disease makes it less likely that we can reach consensus as to what constitutes a disease and what constitutes normal, and thus less likely that we can reach consensus as to the ethical acceptability of genetic trait selections.

Second, Figure 1 contains a question mark for the right tail of the BST distribution curve. Even Boorse is not sure how to describe this segment of the BST curve in all cases. In one article, he contends that "there is no such thing as an excess of function" and so contends that cases falling in the right tail of the BST curve are not diseases.[19] In another article, he labels the right tail of the BST curve "positive health?"

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[18] Similarly, if a society decided accommodating left-handedness was too burdensome, it could declare that the efficiency of part-function of handedness was inefficient enough to place it below the dividing line between disease and health, making left-handedness a disease and allowing the society to consider left-handedness as a disease to be treated.

[19] Boorse, CH, 371.

but is skeptical that such a thing can be described in non-normative terms.[20] For some part-functions, such as thyroid production, then an excessively high level of efficiency seems to be a disease just as excessively low levels of efficiency may be. But for other part-functions, such as visual acuity, excessively high levels of efficiency are not diseases, and may indeed be more desirable than normal levels of efficiency. It is this feature that casts doubt on whether Boorse's definition of disease can provide a non-normative means of assessing the ethical acceptability of genetic trait selections.

As noted above, Boorse's definition of disease requires that a condition or trait must meet three requirements to be a disease: (1) the condition must arise in a "reference class" of an age group of a sex of a species; (2) the "normal function" of the part or process affected by the condition must make a statistically typical contribution to the individual survival and reproduction of the affected member of the reference class; and (3) the condition must be a type of internal state, or be caused by an environmental agent, that reduces the efficiency of the "normal function" below typical efficiency. Can Boorse's definition of disease provide us with a non-normative foundation upon which to assess whether the clinic parents' proposed actions are ethical, such that those actions that treat a disease are ethically acceptable but those actions that do not treat a disease are not ethically acceptable?

Let us review the parents and their proposed actions:

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[20] Boorse, HTC, 568-72.

Table 1 - The Parents

Parents	**Condition Without Genetic Trait Selection**	**Condition With Genetic Trait Selection**
Alphas	Hereditary Deafness	Hearing Capability
Betas	Hearing Capability	Hereditary Deafness
Gammas	4'6" adult height, low growth hormone levels	5'10" adult height
Deltas	4'6" adult height, normal growth hormone levels	5'10" adult height
Epsilons	5'10" adult height	6'10" adult height
Kappas	20/200 vision and tone deafness	20/20 vision and typical tone sensibility
Lambdas	20/20 vision and typical tone sensibility	20/10 vision and perfect pitch

In the case of the Alphas and the Betas, Boorse's definition of disease can provide a non-normative means of assessing the ethical acceptability of the parents' proposed genetic trait selections. A genetic trait that results in deafness arises in a reference class. The "normal function" of hearing likely makes a statistically typical contribution to individual survival and reproduction.[21] The genetic trait reduces the efficiency of the normal function of hearing below typical efficiency. Thus, under Boorse's definition, a child who has a genetic trait that will result in deafness has a disease. Accordingly, the Alphas' proposed action would be treatment of a disease and so would be ethically acceptable. In contrast, a genetic trait that results in hearing in the normal range does not

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[21] This assumes that the person's deafness is not ameliorated by the society in which she lives. If unameliorated, a lack of hearing would expose the person to more environmental hazards, which could decrease survival, and create more difficulty in finding a reproductive partner, which could reduce reproduction. For more on the effects of deafness on survival, see S. Barnett and P. Franks, "Deafness and Mortality: Analyses of Linked Data from the National Health Interview Survey and National Death Index," *Public Health Reports*, 114: 330-36 (1999).

reduce the efficiency of the normal function of hearing below typical efficiency. Under Boorse's definition, a child who has a genetic trait that will result in hearing in the normal range does not have a disease. The Betas' proposed action would not be treatment of disease and so would not be ethically acceptable.

As we move to the Gammas, the Deltas and the Epsilons, though, the utility of Boorse's definition of disease as a ground for ethical distinction starts to weaken. A genetic trait that results in growth hormone deficiency, and thereby results in height significantly less than the standard range, arises in a reference class. The "normal function" of growth hormone production, and its resulting reduction in predicted adult height, seems to make a statistically typical contribution to individual reproduction and survival.[22] The genetic trait reduces the efficiency of the normal function of growth hormone production below typical efficiency. Thus, under Boorse's definition, a child who has a genetic trait that will result in growth hormone deficiency, resulting in height significantly less than the standard range, has a disease. Accordingly, the Gammas' proposed action would be treatment of a disease and so would be ethically acceptable. In contrast, a genetic trait that results in height in the standard range does not reduce the efficiency of the normal function of growth hormone production below typical efficiency. Under Boorse's definition, a child who has a genetic trait that will result in predicted

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[22] Studies suggest that taller men have greater success in mate selection and likely in reproductive success. See B. Pawlowski, et al., "Evolutionary Fitness — Tall Men Have More Reproductive Success," *Nature* 403: 156 (January 13, 2000) and W.E. Hensley, "Height as a Basis for Interpersonal Attraction," *American Journal of Epidemiology* 29: 469-74 (1994). The Hensley study found that taller women were neither advantaged nor disadvantaged in mate selection. One study suggests that taller persons live longer. P. Jousilahti, et al., "Relation of Adult Height to Cause Specific and Total Mortality," *American Journal of Epidemiology* 151: 1112-20 (2000). But another study suggests that shorter persons live longer. T.T. Samara, et al., "Height, Body Size and Longevity," *Acta Medica Okayama* 53: 149-69 (1999).

adult height in the standard range does not have a disease. The Epsilons' proposed action would not be treatment of a disease and so would not be ethically acceptable.

But what of the Deltas? Does a child, whose genetic traits include normal growth hormone production but whose predicted adult height is significantly less than the standard range, have a disease under Boorse's definition? In one sense, the Deltas' child's predicted adult height is "normal" for him or her, in that it results from "normal" levels of growth hormone production. While there is a "normal function" of growth hormone production, is there a "normal function" of predicted adult height where growth hormone production is in the normal range? If not, then the child of the Deltas would not have a disease under Boorse's definition, so the proposed action of modifying that child's genes would not be treatment of a disease and so would not be ethically acceptable. But why should different genetic traits, which both result in the same outcome, result in different ethical assessments? If treatment for short stature caused by growth hormone deficiency is ethically acceptable, then why is treatment for the same short stature caused by other factors ethically unacceptable? For Boorse's definition to help us here, either we must consider predicted adult height as a normal function or we must accept that predicted adult height significantly below the standard range, where growth hormone production is in the normal range, is not a disease that should be treated.

Finally, what of the Kappas and the Lambdas? Genetic traits that result in 20/200 visual acuity and tone deafness arise in a reference class. The "normal function" of vision makes a statistically typical contribution to individual survival and reproduction. The "normal function" of tone sensibility probably does not make a statistically typical contribution to individual survival and reproduction, and so could not result in a disease. The genetic trait reduces the efficiency of the normal function of vision below typical efficiency. Thus, under Boorse's definition, a child who has a genetic trait that will result in 20/200 visual acuity has a disease. Accordingly, the Kappas' proposed action as to their child's vision would be treatment of a disease and so would be ethically acceptable. But their proposed action as to their child's tone sensibility would not be treatment of a disease and so would not be ethically acceptable.

In contrast, a genetic trait that results in 20/20 visual acuity does not reduce the efficiency of the normal function of vision below typical efficiency. Under Boorse's definition, a child who has a genetic trait that will result in 20/20 visual acuity does not have a disease. The Lambdas' proposed action, as to both vision and tone sensibility, would not be treatments of disease and so would not be ethically acceptable. But is using genetic trait selection to give a child 20/10 vision and perfect pitch, instead of 20/20 vision and typical tone sensibility, as the Lambdas wish to do, ethically different from using genetic trait selection to cause a child to be 6'10" tall instead of 5'10" tall, as the Epsilons wish to do? Some people would intuit that the Lambdas' proposed action is ethically acceptable but that the Epsilons' proposed action is ethically unacceptable. If they are correct, what is the basis for that difference? One possible basis is that the Lambdas' proposed action benefits their child regardless of how many other parents take the same action, because those benefits are absolute, but that the Epsilons' proposed action benefits their child only if few other parents take the same action, because those benefits are relative to the heights of others. But Boorse's definition of disease does not provide us with a non-normative distinction between the Lambdas' proposed action and the Epsilons' proposed action.

Beyond not mapping on to our intuitions about the ethical acceptability of the planned courses of action of the clinic parents, using Boorse's definition of disease as a means of assessing the ethical acceptability of genetic trait selections has two defects. First, there is no clear reason why we should consider the normal as normative. Before Francis Galton proposed his theories on eugenics, human attributes and functions were measured against conceptions of the "ideal," such as Leonardo De Vinci's "Vitruvian Man" and other descriptions of the ideal human. Galton proposed the use of statistical distributions to define "normal" human attributes and functions, and in so doing, to define those falling outside the "normal" range as having a defect or a disease.[23] But a statistical distribution describes the range of attributes and functions among a population as they exist at that time, not an optimal level of attributes and functions. And that distribution changes over time.

As one example, in the absence of fluoridation and sealants, most children and adults develop dental caries (cavities) when exposed to the typical Western diet. Thus, a statistical distribution of the part-function of humans' use of their teeth, with which dental caries interferes, would place most humans with dental caries in the normal range. But most of us consider dental caries to be a defect or a disease, and we engage in considerable efforts to avoid and then treat dental caries. How could a condition

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[23] Lennard Davis, *Enforcing Normalcy: Disability, Deafness, and the Body* (London: Verso, 1995), 32-35.

encountered by a large number of the population, who would make up the normal range, also be a disease that would be outside the normal range?

As a second example, because of improvements in public health, nutrition and medical interventions, the average human is four inches taller now than 150 years ago. If the normal is normative, then a five foot two inch tall man was normal in 1850 but has a disease today.[24] Thus, changes in the population alone could change a condition from being considered normal to being a disease.

Further, as H. Tristam Engelhardt recognizes, an inefficiency in part-function may have greater or lesser negative ramifications depending on the environment in which the person lives. Inefficiency in melanin production could be either too much melanin, resulting in darker skin, or too little melanin, resulting in lighter skin. In an environment such as Norway, a person with darker skin (who had to rely on sunlight for vitamin D production) would be at greater risk of developing rickets than would the lighter-skinned person. But in an environment such as Equatorial Guinea, a person with lighter skin (who did not have access to ultraviolet blocking skin coverings) would be at greater risk for melanoma than would the darker-skinned person. So, depending on the environment in which it arises, the same inefficiency of part-function could have great consequence or little consequence.[25] Calling an inefficiency of part-function a disease, under Boorse's definition, when it has little or no negative consequence, strains the concept of disease.

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[24] Richard Steckel, "New Light on the 'Dark Ages': The Remarkably Tall Stature of European Men During the Medieval Era," *Social Science History*, 28: 211-29 (2004). Interestingly, this article suggests that adult height decreased from the medieval era to the seventeenth and eighteenth centuries and increased again after that.

[25] H. Tristram Engelhardt, Jr., *The Foundations of Bioethics (Second Edition)* (New York: Oxford University Press, 1996), 201.

And the alternative, making disease environment-specific, calls into question the treatment of the normal range as the normative state.

Second, Boorse's definition assumes that the normal, and therefore normative, part-functions of humans can be established. But as James Gustafson noted in one of the first discussions of the ethical ramifications of genetic engineering, there are a great many ways of attempting to describe what is normative for humans. They range from the Aristotelian to the Christian to the anthropological.[26] He doubts there is a fixed point from which to measure what is normatively human, particularly given that "man has always been developing new ways to determine his own life and that of the human race."[27] Thus, he proposes that in thinking ethically about genetic engineering, including treatment and enhancement, we "ought not to begin with a fixed image of what was, is, and always ought to be, from which are derived authoritative and unalterable rules."[28]

Others have joined in this objection to a fixed or canonical view of the normative human. Keith Boone argues that "the widely accepted belief that there is a fixed human genome is faulty, given that the 'genetic basis of what is distinctively human continually changes through the random interplay of random mutation and natural selection.'"[29] Audrey Chapman notes that except for identical twins, each person is born with a

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[26] James M. Gustafson, "Genetic Engineering and the Normative View of the Human," in Preston N. Williams, ed., *Ethical Issues in Biology and Medicine* (Cambridge, Massachusetts: Schenkman Publishing Company, 1973), 50-55.

[27] Gustafson 1973, 56.

[28] Gustafson 1973, 57.

[29] C. Keith Boone, "Bad Axioms in Genetic Engineering," *The Hastings Center Report* 18: 9-13 (August/September 1988), 11 (quoting President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Splicing Life: A Report on the Social and Ethical Issues of Genetic Engineering with Human Beings* (Washington, D.C.: U.S. Government Printing Office, 1982), 70).

different genome, so "human beings are clearly born unequal in terms of their genetic endowments."[30] Kevin Wildes comments that "unless one begins moral analysis by viewing nature, however defined, as morally normative, then there is no reason why one should think [of] nature as morally normative" and that "[e]ven if we could establish a common understanding of human nature, we would still face the question of why nature should be normative morally."[31] Michael Reiss notes that "[a] 'natural' event, product, process or tendency (however defined) is not automatically good or desirable" and that we commit the naturalistic fallacy when we deduce what is ethical from what occurs.[32] And Paul Davies argues that "[w]e should relinquish the claim that natural functions are normative in some respect or other" because "functional traits themselves – the tokens possessed of the systemic capacities – are not the bearers of norms of any sort."[33]

I concur in these views. Boorse commits a naturalistic fallacy[34] when he deduces that the statistically normal states of humans are necessarily the normative states for humans. There are a number of statistically normal states that many humans find not to be normative and thus seek to avoid or treat. One example is dental caries, discussed previously. Another is juvenile acne, which is quite undesirable when it occurs but

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[30] Audrey Chapman, *Unprecedented Choices: Religious Ethics at the Frontiers of Genetic Science* (Minneapolis: Fortress Press, 1999), 181.

[31] Kevin Wm. Wildes, "Redesigning the Human Genome: Are There Constraints from Nature?" in Emanuel Agius and Salvino Busuttil, eds., *Germ-Line Intervention and Our Responsibilities to Future Generations* (Dordrecht: Kluwer Academic Publishers, 1998), 44.

[32] Michael J. Reiss and Roger Straughan, *Improving Nature?: The Science and Ethics of Genetic Engineering* (Cambridge: Cambridge University Press: 1996), 63.

[33] Paul Sheldon Davies, *Norms of Nature: Naturalism and the Nature of Functions* (Cambridge, Massachusetts: MIT Press, 2001), 214.

[34] The "naturalistic fallacy" is "identifying the goodness with any natural characteristic." Paul Edwards (ed.), *The Encyclopedia of Philosophy* (New York, Macmillan Publishing Co., 1967), volume 3, 178. If goodness is a property separate from being natural, as I and many others hold, then it is an error to necessarily consider all natural things to be good.

generally resolves itself in time. A third, in some populations, is male pattern baldness, which some men go to considerable lengths to treat. And, as discussed above, the statistically normal range changes across time and across environments. Thus, I contend that Boorse's definition of disease fails to show why we should consider the statistically normal range of human states to be those states that humans deem to be normatively desirable, and conversely, that the statistically abnormal range of human states to be those states that humans find normatively undesirable.

In summary, Boorse's definition of disease will not serve as a non-normative basis for making ethical assessments about parental genetic trait selections because: (1) for some genetic trait selections, such as height and auditory acuity, it must rely in part on normative elements; (2) it does not account for genetic trait selections that would place the child in the right tail of his BST curve, such as extreme height or 20/10 visual acuity; and (3) it fails to show why the normal, in its statistical sense, should be considered normative, in its ethical sense. I will turn to other possible bases for making ethical assessments about parental genetic trait selections that are, in lesser and greater degrees, expressly normative.

3. Species-Typical Functioning

Norman Daniels has built on Boorse's definition of disease to draw a distinction between genetic treatment and genetic enhancement. Here we begin to move from the normal/disease distinction to the treatment/enhancement distinction. Daniels contends that "disease and disability are seen as departures from species-typical normal functional organization."[35] He contends that species-typical functioning is not "merely a statistical notion" but implies "a theoretical account of the design of the organism," from which a "natural functional organization of a typical member of the species" can be determined.[36] Thus, a person suffers from a disease or disability when an impairment of that normal functioning "restricts an individual's opportunity relative to that portion of the normal range his skills and talents would have made available to him were he healthy."[37]

Daniels' "species-typical function" standard for disease or disability, as a means of distinguishing between ethically acceptable genetic treatments and ethically unacceptable genetic enhancements, is subject to many of the same criticisms that I have made of using Boorse's definition of disease to make those distinctions. First, Daniels' standard often injects normative elements into the definition of disease just as Boorse's does. As Jackie Scully and Christoph Rehmann-Sutter recognize, "if a cut-off point is to be set that will exclude some degrees of variation but not others from the category of species-typical, it must therefore be chosen rather than deduced from self-evident biological criteria" and those cut-off points will be "based on culturally mandated decisions as much as biological phenomena."[38]

It is not clear whether Daniels accepts or rejects the idea that species-typical function contains normative elements. He contends that species-typical function arises

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[35] Daniels 1994, 122, citing Boorse.
[36] Norman Daniels, *Just Health Care* (New York: Cambridge University Press, 1986), 28.
[37] Daniels 1986, 34. Thomas Murray supports Daniels' therapy/enhancement distinction, contending that responding to a "genuine need" is therapy, while an enhancement is "a thing we desire greatly but do not actually need." Thomas H. Murray, "The Genome and Access to Health Care: Two Key Ethical Issues," in Thomas H. Murray, Mark A. Rothstein, and Robert F. Murray, Jr., eds., *The Human Genome Project and the Future of Health Care* (Bloomington: Indiana University Press, 1996), 209-223, 222.
[38] Jackie Leach Scully and Christoph Rehmann-Sutter, "When Norms Normalize: The Case of Genetic 'Enhancement.'" *Human Gene Therapy* 12: 87-95 (January 1, 2001), 92-93.

from a theoretical account of the design of the organism, not simply from a statistical distribution. Such a theoretical account of the design of humans, who can make normative assessments about their conditions, would seem to include normative elements. But he also wants to "appeal to a natural baseline" in distinguishing between genetic treatment and genetic enhancement because if we do not, "then we will have to give more complex justifications for drawing the line between cases."[39]

Second, Daniels' standard assumes that species-typical function is normative, just as Boorse's does. Daniels denies that he commits a naturalistic fallacy in appealing to a natural baseline for distinguishing between genetic treatment and genetic enhancement. He contends "the natural baseline both facilitates and reflects moral agreement" as to what conditions are to be treated and what conditions would just be enhanced through an intervention.[40] But as Anita Silvers comments, "why is functioning normally of such value that maintaining or restoring this level becomes a decisive standard?"[41] She suggests that the species-typical function standard may be viewed as a "biological mandate that accredits policies of normalizing people by restoring them to typical or familiar modes and levels of functioning" and may thus perpetuate discrimination and inequality of opportunity.[42] Daniels does not appear to respond to this concern. Rather, he comments "it will be harder to reach consensus on these justifications without the

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[39] Daniels 1994, 126-27.

[40] Daniels 1994, 127.

[41] Anita Silvers, "A Fatal Attraction to Normalizing: Treating Disabilities as Deviations from 'Species-Typical' Functioning." in Erik Parens, ed., *Enhancing Human Traits: Ethical and Social Implications* (Washington, D.C.: Georgetown University Press, 1998) (Parens 1998a), 95-123, 115.

[42] Silvers 1998, 104.

ability to appeal to a natural baseline."[43] Daniels has not demonstrated that species-typical function avoids the objection of committing a naturalistic fallacy in implying a theoretical account of human function from the natural baseline of human functions.

Third, just as Boorse's definition of disease does, Daniels' standard of species-typical function seems to assume some canonical definition of what levels of functioning are "typical" for our species. But John Lachs suggests that while we "can hardly resist the temptation to select some local characteristics and elevate them to the level of universality, or to anoint the statistically normal distribution of traits as the norm," they cannot encompass what levels of functioning are typical for all humans.[44] And Peter Whitehouse, *et al.*, notes that there are "very few open-ended functional goals in our organismic design" but that cognitive capacities may be one of those open-ended goals.[45] If so, then they contend "there is no 'optimum' norm for cognition in human beings" and so there can be no "species-typical function" of cognition upon which we could determine whether a specified level of cognition is a disease to be treated or a trait to be enhanced. Daniels does not respond to these concerns and does not give a reason for believing that there is a species-typical level of functioning that is true of all members of the species.

In summary, Daniels' standard of "species-typical functioning" will not serve as a non-normative distinction between parental genetic trait selections that would be ethically

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[43] Daniels 1994, 127.

[44] John Lachs, "Grand Dreams of Perfect People" *Cambridge Quarterly of Healthcare Ethics* 9:323-329 (2000), 326.

[45] Peter J. Whitehouse, Eric Juengst, Maxwell Mehlman, and Thomas H. Murray, "Enhancing Cognition in the Intellectually Intact" *The Hastings Center Report* 27: 14-22 (May/June 1997), 17.

acceptable genetic treatment and parental genetic trait selections that would be ethically unacceptable genetic enhancements because: (1) for some genetic trait selections, such as height and auditory acuity, it must rely in part on normative elements; and (2) it fails to show why the natural baseline should imply that the conditions at that baseline should be considered normative. To the extent Daniels allows for normative elements in his theoretical account of species-typical functioning, he does not account for the source of those normative elements. I move next to an expressly normative ethical distinction between genetic treatment and genetic enhancement.

4. Malady as an Ethical Boundary

Rather than continuing to search for a non-normative boundary between ethically acceptable genetic trait selections and ethically unacceptable genetic trait selections, Edward Berger and Bernard Gert have proposed an alternative boundary: whether the condition is a malady. Berger and Gert define "malady" as a condition in which a person "is suffering, or is at increased risk of suffering, an evil (death, pain, disability, loss of freedom or opportunity or loss of pleasure) in the absence of distinct sustaining cause."[46] They maintain that their concept of malady is "objective and non-technical."[47] They contend that their definition of "malady" captures more conditions than does Boorse's non-normative definition of disease. As examples, they cite conditions such as broken

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[46] Edward M. Berger and Bernard M. Gert, "Genetic Disorders and the Ethical Status of Germ-Line Gene Therapy" *Journal of Medicine and Philosophy* 16: 667-683 (1991), 671. By "distinct sustaining cause," Berger and Gert appear to mean some externality causing the evil, such as the couch leg on top of one's foot. Once the couch leg is removed from the foot, the evil stops, and so does the pain, eventually.

[47] Berger and Gert 1991, 674-75.

limbs and infertility. They contend these conditions would not fall within the non-normative definition of disease,[48] but would constitute suffering an evil (pain and disability in the instance of a broken limb, loss of opportunity for reproduction in the instance of infertility), and so would fall within their definition of malady.[49] Since medical treatment of these conditions is generally accepted, they contend that malady is a more useful boundary than disease.

Berger and Gert address specifically two genetic traits that they suggest fall within the definition of malady but would not fall within some definitions of disease. The first, low intelligence, I will not address because of the strong non-genetic influences on intelligence. The second is short stature. They suggest that a male fetus whose adult height will be 4'6" has a malady because he is "likely to experience many harms because of his height: he is deprived of the opportunity of carrying out many physical activities available to men of average height and is likely to be the object of life-long social stigmatization of various kinds."[50] Thus, they contend that genetic intervention for that fetus, which would increase his height, is ethically permissible. But they suggest that a male fetus whose adult height will be 5'4" "clear[ly] … does not suffer from a malady."[51]

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[48] This assertion is dubious. Even Boorse's functionalist, non-normative definition of disease could be read to extend to these conditions. A broken leg would be a dysfunction of the locomotive system and could fall within Boorse's definition of disease. While a more difficult proposition, because it assumes reproduction is a necessary function, infertility could also be considered a dysfunction and thus fall within Boorse's definition. But for purposes of argument, I will accept Berger and Gert's assertion.

[49] Bernard M. Gert, Edward M. Berger, et al., *Morality and the New Genetics: A Guide for Students and Health Care Providers* (Sudbury, Massachusetts: Jones and Bartlett Publishers, 1996), 148.

[50] Gert and Berger 1996, 161.

[51] Gert and Berger 1996, 161.

Thus, they contend that genetic intervention for this fetus, which would increase his height, is ethically impermissible.[52]

But what makes being 4'6" tall a malady but being 5'4" not a malady? Both would be below the 5'9" American average for male adult height. Berger and Gert would likely focus on the severity of the harms that the two men would suffer. If that is so, how do we create a criterion for establishing when harm becomes sufficiently severe that it becomes a malady rather than an annoyance? Berger and Gert do not specify, and I have difficulty conceiving of, significant activities available to five foot four inch tall men but not available to four foot six inch tall men. The shorter man might be less successful at some activities, such as basketball, but his height does not foreclose his opportunity to play basketball. But in other activities, such as being a jockey, the shorter man might be more successful than the taller man. And both men might be equally less successful at activities like basketball than yet taller men. Further, the degree of social stigmatization that the shorter man would suffer would likely be culturally dependent. So the severity of harm is a highly subjective basis for distinguishing maladies from non-maladies.

Without a normative foundation other than severity of harm, Berger and Gert's definition of malady does not provide us with a useful basis for distinguishing genetic trait selections that are ethically acceptable treatments from those that are ethically unacceptable enhancements. Berger and Gert's dividing line allows for too much subjectivity in the assessment of whether a genetic trait selection treats a malady or constitutes an enhancement. Before moving to other expressly normative proposed

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[52] Gert and Berger 1996, 182.

distinctions between ethically acceptable genetic treatments and ethically unacceptable genetic enhancements, I pause to consider whether enhancements are necessarily ethically unacceptable.

5. What is Wrong with Enhancement, Anyway?

In many of the discussions of the treatment/enhancement distinction, treatment is assumed to be ethically acceptable while enhancement is assumed to be ethically unacceptable. But are all enhancements that parents would confer on their children ethically unacceptable? Clearly not. Some enhancements, such as education and immunization against disease, are ethically required of parents.[53] Many other enhancements, such as music lessons, dance lessons, sports training and orthodontia, are ethically permissible even if not ethically required.[54] Thus, in order to maintain the treatment/enhancement distinction as an ethical boundary, one must either view genetic trait selection enhancements as being different, in an ethically meaningful way, from post-natal enhancements, or distinguish between ethically acceptable and unacceptable enhancements.

While parental genetic trait selection enhancements are different in time and mechanism than post-natal enhancements, they are not different in most ethically relevant ways.[55] As John Robertson notes,

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[53] Dan W. Brock, "Enhancements of Human Function: Some Distinctions for Policymakers" in Parens 1998a, 48-69, 49.

[54] Brock 1998, 49

[55] Henry I. Miller, "Gene Therapy for Enhancement" *The Lancet* 344: 316-17 (July 30, 1994), 317.

> [P]arents now have wide discretion to enhance offspring traits after birth with actions that range from the purely social and educative, such as special tutors and training camps, to the physio-medico as occurs with orthodontia, rhinoplasty and exogenous growth hormone. Such actions may give the child advantages of other children, exacerbate class and socioeconomic differences, and risk treating the child like a product or object to serve the parent's interest. Yet they fall within a parent's discretion in rearing offspring ....
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> . . .
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> If special tutors and camps, training programs, even the administration of growth hormone to add a few inches to height are within parental rearing discretion, why should genetic interventions to enhance normal offspring traits be any less legitimate?[56]

Thus, since parents have parental autonomy to engage in a wide array of post-natal enhancements, even permanent surgical modifications, why should they not have the autonomy to make those modifications before implantation or before birth of their children? If parents can give their children growth hormone after they are born to make them taller, as part of their parental autonomy, then there seem to be few ethical objections to using parental genetic trait selection to achieve the same result. And if parents can have the children undergo surgery or special training[57] to improve their visual acuity, as part of their parental autonomy, again there seem to be few ethical objections to using parental genetic trait selection to reach the same result. The only difference is the modality by which the parents achieve the desired result.

Post-natal enhancement and parental genetic trait selection may be ethically distinguishable in two regards. First, most post-natal enhancements do not make

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[56] John A. Robertson, *Children of Choice: Freedom and the New Reproductive Technologies* (Princeton, New Jersey: Princeton University Press, 1994), 164-67.

[57] The most likely means to 20/10 visual acuity would be through surgery, particularly laser surgery. Some alternative medicine providers contend that 20/10 visual acuity can be achieved in children through visual exercises.

substantial permanent changes to the child's body, so if the child finds that she does not desire the enhancement, she can ignore or abandon the enhancement without any negative effects. For example, parents may insist that their children endure piano lessons, ballet lessons or tae kwon do lessons. Those children can later quit these activities and will not have suffered any permanent change. In contrast, enhancements made through genetic trait selection will often be substantial permanent changes to the child's body, absent some subsequent intervention,[58] and so are distinguishable from these non-permanent enhancements. If the child finds that she does not desire these sorts of enhancements, she may not be able to ignore or abandon the enhancement without any negative effects. But some post-natal enhancements, such as rhinoplasty and growth hormone treatments, are make substantial permanent changes to the child's body, or at least very difficult to change back to a pre-enhancement condition. These permanent bodily changes, accomplished through post-natal enhancements, seem indistinguishable from permanent body changes achieved through genetic trait selection.

Second, most, if not all, post-natal enhancements would not change the identity of the child. But some genetic trait selections could change the identity of the child. If so, those genetic trait selections would be distinguishable from post-natal enhancements. I will consider these effects on identity later. Thus, except for non-permanent, post-natal enhancements, such as lessons or training, and except for identity-affecting parental genetic trait selections, the mere fact that an enhancement is conferred post-natally does

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[58] For example, a child who would have been deaf but for her parents use of genetic trait selection could still end up being deaf as a result of subsequent disease or trauma.

not make it different ethically from those enhancements that are conferred by parental genetic trait selection.

Further, society typically encourages those parents who have the resources to engage in some forms of post-natal enhancement. While we may have concerns about the distribution of resources, we do not discourage parents from sending their children to private schools, for example. As William Gardner notes, humans "tenaciously seek advantages for their children" through post-natal enhancements, and would be expected to do so with parental genetic trait selection.[59]

Not all enhancements are ethically objectionable. Parents have wide parental autonomy to decide what, if any, enhancements to provide to their children. And some enhancements that might be achieved through parental genetic trait selection can be achieved through post-natal interventions. Thus if some parental genetic trait selections are ethically objectionable enhancements, the source of that objection must rise from grounds other than simply the pre-natal nature of the enhancement.

6. What Enhancements Are Ethically Permissible?

Even if an ethically relevant distinction can be made between those genetic trait selections that are treatments and those that are enhancements, when, if ever, are such enhancements ethically permissible? A number of ethicists have proposed boundaries or

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[59] William Gardner, "Can Human Genetic Enhancement Be Prohibited?" *Journal of Medicine and Philosophy* 20: 65-84 (1995), 71-72. See also Gregory Stock, *Redesigning Humans: Our Inevitable Genetic Future.* (New York: Houghton Mifflin Co., 2002), 178-80.

guidelines for distinguishing ethically acceptable enhancements from ethically unacceptable enhancements. I consider their proposals below.

a. Only Health-Related Enhancements Permitted

LeRoy Walters and Julie Palmer argue for a distinction between ethically acceptable "health-related" enhancements, such as immunization and genetic trait selections that would increase immune function, and ethically unacceptable "non-health-related" enhancements, such as genetic trait selection that would increase size, reduce the need for sleep and slow the aging process.[60] Juan Torres argues that genetic trait selections that result in enhancement are ethically acceptable only if they are "necessary condition[s] for the success of treatment designed to suppress the causes, symptoms or effects of a severe pathology."[61]

These distinctions help us with concerns about whether preventative parental genetic trait selections would be ethically acceptable. By definition, prevention of a disease is not treatment of a disease, and so on a strict reading of the treatment/enhancement distinction, prevention would seem to fall in the enhancement category. By including prevention among "health related" enhancements, thus moving the line from a treatment/enhancement distinction to a health-related/non-health-related distinction, prevention can be accommodated. But these distinctions do not help us assess some non-health-related enhancements, such as improved visual acuity, that many

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[60] LeRoy Walters and Julie Gage Palmer, *The Ethics of Human Gene Therapy* (New York: Oxford University Press, 1997), 110-12.

[61] Juan Manuel Torres, "On the Limits of Enhancement in Human Gene Transfer: Drawing the Line." *Journal of Medicine and Philosophy* 22: 43-53 (1997), 48. See also Paulina Taboada, "Human Genetic Enhancement: Is it Really a Matter of Perfection? A Dialog with Hanson, Keenan and Shuman." *Christian Bioethics* 5: 183-196 (1999), 192-93 (distinguishing between enhancements to treat health problems and enhancements of traits per se).

persons would not find objectionable. Nor do they address why non-health-related enhancements would not fall within the rights to parental autonomy. As I have argued, parents have broad autonomy in the ways they raise their children, including enhancements that they may seek to confer on their children through post-natal intervention. For the objection to non-health-related enhancements to hold, it must show how post-natal interventions differ ethically from pre-natal, and pre-implantation, interventions. But as I have argued, there is no per se difference, ethically, from post-natal and pre-natal interventions, so the objection to non-health-related enhancements does not assist us in assessing parental genetic trait selections.

b. No Enhancements Permitted

Some contend that all enhancing genetic trait selections are ethically objectionable. Skylar Sherwood contends that any genetic trait selection should be prohibited "except for purposes of eliminating or significantly reducing … the likelihood of disease in the resultant individual" because of psychological effects on the child and because of effects on cultural and genetic diversity.[62] Jonathan Brown argues that parental genetic trait selections made to address "restriction defects," which "severely limit a person's ability to pursue a preferred life plan," are ethically permissible, but that parental genetic trait selections made to address "cosmetic defects" are ethically

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[62] Skylar A. Sherwood, "Don't Hate Me Because I'm Beautiful … and Intelligent … and Athletic: Constitutional Issues in Genetic Enhancement and the Appropriate Legal Analysis." *Health Matrix* 11: 633-657 (2001), 637-39. This argument, drawn largely from constitutional law on procreative rights, reads those cases very narrowly, exaggerates the harm to children's welfare, and assumes that genetic trait selection would lead to less diversity.

impermissible.[63] But again, these distinctions do not seem to account for the wide range of autonomy we grant parents or why that autonomy would not extend to a wide range of parental genetic trait selections. We grant parents the autonomy to engage in a broad range of post-natal interventions that are not done for the purposes of eliminating or significantly reducing the possibility of disease in their children. We grant parents the autonomy to engage in post-natal interventions to address "cosmetic defects," even going so far as to grant parents the autonomy to authorize the circumcision of their male children. Without an explanation of how genetic trait selections differ ethically from post-natal interventions, Sherwood's and Brown's boundaries do not help us with ethically assessing many parental genetic trait selections.

c. All Non-Harmful Enhancements Permitted

Some contend that parents may engage in almost any enhancing genetic trait selections. John Robertson argues that absent a showing of tangible harm to the child, parents may engage in genetic trait selections for that child, whether they are enhancing or are engaging in "intentional diminishment," such as selecting for deafness or short stature.[64] As I will later address in more detail, granting parents such broad parental autonomy in making genetic trait selections has the potential to violate some rights of the child. Parents have duties beyond simply refraining from inflicting tangible harms on

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[63] Jonathan S. Brown, "Genetic Manipulation in Humans as a Matter of Rawlsian Justice." *Social Theory and Practice* 27: 83-110 (2001), 90 and 104-05. Brown argues that as a matter of Rawlsian justice, the state should pay for parental genetic trait selection intended to address "restriction defects."

[64] John A. Robertson, "Genetic Selection of Offspring Characteristics." *Boston University Law Review* 76: 421-482 (1996), 436-39.

their children. They have duties to act in the best interests of their children and to respect their children's rights. As I will argue, genetic trait selections that result in "intentional diminishment" violate the child's right to an open future. So Robertson's "tangible harm" standard goes too far in sanctioning parental genetic trait selections as ethically acceptable.

d. Many, But Not All, Enhancements Permitted

Jonathan Glover contends that "it is objectionable for parents to choose genes with a view to impairing or eliminating abilities" but "it is acceptable ... to increase children's abilities, and to opt for them to have one set of desires over another."[65] Under Glover's view, parents have wide authority to select among genetic traits for their children (say musical ability instead of athletic ability), just as they have wide authority to select their children's post-natal training activities (say music lessons instead of sports camps). Glover's objection to genetic trait selections that impair or eliminate the child's abilities is substantially the same as the objection I will argue for, that parental genetic trait selections that restrict the child's range of open futures are ethically unacceptable. But, for reasons I will discuss in the next chapter, I disagree with Glover's view that parental autonomy extends to allowing parents to select among genetic traits for their children.

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[65] Jonathan Glover, *What Sort of People Should There Be?* (Middlesex, England: Penguin Books Ltd., 1984), 158.

e. Only Non-Circular Enhancements Permitted

James Hudson argues that using genetic trait selection in order to adapt to social conditions would create vicious circularity, since the presence of certain genetic traits influence social conditions.[66] For example, to the extent that being 6'0" tall is an advantage over being 5'6" tall, then using genetic trait selection to make children taller would be circular because even if some parents made their 5'6" children six inches taller, other parents would make their 6'0" children six inches taller, so the same advantages would be maintained. Because of this circularity, Hudson argues that parents should engage only in non-circular genetic trait selections, such as increasing intelligence and reducing (but not eliminating) pain.[67]

However, Hudson does not explain how increasing intelligence is not circular and so objectionable in the same way. If some parents whose children would have IQ's of 120 were to use genetic trait selection to increase their children's IQ's by 20 points, other parents whose children would have IQ's of 140 would also use genetic trait selection to increase their children's IQ's by 20 points, so the latter children would maintain the advantage over the former children. Nor does Hudson explain why parents should not be permitted to try to give their children an advantage through genetic trait selection, even if other parents act similarly to counter that advantage. Further, under Hudson's distinction, a tall person who sought to have a tall child by selecting a tall reproductive partner would seem to be engaging in ethically unacceptable circular genetic trait

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[66] James Hudson, "What Kinds of People Should We Create?" *Journal of Applied Philosophy* 17: 131-143 (2000), 133.

[67] Hudson 2000, 135-36.

selection. As I have previously discussed, treating mate selection as a form of genetic trait selection raises a host of problems that are best avoided by excluding mate selection as a form of genetic trait selection. For the above reasons, Hudson's proposed standard, that only non-circular genetic trait selections are ethically acceptable, fails.

f. Enhancements That Advantage the Child in All Societies

Sara Goering suggests that parents should make genetic trait selections as though behind a Rawlsian veil of ignorance. She asks "what if we tried to determine what traits we would desire for [our children], and what traits we would prefer for them not to have if we did not know the details of our society …?"[68] This veil of ignorance would "conceal from us the particular biases that our society has for traits that are otherwise not genuinely physically desirable" and would help us "to determine what physical traits would lead to clear advantages or disadvantages in *any* society."[69] Using that veil, Goering contends parents who used genetic trait selection to select hearing capability over deafness would be acting ethically, because deaf persons would be disadvantaged in a majority hearing capable society, but hearing persons would not be disadvantaged in a majority deaf society, so selecting for hearing capability would be an advantage in both societies. By contrast, parents who used genetic trait selection to select greater height

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[68] Sara Goering,"Gene Therapies and the Pursuit of a Better Human." *Cambridge Quarterly of Healthcare Ethics* 9: 330-341 (2000), 335.

[69] Goering 2000, 335-36 (emphasis in original).

over lesser height would be acting unethically, because tall persons in a majority short society would be as disadvantaged as short persons in a majority tall society.[70]

While Goering's Rawlsian approach is similar to the approach I will argue for in the next chapter, in that they both examine how the genetic trait selection affects the futures the child may have, I suggest it has limitations that my approach does not. Goering contends that those genetic traits that are symmetrical, in that a modification of the trait could be beneficial to the child in one society but detrimental to the child in another society, should not be manipulated.[71] Because height is symmetrical in this way, a parental genetic trait selection to increase height would be ethically unacceptable. But it is not clear whether Goering holds the converse to be true, that all asymmetrical genetic traits, in which the modification of the trait would be beneficial to the child in all societies, should be manipulated. As she notes, Goering's approach is directed toward "bring[ing] us closer to agreement on what traits we should *not* be genetically engineering."[72] It is not as directed toward what asymmetrical traits we should allow to be engineered or toward the extent to which we allow such traits to be engineered. Goering notes, with some trepidation, that intelligence is such an asymmetrical trait and on her view, may be a subject for genetic manipulation. My approach will attempt to address more explicitly those genetic traits that parents can choose to manipulate.

Further, Goering's distinction between ethically unacceptable modifications of symmetrical genetic traits and probably ethically acceptable modifications of

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[70] Goering 2000, 336-37.

[71] Goering 2000, 336.

[72] Goering 2000, 337 (emphasis in original).

asymmetrical genetic traits rests on the idea of a Rawlsian veil of ignorance. It therefore appears to rest on a Rawlsian conception of justice. As I address in more detail later, I question whether justice considerations, including Rawlsian justice, are sufficient to constrain parents in the exercise of their autonomy over parental genetic trait selections. It may be true that in a society where the average adult height is 4'6", a person who was that height would not be disadvantaged but a person who was 6'0" would be disadvantaged. But that is not the society into which today's and tomorrow's parents are bringing their children. I believe that it would be difficult to convince parents, who without parental genetic trait selection would bring a child into this world whose adult height would not exceed 4'6", that they should not use parental genetic trait selection to increase their child's adult height because in some possible society, a 4'6" person would not be disadvantaged. In this society, a 4'6" person would be disadvantaged, and parents would seem to be acting in their child's best interest if they used parental genetic trait selection to eliminate or reduce that disadvantage. Because I question whether justice considerations of the sort proposed by Rawls are sufficient to override parental autonomy regarding their children, I propose an alternative to Goering's symmetricality distinction.

g. Only Improvements Permitted

Finally, some argue that parents, if they use genetic trait selection, must act only to improve their children's lives. Daniel Fenner argues that parental genetic trait selections "must appreciably change the patient's quality of life for the better," "must be explicitly in the best interest of the potential child in question," and "must affect the child in each and every stage of the child's life."[73] Simo Vehmas contends that parents, in so far as possible, must use genetic trait selection in a way "most likely to produce a happy and healthy child."[74]

These distinctions rely explicitly upon on the prospect that we can reach consensus on what constitutes an improved quality of life, which I suggest is a difficult consensus to reach. As I have noted, many people, particularly hearing-capable people, would believe that using genetic trait selection to confer hearing-capability instead of deafness would change the child's quality of life for the better. But as I will discuss in more detail later, some people, particularly those in the Deaf culture, would disagree that being hearing-capable is a better quality life than being deaf. Many people, but not all, would believe that a parental genetic trait selection conferring perfect pitch would improve the child's quality of life. Some might believe that such hearing would decrease the child's quality of life in that they will have to endure listening to imperfect pitch generated by most of us. And while we may be able to set some criteria about what constitutes a "healthy" life, can we do the same about what constitutes a "happy" life? Those features of a life that one person would consider important to a happy life, such as listening to music, to another person might be indifferent. Other features that many people might consider important to a happy life, such as having children, can be features that other people might consider to detract from a happy life.

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[73] David E.W. Fenner, "Negative Eugenics and Ethical Decisions." *Journal of Medical Humanities* 17:17-30 (1996), 25-26. For views on enhancements from a Christian bioethics perspective, see George Khushf, "Thinking Theologically About Reproductive and Genetic Enhancements: The Challenge." *Christian Bioethics* 5: 154-182 (1999), and Mark J. Hanson, "Indulging Anxiety: Human Enhancement from a Protestant Perspective." *Christian Bioethics* 5: 121-138 (1999).

[74] Simo Vehmas, "Is it Wrong to Deliberately Conceive or Give Birth to a Child with Mental Retardation?" *Journal of Medicine and Philosophy* 27: 47-63 (2002), 48.

Philip Kitcher suggests that there are three dimensions to assessing quality of life: (1) developing a conception of what matters, (2) achieving those things that matter most, and (3) achieving a balance between pleasure and pain.[75] In making parental genetic trait selections, Kitcher contends, parents should use the above quality of life criteria, and in particular to give their children the ability to pursue a "life theme" and to exercise autonomy.[76]

While Kitcher's criteria are laudable, they are so broad as to be of little assistance to parents in making genetic trait selections. As I will address in more detail later, in virtually all parental genetic trait selections, parents will believe that they are acting to improve their child's quality of life. In some instances, they may be acting to improve their own quality of life as well, but seldom will they be acting to improve their quality of life by diminishing their child's quality of life. The trait that one set of parents, such as the Alphas, believe would improve their child's quality of life, is the same trait that another set of parents, such as the Betas, believe would diminish their child's quality of life. The converse is also true. Using judgments about quality of life to make distinctions between ethically acceptable and ethically unacceptable parental genetic trait selections, from a perspective outside those of the parents, would require some definable sense of what constitutes quality of life and what does not. Most senses of what constitutes quality in a life are subjective, in that they hinge on beliefs and attitudes of the individual involved. A life without hearing might be of very low quality to those for

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[75] Philip Kitcher, *The Lives to Come: The Genetic Revolution and Human Possibilities*. (New York: Simon and Schuster, Inc., 1997), 289-96.

[76] Philip Kitcher, "Creating Perfect People," in Justine Burley and John Harris, *A Companion to Genethics*. (Oxford: Blackwell Publishers Ltd., 2002), 229-242, 236-37.

whom hearing is important, but be of acceptable quality to others for whom hearing is not as important. In recent years, medical professions have begun to attempt to create non-subjective, or at least inter-subjective measures of quality of life. These measures include means of quantifying pain and of assessing levels of depression. But, as of yet, such measures are not refined sufficiently to allow us to make comparative assessments of qualities of lives with or without a certain parental genetic trait selection.

Without a consensus around the elements of a quality life, which I contend is a difficult consensus to reach, the ethical acceptability of particular genetic trait enhancements would rest on the subjective conception of quality of life that the parents held. And if the ethical assessment of genetic trait enhancement rests on such a subjective conception, then outside examination of the ethically acceptability of the enhancements parents select would be difficult. Because of the subjectivity underlying quality of life assessments, I contend that distinctions between ethically acceptable enhancements and ethically unacceptable enhancements that rest upon such assessments will not provide parents with the guidance they seek regarding parental genetic trait selection. For that reason, I propose an approach that does not rely upon quality of life assessments.

7. Summary

I agree with David Frankford that calling a parental genetic trait selection a genetic enhancement instead of a genetic treatment makes "an ontological statement and a normative conclusion."[77] I have argued above that purported non-normative distinctions between genetic treatment and genetic enhancement, such as those suggested by Boorse and Daniels, fail on a number of grounds. Most notably, they fail because they introduce aspects of normativity in distinguishing health from disease or species-typical function from dysfunction. They also fail because they assume, without sufficient warrant, that the normal, whether measured statistically or assessed theoretically, is normative in the ethical sense.

Since these purported non-normative distinctions between genetic treatment and genetic enhancement turn out to contain normative elements, they cannot alone provide a distinction between ethically acceptable parental genetic trait selections (treatment) and ethically unacceptable parental genetic trait selections (enhancement). Some other normative distinction must be found if there is to be an ethically relevant distinction between genetic treatment and genetic enhancement. Enhancement, per se, cannot be ethically unacceptable, because we often encourage, and sometimes require, that parents engage in post-natal enhancements for their children. So there must be some normative ground on which to separate ethically acceptable genetic trait selections that result in enhancement from ethically unacceptable genetic trait selections that result in enhancement.[78]

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[77] David M. Frankford, "The Treatment/ Enhancement Distinction as an Armament in the Policy Wars" in Parens 1998a, 70-94, 73.

[78] Jackie Leach Scully rejects the idea of creating a dividing line between genetic treatment and genetic enhancement and argues for the use of "reverse ethics" to establish "phase boundaries" between genetic treatment and genetic enhancement to allow for differing viewpoints, such as those discussed in the later section on the disabilities rights critique. Jackie Leach Scully, "Drawing a Line: Situating Moral Boundaries in Genetic Medicine," *Bioethics* 15: 189-204 (2001).

A number of ethicists have proposed such normative grounds. Some of those proposed distinctions between ethically acceptable enhancements and ethically unacceptable enhancements fail to account fully for the range of parental autonomy. For reasons I will elaborate on, some of those proposed distinctions overstate or understate the scope of parental autonomy. Finally, some of the proposed distinctions rest on determinations of the quality of life that the child would enjoy because of the genetic trait selection. In most cases, parents will be acting in ways that they believe will enhance their child's quality of life. For others to assess whether the parents' genetic trait selections are ethical, there must be either a consensus around a subjective conception of the quality of life or some non-subjective standard for quality of life. But reaching such a consensus around something as deeply subjective as what constitutes a quality life is difficult. And finding a non-subjective definition of what genetic traits improve or diminish a child's quality of life is also difficult. Rather than search for such a consensus or such a non-subjective standard for quality of life, in order to support a relevant distinction between ethically acceptable and ethically unacceptable enhancements, I will argue in the next chapter that the ethical acceptability of parental genetic trait selection can be assessed by examining parental duties regarding the rights to an open future that parents hold in trust for their children.

CHAPTER THREE: EXPANDING THE RANGE OF OPEN FUTURES

In the prior chapter, I argued that we should not assess the ethical acceptability of parental genetic trait selections on the grounds of whether the selection will result in a treatment or an enhancement. In this chapter, I will argue that we should assess the ethical acceptability of parental genetic trait selections on the basis of how those selections respect or violate their children's rights to a range of open futures, rights that the parents hold in trust for their children.[79] In particular, I will argue that if parents engage in genetic trait selection, in addition to not restricting the range of open futures for their children, the selection must expand the range of open futures for their children.

1. Parental Duty

Do rights to procreative and parental autonomy include a parental right to engage in any trait selection the parent desires? Most commentators have argued that they do not. With parental rights to autonomy come parental duties. Some have cast these duties as duties the parents owe to the future child regarding the future child's quality of life. Cynthia Cohen argues that parents have a duty not to use genetic trait selection that would cause "substantial harm" to the resultant child.[80] She defines substantial harm not as a life not worth living, but as "devastating or serious deficits."[81] She notes the

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[79] Not all these open futures are those that the children may have upon reaching adulthood. Some of the open futures are those that children can exercise, or take advantage of, during childhood. For example, a parental genetic trait selection that makes a child's height more like the heights of her contemporaries may open futures for her during childhood, in that it may make it easier for her to interact with her contemporaries.

[80] Cynthia Cohen, "'Give Me Children or I Shall Die!': New Reproductive Technologies and Harm to Children" The *Hastings Center Report* 26: 19-27 (March/April 1996), 22.

[81] Cohen 1996, 22.

difficulties in establishing what constitute "devastating or serious deficits" and contends that what constitutes serious deficits may be culturally influenced, depending on a given culture's ability to ameliorate that deficit.[82] Similarly, Laura Purdy argues that parents have a duty, in some cases, to avoid knowingly creating children with "disease or special limitation."[83] And Ronald Green contends:

> Parents have a *prima facie* obligation not to bring a child into being deliberately or negligently with a health status likely to result in significantly greater disability or suffering, or significantly reduced life options relative to the other children with whom he/she will grow up.[84]

As Cohen, Purdy and Green all recognize, and deal with in different ways, if we impose a duty upon parents not to use genetic trait selection that will result in defects or disabilities for the resultant child, we must address the question of what it means to "harm" the resultant child. In post-natal actions, if a parent causes his or her child to have a defect or a disability, we do not question that the parent harmed his or her child. The child is in a diminished state because of the parent's act. But in pre-natal actions, we cannot determine with certainty whether, after the child is born, the child is in a diminished state because of the parent's act. One possibility is that without the parent's pre-natal act, that particular child would never have been born, and so the pre-natal act

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[82] Cohen 1996, 23.

[83] Laura M. Purdy, *Reproducing Persons: Issues in Feminist Bioethics* (Ithaca, New York: Cornell University Press, 1996), 59-60.

[84] Ronald M. Green, "Parental Autonomy and the Obligation Not to Harm One's Child Genetically" *Journal of Law, Medicine & Ethics* 25: 5-15 (1997), 10. In a comment on Green's article, Ellen Clayton contends that Green's *prima facie* obligation suggests that persons with disabilities, whose disabilities may be genetically transmitted, should not procreate at all. Ellen Wright Clayton, "Legal and Ethical Commentary: The Dangers of Reading *Duty* Too Broadly" *Journal of Law, Medicine & Ethics* 25: 19-21 (1997), 20.

could not have "harmed" the child. This complication, known as the "Non-Identity Problem," is addressed next.

2. The Non-Identity Problem

Issues of identity arise in assessing who, if anyone, is affected or harmed by parental genetic trait selection. Derek Parfit has raised a difficult problem, which he calls the "Non-Identity Problem," in finding a ground for our common-sense assessments of whether a parent's actions harm his or her child.

Parfit posits the following scenario:

> There are two rare conditions, J and K, which cannot be detected without special tests. If a pregnant woman has Condition J, this will cause the child to have a certain handicap. A simple treatment would prevent this effect. If a pregnant woman has Condition K when she conceives a child, this will cause this child to have the same particular handicap. Condition K cannot be treated, but always disappears within two months.[85]

To this scenario, Dan Brock adds what I will call Condition L, wherein if a child is born with this same handicap, the handicap can be eliminated by having the child undergo a simple treatment soon after birth.[86]

Let us say that: (1) the woman with Condition J refuses to undergo the treatment, and so bears a mildly retarded child; (2) the woman with Condition K refuses to delay her pregnancy for two months, and so bears a mildly retarded child; and (3) the parents of the child born with Condition L decline to have the child undergo treatment, so the child is mildly retarded. The common sense of most people, including Parfit and Brock, is that

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[85] Derek Parfit, *Reasons and Persons* (Oxford: Oxford University Press, 1984), 367.

[86] Dan W Brock, "The Non-Identity Problem and Genetic Harms - The Case of Wrongful Handicaps" *Bioethics* 9: 269-276 (1995), 270.

the parents in all three situations have acted equally wrongly. Parfit calls our common sense that the women with Conditions J and K have acted equally wrongly, the "No-Difference View."[87] Brock contends that the No-Difference View extends to the parents of the child born with Condition L.

But making clear why there is no difference in the wrongfulness of the parents' actions raises a perplexing problem for one of the parents. Whether or not the woman with Condition J undergoes the treatment, the child she bears will have the same genetic identity,[88] in that the child will have been conceived of the same sperm and the same ovum. The child with Condition L will continue to have the same genetic identity whether or not her parents have her undergo the treatment for the handicap. Parfit calls these situations "Same People Choices," in that the same person is affected by the parental decisions.[89]

The case of the woman with Condition K is different. If she waits two months, for the condition to vanish, and then conceives, the child she bears will not be born with the handicap of mild retardation. But that child would not be the same as the child she would bear if she conceives while with Condition K.[90] The child she conceives two months later would be conceived of a different sperm and a different ovum, and on Parfit's view of personal identity, would be a different child from the child conceived two months earlier. Parfit calls such situations "Same Number Choices," in that the same

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[87] Parfit 1984, 369.

[88] Assuming that Condition J is not identity-affecting, as discussed in chapter 4, section 5.

[89] Parfit 1984, 356.

[90] Assuming the woman with Condition K is not using *in vitro* fertilization using the same sperm and ovum that she was planning to use two months prior.

number of children is affected by the parental decisions, but the children are not the same people.[91]

So if we say the parents in all three cases have harmed the child born with mild retardation, what exactly are we saying? The case of the child born with Condition L is clearest. If the parents had had the child undergo the treatment, the child would not have mild retardation. So by not having the child undergo the treatment, they have harmed the child because they could have prevented the mild retardation. The case of the woman with Condition J is also clear. If she had undergone the treatment while pregnant, her child would not have mild retardation. So by not undergoing the treatment, she has harmed her child because she could have prevented the mild retardation.

But what of the woman with Condition K? If we say that she harms her child by conceiving now, rather than two months from now, we may be saying that the child is worse off than if she had never been born. Recall that in this case, the child conceived now cannot be the same person as a child conceived two months from now, in that he or she would be conceived of different sperm and different ova. So a child who would be conceived now has only two possible outcomes: existence with mild retardation (if the woman decides to conceive) or non-existence (if the woman decides not to conceive). A child conceived now does not have the possible outcome of existence without mild retardation. We cannot measure harm to the child as the difference between having mild retardation and not having mild retardation. We can only measure harm to the child as

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[91] Parfit 1984, 357.

the difference between having mild retardation and not being born at all. Parfit calls this the "Non-Identity Problem."[92]

There may be instances in which we can say that it would have been better for a child not to have been born, and so bearing the child would harm the child. But those instances are few. Joel Feinberg contends that for a condition to be worse than non-existence, such that we could say a child born with that condition would be harmed, the child's basic interests, including "possession of those unimpaired faculties that are essential to the existence and advancement of any ulterior interests," must be doomed to "total defeat."[93] Walter Glannon opines that such a condition "would involve so much disability, pain and suffering as to make life not worth living on the whole."[94] Glannon suggests that severe early-onset disorders, such as Tay-Sachs, Hurler syndrome, Lesch-Nyhan syndrome, Canavan's disease and Duchenne type muscular dystrophy, would meet this standard for "a life not worth living on the whole."[95] But he contends that severe late-onset disorders, such as Huntington's disease, and moderate early-onset disorders, such as Down syndrome, would not meet this standard.[96]

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[92] Parfit 1984, 359. The Non-Identity Problem arises often in discussions of "wrongful life" legal actions, in which children contend that but for the negligence of prenatal medical providers, they would not have been born with certain avoidable conditions. But implicit in wrongful life actions is the reality that but for the negligence of the provider, the children would not have been born at all, because had the providers acted non-negligently, the parents would not have had the children or would have terminated the pregnancies that resulted in their births. For more on wrongful life actions, see Nancy A.S. Jecker, *Obligations to Future Generations: A Critical Study of Teleological and Deontological Moral Theories* (unpublished Ph.D. dissertation, University of Washington, 1986), 127-45, and Eric B. Schmidt, "Public Policy over Metaphysics: Wrongful Birth and Wrongful Life in *Harbeson v. Parke-Davis, Inc.*," 8 University of Puget Sound Law Review 511-36 (1985).

[93] Joel Feinberg, *Harm to Others* (New York: Oxford University Press, 1984), 98-99.

[94] Walter Glannon, "Genes, Embryos and Future People" *Bioethics* 12: 187-211 (1998), 193-94.

[95] Glannon 1998, 198-99.

[96] Glannon 1998, 202-03.

These severe conditions may not implicate the Non-Identity Problem, but neither do they raise significant ethical disputes about parental genetic trait selections to avoid such conditions.[97] And some parental genetic trait selection methods do not implicate the Non-Identity Problem because they involve Same People Choices. Direct pre-implantation genetic trait selection would be a "same person" choice, assuming the same embryo would be implanted with or without the intervention. Direct post-implantation genetic trait selection would also be a "same person" choice, assuming the pregnancy would be allowed to continue with or without the intervention.

But most of the conditions and traits that parents would wish to select for or against, and most of the methods that could accomplish those selections, do implicate the Non-Identity Problem. Indirect pre-conception genetic trait selection, direct pre-conception genetic trait selection and indirect pre-implantation genetic trait selection are Same Number Choices, in that a child will be created, but the child created will not have the same genetic identity as another child that could have been created but was not. So to say that the Betas harmed their child by using pre-conception genetic trait selection or indirect pre-implantation genetic trait selection to ensure that their child was born with genetic deafness would require us to say that it would be better for that child not to have been born than to have been born with genetic deafness. While deafness is a serious, and often undesired, condition, few people would say that life as a deaf person is a life not worth living. Similarly, to say that the Epsilons harmed their child by using pre-conception genetic trait selection or indirect pre-implantation genetic trait selection to

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[97] I dismiss any parental genetic trait selection to select for such conditions as irrational, and even pathological.

ensure that their child would be 6'10" tall rather than 5'10" tall would require us to say that it would be better for that person not to have been born than to become 6'10" tall. While the parental genetic trait selection of that height may thwart some possible futures for that person, few people would say that life as a 6'10" tall person is a life not worth living. So if we are to say that the actions of the Betas or the Epsilons are wrongful, because of the Non-Identity Problem we will need a measure of wrongfulness that does not rest on the wrong of harming that particular child through their genetic trait selections.

Parfit suggests that because of the Non-Identity Problem, a theory of the wrongfulness of the woman's action when she conceives while having Condition K, rather than waiting two months for the condition to vanish, cannot rest on a "person-affecting" principle, such as "it is bad if people are affected for the worse."[98] He proposes a Theory Q, a "non-person-affecting" principle under which "if in either of two outcomes the same number of people would come to live, it would be bad if those who live are worse off, or have a lower quality of life, than those who would have lived."[99]

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[98] Parfit 1984, 369-70.

[99] Parfit 1984, 369. Parfit proceeds to search for a Theory X that would cover "Different Number Choices" and would imply Theory Q that covers "Same Number Choices." Parfit has not developed such a Theory X, and some suggest that such a theory is not possible. For one attempt to develop such a Theory X, see Philip G. Peters, Jr., "Harming Future Persons: Obligations to the Children of Reproductive Technology," *Southern California Interdisciplinary Law Journal* 8: 375-400 (1999), 392-95. I will not enter into this vigorously debated issue.

Brock notes that "non-person-affecting" principles like Theory Q[100] apply to Same Number Choices but not to Same Person Choices. He proposes a broader principle, which he calls Principle N': "It is morally good to act in a way that results in less suffering and less limited opportunity in the world."[101] The woman who conceives while having Condition K would violate Principle N' by not waiting two months for the condition to abate before conceiving because by conceiving a child with mild retardation, her actions have resulted in more suffering, and therefore more limited opportunity, in the world.[102]

But as Brock recognizes, this solution runs contrary to the No-Difference View, in which we consider the woman with Condition K, who declines to wait two months to conceive, to have acted wrongly *in the same way* as the woman with Condition J, who declines to undergo treatment, and the parents of the child with Condition L, who decline to have their child undergo treatment.[103] In the latter cases, the wrongfulness of the parents' inactions rests on the resultant harm to the child. But the wrongfulness of the actions of the woman with Condition K cannot rest on harm to the child. That child cannot be harmed by being born with mild retardation because the alternative, against

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[100] Brock discusses a different "non-person-affecting" principle, which he calls Principle N: "Individuals are morally required not to let any possible child or other dependent person for whose welfare they are responsible experience serious suffering or limited opportunity if they can act so that, without imposing substantial burdens or costs on themselves or others, any alternative possible child or other dependent person for whose welfare they would be responsible will not experience serious suffering or limited opportunity." Brock 1995, 273.

[101] Brock 1995, 273-74.

[102] Brock assumes, and I agree, that an action that increases suffering limits future opportunities. Therefore, a parental genetic trait selection that increases the child's suffering necessarily constricts the child's range of open futures and is ethically unacceptable on that ground.

[103] One possible means of dealing with the No-Difference View would be to amend it to say that the parents may not be acting wrongly in same way, but they are acting equally wrongly in different ways. But the discussions of the No-Difference View seem to insist on the interpretation that the parents are acting wrongly in exactly the same way. I will not venture further into this arena.

which the harm would be measured, would be not to have been born. If we are to say that the woman with Condition K acted wrongly, based on Principle N', we must say she acted wrongly even though she did not harm any particular child that she bore or might have borne while suffering from Condition K. So using Principle N' to solve the Non-Identity Problem creates a conflict with, or at least a challenge to, the No-Difference View, to which many people subscribe.

Rather than attempting to resolve the issues between "non-person-affecting" principles like Principle N' and the No-Difference View as solutions to the Non-Identity Problem, I suggest that we consider doctrines of parents' responsibility toward their children when using genetic trait selection. Under such a doctrine of parental responsibility, we need not be as concerned about whether this or that particular child is harmed by the parents' action, and so can avoid much of the difficulty arising from the Non-Identity Problem. We can look instead to whether the parents have acted responsibly in creating certain states of affairs in which children with certain genetic traits are born.

3. Parental Responsibility

Bonnie Steinbock proposes one such means of addressing parental trait selection without needing to resolve the Non-Identity Problem. Rather than focusing on whether the parents harm a child by causing it to exist with defects or disabilities, she proposes a "principle of parental responsibility."[104] Under this principle, parents must be concerned not only with their own interests in having children, but also concerned with the welfare of the children they will have. She contends that under this principle of parental responsibility, it is wrong for parents to bring children into the world with "the deck stacked against them."[105] Thus, she argues that it can be wrong for parents to have children who will have "bad" lives, even when those children have not been wronged, in the sense that they have been harmed by being born.[106] She quotes Mary Anne Warren to support her point:

> Having a child under conditions which should enable one to predict that it will be very unhappy is morally objectionable, not because it violates the rights of a presently existing potential person, but it results in the frustration of the interests of an actual person in the future.[107]

Read literally, Steinbock's principle of parental responsibility is too broad to be useful. She contends that parents act wrongly if their children are born with the deck stacked against them. But many parents have children against whom the deck may be said to be stacked. Children born to poor and uninsured parents may have the deck stacked against them through inadequate access to medical and educational interventions. Within specific cultures, children born with a non-dominant skin color may have the deck stacked against them through discrimination they may suffer. Children born to parents with low IQ's may have the deck stacked against them through inadequate parental

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[104] Bonnie Steinbock, *Life Before Birth: The Moral and Legal Status of Embryos and Fetuses* (New York: Oxford University Press, 1992), 73-74.

[105] Steinbock 1992, 74.

[106] Steinbock 1992, 75.

[107] Steinbock 1992, 74, quoting Mary Anne Warren, "Do Potential People Have Moral Rights?" in R.I. Sikora and Brian Berry, eds., *Obligations to Future Generations* (Philadelphia, Pa.: Temple University Press, 1978), 25.

educational support. But few people would say that parents in these situations act wrongly if they have children. So, there must be more than merely having children who may have the deck stacked against them to make the actions of those parents violations of a useful principle of parental responsibility.

Similarly, Steinbock's reliance on Warren imputes imprecision to her principle of parental responsibility. Warren contends that if parents can predict that the child will be very unhappy, parents act in a morally objectionable way by having that child. But how unhappy must the child be, and for how long, to make the parents' actions morally objectionable? Parents can predict with a high degree of certainty that their children will be unhappy at various times in their lives. During puberty, for example, those children may be very unhappy indeed. But few people would say that parents act wrongly by having children when they can predict that those children will be very unhappy at times. For Warren's contention to help support Steinbock's principle of parental responsibility, either the severity or the duration of the unhappiness that the parents can predict must be determined.

Steinbock recognizes that her principle of parental responsibility requires us to assess what lives are sufficiently "bad" that parents violate their moral obligation if they have children who will have those lives. She notes that "judgments about the value of life are inescapably subjective" and that people may differ as to whether parents who have the Huntington's disease gene or are HIV-positive violate the principle of parental responsibility if they have children.[108] She suggests that parents violate the principle of parental responsibility if they have children whose lives they have reason to believe will be "terrible."[109] She acknowledges that the principle of parental responsibility does not provide a formula for determining whether a life is sufficiently terrible that the parents should not have the child:

> Prospective parents will have to base their decision on such factors as the risk of transmission, the nature and seriousness of the disease, the availability of ameliorative therapies, the possibility of a cure, and their ability to provide the child with a good life, despite the handicap. ... Reasonable people can differ on what a decent chance at a happy life is, and what risks are worth taking.[110]

Steinbock's principle of parental responsibility provides a theoretical framework for assessing whether parents have acted wrongly in their parental genetic trait selection. But on what is that principle based? Steinbock says "we should be concerned with the happiness or unhappiness of beings who have interests."[111] But why should I be concerned about whether future beings are happy or unhappy? Ronald Dworkin suggests one possible reason. He suggests that our concern for future generations "is not concern for the rights or interests of specific people."[112] He contends that our concern for future generations is "our instinctive sense that human flourishing as well as human survival is

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[108] Bonnie Steinbock and Ron McClamrock. "When is Birth Unfair to the Child?" *The Hastings Center Report* 24: 15-22 (November/December 1994), 20-21. Each child of a person who has Huntington's disease, a progressive, fatal, untreatable illness, has a 50 percent chance of developing Huntington's disease. The outlook for children of HIV-positive parents was decidedly more grim in 1994, when Steinbock wrote this article, than at present.

[109] Steinbock and McClamrock 1994, 21.

[110] Steinbock and McClamrock 1994, 22.

[111] Steinbock 1992, 74.

[112] Ronald Dworkin, *Life's Dominion*. (New York: Vintage Books, 1994), 77.

of sacred importance."[113] If we view Steinbock's principle of parental responsibility as reflecting such an instinctive sense of the importance of human flourishing, then we can more easily apply that principle to people not yet born and people whom we will never know.[114]

As I have argued above, Steinbock's principle of parental responsibility provides a theoretical framework for assessing whether parents act wrongly in the genetic trait selections they make. But depending on how one reads the principle, it is either too broad or too limited to be applied meaningfully to parental genetic trait selection. If the principle of parental responsibility makes it wrongful for parents to have children against whom the deck may be stacked or who may be very unhappy at times in the future, then the principle is too broad to be useful, in that many children are born with the deck stacked against them and many children will be very unhappy at times. Saying that the parents of those children have acted wrongly would garner little support. It would also suggest that parents have an obligation to use parental genetic trait selection to avoid having such children, an obligation I will argue against later. And if the principle applies only to parents whose children's lives would be terrible if they were born, as Steinbock later suggests, then the principle is too limited to be useful in assessing parental genetic trait selections. Few, if any, parents would make genetic trait selections that would make their children's lives terrible. So, under either reading, Steinbock's principle of parental

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[113] Dworkin 1994, 78.

[114] Maureen Junker-Kenny suggests another basis upon which we can base our concerns about the happiness of those not yet born. She argues that the potential freedom to become a moral subject is a normative ground for acting with dignity toward those who have not yet become moral subjects. Maureen Junker-Kenny, "Embryos *in Vitro*, Personhood, and Rights," in Maureen Junker-Kenny ed., *Designing Life? Genetics, Procreation and Ethics* (Aldershot, England: Ashgate Publishing Ltd., 1999), 130-158, 142-43.

responsibility, without elaboration, will not help in assessing whether parental genetic trait selections are ethically acceptable. As an alternative to Steinbock's principle, I turn to the child's right to an open future, as first proposed by Feinberg.

4. A Child's Right to an Open Future

If, under Steinbock's principle of parental responsibility, parents can act wrongly in making parental trait selections without harming the child, then how do we assess whether, and how, the parents acted wrongly? Joel Feinberg proposes recognition of a child's "right to an open future."[115] He distinguishes between: (1) "A-rights" belonging only to adults, such as full autonomy; (2) "C-rights" belonging primarily to children, such as being cared for by others; (3) "A-C rights" belonging to both adults and children, such as not being mistreated directly by others; and (4) "C-rights in trust" belonging to children for them to be able to exercise when they are adults.[116] He contends that adults do not have the right to act in such ways that "when the child is an autonomous adult, certain key options will already be closed to him."[117] Thus, he proposes that a child has a right "while he is still a child … to have these future options kept open until he is a fully formed self-determining adult capable of deciding among them."[118]

Feinberg proposed the recognition of a child's right to an open future in 1980, long before the discussion of genetic trait selection began. He examined the right to an

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[115] Joel Feinberg, "The Child's Right to an Open Future," in William Aiken and Hugh LaFollette, eds., *Whose Child? Children's Rights, Parental Authority, and State Power* (Totowa, New Jersey: Rowman and Littlefield Publishers, Inc., 1980), 124-153.

[116] Feinberg 1980, 124-26.

[117] Feinberg 1980, 126.

[118] Feinberg 1980, 126.

open future in the context of conflicts between a child's "C-rights in trust," regarding her growth and development, and the parents' "A-rights" to control both their general style of life and their upbringing of their child. He focused on conflicts between a child's right to an open future and the parents' rights to practice their religion freely.

One such conflict arose in Wisconsin, between a state law requiring that all children attend school until the age of sixteen and the religious practices of Amish parents, who refused to send their children to school after the eighth grade (generally the age of fourteen). This conflict eventually reached the United States Supreme Court in the case of *Wisconsin v. Yoder.*[119] A majority of the Court held that the Amish parents' interests in their own religious practices, and in guiding their children's religious future, outweighed the children's interests in attaining the additional opportunities that two more years of education would confer. Chief Justice Burger described the conflict as one between the parents' rights to practice their faith and the state's duty, as *parens patriae*, to provide children with the benefits of a secondary education. He conceived the state's concern as follows:

> [The state's argument] appears to rest on the potential that exemption of Amish parents from the requirements of the compulsory education law might allow some parents to act contrary to the best interests of their children by foreclosing their opportunity to make an intelligent choice between the Amish way of life and that of the outside world.[120]

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[119] 406 U.S. 205 (1972).

[120] 406 U.S. at 232.

Having so framed the issue, that additional education would confer upon the child the opportunity to choose "between the Amish way of life and that of the outside world," the Chief Justice's analysis is not surprising:

> [I]f the State is empowered, as *parens patriae*, to "save" a child from himself or his Amish parents by requiring an additional two years of compulsory formal high school education, the State will in large measure influence if not determine, the religious future of the child. … [T]his case involves the fundamental interest of parents, as contrasted with that of the State, to guide the religious future and education of their children.[121]

Thus, the Chief Justice concluded that the parents' right to guide their children's introduction into their religion outweighs the state's interest in providing those children with additional education, even though, in the opinion of the state, the parents' exercise of that right might not be in those children's best interests because it might diminish their opportunities outside the religion.

Feinberg contends that even though the difference between leaving school at fourteen and leaving school at sixteen may be trivial, "from the philosophical standpoint … even the sixteen year old educable youth whose parents legally withdraw him from school has suffered an invasion of his rights-in-trust."[122] He recognizes that parents have the right to autonomy in the way they raise their children, and that this right of parental autonomy should be constrained "only with the greatest reluctance and only for the most compelling reasons."[123] He suggests one such constraint is upon parents from making "certain crucial and irrevocable decisions determining the course of [the child's] life are

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[121] 406 U.S. at 232.
[122] Feinberg 1980, 136-37.
[123] Feinberg 1980, 139.

made by anyone else before he has the *capacity of self-determination* himself."[124] He contends that parents must hold in trust for their children the opportunity for self-determination and with it, the good of self-fulfillment. He contends that parents can foster a child's self-fulfillment most by affording the child self-determination, in ever-increasing degree, during his life. Thus, he contends parents should give their child "opportunities to develop his strongest talents, for instance, after having enjoyed opportunities to discover by various experiments just what those talents are."[125] At the very least, parents should not "try to turn [their child] upstream and make him struggle against his own deepest currents."[126] So, Feinberg concludes parents have the obligation to act in ways in which "the child's future is left open as much as possible for his own finished self to determine."[127]

As noted above, Feinberg's article long predated the issue of genetic trait selection, and does not address it. His conception of the child's right to an open future relies upon giving the child the opportunity to take advantage of those talents that her genetic traits confer. In observing the child's right to an open future, Feinberg contends that parents must "respect that initial bias from heredity" in promoting the child's self-determination and eventual self-fulfillment.[128] But when parents engage in genetic trait selection, the parents modify that heredity by changing the child's genetic structure. So if parents are changing the child's heredity, they are no longer respecting that "initial bias

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[124] Feinberg 1980, 143.
[125] Feinberg 1980, 150.
[126] Feinberg 1980, 151.
[127] Feinberg 1980, 151.
[128] Feinberg 1980, 149.

from heredity." They are no longer simply fostering the open futures that the genetic lottery has allowed their child. They are influencing the open futures from which their child can determine herself and, with luck, fulfill herself. Some parental genetic trait selections may restrict the open futures from which the child can determine herself. Other parental genetic trait selections may expand the open futures from which the child can determine herself. And yet other parental trait selections may restrict some open futures while concomitantly expanding other open futures from which the child can determine herself. Feinberg's idea of a child's right to an open future, taken alone, will not provide us with a basis for making an ethical assessment of the genetic trait selection that the parents make. But I am not alone in thinking that it is a starting point.

Dena Davis builds upon Feinberg's "right to an open future" in assessing genetic trait selections.[129] She extends the parents' obligation to respect the child's right to an open future from parental actions taken after the child's creation to those taken before the child's creation. Thus, in the context of Deaf parents selecting for deafness, such as the Betas, Davis contends that "a decision made before a child is born that confines her forever to a narrow group of people and a limited choice of careers … violates the child's right to an open future."[130] She proposes a normative rule that "parents ought not deliberately to substantively constrain the ability of their children to make a wide variety of life choices when they become adults."[131] While Davis believes a genetic trait

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[129] Davis 2001.
[130] Davis 2001, 65.
[131] Davis 2001, 66.

selection for deafness would violate this rule, she is less sure whether genetic trait selection for other conditions, including extreme short stature, would violate this rule.

Davis's normative rule contains two elements: deliberate action and substantive constraint. She includes the element of deliberate action to allow parents to take their chances in the genetic lottery when having children. Without an element of deliberate action, an observer might contend that those deaf parents who have a considerable chance of having a deaf child should never have children because they run the risk of imposing a substantive constraint on any child who happens to be born deaf. That is a result that neither Davis nor I would wish to have a normative rule reach. Thus, for a parental genetic trait selection to be ethically objectionable under Davis's approach to the child's right to an open future, the parents must act deliberately in ways beyond subjecting themselves, and their children, to the genetic lottery.

By substantive constraint, Davis means more than parents electing to have children when they are in situations that are suboptimal. As mentioned earlier, an observer might contend that poor and illiterate parents, or parents of a non-dominant skin color, should not have children because those children run the risk of being poor and illiterate as well or because those children run the risk of having lives that are "more difficult than the norm."[132] Again, that is a result that neither Davis nor I would wish to have a normative rule reach.

So Davis argues that a parental genetic trait selection that "confines [the child] forever to a narrow group of people and a limited choice of careers" violates the child's

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[132] Davis 2001, 66.

right to an open future.[133] She also argues that for a parental genetic trait selection to be considered a substantive constraint, the selection must result in foreclosure of "momentous pieces of [the child's] adult life."[134] Unfortunately, she does not describe or define what pieces of an adult life are "momentous." I suggest that she means those events and activities that are of such moment and significance that most people, upon learning that they had been subjected to a genetic trait selection that precluded those activities, would regret their parents' action in making that genetic trait selection. Thus, for a parental genetic trait selection to be ethically objectionable under Davis's approach to the child's right to an open future, the genetic trait selection must limit the child's significant cultural, social and career choices in ways beyond the limits imposed by the circumstances in which the child is born and raised.

I agree with Davis's requirement of deliberate action by the parents. And her requirement of substantive constraint addresses genetic trait selections like those of the Betas, in which the parental selection of deafness for their child can be seen as a limitation on their child's significant cultural, social and career choices. But her requirement of substantive constraint does not address genetic trait selections like those of Epsilons, in which the parental selection of atypical height for their child influences their child's significant cultural, social and career choices, but does not confine them to a narrow group of people or a limited choice of careers. Nor does her requirement of substantive constraint address genetic trait selections like those of the Lambdas, in which the parental selection of 20/10 visual acuity and perfect pitch may expand, rather than

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[133] Davis 2001, 65.
[134] Davis 2001, 66.

limit, their child's significant cultural, social and career choices. As I discuss later, I contend that situations like those of the Epsilons and the Lambdas are different ethically. Thus, I contend that assessing a parental genetic trait selection requires more than Davis's requirement of substantive constraint.

Brock also builds upon Feinberg's right to an open future. He contends that in making substituted judgments on behalf of a child, adults must protect the child's opportunity interests, including the right to an open future.[135] More recently, in the context of genetic interventions, Brock contends that:

> Recognizing the right to an open future is compatible with according substantial discretion to parents to use genetic interventions, just as they would other environmental interventions, to attempt to give their children what they might consider to be the best life possible. What is required is that those interventions do not so narrow children's range of opportunities as to violate their right to an open future.[136]

Brock notes that recognition of a child's right to an open future can conflict with parental procreative autonomy and parental autonomy, and that the scope of the child's right must be balanced against the parents' rights to autonomy. But he contends the recognition of the child's right does not create a systematic bar against parents using genetic trait selection to give their child a better life.

Brock also adds an important second foundation for the child's right to an open future. In addition to protecting the child's right to adult autonomy, as Feinberg suggests,

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[135] Allen E. Buchanan and Dan W. Brock, *Deciding for Others: The Ethics of Surrogate Decision Making* (Cambridge, England: Cambridge University Press, 1989), 247-48.

[136] Allen E. Buchanan, Dan W. Brock, Norman Daniels and Daniel Wikler. *From Chance to Choice: Genetics and Justice* (Cambridge, England: Cambridge University Press, 2000) (*From Chance to Choice*), 171. Dan Brock and Normal Daniels share principal responsibility for this portion of *From Chance to Choice*. *From Chance to Choice*, xiii.

Brock contends that a parental obligation to respect the child's right to an open future "hedges against various kinds of uncertainty and error."[137] Brock elaborates:

> Autonomy aside, the best interests of a child may not coincide with parental judgments about what is best. Parents may erroneously project what is good for themselves onto their children. They may tie their judgments about what is good to what is currently socially valued, not what is of enduring value. Their judgments may be tainted by racism, classism or sexism. The history of the genetics movement makes the risks of error all too apparent. A broader array of capabilities should usually provide individuals with greater adaptive capacities to correct for the errors and mistakes of their parents.[138]

Thus, Brock contends that parents may engage in a genetic trait selection so long as that selection does not narrow the child's range of opportunities in the future. He allows for parental genetic trait selections that might give the child "a better life," but does not address whether this means using genetic trait selection to avoid a deleterious condition in the child or means using genetic trait selection to provide the child with an advantageous condition with which she would not otherwise have been born. I will turn shortly to this issue.

Similarly, David Resnik notes that "there is no sharp distinction between violating a child's right to an open future and being a responsible parent."[139] He suggests that a genetic trait selection that enhanced the child's immune system would not violate the child's right to an open future because it would expand the child's opportunities, but that

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[137] *From Chance to Choice*, 172.

[138] *From Chance to Choice*, 172.

[139] David Resnik, "The Moral Significance of the Therapy-Enhancement Distinction in the Human Genome" Cambridge *Quarterly of Healthcare Ethics* 9: 365-377 (2000), 373.

a genetic trait selection to make the child eight feet tall would violate the child's right to an open future because it would limit the child's opportunities.[140]

In summary, Davis extends the parental obligation to respect a child's right to an open future to include a constraint against parents from making genetic trait selections that constrain the "ability of their children to make a wide variety of life choices when they become adults."[141] Brock extends the parental obligation to respect a child's right to an open future to constrain parents from making genetic trait selections that "narrow children's range of opportunities" and that are "currently socially valued, [but are] not . . . of enduring value."[142] Resnik similarly constrains parents from making genetic trait selections that would limit their child's opportunities.

These normative rules address parental genetic trait selections that constrain the future life choices and opportunities of the child whose genetic traits are selected. But they do not address adequately parental genetic trait selections that do not simply constrain such future life choices and opportunities. Their rules do not provide a means of making ethical assessments of those parental genetic trait selections that may favor certain future life choices and opportunities of the child while disfavoring other future life choices and opportunities. Nor do they provide a means of making ethical assessments of those parental genetic trait selections that may expand the future life choices and opportunities of the child.

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[140] Resnik 2000, 372.
[141] Davis 2001, 66.
[142] *From Chance to Choice*, 171-72.

In what follows, I propose an extension of Davis's, Brock's and Resnik's approaches to provide a means of making ethical assessments of all parental genetic trait selections. I contend that the parental obligation to respect a child's right to an open future does not simply constrain parents from making genetic trait selections that limit or reduce the child's range of open futures. The obligation also constrains parents from making genetic trait selections that favor or make possible some of the child's possible futures but simultaneously disfavor or make impossible a significant number of the child's other possible futures. But the obligation permits parents to make genetic trait selections that expand the child's range of open futures. Before elaborating further, I must pause to discuss what I mean by the term of "range of open futures."

5. On Ranges of Open Futures

Terms like "open futures" and "ranges of open futures" are difficult to make clear. At conception, each person faces an almost infinite variety of futures and so on one reading, each person could have an almost infinite range of open futures. Some futures differ markedly from others, such as whether the person is blind or sighted. Some differ less so from others, such as whether the person is tall or short. And some differ trivially from others, such as whether the person prefers vanilla or chocolate ice cream. But only one of the possible futures is the person's future, in that it will become the person's present and then his or her past.

I propose the following metaphor to explain what I mean by open futures and ranges of open futures. Imagine a map containing all possible significant experiences, including but not limited to educational, vocational, aesthetic and cultural experiences. By "significant experiences," I mean those experiences that have the potential to change the path of a person's future. Thus, the experiences of attending law school or welding school are significant educational experiences, in that they have the potential for changing the person's vocational futures, while the experience of learning the yearly batting averages for Edgar Martinez is not a significant educational experience, because it does not have the potential for changing the person's vocational futures. Similarly, the experience of seeing a Mozart opera is a significant aesthetic experience, in that it has the potential for changing the person's future aesthetic interests and activities, while eating a chocolate ice cream cone is not a significant aesthetic experience, because it does not have the potential for changing the person's future aesthetic activities.

These significant experiences, shown as locations on the map, are in some cases connected by paths or roads. Since the locations on the map are both temporal and spatial, some of the roads run in only one direction. For example, the roads from significant childhood experiences to significant adolescent experience would run in only one direction, since one cannot have adolescent experiences, such as high school, before having childhood experiences, such as elementary school. But many roads are bi-directional, in that the significant experiences can be had in either order. For example, the roads from graduate school to work experiences would run in both directions, since one can go to graduate school before working or go to graduate school after working or even go back and forth.

While this map has every imaginable significant experience as a location, roads do not run between all locations. Some significant experiences can be reached only by traveling down a series of roads having a series of experiences. For example, becoming a physician requires a person to go through the experiences of an undergraduate education and then to go through the experiences of a medical school education. A person cannot go straight to medical school or go straight to taking the physician licensing examination. And on each person's map, some significant experiences cannot be reached because no road leads to those experiences. For example, no map for a man can contain a road leading to the experiences of pregnancy and childbirth.

So imagine that at birth, each child is born with such a map of significant experiences, with roads defining, directly or indirectly, those significant experiences that the child can reach. The map does not dictate what roads the child decides to embark on during his or her life. The roads the child will choose influences the experiences he or she will have and in turn, the experiences influence the later roads chosen. Events that occur during the person's life can eliminate roads from the map. For example, a person who is blinded accidentally could no longer travel down a road that would lead them to the experience of being a photographer. But other events that occur during the person's life can add roads to the map. If a child's vision is improved or restored after birth, then previously non-existent roads to experiences that require acute vision are added to the child's map. For example, a child who was born blind but whose vision was restored could now travel down the road to the experience of being a photographer, even though that road was not present on the child's map at birth.

So to summarize, at birth each person has a different map of possible futures that contains many roads to significant experiences during his or her life. That map is the child's "range of open futures." But that map will not have roads to every possible significant experience. As a result of the genetic lottery, some maps will have more roads on them than others, such that some children will have the possibility of more significant experiences than other children will. So some children will have a wider range of open futures than others will. In the course of a life, a person can travel down any of the roads present on her map, but cannot have any experience or opportunity to which a road does not run on her map. Post-natal events, such as medical or educational interventions, may add roads to her map. Other post-natal events, such as deprivations and traumas, may remove roads from her map. But for the most part, the child and then the adult she becomes may pursue any of those significant experiences to which a road runs on her map.

But in parental genetic trait selection, parents can modify the child's map and so modify the child's range of open futures. They can make selections that add roads to the map, allowing the child to have significant experiences that the child could not otherwise have had. Such added roads on the child's map would expand the child's range of open futures. They can make selections that remove roads from the child's map, eliminating or impairing the child's possibility of having significant experiences that the child could otherwise have had. Such removal of roads from the child's map would constrict the child's range of open futures. Finally, they can make selections that add some roads to the map, allowing the child to have certain significant experiences that the child could not otherwise have had, while simultaneously removing other roads from the child's map, eliminating or impairing the child's possibility of having certain other significant experiences that the child could otherwise have had. While the child can have those additional experiences to which a road runs by virtue of the parental trait selection, she can no longer have one of the experiences that she could have had before the road to it was removed by virtue of the parental trait selection. Thus, the addition and removal of roads shifts the child's range of open futures. The child will have no say in which significant experiences are facilitated or foreclosed.

I will employ this imperfect metaphor in the following argument as to parental responsibility to respect their children's rights to a range of open futures when engaging in parental genetic trait selection. While I frequently use significant vocational experiences as examples of experiences that are facilitated or foreclosed by parental genetic trait selection, I do not mean to limit this approach to vocational opportunities. The approach, I suggest, will work for all experiences. But for good and ill, we in American society view our vocations as among the most significant of our experiences. So, I will use such examples in much of what follows.

6. Respecting a Child's Right to a Range of Open Futures

So how do we assess whether a parental genetic trait selection respects or violates a child's right to a range of open futures? Let us return to our hypothetical parents:

Table 2 - The Parents Redux

Parents	Condition Without Genetic Trait Selection	Condition With Genetic Trait Selection
Alphas	Hereditary Deafness	Hearing Capability
Betas	Hearing Capability	Hereditary Deafness
Gammas	4’6” adult height, low growth hormone levels	5’10” adult height
Deltas	4’6” adult height, normal growth hormone levels	5’10” adult height
Epsilons	5’10” adult height	6’10” adult height
Kappas	20/200 vision and tone deaf	20/20 vision and typical tone sensibility
Lambdas	20/20 vision and typical tone sensibility	20/10 vision and perfect pitch

The Alphas’ parental genetic trait selection of hearing capability instead of deafness would, on balance, add roads to their child’s map. It would allow their child to have many experiences she could not otherwise have had. It would limit their child from having a few experiences, such as becoming fluent in sign language, which she could otherwise have had.[143] But the added possible experiences would significantly outnumber the precluded possible experiences. So the Alphas’ parental genetic trait selection would expand their child’s range of open futures and respect their child’s right to a range of open futures.

In contrast, the Betas’ parental genetic trait selection of deafness instead of hearing capability would, on balance, remove roads from their child’s map. It would

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[143] Many in the Deaf culture deny that hearing persons can be fully fluent in sign language. Oliver Sacks, *Seeing Voices: A Journey Into the World of the Deaf* (Berkeley: University of California Press, 1989), 126-29.

limit their child from having many experiences that he could otherwise have had. It would allow their child to have a few experiences, again such as becoming fluent in sign language, that he could not otherwise have had. But the precluded possible experiences would significantly outnumber the added possible experiences. So the Betas' parental genetic trait selection would constrict his range of open futures and violate their child's right to a range of open futures. Thus, except for those who contend that deafness does not limit a child's possible future experiences, an issue I will explore in more detail later, the Alphas' parental genetic trait selection would be ethically acceptable while the Betas' parental genetic trait selection would not.

As to the Alphas and the Betas, Davis's, Brock's and Resnik's normative rules, under which parents cannot use genetic trait selection to constrain or limit their children's open future, would reach the same ethical assessment as my range of open futures approach. Choosing hearing capability over deafness would result in significant expansion, but little constraint or limitation, of the child's open futures, but choosing deafness over hearing capability would result in significant constraint or limitation, but little expansion, of the child's open futures. The latter would be ethically unacceptable and, by implication, the former would be ethically acceptable. So as to these parents, my approach is not novel. But as to the remaining parents, my "range of open futures" approach provides ethical guidance where Davis's, Brock's and Resnik's rules do not.

The Kappas' parental genetic trait selection of 20/20 visual acuity and typical tone sensibility would, on balance, add roads to that child's map. It would allow their child to have many experiences she could not otherwise have had. It would limit their child from having a few experiences, such as being near-sighted, that she could otherwise have had. But the added possible experiences would significantly outnumber the precluded possible experiences. So the Kappas' parental genetic trait selection would expand their child's range of open futures and respect their child's right to a range of open futures. And the Lambdas' parental genetic trait selection of 20/10 visual acuity and perfect pitch would also, on balance, add roads to that child's map. It would allow their child to have many experiences he could not otherwise have had. It would limit their child from having a few experiences, such as needing to learn how to hear pitches in music, that he could otherwise have had. But the added possible experiences would significantly outnumber the precluded possible experiences. So the Lambdas' parental genetic trait selection would expand their child's range of open futures and respect their child's right to a range of open futures. Thus, under my range of open futures approach, even though the Kappas could be said to be engaged in "treatment" while the Lambdas could be said to be engaged in "enhancement," they both would be acting ethically in making their parental genetic trait selections because they are acting to expand their children's ranges of open futures.

Davis's, Brock's and Resnik's normative rules do not address parental genetic trait selections such as these where significant expansion, but little constraint or limitation, of the child's open futures results from the trait selection, so my approach provides greater ethical guidance than do those normative rules. But neither do their normative rules imply that such parental genetic trait selections would be ethically unacceptable. Thus, I move to the last group of parents, in which my approach shows its greatest difference from their normative rules.

The Gammas' parental genetic trait selection of a child with normal growth hormone levels, who will have an adult height of 5'10", instead of a child with subnormal growth hormone levels, who would have an adult height of 4'6", would, on balance, add roads to that child's map. It would allow their child to have experiences he could not otherwise have had. It would limit their child from having a few experiences, such as experiencing life from the perspective of a short person, that he could otherwise have had. But the added possible experiences would significantly outnumber the precluded possible experiences. So the Gammas' parental genetic trait selection would expand their child's range of open futures and respect their child's right to a range of open futures.

Similarly, the Deltas' parental genetic trait selection of a child who will have an adult height of 5'10" instead of a "normally short" child who would have an adult height of 4'6" would, on balance, add roads to that child's map. It would allow their child to have experiences she could not otherwise have had. It would limit their child from having a few experiences, again such as experiencing life from the perspective of a short person, that she could otherwise have had. But the added possible experiences would significantly outnumber the precluded possible experiences. So the Deltas' parental genetic trait selection would expand their child's range of open futures and respect their child's right to a range of open futures. Thus, even though the Gammas could be said to be engaged in "treatment" while the Deltas could be said to be engaged in "enhancement," they both would be acting ethically in making their genetic trait selections because they are acting to expand their children's ranges of open futures.

But what of the Epsilons' parental genetic trait selection of a child who will have an adult height of 6'10" instead of a child who would have an adult height of 5'10"? Does that selection, on balance, add roads to that child's map and expand that child's possible future experiences? Some experiences are more readily available to those who are 6'10" than to those who are 5'10" tall. Those possibilities arise particularly in the realm of those sports where such height is an advantage. So the Epsilons' selection will add some roads to their child's map. But some experiences are less readily available to those who are 6'10" tall than to those who are 5'10" tall. In some other sports, such as horseracing or gymnastics, such height is a disadvantage. In addition, some vocational options, such as fighter pilot, ballet dancer, or submarine sailor, may be foreclosed to persons of such height. And persons who are 6'10" tall may have more difficulty in fitting into a society, so to speak, where they are considerably taller than most others. So along with adding some roads to their child's map, the Epsilons' selection will also remove other roads from their child's map. Rather than simply increasing or reducing the number of roads on their child's map, they have shifted the experiences and opportunities available to their child by making some previously unreachable experiences possible but simultaneously making some previously reachable experiences impossible or more difficult to reach.

We cannot say that the Epsilons' parental genetic trait selection would, on balance, add roads to that child's map and expand that child's possible future experiences, thus respecting that child's right to a range of open futures. Nor can we say that their parental genetic trait selection would, on balance, remove roads from that child's map and limit that child's possible future experiences, thus violating that child's right to a range of open futures.

Davis's, Brock's and Resnik's normative rules do not help us address the Epsilons' parental genetic trait selection because they address only constraints or limitations of the child's open future. I contend that the Epsilons would not be expanding their child's range of open futures. They would only be shifting the child's range of open futures, facilitating some open futures and interfering with others. As I will describe later, I contend that the Epsilons' would not be acting ethically in making their genetic trait selection because they are not acting to expand their child's range of open futures. They are acting only to shift their child's range of open futures and such a shift in the range of open futures does not respect their child's right regarding having a range of open future.

In this way, the cases of the Epsilons and the Lambdas differ. While they both use genetic trait selection to cause their child to be "above normal," the Lambdas' child's range of open futures is expanded because, by having 20/10 visual acuity and perfect pitch, that child gains opportunities to have some experiences she would not have had with 20/20 visual acuity and typical tone sensibility and is foreclosed from few, if any, experiences that she would have had with 20/20 visual acuity and typical tone sensibility. But the Epsilons' parental genetic trait selection shifts their child's range of open futures, rather than expanding it. The Epsilons' child may add some experiences that she may have by being 6'10" instead of 5'10", but she may be precluded from a significant number of other experiences by being 6'10" instead of 5'10".

Thus, because of situations like the Epsilons, my range of open futures approach holds that the parental obligation to respect a child's right to a range of open futures is an obligation, when using genetic trait selection, only to expand the child's range of open futures and to neither constrict the child's range of open futures nor differentially shift the child's range of open futures.[144] Parental genetic trait selection that constrict or differentially shift the child's range of open futures, rather than expanding the range of open futures, do not satisfy the parental obligation to respect the child's right to a range of open futures, and so are ethically objectionable.

This approach of allowing parental genetic trait selection only when it expands the child's range of open futures avoids the problems noted in Chapter Two regarding the use of the normal/diseased distinction as a means of assessing ethically parental genetic trait selections. The action of the Alphas, in making their child hearing capable, is ethically acceptable not because it changes the child from being diseased to being normal but because it expands the range of the child's open futures. The action of the Betas, in making their child deaf, is ethically unacceptable not because it changes the child from

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[144] Nicholas Agar argues for a similar expansion of a person's capacities, which he call "ecumenical enhancement," through genetic trait selection. Nicholas Agar, "Designing Babies: Morally Permissible Ways to Modify the Human Genome" *Bioethics* 9: 1-15 (1995), 13-14. But Agar argues for the societal creation of a list of "the whole range of morally acceptable goals and aim to provide capacities which better enable a person to pursue them in such a way that does not discriminate between them." Agar 1995, 13. Such a societal checklist of capacities raises significant eugenic concerns, as I address later. By allowing parents, who are in the best position to determine which of their children's capacities should modified through genetic trait selection, to make those selections consistent with their obligation to make only those selections that expand the child's range of open futures, procreational autonomy for the parents is preserved and societal eugenic influence is diminished, as I argue in more detail later.

being normal to being diseased but because it restricts the range of the child's open futures. The actions of the Gammas and the Deltas, in making their children 5'10" instead of 4'6", are both ethically acceptable, even where the Gammas' child would otherwise have a disease and where the Deltas' child would otherwise be "normal," because their actions expand the ranges of their children's open futures. Similarly, the actions of the Kappas and the Lambdas, in improving their children's vision and hearing, are both ethically acceptable, even where the Kappas' child would otherwise have a disease and where the Lambdas' child would otherwise be normal, because their actions expand the ranges of the children's open futures.

This approach also avoids the problems noted in Chapter Two regarding the use of the treatment/enhancement distinction as a means of assessing ethically parental genetic trait selections. The action of the Gammas, in making their child 5'10" instead of 4'6" as a result of growth hormone deficiency, is ethically acceptable not because it treats what would otherwise be a disease but because it expands their child's range of open futures. The action of Deltas, in making their child 5'10" instead of 4'6" even though 4'6" would be the "normal" height for that child, is ethically acceptable, even though some might consider it an enhancement of the child's "normal" height, because their action expands the range of their child's open futures. The action of the Epsilons, in making their child 6'10" instead of 5'10", is ethically unacceptable not because it is an enhancement of the child's "normal" height but because it differentially shifts, but does not expand, their child's range of open futures. The action of the Kappas, in giving their child 20/20 vision and typical hearing, is ethically acceptable not because it treats what would otherwise be a disease but because it expands the range of their child's range of open futures. And the action of the Lambdas, in giving their child 20/10 vision and perfect pitch, is ethically acceptable, even though some might consider it an enhancement of the child's "normal" vision and hearing, because their action expands the range of their child's open futures.

In support of my "range of open futures" approach, I have made three claims that need further defense. First, I have claimed that parental genetic trait selections that differentially shift the range of open futures do not respect the child's right to an open future and are therefore ethically unacceptable. Why are differential shifts in the range of open futures different from expansions of the range of open futures? Second, I have claimed that parental genetic trait selections that expand the child's range of open futures respect the child's right to an open future and are therefore ethically acceptable. Is that always so? Third, I have claimed that my approach is more useful than those of Davis, Brock and Resnik in assessing the ethical acceptability of parental genetic trait selections. How, and why, is my approach more useful? I examine these claims in turn.

7. What is Wrong with Differentially Shifting the Range of Open Futures?

A significant question that will arise regarding my approach is what, exactly, is ethically unacceptable about parents engaging in genetic trait selections that differentially shift the child's range of open futures but do not expand the range of open futures. Take the Epsilons, again, as an example. The Epsilons' child might well desire the futures that being 6'10" would make possible, and might desire those futures more than the ones she would be forgoing by not being 5’10”. And even though she would lose the ability to pursue some futures by being 6’10” instead of 5’10”, there are still a considerable number of desirable futures available within the range of open futures for a 6’10” person. So if there are desirable futures within that range of open futures, why should the Epsilons be considered to have acted unethically if they make the genetic trait selection that leads to that height?

I contend that differential shifting of the range of open futures, such as that proposed by the Epsilons, is ethically unacceptable because it is a form of parental over-determination regarding their children’s futures. A great many parental actions, both pre-natal and post-natal, influence and help determine a child’s future. The quality of pre-natal care, the parents’ approaches to child-raising, the quality of educational experiences and the types of enrichment activities all help determine the child’s future. And as discussed previously, we in American society confer upon parents a good deal of autonomy in those actions. It would be foolish to hold that parental decisions and actions do not, to some extent, determine their children’s futures.

But there are limits we impose upon parental decisions and actions. At the extremes, we punish parents who abuse or neglect their children. And even where parental actions do not result in abuse or neglect, we sometimes consider those actions ethically objectionable. Take, for example, the stereotypical stage mother or hockey father. For reasons primarily personal to the parent, the parent compels the child to engage in activities that the child either dislikes or is ambivalent about. Such parents take parental actions beyond routine levels of compulsion, such as requiring their children to practice the piano or to eat their green beans, to levels of compulsion that interfere with the children's development of their own interests. I suggest that in so doing, parents over-determine their children's futures by imposing the parents' conceptions of the child's future and displacing the child's own development of her future.

I suggest that parents could engage in a similar form of over-determination by making genetic trait selections that differentially shift the child's range of open futures. If the Epsilons want to make their child 6'10" so as to improve her chances of being a professional basketball player, they may be doing so to impose their own conceptions of what kind of future their child would have wanted, upon reaching adulthood and looking back on her parents' choice. They might prove to be right. Just as the stage mother's daughter may turn out to have wanted to be an actor, the Epsilons' child may turn out to have wanted to be a professional basketball player. In that case, the Epsilons' parental genetic trait selection will have been beneficial. But they might also prove to be wrong. Just as the hockey father's son may come to resent his father's insistence that he play hockey in lieu of other activities, the Epsilons' child may come to resent her parents' genetic trait selection because she does never wanted to be a professional basketball player and because her height interferes with other activities she would like to have pursued. In that case, the Epsilons' parental genetic trait selection will have not have been beneficial.

In order to minimize this risk that a genetic trait selection will be made based on the parents' conceptions of the child's desired future, but will instead prove to be futures that the child never wanted, I contend that parents should not be permitted, ethically, to engage in parental genetic trait selections that shift the range of the child's open future, based on the parents' conceptions of the futures they desire for their child. As I discuss later, there is always a risk that a child will come to resent any parental action, whether made for ethically acceptable or ethically unacceptable reasons. Even where a parental genetic trait selection adds many open futures and removes only a few open futures, the child may turn out to want to have pursued one of the futures made unavailable through the genetic trait selection and so may be resentful of his parents' selection. But where a child's range of open futures is expanded, it is more likely that a child will find her desired future is possible within that range of open futures. The amount and effect of parental determination is therefore reduced.

In contrast, where a child's range of open futures is differentially shifted, there is a greater risk that a child will find that her desired future is no longer possible within the range of open futures selected by her parents. Her futures are left more under the control of her parents and her parents' conception of her futures may not coincide with her own. As Glenn McGee has argued, such parental genetic trait selections would commit the sins of "calculativeness," in which parents "overemphasize the importance of planning and systemic choices" in how their children will develop, and the sin of "overbearingness," in which rigid parental expectations could steal the child's right to as much freedom of identity as possible.[145]

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[145] Glenn McGee, *The Perfect Baby: A Pragmatic Approach to Genetics*. (Lanham, Maryland: Rowman and Littlefield Publishers, Inc., 1997), 124-27. McGee identifies three additional sins that parents should avoid in making genetic trait selections: shortsightedness, hasty judgment and pessimism. McGee 1997, 127-32.

I contend that the parents engage in objectionably excessive genetic over-determination if they make such genetic trait selections because of this potential that the parents' selection of futures made more possible and futures made less possible may not coincide with the child's desires in determining her own future. The parental genetic trait selection moves from an expansion of the range of open futures to a differential shift among the range of open futures as the numbers of futures gained and lost become more equivalent. I contend that the parental genetic trait selection becomes an ethically objectionable differential shift among the range of open futures when the number of futures lost becomes substantial and approaches the number of futures gained.

As I have noted, many parental actions determine their children's futures to some extent. At the very least, they change the child's history. And some shape the child's beliefs and attitudes in ways that will affect them throughout their lives. But the scope of parental autonomy allows for most parental actions regarding their children. Even beyond the stage mother or hockey father examples I have proposed, parental autonomy allows parents to take actions that are highly likely to determine, and even over-determine, their children's developments of their own futures. As I noted in the discussion of *Wisconsin v. Yoder*, parental autonomy and freedom of religion protect the parents' rights to deny their children an education after age 14. That restriction on education, and the other restrictions that are part of life in an Amish community, are highly likely to determine large amounts of the children's futures and lives. Similarly high degrees of parental determination of their children's lives could arise from parents' decisions to live in a commune or to move to a different country with a very different culture and language. Yet, so long as these actions do not harm the children, we allow parents to take these actions. What, if anything, makes the over-determination from parental genetic trait selections different from the over-determination from post-natal parental actions, such that the former are ethically objectionable but the latter are not?

I contend that the permanent nature of genetic trait selections makes genetic over-determination from parental genetic trait selections ethically objectionable while genetic over-determination from post-natal parental actions are not. The would-be actor or hockey player can eventually change course, despite their parents' wishes that they continue the activity. And even the child raised in the Amish community, the commune or the foreign country, has the opportunity to leave those situations. The parental actions will have changed them, certainly. They have the opportunity to escape or overcome the effects of their parents' actions, although they may not be able to overcome all of the effects.[146] But the child's whose genetic traits have been selected cannot easily escape the effects of her parents' actions. Barring some extraordinary intervention, a child whose genetic traits are selected for him or her will attain those genetic traits whether he or she wants them or not. As a result, parental genetic trait selections must be scrutinized for over-determination to a degree greater than that for parental actions that do not modify the child's genotype and genetic trait expressions.

As noted above, the parental obligation to act in the best interests of their children underlies the parental obligation to respect the child's range of open futures. Allowing

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[146] Parents sometimes make physical alterations to their children's bodies, such as male circumcision, that are either not reversible or reversible only with extreme difficulty. And some parental actions may have psychic effects on their children that, despite their later best efforts, the children cannot overcome or escape.

parents to engage in differential shifting of a child's range of open futures creates too high a risk that the parental genetic trait selection will prove not only to fail to foster the child's best interests but will prove to be contrary to the child's best interests in that it over-determines the child's development of her own future. For this reason, I contend that parents would act unethically if they engage in parental genetic trait selections that differentially shift among the child's range of open futures.

8. Are More Futures Always Better?

Another question that may arise in response to my approach is whether parental genetic trait selections that provide the resultant children with an expanded range of open futures are necessarily of benefit to those children. This question may come in three forms. First, is expanding the range of open futures necessarily beneficial? Second, what if some or all of the open futures added through the genetic trait selections are undesirable or negative futures? Third, are more, but lower quality, open futures necessarily better than fewer, higher quality open futures?

a. Is Having More Futures Necessarily Good?

Gerald Dworkin denies, in the context of the exercise of autonomy, that having more choices is necessarily good. He cites an example proposed by Tibor Scitovsky in which a person, who in the past has only been able to select one kind of shirt, can now select from among ten kinds of shirts.[147] While the nine newly available kinds of shirts provide some benefit, they also impose a cost. In the past, the person did not have to incur any costs in choosing the only kind of shirt he could choose. But now, the person must incur the cost of rejecting the nine kinds of shirts he does not choose. And, as Scitovsky notes, "it is more likely that he will be tempted, then, to risk spending an unpredictable amount of time and trouble in the hope of finding a more suitable shirt."[148]

Giving a child an expanded range of open futures, through parental genetic trait selection, could impose this kind of cost on the child. It could require her to expend more effort in deciding which, if any, of the added futures to pursue. But this cost will be largely transparent to the child. In Scitovsky's shirt example, the person has had the experience of having no choice in kinds of shirt and now has the opportunity to exercise choice where he has not done so before. But a child whose range of open futures has been expanded through parental genetic trait selection will have had no such prior experience to measure her current experience against. While she may be told that without the parental genetic trait selection she would have had fewer choices, she will not have experienced that limitation herself. This possible cost of having an expanded range of open futures is not sufficient reason to refrain from engaging in parental genetic trait selections that expand the range of open futures.

It might be possible, at some point, for parents to engage in so many genetic trait selections that their child's range of open futures is so expanded as to be a burden to the

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[147] Gerald Dworkin, *The Theory and Practice of Autonomy* (Cambridge: Cambridge University Press, 1988), 72-73, citing Tibor Scitovsky, *The Joyless Economy* (New York: Oxford University Press, 1976), 98.

[148] Dworkin 1988, 73 (quoting Scitovsky 1976, 98).

child. Dworkin quotes from Soren Kierkegaard regarding the possibility of a "despair of possibility" in which possibilities "appear[] to the self ever greater and greater, more and more things become possible" until "at last it is as everything were possible – but this is precisely when the abyss has swallowed up the self."[149] It is possible that parents could make their child so intelligent, so strong, so emphatic, so good-looking, etc., that the child would wrings his hands over which futures, of the possible futures available to him, he should pursue. He might not be able to decide which futures to pursue. But this possibility is not a significant argument against parental genetic trait selections that expand the range of open futures. Parents are unlikely to be able to expand their child's range of open futures to the extent that the choices of futures becomes paralyzing. Even if they do, they still have an obligation to assist their child in selecting from among the expanded range of open futures they have given her. While the scenario of giving their child too many choices is one that the parents should consider when deciding what genetic trait selections to make, the scenario is not an argument against parental genetic trait selections that expand the range of open futures.

Finally, Dworkin argues that having more choices is not necessarily good, in that it is not always instrumentally good, because the added choices may not be any that the person wants to have, and in that it is not intrinsically good, because having more choices is not desirable for its own sake.[150] But I am not arguing that expanding the child's range of open futures is necessarily good. I am arguing that expanding the range of open

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[149] Dworkin 1988, 73 (quoting S.A. Kierkegaard, *Fear and Trembling and the Sickness Unto Death*, trans. Walter Lowrie (Garden City, N.J.: Anchor Press, 1954), 169).

[150] Dworkin 1988, 78-80.

futures is instrumentally good, in that it gives the child a greater range of futures to select from. The benefits created by that expanded range of open futures greatly exceeds any costs attendant to receiving those benefits. So a parental genetic trait selection that expands the child's range of open futures does not need to be necessarily good, it needs only be instrumentally good for the child.

b. What if the Added Futures are Undesirable Futures?

It is certainly possible that among the futures added by expanding the range of open futures through parental genetic trait selection are futures that many might find undesirable. The same genetic trait selection could lead to both desirable and undesirable open futures. For example, an improvement in a child's auditory acuity could be put either to the desirable use of playing music expertly or to the undesirable use of safecracking. In these instances, so long as the parents engage in the genetic trait selection to expand the child's open futures to add some desirable futures, the fact that the trait selection may also expand the child's open futures to include some undesirable futures does not make the parental genetic trait selection ethically objectionable. Most basic human attributes can be placed in service of both desirable and undesirable futures. The parental genetic trait selection modifies just those human attributes. Subsequent rearing by the parents, and the child's own development, will determine whether the child puts to desirable use or undesirable use the genetic trait that her parents have given her.

But what if the parental genetic trait selection expands the range of open futures by adding primarily undesirable open futures? For example, say parents wanted to engage in genetic trait selection that would render their child unable to have empathy or sympathy for others. This might expand the range of open futures to add some desirable futures, such as greater success as a fighter or a commando. But it would expand the range of open futures to add many undesirable futures, such as being a cruel partner, a heartless parent or, in the worst case, a sociopath. How shall we assess such a parental genetic trait selection?

There are two variations of this scenario and they lead to different conclusions about the ethical acceptability of the parents' action. First, and less likely, let us say that the parents propose to use parental genetic trait selection to expand the range of the child's open futures to add predominantly futures that they believe to be undesirable futures, in that they would not want their child to have those futures, and that most people in the parents' society would believe to be undesirable futures, in that those people would not want their children to have those futures. As a possible example, say that parents want to use genetic trait selection to make their child eight feet tall but not because they believe that being eight feet tall will lead to many additional desirable futures. They realize that most futures added through being eight feet tall will be negative futures, and they hope that their child does not pursue those futures. But they hope there is a chance that their child will have the skills to be a professional basketball player and think that being eight feet tall will benefit him in that possibility.

In this variation, I contend that even though the parents are using parental genetic trait selection to expand the range of open futures, because they know they are expanding the range of open futures predominantly with futures they would not want their child to have, even if there are a few added futures that they would want their child to have, they are failing to act in the best interests of their child. This parental duty to act in the best interests of the child underlies the parental duty to respect the child's open future. Where, as in this scenario, those duties seem to call for different action, I contend the duty to act in the child's best interest prevails. Accordingly, I contend that parental genetic trait selections that would expand the range of open futures, but predominantly with futures that the parents would not want their child to have, would be ethically unacceptable.

Second, and more likely, let us say that the parents propose to use parental genetic trait selection to expand the range of the child's open futures primarily with futures that they believe to be desirable futures, in that they would want their child to have those futures, but that most people in the parents' society would believe to be undesirable futures, in that those people would not want their children to have those futures. As a possible example, say that parents want to use genetic trait selection to give their child increased aggression. The parents acknowledge that increased aggression may add some undesirable futures, such as possible spousal abuse, but believe that on balance it will add desirable futures, such as service in the military, participation in sports that require aggression, and success in the business world. But the parents are part of a society in which most people believe that most of the futures added through increased aggression would be undesirable futures, in that they would not want their children to have such increased aggression.

In this variation, I contend that the parental genetic trait selection is ethically acceptable even though most in the society would not agree with it. This is an unsettling conclusion. But for parental autonomy to have a robust meaning, it must mean more than the autonomy to act in ways that most in society would act. It must mean that, within limits, parents can act in ways that most in society would not act. Even though most in society would not use parental genetic trait selection to expand the range of open futures in the way the parents wish to, so long as they are expanding the range of open futures that they believe to be desirable futures, the parents are acting within the scope of their parental autonomy and their actions are ethically acceptable.

Because the genetic trait selection expands the range of open futures, the child is not losing any significant number of possible futures. He still will have the chance to pursue futures other than those added through the parental genetic trait selection. While he may pursue some of the futures that are added through the parental genetic trait selection, and while many in his society would find such futures undesirable, we should allow parents the autonomy to give their child those options, even though that autonomy may come at a price to society.

c. More Moderate-Quality Futures Versus Fewer High-Quality Futures

Finally, what if parents engage in a parental genetic trait selection that expands the range of open futures to add a large number of moderate quality futures that the child may pursue? In general, my approach would hold that such a parental genetic trait selection would be ethically acceptable. But what if the parents had an option between engaging in that genetic trait selection and engaging in a genetic trait selection that expands the range of open futures to add a smaller number of high quality futures? For example, if the parents had the choice between a genetic trait selection that would add nine futures of quality X and a genetic trait selection that would add five futures of quality 2X?[151] Would parents who choose the former genetic trait selection be making an ethically acceptable choice?

Some might contend that because the latter genetic trait selection would increase the quality of the child's possible futures by 10X (five futures times 2X), while the former would increase the quality of the child's possible futures by only 9X (nine futures times X), parents should engage in the latter genetic trait selection because it confers the maximum benefit. But I contend that either parental genetic trait selection would be ethically acceptable.

I do not contend that when using genetic trait selection, parents are obliged to make the selection that maximizes the number of futures added to the child's range of open future. Neither do I contend that when using genetic trait selection, parents are obliged to make the selection that maximizes the quality. I contend only that when parents use genetic trait selection, their selection must expand the child's range of open futures. Parents would be free to choose a genetic trait selection that adds a larger number of moderate quality futures or a genetic trait selection that adds a smaller number of high quality futures. For example, parents might choose to use genetic trait selection

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[151] This assumes that such quantifiable levels of qualities of future can be established. As I have argued in the prior chapter, I am skeptical about whether such levels can be established in a way that this calculation and comparison could be made.

to increase their child's muscular strength instead of using genetic trait selection to increase their child's auditory acuity, and vice versa. Even if parents believe that the increase in muscular strength results in the addition of more but more moderate quality futures, and that an increase in auditory acuity would results in the addition of fewer but higher quality futures, either genetic trait selection would be ethically acceptable because both genetic trait selections expand the child's range of open futures to add possible futures he or she did not have before.

Some may argue that the parental duty to act in the best interests of their children should compel them to maximize the quality of the futures added through parental genetic trait selection. I respond that allowing parents the choice not to maximize the quality of futures added through parental genetic trait selection is a necessary part of allowing parents autonomy in their reproductive decisions. As noted previously, we do not compel parents to provide maximum benefits to their children at all times. We allow parents to provide sub-maximal benefits at times, so long as the level of benefit is not too low. The same, I suggest, applies to decisions about what, and how many, futures parents seek to add to their child's range of open futures. So long as they expand the child's range of open futures, rather than constricting or differentially shifting that range, the parents' choices as to the number and quality of the added futures are within the scope of their parental autonomy and are ethically acceptable.

9. Advantages of This Approach

As I have noted above, my approach to the ethical assessment of parental genetic trait selection builds on the normative rules proposed by Davis, Brock and Resnik. Under their normative rules, parents should not engage in genetic trait selections that constrain the range of open futures available to their child. But their rules do not address explicitly those genetic trait selections that would expand the range of open futures or those genetic trait selections that differentially shift the range of open futures. As I have argued, the former parental genetic trait selections are ethically acceptable but the latter parental genetic trait selections are not. I believe that this approach is an improvement on those of Davis, Brock and Resnik for two reasons: utility and consistency with a wider sense of parental obligation toward their children.

First, my approach will be useful in more situations than those of Davis, Brock and Resnik. Occasions when parents will propose to engage in a genetic trait selection that they know will constrict the range of open futures will be exceedingly uncommon. Most parents act, or seek to act, in ways that improve their children's lots in life, and there is every reason to believe that they will do so when engaging in genetic trait selection. Thus I doubt that many parents will seek to diminish their children's lots in life by intentionally constricting the range of their children's open futures.

A more likely scenario is one in which in their zeal to improve the chances of a few open futures, parents seek to engage in a genetic trait selection that actually constricts the overall range of open futures. For example, say that parents sought to use genetic trait selection to give their child an adult height of eight feet in a sincere belief that they were improving his future. There are a few open futures that would be more available to the child than if he was of typical height. But there are many more open futures that would no longer be available to that child, so overall his or her range of open futures would be constricted. In such cases, parents would be proposing an ethically unacceptable genetic trait selection that constricts the range of open futures without realizing they would be doing so.

I suggest that most proposed parental genetic trait selections would either expand the range of open futures or differentially shift the range of open futures. My approach holds expressly that the former parental genetic trait selections are ethically acceptable, in contrast to Davis's and Brock's approaches that are silent on such selections, and so provides clearer guidance to parents.

More importantly, my approach addresses those parental genetic trait selections that are the most ethically troubling, those that increase the possibility of some of futures but decrease the possibility of a significant number of other futures. A number of genetic trait selections, such as height, weight and strength, may result in "trade-off" situations in which possible futures are both gained and lost. As I have argued, these genetic trait selections are less clearly in the best interests of the child and may more often be primarily in the best interests of the parents. This makes such parental genetic trait selections more troubling ethically and necessitates a means of assessing ethically those selections. The approach I have proposed will help assess these most troubling proposed parental genetic trait selections.

Second, my approach is more clearly consistent with the overall parental obligation to their children, both before and after conception, than are Davis's, Brock's and Resnik's. Parents have a clear obligation not to harm their children. Restricting the range of a child's open futures would be a harm to that child, so parents have an obligation not to engage in genetic trait selections that would have this result. Davis, Brock and Resnik deal correctly with such genetic trait selections.

But parents have more than an obligation to not harm their children. They have an obligation to foster satisfying futures for their children. After their children are born, we oblige parents to provide them with nutritional, educational and development opportunities that will help foster their futures. We should obligate parents similarly in their actions before their children are conceived. As Feinberg suggests, parents hold in trust for their children their rights to open futures. That trust relationship imposes a fiduciary duty on the parents. Under such a duty, parents must act in the best interests of their children, even before they are conceived.

When a parental genetic trait selection will expand the child's range of open futures, parents are most likely to be acting in the best interests of their children. Even if the genetic trait selection does not expand the range to include a particular future that the child will come to desire, the expanded range is likely to contain a number of futures the child would find desirable. The parents' action would foster the child's path toward a desirable future and so would be consistent with their fiduciary duty toward their child.

However, as I have argued, when a parental genetic trait differentially shifts the range open futures, there is a greater chance that the parents may be acting in their best interests rather than in the child's best interests. As the number of futures lost through a genetic trait selection approaches the number of futures gained through that genetic trait selection, there is a greater likelihood that some futures that the child would have liked to pursue are no longer possible, or are made more difficult to pursue, because of the parental genetic trait selection. Genetic trait selections that differentially shift the child's range of open futures do not clearly foster the child's path toward a desirable future and so are not consistent with the parents' fiduciary duty toward the child.

In my view, the hardest situations are those not addressed by Davis's, Brock's and Resnik's approaches and are those that most need a means of ethical assessment. For the above reasons, I suggest that my approach, in which parental genetic trait selection that expand the child's range of open futures are ethically acceptable but parental genetic trait selections that either constrict the child's range of open futures or differentially shift the child's range of open futures are ethically unacceptable, is an improvement on Davis's, Brock's and Resnik's approaches that address primarily parental genetic trait selections that constrict the child's range of open futures.

10. Summary

Rather than attempt to make ethical assessments of parental genetic trait selections based on distinctions between normal and diseased states, or on distinctions between treatments and enhancements, we should base such ethical assessments on how the genetic trait selection changes the child's range of open futures. Those genetic trait selections that expand the child's range of open futures respect the child's right to an open future held in trust for her by her parents. Those genetic trait selections that restrict the child's range of open futures violate the child's right to an open future held in trust for her by her parents. And those genetic trait selections that differentially select among the child's open futures, without expanding the range of open futures, also violate the child's right to an open future held in trust for her by her parents.

CHAPTER FOUR: OBJECTIONS AND CONCERNS

In this chapter, I address a number of objections to and concerns about my approach for assessing parental genetic trait selections and about parental genetic trait selection in general.

1. From Option to Obligation?

If we permit parents the option to engage in genetic trait selections, might we sometimes morally oblige them to do so? If parents have the opportunity to use genetic trait selection to ensure that their child is not born with Down syndrome but decline that opportunity, is their decision ethically objectionable?[152] If parents have the opportunity to use genetic trait selection to ensure that their child is hearing capable and does not have genetic deafness, should they not always be required to do so? Julian Savulescu suggests that they should. He proposes the following Principle of Procreative Beneficence:

> couples (or single reproducers) should select the child, of the possible children they could have, who is expected to have the best life, or at least as good a life as the others, based on the relevant, available information.[153]

Savulescu argues that if parents have the choice between implanting embryos that differ only in that one embryo has a genetic predisposition to asthma and that one does not, parents are "morally required" to implant the embryo that does not have the genetic

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[152] Dena Davis comments on her own change in views regarding children with Down syndrome. "Twenty years ago, seeing a woman in the supermarket with a child who has Down syndrome, my immediate reactions were sympathy and a sense that the woman could be me. Now when I see such a mother and child, especially if the mother is older, I am more likely to wonder why she didn't get tested [and abort]." Davis 2001, 18.

[153] Julian Savulescu, "Procreative Beneficence: Why We Should Select the Best Children." *Bioethics* 16: 413-426 (2001), 415.

predisposition to asthma.[154] He defines "morally required" as justifying moral persuasion by doctors but not coercion.[155] He contends that a child without asthma will have a better life than a child with asthma, because that life has the most "well-being" under a number of theories of well-being.[156] He extends his argument to "non-disease genes" as well. He suggests that if we could test for a genetic contribution to memory skills, parents would be morally required to implant those embryos whose tests showed they had greater memory skills, because those embryos would have a better life.[157]

Savulescu recognizes that the Principle of Procreative Beneficence may conflict with parental rights to procreative autonomy. Indeed, he conceives of the Principle of Procreative Beneficence as a limit on procreative autonomy, in that it would require parents to have a "good reason" for their genetic trait selections.[158] But it is not clear what Savulescu would consider a "good reason" other than giving their child the best life possible. He raises the case of dwarves who wish to use genetic trait selection to have a dwarf child "because their house is set up for dwarves" as an example of a violation of the Principle of Procreative Beneficence.[159] Savulescu concludes that where procreative autonomy rights conflict with the Principle of Procreative Beneficence, procreative autonomy prevails. "If, in the end, couples wish to select a child who will have a lower

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[154] Savulescu 2001, 416.

[155] Savulescu 2001, 425. It is not clear whether Savulescu means legal coercion, moral coercion or emotional coercion.

[156] Savulescu 2001, 419-20. He notes three such theories: hedonistic, desire-fulfillment and objective list.

[157] Savulescu 2001, 420-21.

[158] Savulescu 2001, 425.

[159] Savulescu 2001, 424.

chance of having the best life, they should be free to make such a choice. That should not prevent doctors from attempting to persuade them to have the best child they can."[160]

Savulescu's Principle of Procreative Beneficence sounds plausible and productive. Most of us believe that parents should do the best for their children that they can. But depending on how it is interpreted, the Principle of Procreative Beneficence either goes too far, in that it overrides parental procreative autonomy, or adds little in helping parents decide what, if any, genetic traits to select for their children. If, as it appears in the early parts of Savulescu's argument, the only good reason for choosing which embryo to implant is maximizing the chance of the child having the best life possible, then that could override procreative autonomy. If, by the "best life possible," we mean the parents' subjective belief as to the best life possible, then the Principle of Procreative Beneficence would never conflict with the parents' procreative autonomy, on pain of inconsistency. But if, as I believe Savulescu means, by the "best life possible" we mean an evaluation by society as to what lives are better than other lives, then the parents' procreative autonomy would be constrained by this external assessment of better and worse lives.[161] While Savulescu stops short of using coercion (or force) to stop the parents from selecting a child with a lower chance of having the best life, he would still deem them to have violated a moral requirement, and thus to have acted unethically.

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[160] Savulescu 2001, 425.

[161] Immaculada de Melo-Martín notes that Savulescu presents simple examples of genetic trait selections that would not "solve the difficulties that the parents are going to experience in deciding what traits, as a whole, make the child better off." Immaculada de Melo-Martín, "On Our Obligation to Select the Best Children: A Reply to Savulescu," *Bioethics* 18: 72-83 (2004), 79.

Further, while Savulescu limits his argument to those parents using pre-implantation genetic diagnosis to determine which embryo to implant, his Principle of Procreative Beneficence would seem to extend farther. Forcing parents to reproduce through pre-implantation genetic diagnosis and *in vitro* fertilization would violate their rights to bodily integrity as well as procreative autonomy.[162] But future technologies could allow for genetic trait selections without significant invasions of bodily integrity. And why should the Principle of Procreative Beneficence apply only to embryo selection decisions? If a person is under a moral requirement to take steps to have a child with the "best life, or at least as good a life as the other, based on the relevant, available information,"[163] then should that moral requirement not extend to the parents' choices of genetic partners? If a person has the choice between a genetic partner with high intelligence and a genetic partner of low intelligence, and assuming that intelligence includes a genetic contribution, under the Principle of Procreative Beneficence, is the person morally required to choose the genetic partner with higher intelligence, since the child would have a better chance at the best life with a genetic contribution from that partner? The same would seem to apply to other genetic traits that contribute to conceptions of the "best life possible." Savulescu has not argued for this, and may not want to go that far. But, if we take his Principle of Procreative Beneficence as a principle strong enough to limit parental procreative autonomy, I do not see what stops such an extension.

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[162] See de Melo-Martín, 75-79 (describing how effects of *in vitro* fertilization would overburden women under Savulescu's approach).

[163] Savulescu 2001, 416.

In contrast, if by the best life possible, we mean the parents' subjective belief as to the "best life possible," then the Principle of Procreative Beneficence is of little assistance in assessing parental genetic trait selections. As I have stipulated in the beginning of this work, I assume that in making genetic trait selections, parents are acting in what they believe to be the best interests of their child, and make their genetic trait selections consistent with that belief. It seems implausible that parents would make genetic trait selections intended to diminish their child's chances of what they conceive to be the best life. The conceptions of others as to the best life possible may differ substantially from those of the parents. If we use this external measure of the best life, then we encounter the problems I have described above. If we use the parents' subjective measure of the best life, then the Principle of Procreative Beneficence provides no help in guiding parents as to what, if any, genetic trait selections to make for their children.

As I have argued above, the Principle of Procreative Beneficence does not move the option of using parental genetic trait selection to an obligation to use parental genetic trait selection. But other arguments may be made in support of the move from option to obligation. If parents have an obligation to act in their children's best interests, should not that obligation extend to genetic trait selections that will benefit their children? What, if anything blocks the move from option to obligation?

In post-natal activities and interventions, the fact that parents can do things to better their child's life does not compel them, ethically, to do so. So long as the parents do not harm the child, they are not ethically obliged to provide whatever interventions might give the child a better life. We do not oblige parents to bankrupt themselves providing developmental or educational interventions for their children. Even when cost is not a concern, we do not declare unethical a parental decision not to provide every desirable intervention. Parental autonomy gives the parents the right to choose whether or not to provide their children with such interventions.

Similarly, procreational autonomy gives parents the same right to not use genetic trait selection as they do to use genetic trait selection.[164] Just as some parents may decline to provide their children with piano lessons, some parents may decline to use genetic trait selection to give their children perfect pitch. Just as different parents select different post-natal interventions, different parents will select different genetic trait selections, and some will not intervene in selecting any. They may wish to rely upon the genetic lottery in forming the genomic structure of their children. So long as they do not harm their child by not using genetic trait selection, the parents' procreational autonomy rights block the move from an option of using genetic trait selection to an ethical obligation to use genetic trait selection.

One objection to this position, that parents have the right not to use parental genetic trait selection, is that it permits parents to decline to engage in genetic trait selection when it would reduce the risk of harm to the child. For example, if parents know their children are at risk of being born with genetic deafness, but choose not to engage in parental genetic trait selection to ensure that their children are not born deaf, are they harming their children by leaving them at risk of being born deaf? Is this different from using parental genetic trait selection to ensure that their children are born

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[164] Robertson 1996, 425-429; Robertson 1994, 152-53.

deaf? I have argued above that this use of genetic trait selection would be ethically objectionable because it restricts the range of open futures. In the event that a child is born deaf, and that deafness could have been prevented through the use of parental genetic trait selection, is the parents' failure to use genetic trait selection just as ethically objectionable? I address this concern in the next section.

2. When Parents Make Unpopular Choices

There will be cases where parents use, or decline to use, parental genetic trait selection in ways that many of us may find objectionable. First, as noted above, they may decline to use available and affordable technologies to determine whether their child may have genetic traits that they could modify. They may decline to use parental genetic trait selection even when it could ensure their child not to have a condition that restricts their range of open futures. Is this failure to use parental genetic trait selection to ensure the absence of a restricting condition any different ethically from the use of genetic trait selection to ensure the presence of the same restricting condition? I have argued the latter is ethically objectionable. Is the former?

At present, there is a distinction between parents acting to ensure that their child will be born with a condition that restricts her range of open futures and parents failing to act to remove the risk that their child will be born with that same condition. All forms of parental genetic trait selection require substantial invasions of the parents' rights to autonomy, particularly the mother's right to bodily autonomy. Post-implantation genetic trait selection requires the mother to undergo an invasive procedure to ascertain the fetus's genomic structure and then to undergo a termination of the pregnancy if the fetus has a restricting condition. Compelling a mother to use post-implantation genetic trait selection would substantially invade her rights to bodily autonomy.[165] Pre-implantation genetic trait selection also requires the mother to undergo invasive procedures to obtain ova and to prepare the mother's body for implantation of the embryo. Thus, at present we cannot ethically compel parents to use genetic trait selection, even where it would eliminate the risk that their child will be born with a condition that restricts her range of open futures, because of the degree of the invasion of parental bodily autonomy and procreative autonomy that involuntary parental genetic trait selection would necessitate.

There may come a time, however, when parental genetic trait selection could be accomplished with little or no invasion of the parents' rights to bodily autonomy. At that time, society may have a stronger argument for ethically compelling parents to engage in genetic trait selections that reduce the chance that their children will be born with conditions that restrict their range of open futures. Parents act unethically if they have the resources to provide their children with pre-natal care but fail to do so. And we criticize parents on ethical grounds if they fail to use minimally invasive techniques to

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[165] Heather Draper and Ruth Chadwick argue that if the parents believe a life with a Down syndrome or deafness is a good quality life, then procreative autonomy protects parental decisions to implant (or decline to abort) children with those conditions, even if most parents would not. Heather Draper and Ruth Chadwick, "Beware! Preimplantation Genetic Diagnosis May Solve Some Old Problems But It Also Raises New Ones." *Journal of Medical Ethics* 25: 114-120 (1999), 117-18. Alexander Capron contends that parents who make such a decision should not be considered legally or morally liable, so long as the child's life is a life worth living. Alexander Morgan Capron, "Punishing Reproductive Choices in the Name of Liberal Genetics." *San Diego Law Review* 39: 683-692 (2002), 689-91. While I agree with Draper, Chadwick and Capron that procreative autonomy protects parental decisions to decline to abort children with those conditions, I disagree that it protects parental decisions to knowingly implant embryos that have those conditions. Such parental decisions go beyond mate selection and the genetic lottery and constitute genetic trait selection. As I have argued, parents may only engage in genetic trait selections that expand the range of open futures for the child, and neither Down syndrome nor deafness expands the range of open futures for the child.

reduce the risk that their children will be born with restricting conditions. For example, if mothers take folic acid during pregnancy they substantially reduce the risk that their children will be born with spina bifida and other neural tube defects. In order to improve the likelihood that mothers are getting enough folic acid, manufacturers now add folic acid to many processed foods. We would have grounds to ethically criticize a mother who, knowing this information and easily able to obtain folic acid, chose to avoid consuming folic acid. Similarly, if the techniques for parental genetic trait selection become as minimally invasive as consuming folic acid, the failure to use genetic trait selection could be ethically criticized. At that point, we may move to a view in which certain parental genetic trait selections are ethically required and hold that parents' refusal to make those selection would be ethically objectionable. We may need to create a decent genetic minimum that parents must provide their children if they have the means to do so. I address the concept of a decent genetic minimum in a later section. But given the unpredictability of the time before which such minimally invasive parental genetic trait selection would become possible, we cannot now say that parents who decline to use parental genetic trait selection, even where it would reduce or eliminate the risk of their children being born with restricting conditions, are acting unethically.

Second, giving parents wide autonomy to make parental genetic trait selections will sometimes result in parents making unpopular genetic trait selections. A highly contentious example of such unpopular genetic trait selection is sex selection. Since most current forms of parental genetic trait selection involve the termination of a pregnancy, engaging in sex selection is widely criticized.[166] But with the development of preimplantation genetic diagnosis, an embryo of a specific sex can be selected for implantation. Since that approach would not require the abortion of a fetus, some argue that sex selection done through preimplantation genetic diagnosis and *in vitro* fertilization is not necessarily unethical.[167] Some parents might contend that engaging in preimplantation genetic trait selection to select for a child of a particular sex would expand the range of that child's open futures. For example, parents might believe that being a girl in a family with four older brothers might expand the range of open futures for that child over being the fifth of five boys. But in most instances, preimplantation genetic trait selections for sex would not expand the range of open futures for the child.[168] It would only differentially select among open futures, and on my view, would be ethically objectionable.

As I have argued, when using parental genetic trait selection, parents must act in the best interests of their child, particularly in respecting the child's right to an open future by acting to expand, not restrict or differentially select among, the range of open futures available to the child. I contend that ethical oversight of parental genetic trait

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[166] Jeffrey R. Botkin, "Line Drawing: Developing Professional Standards for Prenatal Diagnostic Services," in Erik Parens and Adrienne Asch, eds., *Prenatal Testing and Disability Rights* (Washington, D.C.: Georgetown University Press, 2000), 288-307; Dorothy C. Wertz and John C. Fletcher, "Fatal Knowledge? Prenatal Diagnosis and Sex Selection," *The Hastings Center Report* 19: 21-27 (1989).

[167] Bonnie Steinbock, "Sex Selection: Not Obviously Wrong," *The Hastings Center Report* 32:23-28 (January/February 2002); John A. Robertson, "Preconception Gender Selection," *American Journal of Bioethics* 1: 2-9 (2001).

[168] Some would contend that in some cultures, boys have more open futures that do girls, so preimplantation genetic trait selection for sex would be ethically acceptable. I would respond that the reasons why boys may have better futures than girls are the result of systemic discrimination and not some natural advantages conveyed by being a boy. We should not reinforce such systemic discrimination by sanctioning the use of sex selection in such instances.

selection should be limited to ensuring that parents use genetic trait selections consistent with these principles of acting in the child's best interest. Just as some parents make unpopular choices in how they raise their children once they are born, some parents will make unpopular choices in their parental genetic trait selections. But so long as they make those selections in order to expand their child's range of open futures, the parents are acting ethically, even if others would not make those selections they make.[169]

Another concern is that genetic trait selections may "go wrong," in that the children resent the selections made for them by their parents. Children could resent the genetic trait selections in two different ways. First, they could appreciate the skills that their genetic trait selections allow them to display (musical ability, for example) but resent the fact that they acquired these skills through genetic trait selection rather than through their own efforts and struggle.[170] Second, they could resent the conflict between their parents' desires, as expressed through the parental genetic trait selection, and their own desires. Michael Reiss and Roger Straughan imagine parents saying "we didn't pay for you to be musically gifted just to have you spend all your time playing baseball," or conversely, "we didn't pay for you to be an outstanding baseball player just to have you spend all your time in a rock band."[171]

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[169] Judith Andre argues that so long as the parents gave due consideration to the genetic ramifications of their parental trait selection, their choice may be morally objectionable but is not irresponsible. Judith Andre, Leonard M. Fleck, and Tom Tomlinson, "On Being Genetically 'Irresponsible'" *Kennedy Institute of Ethics Journal* 10: 129-146 (2000), 140-42.

[170] Roberta M. Berry, "Genetic Enhancement in the Twenty-First Century: Three Problems in Legal Imagining" *Wake Forest Law Review* 34: 715-735 (1999), 729-30.

[171] Michael J. Reiss and Roger Straughan, *Improving Nature?: The Science and Ethics of Genetic Engineering*. (Cambridge: Cambridge University Press: 1996), 85.

Because of this risk of resentment, Toby Schonfeld argues that parents breach their fiduciary responsibilities to their future children by engaging in enhancing genetic trait selections.[172] He contends that "there is a moral difference between encouraging someone to develop a naturally occurring ability and artificially creating or augmenting that ability in the first place."[173] But he does not elaborate on where that purported moral difference comes from. It appears to be based on a natural/artificial distinction similar to the treatment/enhancement distinction. However, just as the treatment/enhancement distinction does not provide us with a meaningful way of assessing morally parental genetic trait selections, a natural/artificial distinction does not provide us with a meaningful way of assessing morally parental genetic trait selections. Thus, I disagree with the claim that parents violate their fiduciary responsibilities to their children if they engage in genetic trait selection.

The risk of resentment arising from parental genetic trait selection is not different in kind from resentments children already may have against their parents' decisions regarding their raising. A child enrolled in a superior school and given special tutoring, as a result of their parents' desires and superior financial resources, may come to believe that he did not "earn" his education and skills in the same way as some of his less-advantaged colleagues. And a child who wishes to play sports after her parents spent considerable money on music lessons and instruments, or conversely a child who wishes to play music after her parents spent considerable money on sports training and

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[172] Toby Schonfeld, "Parents of Unhappy Poets: Fiduciary Responsibility and Genetic Enhancements," *Cambridge Quarterly of Healthcare Ethics* 12: 411-17 (2003).
[173] Schonfeld, 416.

equipment, may resent the choices her parents made and may resent the psychological pressure her parents may use to get her to follow her parents' wishes. Genetic trait selections for musical aptitude or athletic ability are more permanent than piano lessons and tennis lessons. But a child can choose to ignore the benefits that those genetic traits confer, just as he can choose to forget the skills he learned through lessons. Having a genetic trait for musical aptitude does not compel a person to employ that aptitude.

Parents will sometimes make unpopular genetic trait selections, sometimes in the eyes of the broader society and sometimes in the eyes of the children for whom they made the genetic trait selections. But we grant parents the latitude to make unpopular decisions regarding how they raise their children, as part of their parental autonomy, so long as those unpopular decisions do not harm their children. In the latter instances, such as refusals to provide children with medical care or with basic education, parental autonomy gives way to the children's best interests because the parents are not acting in the children's best interests. Similarly, we should grant parents the latitude to make unpopular genetic trait selections, as part of their procreative autonomy, so long as they are acting in the best interests of their children, by expanding the range of open futures for the child. But if parents seek to make genetic trait selections that are not in the best interests of their children, because they constrict the range of open futures or because they discriminate between open futures, then they exceed the ethical authority that procreative autonomy grants them.

3. The Specter of Eugenics

The specter of eugenics hovers over any discussion of genetic trait selection. When the Nazis used forced sterilization and then extermination to eliminate what they perceived to be undesirable genetic traits, including being Jewish, being a Gypsy, being homosexual or being mentally defective, they were engaging in forms of genetic trait selection. When Americans used involuntary sterilization upon those with mental diseases or developmental delays in order to prevent transmission of what they believed to be genetic traits to another generation, they were engaging in forms of genetic trait selection. And when societies such as China and India favor male children over female children and pressure parents into aborting female children, they are engaging in forms of genetic trait selection. Given that history, it is understandable that one of the major objections to parental genetic trait selection is that permitting its use will result in further eugenic episodes.

But before rushing to a conclusion that parental genetic trait selection leads necessarily to eugenic abuses, we should consider the characteristics of these odious examples of genetic trait selections that we denounce as eugenic. "Eugenics," standing alone, is either a positive or a value-neutral term. It means simply "good genes."[174] The problems with eugenics arise from three questions: (1) how do we accomplish creating children with "good genes"?, (2) who decides what are "good genes" or "bad genes"?, and (3) how are those decisions made? In early discussions of eugenics (prior to the Nazi

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[174] Francis Galton, the founder of eugenics, defined it as "the science which deals with all influences that improve the inborn qualities of a race; also with those that develop them to the utmost advantage." Francis Galton, "Eugenics: Its Definition, Scope and Aims," reprinted in *Essays in Eugenics* (Washington, D.C.: Scott-Townsend Publishers, 1996), 35.

use of eugenics), a distinction was frequently drawn between "positive eugenics," in which healthy people were encouraged to raise large and healthy families, and "negative eugenics," in which unhealthy persons were discouraged or prevented from having children. The most notable examples of "positive eugenics" were exhibitions at state fairs of large and healthy families, complete with the awarding of ribbons. By current sensibilities, this practice seems either quaint or surreal. But it points out that eugenics can be aimed at creating children with "good" genes, not just aimed at preventing the creation of children with "bad" genes.

More significantly, the abuses of eugenics have arisen from issues of who decides what constitute "good genes," what constitute "bad genes," and how they make those distinctions. In many cases of negative eugenics, the "genetic traits" that societies sought to prevent transmitting to the next generation were not genetic traits at all. Being Jewish, or being a Gypsy, may result from one's parents being Jewish or Gypsy, but that does not make them genetic traits. They are conditions born of societal definitions. While many mental conditions are genetic in origin, they may or not may be transmissible, and they may arise in families where no previous instances of those mental conditions have arisen. These instances of negative eugenics result from either mistaken genetic determinism, in that they ascribe a genetic basis to statuses or conditions that are not genetic traits, or genetic over-determinism, in that they ascribe a genetic basis to statuses or conditions that may or may not be genetic traits. This mistaken determinism or over-determinism is then used to justify, through the invocation of the science of genetics, efforts to cause people with certain statuses or certain conditions not to exist, either by preventing those people from having children or by eliminating them outright. In these ways, "negative eugenicists" believed that those statuses or conditions could be eliminated from the "gene pool."

In these examples, persons other than parents were deciding what genetic traits should be selected for or against. Most often governments acted directly to prevent certain people with certain conditions from having children, because the governments believed those children would have the same condition. In other instances, societies have placed pressure on parents to select for or against genetic traits such as the sex of their children, based on perceived different values of male and female children. I will call these instances of "societal eugenics."

But should we necessarily prevent parents from engaging in "eugenics," if what they attempt to do is to create children with what they believe to be "good genes"? One means of preventing the birth of a child with Tay-Sachs disease would be to prohibit all persons from the affected populations, who are primarily Jewish, from intermarrying. Such a step would be over-broad, of course, in that the births of many unaffected children would be prevented as well. It would be an example of "societal eugenics."[175] But if parents from the affected populations use genetic trait selection to avoid the birth of a child with Tay-Sachs, are they engaging in "eugenics" any less than when the government seeks to prevent the birth of children with Tay-Sachs through more onerous

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[175] Another such example is the legal prohibition on marriage between persons who are closely related by blood. Many states prohibit marriage between first cousins and all prohibit marriage between siblings. This prohibition is founded on the belief, at least in part, that children born of such marriages would suffer from abnormalities. As such, the prohibition is a form of societal eugenics. It may also reflect other social mores. Even if the prohibition is a form of societal eugenics, it is a generally accepted one.

means? They both act toward the same end, but by different means. Thus, I will call instances of parents using genetic trait selection "parental eugenics."[176]

As I argue in this work, parents may engage in genetic trait selections so long as they make those selections that expand the range of open futures available to the child. Thus, I argue that parents may engage in parental eugenics with this same constraint, and so I contend that the claim of eugenics, standing alone, does not make parental genetic trait selection ethical unacceptable.

David King suggests that allowing parents to engage in unregulated genetic trait selection will result in "laizzez faire" eugenics intended to reduce the number of children born with congenital disorders.[177] He contends that parental eugenics are not a matter of free choice, but are choices shaped by societal forces, and so are actually a form of societal eugenics.[178] I agree with King that societal forces influence parental genetic trait selections, sometimes more directly than others. The choices of what genetic traits will be tested for, and of which tests will be paid for by health care systems, can directly influence parental genetic trait selection. Choices of what governmental benefits are offered for what genetic conditions may also influence parental genetic trait selection. For example, parents may be more willing to have a deaf child or a child with Down syndrome in a society where the government helps with the higher costs attendant to being a child with those conditions than in a society where the government does not help.

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[176] Arthur Caplan makes a similar distinction, using the terms "population genetics" and "individual genetics." Arthur Caplan, "What's Morally Wrong with Eugenics?" in Phillip R. 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), 209-222, 213-14.

[177] David S. King, "Preimplantation Genetic Diagnosis and the 'New' Eugenics" *Journal of Medical Ethics* 25: 176-182 (1999), 178.

[178] King 1999, 181.

And parents might be less likely to have a deaf child or a child with Down syndrome in a society where the government refuses to help with such higher costs when the parents could have used genetic trait selection to avoid having children with those conditions but chose not to. As I discuss in the section on the disability critique, we must not allow the potential for using genetic trait selections that avoid certain conditions to undercut societal and governmental support for people who are born with those conditions. Thus, we must scrutinize societal and governmental policies for their influence on parental genetic trait selections and for their potential for societal eugenics.

But I suggest that allowing parents to engage in genetic trait selection can help serve as a counter-weight against instances of societal eugenics.[179] As discussed above, much of the odium of societal eugenics is that persons or powers other than parents are deciding what genetic trait selections parents may or may not make. But if we allow parents to use parental genetic trait selection to avoid the creation of children with certain conditions, such as Tay-Sachs, then we can reduce the possibility that governments or other powers may try to use societal eugenics to accomplish the same goal.[180] And if we allow parents to use genetic trait selection to expand the range of open futures of their children, then we can reduce the power of government or others to dictate those genetic traits that are desirable or undesirable, and thus reduce the power to attempt to create societies such as "master races" made up of individuals with those desirable traits.

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[179] To the charge that this view of parental genetic trait selection is utopian, I plead guilty.

[180] Ruth Cowan argues that we should fear governmental control over any part of the genetic trait selection process, rather than fear the choices that parents may make in those selections. Ruth Schwartz Cowan, "Genetic Technology and Reproductive Choice: An Ethics for Autonomy" in Daniel J. Kevles and Leroy Hood, eds., *The Code of Codes: Scientific and Social Issues in the Human Genome Project* (Cambridge, Massachusetts: Harvard University Press, 1992), 244-263, 262-63.

As Troy Duster notes, there needs to be a "vigorous and informed" debate about what genetic traits are considered desirable or undesirable, taking into account "the role of power and social locations of key actors" in making those assessments and examining the "hidden arguments underneath the surface language of neutrality of disease prevention and treatment."[181] Allowing parents to participate in that debate, through their uses of parental trait selection to expand the range of the child's open future, will help elucidate the hidden arguments of social location and power in determining, as a society, what genetic traits are desirable or undesirable. Parental genetic trait selection might help avoid having an elite group decide what genetic traits are desirable or undesirable.

4. The Disability Critique of Parental Genetic Trait Selection

In response to developments in treatment of genetic disabilities and in indirect pre-implantation parental genetic trait selection, advocates for those living with disabilities have developed a disability critique of those technologies. The disability critique holds that some treatments that counter genetic disabilities, and that some parental genetic trait selections to avoid having children born with disabilities, are morally problematic for two reasons. First, the action "expresses negative or discriminatory attitudes not merely about a disabling trait, but about those who carry it."[182] Second, the action "signals an intolerance of diversity not merely in the society but

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[181] Troy Duster, *Backdoor to Eugenics* (New York: Routledge, 2003), 130-31.

[182] Erik Parens and Adrienne Asch, "The Disabilities Rights Critique of Prenatal Genetic Testing" *The Hastings Center Report* 29: S1-S22 (September/October 1999), S2.

in the family, and ultimately it could harm parental attitudes toward children."[183] The disability critique is concerned that if we act to eliminate a disabling genetic trait, we are not only eliminating the trait, we are sending a message that we wish to eliminate those who have the trait.[184]

Applications of the disability critique have arisen in two situations involving those born with genetic deafness. First, it arose in response to the development of cochlear implants for children with genetic deafness. Later, it was offered in response to the use of indirect pre-implantation parental genetic trait selection by deaf parents to increase the chances of having a deaf child.

Before discussing those situations, a brief note on Deaf culture is warranted. Most of us who can hear consider deafness a disability. But for some who cannot hear, deafness is a linguistic and cultural identity. Bonnie Poitras Tucker explains that "people who call themselves 'Deaf' ... view and define deafness as a culture rather than as a disability for some purposes."[185] Within this "Deaf culture," deafness is not something to be avoided or fixed. Deafness is an ethnicity, with its own language and culture, in which the Deaf can bond, "the same way that Native Americans or Italians bond

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[183] Parens and Asch 1999, S2.

[184] Similarly, the critique suggests if we can eliminate the disabling effect of the trait, such as using cochlear implants to permit a deaf child to hear, we are saying we want to eliminate deaf children.

[185] Bonnie Poitras Tucker, "Deaf Culture, Cochlear Implants, and Elective Disability," *The Hastings Center Report* 28: 6-14 (July/August 1998), 6. For an extended look into the Deaf culture, see Sacks 1989.

together."[186] And members of the Deaf culture "characteristically think it is a good thing to be DEAF and would like to see more of it."[187]

In the 1990's, scientists began to develop devices called cochlear implants that would allow some profoundly deaf children, including some with genetic forms of deafness, to hear. If provided to children early enough, they can allow those children to acquire oral language. While widely hailed, some question the use of cochlear implants on ethical grounds. Robert Crouch questions whether parents, even those who are hearing capable, should choose cochlear implants for their deaf children. He notes that cochlear implants do not always permit children to develop sufficient hearing and oral language to be fully part of the hearing community.[188] He suggests that it may be better for the child to have the parents decline cochlear implants, which then "opens the child up to membership in the Deaf culture, a unique community with a rich history, a rich language, and a value system of its own."[189] By declining cochlear implantation for their children, parents would allow them to develop American Sign Language, or some other signed language, as a first language with a higher level of competency than they could develop oral languages through the use of cochlear implants.[190]

From those within the Deaf culture, a different argument against cochlear implants arose. As Tucker notes, some leaders of the Deaf culture movement oppose

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[186] Roslyn Rosen, a former president of the National Association of the Deaf, quoted in Edward Dolnick, "Deafness as Culture," *The Atlantic Monthly* 272: 37-53 (1993), 38.

[187] Harlan Lane and Michael Grodin, "Ethical Issues in Cochlear Implant Surgery: An Exploration into Disease, Disability and the Best Interests of the Child," *Kennedy Institute of Ethics Journal* 7: 231-51 (1997), 234.

[188] Robert A. Crouch, "Letting the Deaf Be Deaf: Reconsidering the Use of Cochlear Implants in Pre-Linguistically Deaf Children" *The Hastings Center Report* 27: 14-21 (July/August 1997), 16.

[189] Crouch 1997, 17.

[190] Crouch 1997, 19.

cochlear implants because they represent "the ultimate denial of deafness, the ultimate refusal to let deaf children be Deaf."[191] They contend that Deaf parents who choose to provide their children with cochlear implants are in effect saying "I don't respect the Deaf community, and I certainly don't want my child to be part of it."[192]

Thus, from perspectives outside and inside the Deaf culture movement, some opposed cochlear implants on the grounds that: (1) deafness was not a disability; (2) allowing deaf children to participate in the Deaf culture would be in their best interest; and (3) considering deafness as a condition to be treated, through cochlear implants, denies or fails to respect the Deaf culture and signals that being deaf is a bad condition to be in.

In the early 2000's, the increasing use of parental genetic trait selection led to a situation, similar to that faced by our hypothetical Betas, which again raised the disability critique regarding deaf children. Sharon Duchesneau and Candy McCullough are a lesbian couple.[193] They are deaf and consider themselves part of the Deaf culture. They are both professionals in the mental health field. They both hold graduate degrees from Gallaudet University. Duchesneau's undergraduate degree is in bioethics.[194] They

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[191] Tucker 1998, 9, quoting Dolnick 1993, 40.

[192] Neil Levy, "Reconsidering Cochlear Implants: The Lessons of Martha's Vineyard" *Bioethics* 16: 134-153 (2002), 141, quoting Dolnick 1993, 43 (Levy 2002a).

[193] The following facts are abstracted from Liz Mundy, "A World of Their Own," *The Washington Post Magazine*, March 31, 2002, W32 (accessed on November 30, 2002, at washingtonpost.com).

[194] Sharon was a student of John Fletcher at the University of Virginia, who suggested that she study at Gallaudet. *See* John C. Fletcher, "Deaf Like Us: The Duchesneau-McCullough Case," *L'Observatoire de la Génétique* No. 5 (2002), accessed on December 1, 2002, at "http://www.ircm.qc.ca/bioethique/obsgenetique/cadrages/cadr2002/c_no5_02/ca_no5_02_1.html.".

decided they wanted to have a baby. "One thing they knew was that they wanted a deaf donor."[195]

They asked a local sperm bank for a deaf donor. The sperm bank informed them that it does not accept sperm donations from congenitally deaf men. Not deterred, they asked a deaf man with five generations of deafness in his family to be a sperm donor. He agreed. Duchesneau, who has four generations of deafness on her mother's side, agreed to be inseminated with the donor's sperm. A genetic counselor informed them there was a 50 percent chance that a child so conceived would be deaf.

The home-based artificial insemination worked. Duchesneau gave birth to a girl, Jehanne. Jehanne is profoundly deaf.[196] Duchesneau and McCullough decided to have another baby. Using the same sperm donor and the same approach, Duchesneau got pregnant again. Before giving birth, Duchesneau said "I hope the baby is deaf."[197] McCullough said "If the baby's hearing, I'll be shocked."[198] Duchesneau told McCullough they should be prepared for a hearing baby, which would require them to learn about hearing children, noting "It's not that it's my preference, but I'm trying to think of something positive."[199] Duchesneau gave birth to a boy, Gauvin. Gauvin, it appears, is not completely deaf.[200]

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[195] Mundy, 3 of 19.

[196] McCullough wrote the following in Jehanne's baby book, under the section marked "first hearing test": "Oct. 11, 1996 -- no response at 95 decibels -- DEAF!" Mundy, 10 of 19.

[197] Mundy, 13 of 19.

[198] Mundy, 13 of 19.

[199] Mundy, 13 of 19.

[200] At his first hearing test, while Gauvin had no response in his left ear at 95 decibels, he responded at 75 decibels in his right ear.

Duchesneau and McCullough take issue with the claim that they were "trying" to have a deaf baby. Duchesneau said: "A hearing baby would be a blessing. A deaf baby would be a special blessing."[201] But McCullough said "we wanted to increase our chances of having a baby who is deaf."[202] And later, when contemplating the possibility that gene therapies could allow the replacement of the genes causing deafness, McCullough noted that there might be no more deaf children "except for those of us who choose to make more deaf children."[203]

Because Duchesneau and McCullough used genetic counseling and a congenitally deaf man's sperm to increase the chance of having a child with a specific genetic trait, rather than selecting a sperm donor based on general bodily characteristics and relying on the genetic lottery, I consider Duchesneau's and McCullough's actions to be instances of parental genetic trait selection. Many people, particularly hearing-capable people, would contend that Duchesneau and McCullough's actions would restrict, rather than expand, the range of Jehanne's and Gauvin's open futures, and so would be ethically unacceptable.

But the disability critique suggests another view. Under that critique, which would be embraced by the Deaf culture, Duchesneau and McCullough have not acted to restrict the range of Jehanne's and Gauvin's open futures. Rather, they have acted to give Jehanne and Gauvin a different range of open futures – the open futures that are available in the Deaf culture but not available in the hearing culture. Particular to those open

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[201] Mundy, 3 of 19.
[202] Mundy, 3 of 19.
[203] Mundy, 16 of 19.

futures will be Jehanne's and Gauvin's opportunity to communicate with others in sign language, which some members of the Deaf culture contend is a more expressive language than are spoken languages. And by being deaf, Jehanne and Gauvin will be able to participate with their parents in the Deaf culture, rather than participating in a culture that their parents cannot be a part of. Thus, Duchesneau and McCullough have acted to provide Jehanne and Gauvin with a range of open futures different from those that they would have if they were hearing-capable, but not a restricted range of open futures or a range of open futures less valuable than they would have if they were hearing-capable.[204] Thus, the disability critique would conclude that Duchesneau's and McCullough's actions were ethically acceptable.

I suggest that the disability critique fails to show that Duchesneau's and McCullough's actions were ethically acceptable for three reasons. First, it rests upon the mistaken supposition that if parents act to treat genetic deafness or to avoid creating children with genetic deafness, they are disvaluing persons who are deaf. We sometimes slip between descriptive claims about traits (John is deaf) and evaluative claims against persons with traits (John is disvalued because of his deafness).[205] And, as Adrienne Asch notes, we sometimes allow a trait to stand in for, and obliterate, the whole person (John is

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[204] Whether the disability critique, and the Deaf culture movement, would go so far as to support the selective abortion of a hearing capable fetus by Deaf parents is unclear. Dorothy Wertz argues that doing so would violate the goal of medicine of "helping people to live to the fullest extent possible." Dorothy Wertz, "Drawing Lines: Notes for Policymakers" in Erik Parens and Adrienne Asch, eds., *Prenatal Testing and Disability Rights* (Washington, D.C.: Georgetown University Press, 2000), 261-287, 265-66.

[205] Parens and Asch 1999, S10.

a deaf person rather than John is a person who is deaf).[206] But that is a philosophical mistake that we must guard against.[207] As Laura Purdy notes:

> My disability is not me, no matter how much it may affect my choices. With this point firmly in mind, it should be possible mentally to separate my existence from the existence of my disability. Thus I could rejoice, for instance, at the goal of eradicating nearsightedness, without taking that aim as an attempt to eradicate *me*, or people like me.[208]

Acting to avoid deafness in children does not mean that we are acting to eradicate people who are deaf or disvaluing people who are deaf. Disability advocates are concerned that if we are able to avoid deafness in children, our level of support for those persons who are deaf may diminish, and we may come to "blame" those parents who are not able to avoid, or choose not to avoid, deafness in their children. Those are valid concerns. We should not allow our increasing ability to avoid or remedy genetic conditions to result in diminishment of our support for those born with those genetic conditions. Nor should we engage in blame of parents whose children are born with those genetic conditions in the absence of genetic trait selection.[209] But those concerns do not explain away the confusion that seems to underlie part of the disability critique.

Second, the disability critique misinterprets "range of open futures" as meaning "range of sensory experiences." Unquestionably, a deaf person will have a different range of sensory experiences than will a hearing person. Those differences could be viewed as being negative (the inability to experience bird song) or as being positive (the

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[206] Parens and Asch 1999, S3.

[207] Levy 2002a, 142; John Gillott, "Screening for Disability: A Eugenic Pursuit?" *Journal of Medical Ethics* 27: II23-II27 (Supplement, October 2001), II22.

[208] Purdy 1996, 68. See also Bonnie Steinbock, "Preimplantation Genetic Diagnosis and Embryo Selection" in Burley and Harris 2002, 175-190, 182-83.

[209] For an exploration of why we should not blame parents who do not use parental genetic trait selection to avoid having a child with a deleterious genetic condition, see sections 1 and 2 of this chapter.

opportunity to communicate in sign language). But open futures are not the same as types of sensory experiences. As I have argued previously, open futures are paths to opportunities, which are significant social, cultural, educational and vocational events and experiences. On this view, there are some opportunities, such as listening to the radio or becoming a concern violinist, which deaf people cannot have or attain because of their deafness. Thus, the range of open futures for a deaf person is more restricted than that of a hearing-capable person. This is not to say that the open futures for a deaf person are less valuable than the open futures for a hearing-capable person. It says only that the range of open futures for the deaf person is more restricted.

Third, the disability critique seems to rest in part upon the view that disabilities, like abnormalities, are socially constructed.[210] Under this view, the disability resulting from deafness does not stem from the inability to hear, but rather from the societal assumption that all persons are able to hear and the absence of societal accommodations of those who are unable to hear. The degree to which a trait is employed and needed in a given society influences the extent to which an absence or deficit in that trait is considered a disability[211]. As examples, dyslexia may not be a disability in a non-literate society, blue-green colorblindness can be accommodated in a modern society and so not be a disability, and deafness was, for a time on Martha's Vineyard,[212] accommodated by

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[210] Christopher Newell, "The Social Nature of Disability, Disease and Genetics: A Response to Gillam, Persson, Holtug, Draper and Chadwick" *Journal of Medical Ethics* 25: 172-175 (1999), 173.

[211] Carl Elliott, *A Philosophical Disease: Bioethics, Culture and Identity* (New York: Routledge, 1999), 47-48.

[212] In the early part of the twentieth century, Martha's Vineyard was isolated from the rest of Massachusetts and had a high percentage of deaf residents. As a result, most non-deaf persons in the community learned sign language. In addition to using sign language to communicate with their deaf neighbors, non-deaf

the hearing-capable population and was not a disability in terms of communicating with others.[213]

But not all aspects of all disabilities are socially constructed because not all aspects of all disabilities can be overcome or accommodated.[214] As Adrienne Asch recognizes:

> Not all problems of disability are socially created and, thus, theoretically remediable. … Disability itself limits some options. Listening to the radio for someone who is deaf, looking at paintings for someone who is blind, walking upstairs for someone who is quadriplegic, or reading abstract articles for someone who is intellectually disabled are precluded by impairment alone.[215]

So, while parental genetic trait selection would be inappropriate to deal with those elements of disabilities that are socially constructed, there remain elements of disability that are not socially constructed. Accommodations, such closed captioning for the deaf and audio books for the blind, can go only so far in removing the limits that such disabling genetic traits impose. In such cases, the presence or absence of the genetic trait affects the range of open futures for the child and so becomes subject to the parental obligation to act to expand, and not to restrict or differentially select among, the child's range of open futures.

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persons sometimes communicated with each other using sign language just as they would with a deaf person. See Levy 2002a.

[213] Despite the accommodation of their deafness in communicating with non-deaf persons, deaf persons on Martha's Vineyard remained disabled in other ways, such as being able to hear train warning signals or other alarms or in being able to listen to some music.

[214] Bonnie Steinbock, "Disability, Prenatal Testing, and Selective Abortion" in Parens and Asch 2000, 108-123, 115.

[215] Steinbock 2000, 115, quoting Adrienne Asch, "Reproductive Technology and Disability" in Sherrill Cohen and Natalie Taub, eds., *Reproductive Laws for the 90's* (Clifton, N.J.: Humana Press, 1989), 66-124, at 73.

Thus, I conclude that the disability critique does not defeat my argument that when using parental genetic trait selection, parents must act to leave the same or expand the range of open futures for their children. The diminishment of the range of open futures that would result from using parental genetic trait selection to create a child with a disabling genetic trait is not entirely socially constructed. Some of the diminishment will result from impairment of capacity alone. Allowing parents to use genetic trait selection to avoid creating children with a disabling genetic trait does not imply that there is anything wrong with those persons who have been born with that genetic trait. Nor does it imply that we should not accommodate and support those persons who have been born with that genetic trait.

5. Justice Concerns

Parental genetic trait selection raises at least two types of justice concerns.[216] First, will parental genetic trait selection result in unjust advantage for those children who have undergone genetic trait selection over those who have not undergone genetic trait selection? Second, will access to parental genetic trait selection be unjustly limited to those who can afford it?

Without parental genetic trait selection, we are subject to the genetic lottery. Some of us will acquire genetic traits that will advantage us, and some of us will acquire genetic traits that will disadvantage us. For those of us who have received disadvantageous genetic traits, we can "blame" the genetic lottery. And for those of us

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[216] Justice concerns would justify a dissertation of their own, so I will only sketch these two.

whose advantageous genetic traits have assisted our successes in life, we can temper some of our pride about those successes by realizing our indebtedness to the genetic lottery.

But parental genetic trait selection has the potential to change all that. Rather than blaming, or acknowledging, the genetic lottery, we can blame or acknowledge the genetic trait selections that our parents made for us. We will no longer have the rough equality, and the rough justice, that genetic chance provides. Some of us will be exempted from the full effects of the genetic lottery and some of us will not.

Maxwell Mehlman worries that unequal access to genetic enhancement may "divide society into the enhanced and the un-enhanced" and over time, may create "a hereditary aristocracy," or as he calls it, a "gennobility."[217] He is concerned that this division may threaten our belief in the equality of opportunity and that the development of a "gennobility" may block the less advantaged from achieving social advancement through traditional means such as education and intermarriage.[218]

While these concerns are important, and should be kept in mind by parents in making genetic trait selections, we should also keep in mind that the potentials for inequality of opportunity and for the development of a "gennobility" are not

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[217] Maxwell J. Mehlman, "How Will We Regulate Genetic Enhancement?" *Wake Forest Law Review* 34: 671- 714 (1999), 687.

[218] Mehlman 1999, 688. While raising these justice concerns, Mehlman doubts they, or any regulatory process, will have much success in preventing unjust genetic trait enhancements. He doubts that parental self-regulation, professional self-regulation or governmental regulation will have much success. Mehlman 1999, 689-707. In a later article, Mehlman raises the possibilities of creating a genetic "licensing" system for those who wish to employ genetic trait enhancement and of creating a national lottery for those wishing to employ genetic trait enhancement. Maxwell J. Mehlman, "The Law of Above Averages: Leveling the New Genetic Enhancement Playing Field" *Iowa Law Review* 85: 517-593 (2000), 570-74. While intriguing, enforcing compliance with such licensing or lottery schemes would suffer the same regulatory difficulties that Mehlman discusses in the prior article.

fundamentally different from those resulting from other parental interventions. Unequal access to interventions such as education and health care can result in inequality of opportunity. And successive generations of such unequal access to parental interventions can result in the development of "nobilities," which may be difficult for the less advantaged to overcome. In most cases, we will not be able to distinguish those children who have undergone parental genetic trait selection from those who have not, unless they or their parents tell us. They will not come with a label noting what genetic trait selections they have received.

So, just as inequalities of opportunity resulting from parental genetic trait selection are not fundamentally different from inequalities of opportunity resulting from other parental interventions, our responses to those inequalities of opportunity should not be fundamentally different. Just as we should not confer greater rights on those who have received the advantages of greater education or greater resources, we should not confer greater rights on those who have received the advantages of genetic trait selection.[219]

In some situations, we may wish to mitigate the differences resulting from genetic trait selections. For example, if people with 20/10 visual acuity had a disproportionate advantage in some activity over those with 20/20 visual acuity, we might create a separate group in which those with 20/10 visual acuity compete with each other, just as we mitigate differences in strength in athletic events by creating weight categories.[220] But such mitigation would address the outcome of the genetic trait selection, not the fact

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[219] David Resnik, "Debunking the Slippery Slope Argument Against Human Germline Gene Therapy" *Journal of Medicine and Philosophy* 19: 23-40 (1994), 36-37.
[220] Mehlman 2000, 581-83.

that the trait was achieved through parental genetic trait selection. If we created a separate group for those with 20/10 visual acuity, it would apply to both those who achieved that acuity through genetic trait selection and those who achieved that acuity through the genetic lottery. Genetic trait selection may reach the point that it results in traits that do not occur through the genetic lottery. At that point, we might create a separate group for those born with such traits. But again, we are addressing the outcome of the genetic trait selection, not the fact that it was achieved through genetic trait selection rather than through the genetic lottery.

Inequalities of opportunity may result from parental genetic trait selection. But those inequalities can be mitigated just as inequalities of opportunities are currently mitigated among those favored and disfavored in the genetic lottery. Where genetic trait selections confer advantage over those who have not received such selections, society can provide services and support to minimize that advantage. For example, if genetic trait selection that increases intelligence becomes feasible, society could dedicate more educational resources to increase the intelligence of those children who do not receive that genetic trait selection. The same mitigation would be appropriate whether the population of children with increased intelligence became more pronounced through parental genetic trait selection or through unselected changes in the population. So long as the effects are mitigated, the possible inequality of opportunity arising from parental genetic trait selection does not make such trait selection unjust.

The second justice concern, related to the inequality of opportunity concern, is whether there will be unequal access to parental genetic trait selection. At present, the limited forms of parental genetic trait selection available are quite expensive, and few if any third-party payers, such as medical insurance or benefit plans, pay for those interventions. Some argue that it is unjust for genetic trait selection to be available for those parents who have considerable resources but not available to those parents who do not have such resources, especially for genetic trait selections intended to avoid severely restricting genetic conditions.

Nils Holtug argues that since justice supports society compensating those persons who have been disadvantaged in the genetic lottery by being born with severe genetic conditions, justice provides a *pro tanto* reason to provide parents with access to genetic trait selection to avoid severe genetic conditions.[221] Norman Daniels argues that justice obliges us to provide parents with access to genetic trait selections that will bring a child up to "species-normal" functioning, but justice does not oblige us to provide parents with access to other genetic trait selections.[222]

But again, the concerns about unequal access to parental genetic trait selection based on resources are not fundamentally different from concerns about unequal access to other parental interventions based on resources. Parents with greater resources can confer a number of advantages on their children that parents without such resources cannot. Thus, we should address the unequal access to parental genetic trait selection in the same ways that we address unequal access to other parental interventions. Just as society provides access to a threshold level of education for children, society should

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[221] Nils Holtug, "Does Justice Require Genetic Enhancements?" *Journal of Medical Ethics* 25: 137-143 (1999), 142.

[222] Daniels 1994, 125-27.

provide access to parental genetic trait selection that permits children to be born with a threshold level of genetic health.[223] And we should consider funding mechanisms, similar to scholarships or financial assistance, to provide access to parental genetic trait for those parents who would not otherwise be able to afford it.

We should not, however, prohibit parental genetic trait selection because of inequality of access to them. As Ronald Dworkin notes, we should not "improve equality by leveling down."[224] Just as with other technologies, such as computers, "techniques available for a time only to the very rich often produce discoveries of much more general value for everyone."[225] And as genetic technologies develop, their costs are likely to drop, making them more widely available. Thus, we should look to societal funding of parental genetic trait selection where necessary to achieve a decent genetic minimum, and to financial assistance for some other types of parental genetic trait selection, because "the remedy for injustice is redistribution, not denial of benefits to some with no corresponding gain to others."[226]

These justice concerns about parental genetic trait selection are significant. But I contend that they are not fundamentally different from other justice concerns about inequality of opportunity and inequality of access, and so should be addressed in the same ways as non-genetic inequalities of opportunity and access.

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[223] See the following section discussing a "decent genetic minimum."
[224] Ronald Dworkin, *Sovereign Virtue* (Cambridge, Massachusetts: Harvard University Press, 2000), 440.
[225] Dworkin 2000, 440.
[226] Dworkin 2000, 440.

6. Decent Genetic Minimum

Some object to unrestricted parental genetic trait selection on grounds of fairness.[227] Resnik asserts that unrestricted parental genetic trait selection "should be rejected because it could undermine equality of opportunity by generating extreme inequalities."[228] He contends that parental genetic trait selections should be restricted to a range of "genetic minimum/maximums" in which genetic traits "should not fall below or rise above these lower and upper limits."[229] Buchanan, Brock and Daniels also argue for limitations on parental genetic trait selection "to prevent inequalities of opportunity."[230] They suggest that parental genetic trait selections should be aimed at assuring a "genetic decent minimum," rather than seeking either genetic equality or allowing unlimited genetic trait selection.[231]

All of these authors recognize the practical difficulties of establishing such genetic minima or maxima. For example, how short is too short and how tall is too tall? And in the event that intelligence can be a result of genetic trait selection, what minima or maxima would we create? But assuming that the relevant societies could establish genetic minima or maxima, should we allow those minima and maxima to constrain parents from making genetic trait selections, when parents can afford to engage in genetic trait selection?

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[227] While the writers addressed in this section follow John Rawls and equate justice with fairness, not all philosophers treat the concepts synonymously.
[228] David Resnik, Pamela J. Langer, and Holly B. Steinkraus, *Human Germline Gene Therapy: Scientific, Moral and Political Issues* (Austin, Texas: R.G. Landes Company, 1999), 136.
[229] Resnik, Langer and Steinkraus 1999, 136.
[230] *From Chance to Choice*, 187.
[231] *From Chance to Choice*, 81-82.

I suggest that educational interventions again are analogous to genetic trait selection interventions in this regard. Parents with greater resources can obtain more and better educational opportunities for their children than parents with lesser resources. This can and does result in inequalities of educational opportunities among children, based on their parents' resources. But we do not constrain those parents who have the greater resources from expending them on educational opportunities for their children. While we set some educational minima, in terms of a certain number of years of compulsory education, we do not set educational maxima limiting the years of education that parents can provide for their children or limiting the amount of money parents can spend on such education.[232] We do not set such educational maxima even for those parents who are exacerbating inequalities of educational opportunities by disproportionately high spending on education over many generations. So if we do not limit the educational advantages that parents can provide for their children, why should we limit the genetic trait advantages that parents can provide for their children?

Again, I do not wish to minimize the concern that parental genetic trait selection raises for equalities of opportunity. Unlimited parental genetic trait selection does create the concern that the rich will get richer and the poor will get poorer. But as discussed above, so does unlimited parental educational expenditure. I suggest that restriction of parental genetic trait selection based on criteria such as genetic minima or maxima is neither the appropriate nor an effective means for addressing the inequalities of opportunity that may arise out of such selections. First, such restrictions are unlikely to

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[232] Although those families who have financially supported graduate students for extended periods of time might advocate such educational maxima.

be effective or enforceable. Those parents who have the resources and the desire to engage in genetic trait selections that fall outside the approved genetic minima and maxima will find ways to avoid being limited to those minima and maxima.[233] Second, we can address the inequalities of opportunity through other means. As in the educational realm, we can create resource-shifting mechanisms, such as grants and loans, to allow some of those parents who would not otherwise have the resources to engage in parental genetic trait selection.[234] Such mechanisms might be funded through surcharges on the parental genetic trait selections by parents who can afford them, through charitable systems, or through governmental funding, should a society so choose.[235] These systems would be more effective in reducing inequalities of opportunity through parental genetic trait selection than would attempts to limit or restrict parental genetic trait selection to some socially determined set of genetic minima and maxima.

While I contend that the concept of a "decent genetic minimum" does not provide an appropriate "ceiling" on parental genetic trait selection, it may prove useful in establishing a "floor" above which parents should be given access to genetic trait selection without regard for their resources. Just as many societies establish minimum amounts of compulsory publicly funded education, to reduce inequalities of opportunity, some societies might establish "decent genetic minima" in certain areas, and provide for

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[233] Françoise Baylis and Jason Scott Robert argue that some parents will inevitably engage in genetic trait selection, as it becomes available, because there are some among us "who are intent on achieving self-actualization by controlling the human evolutionary story." Françoise Baylis and Jason Scott Robert, "The Inevitability of Genetic Enhancement Technologies," *Bioethics* 18:1-26 (2004), 25. I agree that parental genetic trait selection is inevitable, but I question whether it necessarily results from such a concept of self-actualization.

[234] See Dworkin 2000, 299-303 (addressing Sen's theory of equality of capabilities).

[235] Such resource-shifting mechanisms might be difficult to create in laissez-faire societies like the United States. They might fare better in societies with more social cohesion, such as Scandinavian countries.

publicly funded parental genetic trait selections to reach those minima.[236] Elizabeth Cooke makes a similar argument, although it rests upon Amartya Sen's theory of "capability sets" rather than Daniels' theory of a decent genetic minimum based on normal species functioning.[237]

As noted above, establishing such a "floor" of a decent genetic minimum, for which parents should be given access to genetic trait selection even if they cannot afford it, is a contentious issue. It is here where Boorse's definition of disease and Daniels' definition of normal species functioning may come back into play. I contend that a "floor" of a decent genetic minimum would call for societal funding of parental genetic trait selection when in the absence of such selection, the child will suffer from such restrictions on his or her physical or mental functioning as to be considered subnormal species functioning. Thus, when a child would suffer from Tay-Sachs disease without genetic trait selection, his parents should be provided funding for genetic trait selection to avoid that disease because the disease would result in grave physical dysfunction. And when a child would suffer from genetic deafness or achondroplasia without genetic trait selection, her parents should be provided funding for genetic trait selection to avoid those conditions because they would result in levels of function of hearing or stature that would

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[236] In lieu of a decent genetic minimum, which he criticizes as not taking into account scarcity of resources, Colin Farrelly proposes a "genetic difference principle," built upon Rawls's difference principle, under which resources for parental genetic trait selection are distributed in such a way as to provide "the greatest reasonable benefit of the least advantaged." Colin Farrelly, "The Genetic Difference Principle," *American Journal of Bioethics* 4: W21-28 (2004), W26. While Farrelly makes good points regarding the problems of implementing a decent genetic minimum, I disagree with his view that the decent genetic minimum is flawed because it fails to address scarcity concerns. A child may still have a moral claim to be given access to a decent genetic minimum even though the society she is in cannot always provide such access because of resource scarcity.

[237] Elizabeth Cooke, "Germ-Line Engineering, Freedom, and Future Generations" *Bioethics* 17: 32-58 (2003), 42-44.

be below those considered normal. But when a child's physical or mental functioning without use of genetic trait selection would be within the ranges considered normal, his parents would not be provided funding for genetic trait selection because their child already has a decent genetic minimum. Those parents can still make parental genetic trait selections that comply with their obligation to expand their child's range of open futures, but they must pay for them themselves or find other sources of funding, just as parents who wish to send their child to a private school must pay to do so.

In summary, my contention is not that socially determined genetic minima, or socially determined capability sets, are irrelevant -- only that such minima should not constrain parents from engaging in genetic trait selections. They may be relevant to decisions on what parental genetic trait selections should be paid for by society when the parents cannot afford them.

7. Inauthenticity

Another concern about some genetic trait selections is whether the recipient child would be, or would perceive himself or herself to be, inauthentic. Take academic achievement as an example. Much of what we find laudable in academic achievement is the effort put forth to reach that achievement. The achievement itself is sometimes irrelevant. A computer will perform complex mathematical tasks perfectly, but we assign no great significance to this event.[238] But where a child performs the same complex

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[238] If the computer demonstrated some creativity or novelty in performing the mathematical tasks, we would assign significance to the event. I will assume the computer has not shown such creativity or novelty.

mathematical tasks, we assign significance to the effort put forth to learn to perform these tasks. And the more difficulty the child had had in mathematics in the past, the greater the significance we attach to the effort expended to reach his achievement. So a child who had learned, through his own efforts, how to perform complex mathematical tasks would feel that his accomplishments were authentic.

But might a young man, upon learning that his parents used genetic trait selection to give him increased intelligence,[239] question whether his ability to perform complex mathematical tasks was authentic? And if some genetic trait selections carry with them this risk that the recipient child would feel inauthentic, is that risk a reason not to engage in those genetic trait selections?

Gerald McKenny suggests that vulnerabilities may not be mere "obstacles to be overcome to whatever extent possible."[240] He suggests that vulnerabilities "might have ethical significance that is imperiled by efforts (whether successful or not) to overcome" those vulnerabilities.[241] He concludes that "to the extent that enhancements overcome, or lead us to deny, the vulnerability of the body, they also foreclose the kinds of self-formation that our awareness of vulnerability makes possible."[242] Erik Parens shares this

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[239] This concern arises more in behavioral genetic trait selections than in physical genetic trait selections. It is unlikely that a young woman, upon learning that she will be six feet tall rather than five feet tall because of her parent's use of genetic trait selection, will feel inauthentic on account of her height.

[240] Gerald P. McKenny, "Enhancements and the Ethical Significance of Vulnerability" in Parens 1998a, 222-237, 223.

[241] McKenny 1998, 223.

[242] McKenny 1998, 235.

concern, noting that even though inauthenticity is not a new problem, it is a problem that new enhancement technologies may exacerbate.[243]

So what if parents used genetic trait selection to improve their child's mathematic ability? Would we discount that child's academic performance, particularly where mathematics are involved? Would we consider that performance similar to the mathematical feats that some autistic savants can perform, to which we attach amazement but no sense of accomplishment? The child who had the genetic trait selection may not have to expend the same effort to reach a level of academic achievement as other children who have not had the genetic trait selection. Has he lost anything by this lack of need to struggle against his own vulnerability?

It seems to me that a child may lose something by having been born with the "silver spoon" of genetic trait selection, and that this potential loss is something that parents should consider in deciding whether to engage in genetic trait selection. But, as Parens notes, this problem is not special to genetic trait selection. Those children who, through the genetic lottery, are born with genetic traits that enhance their intellectual abilities, may face the same loss of the need to struggle against their vulnerabilities. Some may feel inauthentic as a result, because the achievements their contemporaries must expend effort to reach simply comes "naturally" to them. This feeling often arises among "gifted children," who may feel guilty for reaching achievements with so much less effort than their contemporaries exert. But while we sometimes denigrate such "natural" academic achievements, we more often positively acknowledge the genetic

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[243] Erik Parens, "Is Better Always Good? The Enhancement Project" *The Hastings Center Report* 28: S1-S15 (January/February 1998), S13 (Parens 1998b).

traits that lead to those achievements by assigning words like "gifted" and "genius" to such children. And we sometimes create special educational programs for such children. So whatever loss of authenticity may result from the absence of need to struggle against an academic vulnerability may be balanced out by the positive acknowledgement given to having those genetic traits.

The same may not be true, however, where the advantages are conferred directly by the parents. Where such increased ability comes from the genetic lottery, we celebrate it. But where the increased ability comes from advantages conferred by the parents, we are more skeptical. Some parents have the resources and the desire to provide their children with advantages that their colleagues lack. Those advantages may include special schools, tutoring and other training opportunities. We may be more dismissive of the achievements of those children who have received those advantages. We may be concerned about the inequality of access to those advantages.[244] And the children who have received those advantages may feel inauthentic as compared with their less advantaged colleagues. But it is notable that we do not try to stop those parents who have the ability to confer such advantages on their children from doing so, even when we may express some jealously over their ability to do so.

Inauthenticity is a concern that parents should take into account in deciding to engage in genetic trait selection. Parents may have an obligation to ameliorate the risks

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[244] One example of potentially inequitable access to advantages are "legacy admissions" to colleges and universities, in which children of graduates of a college or university receive more favorable treatment in admission than are children of non-graduates who are similarly situated. In highly competitive colleges and universities, such legacy admissions create the potential for an unjust admission system that reinforces educational access to a selected class (families of prior graduates) and denies educational access to others.

of inauthenticity by addressing this issue with their children. And we may have understandable concerns about the inequality of access to genetic trait selection that may underlie much of this inauthenticity. But the risk of inauthenticity, alone, is not a reason to prohibit parents from engaging in genetic trait selections. So long as the genetic trait selections expand the child's range of open futures, the parents' actions are ethically permissible, even if they must address the issue of inauthenticity with their children later in their lives.

8. Shortcutting

In a line of criticism similar to the inauthenticity argument, Eric Juengst suggests that a genetic trait selection could be a "biomedical shortcut [that] some how cheats or undercuts the specific social practices that would make the analogous human achievement valuable in the first place."[245] This "shortcutting" concern applies less to the genetic trait selections sought by our hypothetical parents, all of whom wish to select for particular physical conditions, than to other genetic trait selections that would select for particular behavioral conditions. As discussed above, if parents could select a genetic trait of "increased intelligence," would that child's academic performance be as laudable as the same level of performance achieved by a child who had not undergone the same genetic trait selection? If parents could select a genetic trait of "increased courage," would that child's performance of courageous acts be as laudable as those performed by a child who had not undergone the same genetic trait selection?

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[245] Eric T. Juengst, "What Does *Enhancement* Mean?" in Parens 1998a, 29-47, 39. Juengst addresses enhancing technologies in a broader context, including pharmacological or surgical interventions.

Erik Parens raises an example of how a genetic or technical shortcut may deprive the child of the value of struggling through vulnerability. He considers the outcome of the creation an "acceleration hormone" that could speed children through adolescence.[246] He acknowledges that "adolescence is a time of pain and danger to the people going through it, as well as to the rest of us" and that compressing adolescence "could significantly reduce pain and the expenditure of valuable social resources."[247] Despite these advantages, he suggests that society would not want to use such an acceleration hormone because "we think that we ought to caringly respond to the pain of adolescence rather than engineer a way around it."[248] He contends that by accelerating a child's adolescence, the child would lose "the shared recognition and acceptance of human neediness," which he believes is profoundly valuable.[249]

Parens does raise a significant concern about genetic trait selections and their possible effects on the children for whom such selections are made. Behavioral genetic trait selections, such as increasing intelligence, increasing courage or reducing the angst of adolescence may be shortcuts. But they are in some ways like traits selected for indirectly or traits emphasized by parents after birth. A person seeking to have a child with "increased intelligence" may seek out a partner with high intelligence, so as to increase their chances in the genetic lottery of having a child with increased intelligence. The same could occur for increased courage. After birth, parents may engage in a broad

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[246] Erik Parens, "The Goodness of Fragility: On the Prospect of Genetic Technologies Aimed at the Enhancement of Human Capacities" *Kennedy Institute of Ethics Journal* 5: 141-153 (1995), 144-145 (Parens 1995b).
[247] Parens 1995b, 145.
[248] Parens 1995b, 145.
[249] Parens 1995b, 145.

variety of interventions to attempt to increase their child's intelligence: nutritional, behavioral, educational, and even medical.[250] So too may parents engage in interventions to attempt to increase their child's courage. While we may find more laudable those who accomplish feats of intellect or courage who have not had the advantages of these technologies, we do not dismiss accomplishments by those who have been advantaged.

So, at what point, if any, would such a shortcut created by parental genetic trait selection make the parents' action ethically objectionable? I contend that unless the genetic trait selection makes a person able to engage in otherwise laudable behaviors (such as solving differential equations or entering a burning building) without effort or reflection, the advantage conferred by the genetic trait selection does not undercut the moral significance of the actions performed and so does not make the parents' action ethically objectionable. A person with increased intelligence, whether through genetic trait selection or through post-natal education, may or may not put that increased intelligence to use. If he does, then his accomplishment is laudable, regardless of the source of that increased intelligence, unless the accomplishment required no effort. If he does not, then his failure is lamentable, again regardless of the source of his increased intelligence. Similarly, a person with increased courage, whether through genetic trait

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[250] But such interventions to emphasize intelligence and education may have negative side-effects. Some parents of particularly intellectually capable children face the choice of having their child skip most or all of high-school and enter college or university early. While taking that option may enhance the child's intellectual development, it may hinder the child's emotional development. As a biographical example, my parents took advantage of an option of having me skip from first grade to third grade. While this certainly enhanced my intellectual development, it had an unintended effect on my emotional and social development. By skipping that grade, when I entered junior high school and high school I was younger (and for much of that time, smaller) than my classmates. This, I believe in hindsight, made my emotional and social development during adolescence more difficult than it would have been if I had been the same age as my classmates. While my parents choice for me was appropriate, it was not wholly good.

selection or through post-natal training, may or may not put that increased courage to work. If she does, her accomplishment is laudable, regardless of the source of that increased courage, unless the accomplishment required no risk. But if she has feet of clay and fails to act, then her failure is lamentable, again regardless of the source of her increased courage. So in most circumstances, the parents' use of genetic trait selection to select for behavioral traits does not create an ethically objectionable shortcut to the behaviors exhibited by the children for whom those traits have been selected.

As with inauthenticity, shortcutting is a concern that parents should take into account in deciding to engage in behavioral genetic trait selection. The children who receive such selections will likely encounter negative reactions from those who believe that shortcuts of any form, genetic or not, are simply unfair to those who have not received such selections. In addition, Darren Shickle contends that enhancement may diminish the value of struggle. He contends that "the more we have to struggle to attain a thing, the stronger the claim to possession."[251] He worries that enhancement may allow a person to possess a status, which other persons must attain through struggle, without having engaged in any struggle, and thus be unprepared for the trials of life that require struggle.[252] But he also notes that "even if genetic enhancement were able to satisfy all the goals for which we normally struggle, human nature is unlikely ever to be satisfied; new desires will emerge and the struggle will continue until technological solutions are

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[251] Darren Shickle, "Are 'Genetic Enhancements' Really Enhancements?" *Cambridge Quarterly of Healthcare Ethics* 9: 342-352 (2000), 349.

[252] Shickle 2000, 349.

found for these too."[253] I agree. Parents should be concerned that they not create so many shortcuts for their children, whether through genetic trait selection or through post-natal interventions. If their children do not have areas in which they are needy and must struggle, they may not develop the drive, persistence and ambition needed to overcome challenges they will encounter when they are adults. If they create that many shortcuts, then the parents may be restricting the child's range of open futures, in that the child may not be able to pursue those futures that require persistence, drive and ambition.[254] Further, without some challenges against which they must struggle, children may not develop levels of sympathy and empathy that are necessary to certain open futures, such as those in the helping professions. And as I have argued, such parental genetic trait selections that restrict the child's range of open futures are ethically objectionable. But the risk of loss through shortcutting, alone, is not a reason to prohibit parents from engaging in genetic trait selection.

Genetic trait selections that select for particular physical conditions may not be objectionable shortcuts to accomplishment in the same way as are behavioral genetic trait selections. As a University of Washington basketball coach once noted, "you can't coach height." But they may raise a related objection: artificial advantage. A person with 20/10 vision may have an advantage in hitting a baseball over a person with 20/20 or worse vision. A person who stands seven feet tall may have an advantage in a basketball

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[253] Shickle 2000, 350.

[254] Such shortcuts may also restrict the child's opportunities for happiness. For example, John Dewey argues that value itself, including the value of happiness, arises from struggling against such challenges. "Happiness is found only in success; but success means succeeding, getting forward, moving in advance. It is an active process, not a passive outcome. Accordingly it includes the overcoming of obstacles, the elimination of sources of defect and ill." John Dewey, *Reconstruction in Philosophy* (New York, New American Library of World Literature, 1950), 143.

game over one who stands six feet tall. So if parents select for such genetic traits, are the athletic accomplishments of those children compromised? Should their hits or baskets count less than those of persons who have not undergone genetic trait selection? Perhaps they should not even be allowed to compete against those who have not undergone genetic trait selection.

Again, this objection to genetic trait selection assumes, incorrectly, that there is some difference in kind between traits achieved through genetic trait selection and those traits selected for indirectly or emphasized by parents after birth. A tall person seeking a tall child may select a tall partner to increase her chances. Heights of seven feet or greater can be obtained through the genetic lottery, as can vision more acute than 20/20. Uncontroversially, parents may use nutritional interventions to maximize their child's growth potential. Controversially, parents may use medical interventions, such as injections of human growth hormone, to increase their child's height. And parents may use training techniques to improve their child's visual acuity. These interventions do not invalidate the accomplishments of the children. Nor do they result in the children being ineligible to compete with or against those who have not had the advantages of these interventions.[255] So why would we invalidate the accomplishments, or restrict the

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[255] It is conceivable that the physical traits that might be achieved through genetic trait selection could force changes in competitive events. If we could select for children who grew to be nine feet tall, the sport of basketball, for example, might change. But it is the presence of such physical traits, not the means by which they are accomplished, that would necessitate the change. Basketball players over seven feet tall were rare before the 1970's. Now, as a result of developments other than genetic trait selection, basketball players of such height are relatively common. Basketball initially chose to reduce the advantage of such players by prohibiting the dunk shot. But over time, it became apparent that such height alone did not give those players such an advantage that shorter players could not compete, and so the prohibition was lifted. At juvenile and recreational levels of some sports, some competitions are limited to players of certain ages, heights or weights, so as to reduce undue advantage and to increase competition. Sports such as basketball

participation, of those who have undergone genetic trait selection? Only if we view genetic trait selection as different in kind from these other interventions. In most cases, there is not enough difference in kind between traits achieved through genetic trait selection and traits achieved through other interventions to make those parental genetic trait selections ethically objectionable.

In some cases, though, the trait achieved through genetic trait selection might be so different in degree from that achievable through other interventions as to make them different in kind. For example, while interventions like nutrition or even growth hormone administration might make a child an inch or two taller than she would have otherwise been, a genetic trait selection might result in the child being two feet taller than she would have otherwise been. This might be said to be a difference in kind between the interventions. But as I have argued above, a genetic trait selection that would make a child, who would otherwise be of typical height, two feet taller would either restrict the child's range of open futures or differentially select among the child's open future. While the creation of a nine-foot tall person, through genetic trait selection, would give that person an advantage in some sports,[256] his range of open futures in other areas would be restricted. Given that society would not have had time to adjust to the presence of persons of such height, as it has been able to adjust to gradually increased height through non-genetic interventions, many opportunities would be foreclosed to persons of such

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might have to adopt such limitations if players started appearing with physical traits that gave them such an undue advantage that competition would be stilted. But again, that would result from the appearance of the trait, not just the fact that the trait was achieved through parental genetic trait selection.

[256] The advantages conferred on such a player could be reduced by changes in the rules, as basketball did when it banned the dunk shot for a time after the sudden appearance of players who were tall and athletic enough to dunk.

height. They would have difficulty finding mates, jobs, houses, vehicles, clothes and many other elements of life that would accommodate such height.[257] So, in instances where a genetic trait selection results in a trait so different in degree from that achievable through other interventions, that genetic trait selection is likely to restrict the child's range of open futures or at least select differentially among the child's open futures. As a result, such parental genetic trait selections would be ethically objectionable on that ground, not on the ground that the genetic trait selection created a shortcut or unfair advantage to the child.

9. Fragility and Diversity

Another concern that some ethicists have raised is whether parental genetic trait selection may cause us to lose another part of our humanness, our fragility. Parens asks "in some of our attempts to enhance humans, [will we] inadvertently impoverish them by reducing what I will call their fragility?"[258] He defines fragility as being "subject to change and to chance."[259] He notes that if we can select for traits resulting in longer life spans, we may change the experiences of caring and being cared for, and so may change that part of our human nature that involves "the shared recognition and acceptance of human neediness."[260] Similarly, he is concerned that if genetic trait selection reduces the

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[257] Some people with pituitary disorders attain heights of eight feet and often have difficult lives, both because the lack of accommodations for their heights and because of other health problems caused by the disorders. While genetic trait selection for such height would likely avoid the latter problem, it would not avoid the former problem until there were enough people of that height to spur accommodation of such heights.

[258] Parens 1995b, 143.

[259] Parens 1995b, 143.

[260] Parens 1995b, 145.

diversity among people, we might "reduce the need to respond to the vulnerability of others that results from our subjection to chance" and so may lose the goodness of chance.[261] So, he is concerned that enhancements may "promote a turning away from the vulnerability, imperfection and finitude that is constitutive of life altogether" and risk missing our "full humanity."[262]

Parens' concerns should be heeded in assessing whether parental genetic trait selection truly expands the range of open futures for the child. The anticipation of variability in a child is part of the reproductive process. Will the baby have her father's nose? Her mother's eyes? Will he grow up to be a teacher or a soldier? In making genetic trait selections, parents should be concerned with whether they are trying to specify too many of the variable elements of their children's genetic traits, and so may be trying too hard to control their children's destinies. But parents should have the same concern about trying too hard to control their children's destinies through the education, activities and interventions they select for their children after birth. Parents should also worry whether they are trying to make their children too much like other children. Just as not too many parents should name their children Ethan or Emily,[263] not too many parents should select the same genetic traits for their children. Fragility and variability are important concerns. Just as with inauthenticity and shortcutting, parents who go too far

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[261] Parens 1995b, 147.

[262] Parens 1998b, S13. Christian bioethicists raise similar concerns about vulnerability and variability as being constitutive parts of human nature that should not be eliminated through genetic trait selection. See James F. Keenan, "Whose Perfection is it Anyway? A Virtuous Consideration of Enhancement" *Christian Bioethics* 5: 104-120 (1999), and Joel Shuman, "Desperately Seeking Perfection: Christian Discipleship and Medical Genetics" *Christian Bioethics* 5: 139-153 (1999).

[263] Ethan and Emily were the most popular names for babies in the state of Washington born in 2002. See www.doh.wa.gov/ehsphl/chs/chs-data/birth/bir_100.htm.

in using genetic trait selection may restrict the range of the child's open futures by denying them futures that depend on their diversity from other people and their ability to respond to such diversity. But so long as the parents do not go so far as to restrict the range of their child's open futures, concerns about fragility and variability alone do not make the parents' use of genetic trait selection ethically objectionable.

10. Just Saying No: The "Playing God" and Repugnance Objections

In one of the first published comments on the ethics of genetic intervention, Paul Ramsey wrote "men ought not to play God before they learn to be men, and after they have learned to be men they will not play God."[264] Since then, some opposed to genetic trait selection, particularly those opposed to genetic enhancement, have asserted that if we engage in genetic trait selection, we are "playing God." More recently, Leon Kass has invoked the "playing God" objection,[265] and has added the objection of repugnance,[266] to genetic enhancement. In this section, I consider what these objections mean and conclude they are not sufficient to justify a bar to parental genetic trait selection.

First, what do people mean when they say others are "playing God" if they engage in parental genetic trait selection? Ted Peters suggests that the term "playing God" has three meanings: (1) learning God's awesome secrets; (2) wielding power over

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[264] Paul Ramsey, *Fabricated Man: The Ethics of Genetic Control* (New Haven: Yale University Press, 1970), 138.
[265] Leon R. Kass, "Triumph or Tragedy? The Moral Meaning of Genetic Technology" *American Journal of Jurisprudence* 45: 1-16 (2000), 9.
[266] Leon R. Kass, "The Wisdom of Repugnance: Why We Should Ban the Cloning of Humans" *Valparaiso University Law Review* 32: 679-705 (1998), 699-700.

life and death; and (3) altering life and influencing human evolution.[267] Peters contends that the third meaning is the meaning invoked by opponents of parental genetic trait selection, in that "we are substituting ourselves for God in determining what human nature will be."[268] He suggests that a correlate of this meaning of "playing God" is that "DNA has come to function in effect as an inviolable sacred entity, a special province of the divine that should be off limits to mere mortals."[269] Peters then rejects both contentions, arguing that humans are co-creators with God of human nature, and in using genetic trait selection to seek a better future, humans are "playing human" as God intended.[270] He also rejects as arbitrary any special, sacred position of DNA making it immune from human intervention.[271]

Kass, by contrast, believes that the "playing God" objection does support a bar to genetic trait selection. He defines "playing God" slightly differently: "not only are [men] creating life, but they stand in judgment of each being's worthiness to live or die (genetic screening and abortion) – not on moral grounds, as is said of God's judgment, but on somatic and genetic ones; they also hold out the promise of salvation from our genetic sins and defects (gene therapy and genetic engineering)."[272] He suggests that without the "norm of health" conferred by God when creating man, there are no standards to guide

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[267] Ted Peters, *Playing God? Genetic Determinism and Human Freedom* (New York: Routledge, 1997), 10-11.
[268] Peters 1997, 11.
[269] Peters 1997, 12.
[270] Peters 1997, 144. See also Ted Peters, "'Playing God' and Germline Intervention" *Journal of Medicine and Philosophy* 20: 365-386 (1995), 377-79.
[271] Peters 1997, 13.
[272] Kass 2000, 9.

genetic trait selection, resulting in the commodification of the human body and in the loss of human dignity.[273]

In an earlier work, directed primarily at human cloning, Kass suggested that when we oppose something on the grounds of "playing God," we are expressing "repugnance" about "the violation of things that we rightfully hold dear."[274] "Repugnance," in Kass's view, "revolts against the excesses of human willfulness, warning us not to transgress what is unspeakably profound … repugnance may be the only voice left that speaks up to defend the central core of our humanity."[275]

Kass contends that any means of reproduction other than sexual reproduction becomes a process of manufacture that moves us away from our humanity. Thus, he opposes the use of *in vitro* fertilization and pre-implantation genetic diagnosis. He engages in a classic slippery slope argument in which once one form of intervention in reproduction is permitted, all forms of intervention in reproduction, including cloning, are permitted.[276]

But Kass does not address why parental genetic trait selection through indirect pre-implantation genetic trait selection or through direct genetic manipulation is different from indirect pre-conception genetic trait selection through mate selection. As noted earlier, humans have engaged in some form of genetic trait selection throughout their

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[273] Kass 2000, 11.

[274] Kass 1998, 687.

[275] Kass 1998, 687.

[276] Kass may be engaging in either a logical slippery slope argument or a psychological slippery slope argument. If he is engaging in the former, I contend that one of his premises, that all interventions in reproduction are identical ethically, is false. If he is engaging in the latter, he is unduly pessimistic about our ability to create ethically meaningful distinctions among interventions in reproduction. If we can fashion a sufficiently sharp tool, we can stop ourselves from sliding down the slipperiest of slopes.

evolution. Genetic trait selection through pre-implantation or direct genetic trait selection is only a change in technique. And humans have influenced their evolution through other actions, such as modifications to their environments through improvements in public health and nutrition, and through degradations such as pollution. Nor is DNA immutable and sacred. Even during the course of one's life, the DNA in some cells mutates, sometimes causing disease. But few people suggest that societal interventions regarding the environment, or medical interventions regarding a disease caused by mutation, constitute "playing God" in a way that bars us from intervention. If the notion of "playing God" is to serve as meaningful bar to parental genetic trait selection, we must look elsewhere.

Kass's concern may be the issue of control over the likelihood of success of the genetic trait selection – using pre-implantation genetic diagnosis or direct genetic modification to increase height is a more certain means of selecting a tall child than selecting a tall mate. But Kass seems to be making a stronger claim, in which part of our humanness comes from our coming about through sexual reproduction, as he contends God intended,[277] without "repugnant" interventions by humans.

Much of Kass's concern about reproducing in ways other than sexual reproduction is that we may be commodifying the resulting children. He contends that "the price to be paid" in reproducing in ways other than sexual reproduction is "the transfer of procreation from the home to the laboratory and its coincident transformation

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[277] One may wonder why, on this view, God allowed humans to learn how to perform *in vitro* fertilization and how to engage in cloning, at least in some species. Kass would likely reply that God gave humans the wisdom to not use those technologies on humans, even though they knew how to do so.

into manufacture."[278] He asserts that "such an arrangement will be profoundly dehumanizing, no matter how genetically good or healthy the resultant children."[279] This assertion seems to assume that humanity attaches to a child by virtue of its production through sexual reproduction. I see no grounds for such an assumption. Parents are just as capable of commodifying a child, producing a child as a product or commodity, through sexual reproduction as they are through reproduction using genetic interventions. They can have and raise a child with the intent of making her a concert pianist, or of making him a professional football player, so that child can make a great deal of money and support them in their old age. If this is their sole intent, then those parents would seem to be treating their child as a commodity.

This argument regarding commodification has arisen in cases where parents, who have a child who suffers from a bone marrow disorder, have used pre-implantation genetic diagnosis to select for an embryo that is free of the disorder, such that stem cells from the later child could be transplanted into the earlier child as a means of treating the bone marrow disorder.[280] Those who view parental genetic trait selection as playing God assert that the parents are creating the later child simply as a means of creating stem cells that can treat the earlier child's disorder, thus turning the later child into a commodity. But if the parents are committed to raise and love the later child just as they would if she did not have stem cells that were compatible with her elder sibling, then the fact that the parents can both have another child to love and raise who they ensure also has compatible

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[278] Kass 2000, 10.

[279] Kass 2000, 10.

[280] Yury Verlinsky, et al., "Preimplantation HLA Testing," *Journal of the American Medical Association* 291: 2079-85 (2004).

stem cells does not make the later child a commodity. Denying parental genetic trait selection for such purposes would result in: (1) the elder child not receiving optimally compatible stem cells; (2) the parents having a child without using pre-implantation genetic diagnosis who would have only a 1 in 4 chance of having compatible stem cells; or (3) the parents using pre-natal testing to determine whether their fetus has compatible stem cells and then deciding whether to terminate the pregnancy of fetuses who do not have compatible stem cells. Given these alternatives, parental genetic trait selection to ensure compatible stem cells does not seem ethically objectionable. It is also consistent with my thesis that in using parental genetic trait selection, parents must expand the range of open futures for their child. By using pre-implantation genetic diagnosis to ensure that the embryo they implant has compatible stem cells, the parents are expanding their child's future to include a future where the child has the chance to assist her elder sibling by providing compatible stem cells, a future she might not otherwise have.

While Kass is right that we must be concerned about parents commodifying their children, he is wrong in believing that such commodification arises necessarily and exclusively from parents using means other than sexual reproduction to bring children into the world. By contrast, if parents use genetic interventions in order to have a child, and do so with the intent to love that child and give him or her the means of pursuing whatever open futures are available to that child, then those parents seem to be no more engaged in commodification than other parents who have a child through sexual reproduction.

If, as Kass claims, "playing God" means any intervention in the process of sexual reproduction, then, of course, it serves as a bar against parental genetic trait selection by any means other than mate selection. But it would also serve as a bar against any other genetic interventions, including those that return a child to a norm of health. Curiously, Kass seems to want to have it both ways. At one point, Kass says he is not in favor of "killing the goose of genetic technology even before she lays her golden eggs."[281] But he also maintains that we will not be able to "defend the boundary between therapy and genetic enhancement."[282] So if Kass opposes genetic enhancement, he must oppose genetic treatment, and thus kill the goose.

Kass's "playing God" argument against genetic trait selection works only if all interventions in sexual reproduction are barred. Without a boundary between therapy and enhancement, he does not adequately show why some interventions would not be "playing God," while genetic trait selection would be "playing God." And he fails to show why such interventions necessarily commodify and dehumanize the resultant children. So Kass's argument does not serve as a bar against all parental genetic trait selection.

11. Shopping at the Genetic Supermarket

At the other end of the spectrum, some contend there should be no limits on what genetic trait selections parents may make on behalf of their children. They invoke the concept of a "genetic supermarket," a term coined by Robert Nozick, in which parents

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[281] Kass 2000, 16.
[282] Kass 2000, 3.

may make genetic trait selections to meet their individual specifications.[283] Gregory Pence, who enthusiastically supports genetic trait selection, contends that "the only place where some parental decisions about children could be banned in advance is where people clearly agree that such decisions harm children."[284] But he questions the ability of the government to determine in advance which parental decisions harm children. So he invokes an optimistic view in which he sees "no reason to assume the worst in people, especially about parents in relation to their own kids" and contends "eugenics-from-parental-choice is a widespread fear -- the 'perfect baby' fear -- but it is largely just that, a fear, not an empirical fact."[285]

Should we give the green light to parents to engage in any genetic trait selections they desire? No. Nozick noted that even in the genetic supermarket, parents would be bound to make their genetic trait selections "within certain moral limits," although he does not elaborate on what those limits might be.[286] Pence concedes that parents could be prohibited from genetic trait selections when those selections clearly harm children, although he questions what such selections might be. Matthew Clayton contends that the genetic supermarket should not offer genetic trait selections that restrict the child's capabilities of developing a sense of justice and for leading an autonomous life.[287]

I suggest that to make a genetic supermarket approach ethically acceptable, two limits would apply to genetic trait selections that parents might make. The clearer is a

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[283] Robert Nozick, *Anarchy, State, and Utopia* (New York: Basic Books, Inc., 1974), 315.

[284] Gregory E. Pence, *Re-Creating Medicine: Ethical Issues at the Frontiers of Medicine* (Lanham, Maryland: Bowman & Littlefield Publishers, Inc., 2000), 116.

[285] Pence 2000, 116-17.

[286] Nozick 1974, 315.

[287] Matthew Clayton, "Individual Autonomy and Genetic Choice" in Burley and Harris 2002, 191-205, 198.

limit against genetic trait selections chosen to improve the condition of the parents at the cost of restricting the child's range of open futures. Take, for example, parents who have three children with celiac disease.[288] Celiac disease is a genetic disorder in which a person is intolerant to gluten, a protein found in wheat, rye and some other grains. Treatment of celiac disease is limited to strict adherence to a gluten-free diet, and such strict adherence is very difficult, given the prevalence of gluten in prepared foods. These parents are now planning a fourth child. They seek genetic trait selection to assure that their fourth child also has celiac disease, not because it would be beneficial for the child, but because it would make it easier to care for all four children on the same diet, rather than a gluten-free diet for the first three children and a regular diet for the fourth child.[289] This genetic trait selection might improve the parents' condition, but it would do so at the cost of restricting the child's range of open futures, and so would need to be prohibited under a genetic supermarket model to make it ethically acceptable.

The second limit under the genetic supermarket model, which is murkier, involves genetic trait selections chosen to improve the condition of the parents, which may or may not restrict the child's range of open futures. Take, for example, parents who wish their child to be a star athlete, not because they think it would be in the best interests of the child to be a star athlete, but because they think they could get rich because of their child's stardom. So they make genetic trait selections that improve the chances of their

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[288] I take this example from Green 1997, 12-13.

[289] The child without celiac disease could be raised on a gluten-free diet. But given the limitations of such a diet, once the child became aware that she did not have to be on such a diet in order to stay healthy, the parents might have a difficult time convincing her that she needed to stay on the diet along with her siblings.

child becoming a star athlete. None of those genetic trait selections restricts the child's range of open futures, in contrast to the celiac disease example. But some of those genetic trait selections, such as making the child significantly taller or bigger than he would otherwise have been, decrease the chances of the child pursuing other possible futures. It may turn out that the child does want to become a star athlete, and so has not been harmed by the parents' genetic trait selections. But does that "good result" justify the parents' decision? I contend it does not, because the parents did not expand the range of open futures for their child. They have selected differentially among open futures. Their child may not want to become a star athlete but rather may want to pursue one of the possible futures that the parents' genetic trait selection made more difficult to achieve. Such parental trait selections, made in the parents' best interest but not made to expanding the child's range of open futures, would also need to be prohibited under a genetic supermarket model to make it ethically acceptable.

So even under a genetic supermarket approach to genetic trait selections, parents must act within the limit of acting to expand the child's range of open futures. They must not use genetic trait selection solely for their interests, either by making a genetic trait selection that restricts their child's range of open futures (the celiac disease example) or by making a genetic trait selection that differentially selects among their child's open futures (the star athlete example). Like Pence, I am optimistic that few parents would engage in genetic trait selections solely for their own benefit. I believe that most parents would engage in genetic trait selection in what they believe to be the best interests of their child. But is this subjective constraint sufficient? Does the parents' mere assertion that they are acting in their child's best interests make their genetic trait selection ethically acceptable, even when that genetic trait selection seems to others not to be in the child's best interests? No. In order to protect against parental self-delusion or dissembling, the parents' genetic trait selection must be measured against the standard of whether the genetic trait selection expands the range of open futures available to the child.

12. Effects on Identity

Some, particularly those who subscribe to the playing God objection to genetic trait selection, might object to parental genetic trait selection on the ground that in using it, the parents are changing the child's identity. They might also contend that changing the child's identity through parental genetic trait selection would interfere with the identity that the child was intended to have, making the use of genetic trait selection ethically objectionable.

Many parental actions can change their child's identity, in that they change the child's history and change the experiences, attitudes and beliefs that their child has. Parental genetic trait selections could change the identity of their child because they make the child's genomic structure, and the traits that structure expresses, different from what it would have been without the genetic trait selection. But some changes to the child's genomic structure result in no change to the traits expressed by that structure. And some changes to the child's genomic structure result in only trivial changes to the traits expressed by that structure. Further, even when children have the same genomic structure, they may not have the same identity. We refer to those twins who are conceived of a single ovum and single sperm as identical twins, because they have the same genomic structure. But even identical twins have separate identities. So, in claiming that parental genetic trait selection changes the identity of the child, we must be referring to something other than simply a change in the child's genomic structure. I will use the term "personal identity" for this notion of identity that is other than genomic identity.[290]

Some genetic trait selections, such as eye color or hair color, seem unlikely to affect the personal identity of the child. But what of the children of the Alphas and the Betas? Does being born hearing capable instead of deaf change the Alphas' child's personal identity? Does being born deaf instead of hearing capable change the Betas' child's personal identity? Similarly, would the genetic trait selections regarding height, as sought by the Gammas, the Deltas and the Epsilons, affect the personal identities of those children? Claims that these types of genetic trait selections affect personal identity are not so easily dismissed. What kinds of genetic trait selections might result in changes to the personal identity of the child?

As part of his work on the Non-Identity Problem, Derek Parfit proposes that identity is fixed at the point of conception, such that interventions before conception are

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[290] The concepts of "identity" and of "personal identity" are debated vigorously in the philosophical literature and are used in many contexts. I make no effort to settle or adjudicate those debates. I merely suggest one basis for assessing whether a parental genetic trait selection might be said to change the child's personal identity, and if so, whether that would be ethically objectionable.

not person-affecting and interventions after conception are person-affecting.[291] But he does not address genetic trait selections, no doubt because the technology to effect such selections did not exist at that time. More recently, Ingmar Persson, Robert Elliot and Eric Olson have contended that identity is fixed when the cells of an embryo differentiate and a zygote (a "conceptus" in Persson's and Elliot's terminology) is formed at 14-17 days after conception.[292] At this developmental stage, twinning is no longer possible, so on their views, identity is established. Thus, genetic therapy on fetuses once they reach the zygote stage does not affect their identity.[293]

But what of genetic trait selections, many of which would occur before differentiation of the embryo into a zygote? What types of genetic trait selections should cause us to worry about whether the identity of the child will be changed as a result? As suggested above, minor cosmetic selections, like eye color or hair color would not change the child's personal identity. But if parents use genetic trait selection to change an embryo's sex chromosomes from XY to XX, thus resulting in the birth of a girl instead of

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[291] Derek Parfit, "On Doing the Best for Our Children" in M.D. Bayles, ed., *Ethics and Population.* Cambridge, Massachusetts: Schenkman Publishing Co., 1976), 101-02.

[292] Robert Elliot, "Identity and the Ethics of Gene Therapy" *Bioethics* 7: 27-40 (1993), 31; Ingmar Persson, "Genetic Therapy, Identity, and the Person-Regarding Reasons" *Bioethics* 9: 16-31 (1995), 20-21; Eric T. Olson, *The Human Animal: Personal Identity Without Psychology* (New York: Oxford University Press, Inc., 1997), 91-93; Robert Elliot, "Genetic Therapy, Person-Regarding Reasons and the Determination of Identity" *Bioethics* 11: 151-160 (1997), 151-52; Ingmar Persson, "Genetic Therapy, Person-Regarding Reasons and the Determination of Identity – A Reply to Robert Elliot" *Bioethics* 11: 161-169 (1997), 161-62.

[293] Elliot and Persson differ on what effect genetic therapy might have on the "personal identity" of the zygote upon whom the genetic therapy is performed. Elliot adopts a "personalist" position, in which personal identity is more than biological identity, and so through changes during development, different "persons" may develop from a single zygote. Elliot 1993, 36; Elliot 1997, 155-57. Persson takes an "animalist" position, in which personal identity is continuous with biological identity. Persson 1995, 20-24; Persson 1997, 163-65. Olson takes a position similar to Persson, referring to a "Biological Approach" to personal identity. Olson 1997, 91-93. As noted above, I shall not attempt to wade into the thicket of the debate over personal identity.

a boy, most of us would be hard-pressed to say that this selection does not change the personal identity of the child. Is there a plausible boundary between these extremes?

Philosophers have long struggled with marking a boundary between identity-affecting genetic trait selections and non-identity-affecting genetic trait selection. In an early work on the ethics of genetic engineering, David Heyd noted that:

> the exact combination of genetic qualities that fix identity cannot be abstractly formulated. I still would have been *I*, had my parents genetically caused a change in the color of my eyes. It would *not* have been I, had they – immediately after "my" conception – brought about a change in the sex of the embryo. But in between these two extreme poles there is an indefinite number of possible configurations of traits that separately and in combination contribute to the way I see myself as a unique individual.[294]

But Heyd provides little help in determining which genetic trait selections would affect identity. He proposes that identity is a "genesis problem," in which identity is formed through a "tree-like process" where "constraints on branching [are] imposed by the nature of the already existing stem."[295] In this model, the "stems" are traits that are fixed and actual, while the "branches" are potential and developing traits, constrained by the nature of the stem. I would think that a more "stem-like" trait, such as sex, would be more identity-affecting, than a more "branch-like" trait, such as eye color. But Heyd contends that parents would be able to change even "stem-like" traits, like the sex of their child, without later regret or objection from the child, because the child has no right to the identity that would have arisen had the trait not been changed. So on Heyd's view, even

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[294] David Heyd, *Genethics: Moral Issues in the Creation of People* (Berkeley: University of California Press, 1992), 175-76.
[295] Heyd 1992, 160, 164.

a prenatal change in sex does not affect a given child's identity. It only creates a different child with a different identity and cannot harm the child.[296]

Heyd then muddies the water by suggesting that "morally acceptable parents … are those who respect the already actual 'core' identity of the child in the process of further developing it into a fully grown human personality."[297] Thus, it appears that Heyd contends that parents are not constrained in genetic trait selections made before the "actual core identity" of the child is formed, but then are constrained in other developmental action. But I suggest that Heyd fails to identify when, exactly, the "actual core identity" of the child is formed. And why should "identity-forming" interventions, such as genetic trait selection, be less constrained than "identity-developing" interventions, such as education? Heyd provides us no answer, other than that the child whose identity was formed cannot, under a person-affecting approach, claim that her parents acted morally unacceptably by giving her the identity they did. Heyd does not assist us in looking for a boundary between identity-affecting genetic trait selection and non-identity affecting genetic trait selections.

Jeff McMahan notes that while minor genetic alterations, such as eye color, would be identity-preserving and not identity-determining, some other genetic alterations might be identity-determining. He expressly does not set forth a criterion between identity-determining and identity-preserving genetic alterations. He suggests that a genetic alteration is more likely to be identity-determining (1) if "it significantly affects the way that the brain develops and thus is profoundly determinative of the subsequent person's

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[296] Heyd 1992, 176.
[297] Heyd 1992, 176-77.

psychological properties and capacities, or (2) if it does not significantly affect brain development, "the more radical or extensive the physical changes it causes would be."[298] He supposes that being born without a left hand would not be identity-determining, but being born male instead of female (and vice versa) would be identity-determining.[299]

McMahan's suggested differentiation among genetic trait selections in their effect on identity gives us more guidance than does Heyd's, in that it ties changes in identity to substantial changes in psychological or physical traits. But it is helpful only on the extremes of genetic traits.[300] Would making a child a foot taller be a "radical or extensive" physical change? The Gammas, the Deltas and the Epsilons all wish to use genetic trait selection to make their children taller. But the Gammas and the Deltas want to give their children "normal" height, while the Epsilons want to give their child greater than "normal" height. Would the change from short to normal height be "radical or extensive" but the change from normal to above normal height not be "radical or extensive?" Many would say so, given the differences in the way society treats short and tall people. Standards like "profoundly determinative", "radical" or "extensive" trait selections are highly subjective, and so are less useful in assessing the moral acceptability of the parents' genetic trait selection. McMahan's suggestions may help us in extreme cases, such as changes in sex, but do not help us much in determining whether the genetic

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[298] Jeff McMahan, "Wrongful Life: Paradoxes in the Morality of Causing People to Exist" in Jules Coleman and Christopher W. Morris, *Rational Commitment and Social Justice: Essays for Gregory Kafka* (Cambridge, England: Cambridge University Press, 1998), 208-247, 212-13.

[299] McMahan 1998, 213.

[300] Since many events, both pre-natal and post-natal, may affect a child's brain development, we might have difficulty in assessing whether a given genetic trait selection affected the child's brain development and in assessing the extent to which the genetic trait selection affected the child's subsequent psychological properties.

trait selections most parents would wish to make would be identity-affecting genetic trait selections.

More recently, Michael Boylan and Kevin Brown have suggested that genetic trait selections that alter the child's "personal worldview" alter the child's personal identity, and are therefore ethically objectionable.[301] Their concern is primarily with genetic trait selections that would "tinker with intelligence, personality and behavior" rather than those genetic trait selections our hypothetical parents are considering.[302] And they are not particularly clear on what constitutes a "personal worldview." For example, would deafness be part of a "personal worldview," such that genetic trait selection of hearing capability would alter the child's personal identity? The Deaf culture would likely say that deafness is part of a "personal worldview," so that selecting for hearing capability would alter the child's personal identity. Would blindness be part of a "personal worldview?" I am unaware of any "Blind culture," paralleling the Deaf culture, that would assert that blindness is part of a "personal worldview" that would be constitutive of the child's personal identity. Without a clearer sense of what makes up a child's "personal worldview," Boylan and Brown's differentiation between identity-affecting genetic trait selection and non-identity-affecting genetic trait selection is not particularly helpful.

Because of the complexity of distinguishing between identity-affecting traits and non-identity-affecting genetic traits, I offer only a gesture toward developing criteria for

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[301] Michael Boylan and Kevin E. Brown, *Genetic Engineering: Science and Ethics on the New Frontier* (Upper Saddle River, New Jersey: Pearson Education, Inc., 2001), 122-23.
[302] Boylan and Brown 2001, 122.

distinguishing which genetic trait selections affect identity and which do not. I suggest that the effect trait alterations have on identity when they occur after birth may help guide us in assessing similar genetic trait selections made before birth. As a first example, take a child who loses his or her hearing capacity due to disease or accident. It seems unlikely that the child would believe that her identity has changed by becoming deaf. Do others view that child's identity as having been changed by that loss of hearing capability? Most, I suggest, would not. While we would have to communicate with her, and she with us, in ways different than before, nothing else about her has changed as a result of becoming deaf.

As a second example, take a child who does not reach his predicted adult height because of disease. Again, it seems unlikely that the child would believe that his identity has changed by being shorter than he would have been but for the disease. Do others view that child's identity as being different than it would have been if he had reached the predicted adult height? Again, I suggest most do not. Nothing, other than some opportunities in life, has changed about the child as a result of being shorter than he otherwise would have been.

Thus, I suggest that genetic trait selections that would change a trait in such a way that if it occurred after birth, (1) the person would believe his or her identity had been changed,[303] and (2) most others would view his or her identity has having changed, are

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[303] This assumes either that the person can make that assessment after the change in trait or that we can determine what the person's belief would have been. In cases of profound changes in mental functioning, such as dementia, we may no longer be able to ascertain from the affected person whether she believes that her identity has changed as a result. But, based on prior statements and actions, we may be able to assess whether the dementia has changed her identity, even if she cannot tell us.

identity-affecting genetic trait selections. Conversely, those genetic trait selections that change a trait in a way that if the change occurred after birth, the person would not believe his or her identity had been changed, and most others would not view his or her identity as having changed, are non-identity-affecting genetic trait selections.

I include internal and external views on identity to block purely subjective claims of changes in identity. A person might claim, in all sincerity, that going from brunette to blonde has changed his identity, but most others would not likely join in that claim and would not consider him to have changed his identity. Similarly, a society might banish a person from the society for bad acts and treat him as a "non-person," but as long as he still considers himself to be a person, his banishment has not changed his identity.

This distinction would make identity-affecting genetic trait selections very uncommon indeed. But this is not an argument against the distinction. There are relatively few genetic traits that most of us believe to be essential and constitutive of a person's identity. Sex, I suggest, may be among them.[304] Living many years longer than we otherwise would have might be.[305] The presence or absence of major psychiatric conditions, such as schizophrenia, may or may not be. Radically different weight may or may not. Hearing is not. And height, other than perhaps in extreme examples, is not. So

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[304] But take a man who goes through sex reassignment. Does she believe that her identity has changed as a result of the sex reassignment? Beyond the changes to her body, she interacts with the world in different ways that range from the prosaic (which restroom she uses) to the profound (whether she will be allowed to marry a man). She typically modifies her name to reflect her change in sex. Some of her prior relationships will endure but her future relationships may be much different than before. Others may view her identity as having been changed by that reassignment. But she may view herself as having the same identity and that the sex reassignment makes her body conform to the female identity she had previously believed she already had. So even sex may not be constitutive of identity.

[305] See Walter Glannon, "Identity, Prudential Concern, and Extended Lives" *Bioethics* 16: 266-283 (2002), 275-77.

most genetic trait selections that parents would choose to make would not affect the identity of the child, and so concerns about changing the child's personal identity does not justify a bar against parental genetic trait selection. And even in those instances where a genetic trait selection might be said to change the child's personal identity, that alone does not make the parental genetic trait selection ethically objectionable. So long as the parental genetic trait selection expands the child's range of open futures, and does not restrict or differentially select among those open futures, the parents' action is ethically permissible, even if it changes the child's personal identity.

13. Germline Modification Issues

Most of the parental genetic trait selections discussed to this point have been indirect pre-implantation genetic trait selections, in which (in the present methodology) the genes of an embryo are examined and the desired embryo is implanted. In the future, we may be able to engage in direct pre-implantation genetic trait selections, directly modifying the genes of an embryo rather than selecting among embryos for implantation or destruction. And in the future we may be able to engage in direct post-implantation genetic trait selections, directly modifying the genes of the fetus rather than engaging in selective abortion. These forms of genetic trait selection are often called "somatic cell" genetic trait selection because they involve non-reproductive cells.

Another kind of direct genetic trait selection may become possible in the future. Rather than modifying the cells of an embryo after conception, we may be able to modify the sperm or ovum before conception. I have referred to this as direct pre-conception genetic trait selection. Most other commentators have referred to it as "germ-line" genetic trait selection because it involves the reproductive, or germ, cells.

Direct pre-conception genetic trait selection offers an advantage over direct pre-implantation genetic trait selection, in that once the genetic modification is made in a germ cell (the sperm or the ovum), that genetic modification will be present in the germ cells of the child conceived of that sperm or ovum. The genetic modification will then be passed to succeeding generations without need for further genetic modifications. For example, if the genes in the germ cell of a person with sickle cell trait were modified to eliminate that trait, then not only would the sickle cell trait not be passed on to the child conceived of that germ cell, but that trait would not be passed on to succeeding generations of that person.[306] So a deleterious genetic condition, such as sickle cell trait,[307] could be eliminated from many generations through a single genetic trait modification.

This potential advantage in direct pre-conception genetic trait selection, that multiple generations could be affected by a single germ cell modification, is also its greatest concern. The traits that parents would be selecting would not just be traits for their own children, but could be traits for their grandchildren, great-grandchildren, and beyond.

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[306] Unless those in the succeeding generations were conceived of germ cells from others that had sickle cell trait.

[307] Sickle cell trait may be a problematic example because it is not always a deleterious condition. If parents who both have sickle cell trait have a child, that child may have sickle cell disease, which is a painful and life-threatening condition. But sickle cell trait, alone, is asymptomatic and it confers advantages against the acquisition of malaria in those parts of the world where malaria is endemic.

A number of ethicists raise concerns about the risks of adverse effects in making such multi-generational genetic trait modifications.[308] Others argue that direct pre-implantation genetic trait selection would be safer and more effective than direct pre-conception genetic trait selection, so we should limit ourselves to direct pre-implantation genetic trait selection for the foreseeable future.[309] But as I stipulated earlier, any form of genetic trait selection, including direct pre-conception genetic trait selection, would have to be reasonably safe and effective before parents could ethically consider using it. The clinical risk and adverse effects concerns of direct pre-conception genetic trait selection are again not different from those in other forms of genetic trait selection.

Another possible concern about multi-generational genetic trait modifications is whether they violate the autonomy rights of those in later generations. A direct pre-conception genetic trait selection made by a parent now could have effects on her descendents many generations hence, who will never have known the person who made the genetic trait selection.[310] But most ethicists who have addressed this concern conclude that those future generations have no rights, including a right of autonomy, to be violated by a predecessor's pre-conception genetic trait selections because they are

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[308] Eric T Juengst, "Germ-Line Gene Therapy: Back to Basics" *Journal of Medicine and Philosophy* 16: 587-592 (1991), 590; Marc Lappé, "Ethical Issues in Manipulating the Human Germ Line" *Journal of Medicine and Philosophy* 16: 621-639 (1991), 630-31; Thomas Stuart Patterson, "The Outer Limits of Human Genetic Engineering: A Constitutional Examination of Parents' Procreative Liberty to Genetically Enhance Their Offspring" *Hastings Constitutional Law Quarterly* 26: 913-933 (1999), 916-18.

[309] Bernard D. Davis, "Germ-Line Therapy: Evolutionary and Moral Considerations" *Human Gene Therapy* 3: 361-363 (1992), 362; Erik Parens, "Should We Hold the (Germ) Line?" *Journal of Law, Medicine & Ethics* 23: 173-176 (1995), 174-75 (Parens 1995a); Gerd Richter and Matthew D. Bacchetta, "Interventions in the Human Genome: Some Moral and Ethical Considerations" *Journal of Medicine and Philosophy* 23: 303-317 (1998), 314-15.

[310] Nils Holtug, "Altering Humans - The Case For and Against Human Gene Therapy" *Cambridge Quarterly of Healthcare Ethics* 6: 157-174 (1997), 163-64.

merely future persons to whom moral and legal rights cannot be meaningfully assigned.[311]

Conversely, some ethicists support parental autonomy to engage in direct pre-conception genetic trait selection, in order to "ensure a normal pregnancy and a healthy baby" and to avoid multiple pre-implantation genetic trait selections when a single pre-conception genetic trait selection will accomplish the same goal.[312] And because of this greater potential efficacy, others argue that medicine has a positive duty to pursue pre-conception genetic trait selection.[313]

There is no good reason to treat pre-conception, or germ-line, genetic trait selections, differently from pre-implantation, or somatic, genetic trait selections. The only biological difference is that pre-conception genetic trait selections may continue into future generations, while pre-implantation genetic trait selections will not. Contrary to some critics of pre-conception genetic trait selections, those selections are not necessarily permanent. The selection may be modified in succeeding generations by the genetic traits of those whom the selected person procreates with in the succeeding generations. For example, if a recessive gene is modified in the selected person, through pre-conception genetic trait selection, but in a succeeding generation, a successor procreates with a person who has that recessive gene, then the resultant child, and succeeding generations, may have that recessive gene again. And if we have the ability to engage in

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[311] Ronald Munson and Lawrence H. Davis, "Germ-Line Gene Therapy and the Medical Imperative" *Kennedy Institute of Ethics Journal* 2: 137-158 (1992), 141-45; H. Tristram Engelhardt, Jr., "Human Nature Genetically Re-Engineered: Moral Responsibilities to Future Generations" in Agius and Busuttil, 51-63, 59-62.

[312] Burke K. Zimmerman, "Human Germ-Line Therapy: The Case for Its Development and Use" *Journal of Medicine and Philosophy* 16: 593-612 (1991), 597-98.

[313] Lappé 1991, 634-36; Munson and Davis 1992, 153-55.

a pre-conception genetic trait selection for one generation, and if subsequent generations conclude that they do not want that genetic trait selection to apply to their children, then it is likely we will have the ability to reverse that pre-conception genetic trait selection. So pre-conception genetic trait selection is not necessarily more permanent than post-conception genetic trait selection.

Nor is pre-conception genetic trait selection different from other actions we take that can affect future generations. Our pollution of the environment with teratogenic agents can affect the genetic traits of our descendents just as much, or more, than pre-conception genetic trait selection can. As Ray Moseley notes, "germ-line manipulations that effect future generations are not different ethically from any other human decisions that effect future generations."[314]

Thus, the ethical issues in pre-conception genetic trait selection are analogous to those for post-conception genetic trait selection. Pre-conception genetic trait selection must be safe and effective before parents can employ it. If they choose to do so, they must make their selection in the best interest of not only the child they are creating, but in the best interests of the descendents of that child. And they must make selections that not only expand the range of open futures for the child they are creating now, but similarly expand the ranges of open futures for the descendents of that child.

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[314] Ray Moseley, "Commentary: Maintaining the Somatic/Germ-Line Distinction: Some Ethical Drawbacks" *Journal of Medicine and Philosophy* 16: 641-647 (1991), 643.

CHAPTER FIVE: CONCLUSION

People have always engaged in some amount of genetic trait selection on behalf of their children, although they have not always realized they are doing so. They do so through the indirect, and imprecise, method of mate selection. If a person wants tall children, he seeks out tall mates. If a person wants children with blond hair and blue eyes, she seeks out mates with blond hair and blue eyes. But given the science of genetics, these genetic trait selections do not always work.

We now have technologies that allow parents to engage in more direct, and more precise, methods of parental genetic trait selections. Parents can use pre-natal testing to determine whether their fetus has certain genetic traits or conditions, and if they do not want to bring a child into the world with that trait or condition to term, can terminate the pregnancy. For some genetic traits, parents can use *in vitro* fertilization and pre-implantation genetic testing to determine whether their embryo has certain genetic traits or conditions and then decide whether to implant an embryo that does or does not have that trait or condition. In the future we may be able to modify the fetus's or the embryo's genomic structure to eliminate an undesired genetic trait and replace it with a desired genetic trait. And in the future we may be able to modify a parent's sperm or egg cells to eliminate the chance of any child conceived of those cells, and eliminate the chance of any progeny of that child, having an undesired genetic trait.

But these technologies, current and future, require us to assess whether the genetic trait selections that parents want to make are ethically acceptable or unacceptable.

Ethicists and others have proposed a number of bases on which to assess the ethical acceptability of specific parental genetic trait selection. One possible basis is whether the genetic trait to be selected for or against is a diseased state or a normal state, such that using parental genetic trait selection to avoid a diseased state is ethically acceptable but that using parental genetic trait selection to modify a normal state is ethically unacceptable. I have argued that such a distinction between diseased and normal states does not adequately distinguish between ethically acceptable and ethically unacceptable parental genetic trait selections because of the difficulties in defining both "disease" and "normal" in these contexts.

Another suggested basis for ethical assessment is whether the parental genetic trait selection is treatment or enhancement, such that using parental genetic trait selection for treatment of, or avoidance of, a diseased state is ethically acceptable but that using parental genetic trait selection for enhancement of a normal state is ethically unacceptable. I have argued that such a distinction between treatment and enhancement does not adequately distinguish between ethically acceptable and ethically unacceptable parental genetic trait selection because of the difficulties in distinguishing treatment from enhancement, because of similarities between some ethically acceptable post-natal parental interventions and some pre-natal parental genetic trait selections, and because of the difficulties in establishing what enhancements, if any, would be ethically acceptable.

A third possible basis for distinguishing between ethically acceptable and ethically unacceptable parental genetic trait selection, and the basis upon which I build in this dissertation, is to examine whether parental genetic trait selection respects an obligation that parents have to any children they may have. Feinberg proposes that children have a right to an open future and that parents hold that right in trust for their children. That right-in-trust obliges parents not to act in ways that diminish their child's open future by closing off options during childhood.

Feinberg's right to an open future was based in part on allowing children to have those options that their genomic structure allows. But in parental genetic trait selection, parents are changing that genomic structure, so standing alone, Feinberg's right to an open future will not allow us to make ethical assessments of parental genetic trait selections. Davis, Brock and Resnik have extended Feinberg's right to an open future to apply to parental genetic trait selections by arguing that just as parents should not unnecessarily close off options for their children after birth, they should not close off options for their children before birth. Thus, they propose normative rules under which parental genetic trait selections are ethically unacceptable if those selections constrain or limit the child's open future.

In this dissertation, I have argued that those normative rules are not adequate for assessing all parental genetic trait selections. While they address parental genetic trait selections that constrain or restrict a child's open future, they do not address parental genetic trait selections that could expand a child's open future. Nor do they address parental genetic trait selections that enhance the possibility of certain futures for the child while simultaneously diminishing the possibility of other futures for the child. Because of these shortcomings, I have proposed a more detailed normative rule.

I propose that when using parental genetic trait selections, parents are obliged to respect their child's right to a "range of open futures." If the parental genetic trait selection expands the child's range of open futures, in that it gives the child more possible future opportunities, then the parents' action is ethically acceptable. But if the parental genetic trait selection constricts the child's range of open futures, in that it gives the child fewer possible future opportunities, then the parents' action is ethically unacceptable. And if the parental genetic trait selection differently selects among or shifts the child's range of open futures, in that it makes more possible some future opportunities and experiences while simultaneously making less possible a significant number of other future opportunities and experiences, then the parents' action is also ethically unacceptable.

I have attempted to motivate this "range of open futures" through the metaphor of a map containing all possible future significant opportunities and experiences as locations. Not all of those opportunities and experiences are connected by roads, and where a road does not run to an opportunity or experience, that opportunity or experience cannot be had. But where a road runs to an opportunity or experience, the child can choose to, but is not obliged to, have that opportunity or experience.

At conception, each child receives such a map. Without parental genetic trait selection, the genetic lottery determines the map and determines which opportunities and experiences are connected by roads, making it possible for the child to pursue those opportunities and experiences, and which opportunities and experiences are not connected by roads, making it impossible for the child to pursue those opportunities and experiences.

Like post-natal interventions and events, parental genetic trait selections would change the child's map. If the parental genetic trait selection adds roads to the child's map, in that the child can have more opportunities and experiences than she otherwise could have had, then the selection expands the child's range of open futures and is ethically acceptable. If the parental genetic trait selection removes roads from the child's map, in that the child loses the possibility of having opportunities and experiences she otherwise could have had, then the selection restricts the child's range of open futures and is ethically unacceptable. And if the parental genetic trait selection adds some roads to the child's map, such that the child can have certain additional opportunities and experiences, but simultaneously removes other roads from the child's map, such that the child loses the possibility of having opportunities and experiences she otherwise could have had, then the selection shifts or differently selects among the child's range of open futures and is ethically unacceptable.

This "range of open futures" approach avoids the problems with the disease/normal distinction and the treatment/enhancement distinction. It is also consistent with the limits on parental autonomy regarding post-natal interventions made on behalf of their children. It proscribes parental genetic trait selections that differentially shift the child's range of open futures because such shifts in the range generate too much risk that the parents will over-determine their child's choices about the futures she wishes to pursue. But it allows for parental genetic trait selections that expand the range of open futures, even when some of the added futures are undesirable futures, because parental autonomy allows parents to make unpopular genetic trait selections, so long as the selections do not harm the child.

I have also addressed a number of the concerns about and critiques of parental genetic trait selection. At present, parental genetic trait selection should be an option but not an obligation. While in the future parental genetic trait selection techniques might become minimally invasive, current techniques require substantial invasion of procreational autonomy and in the case of the mother, substantial invasion of bodily autonomy. Given that conflict between the interests of the child and the rights of the parents, parents should be permitted to but not obliged to engage in genetic trait selection, even when such a decision is unpopular.

Societal eugenics will not necessarily result from parental genetic trait selection and may actually be prevented by allowing parents the autonomy to engage in a variety of genetic trait selections. We must guard against allowing the ability to use parental genetic trait selection to avoid creating children with disabling genetic traits to diminish our support for and accommodation of those children who are born with those disabling genetic traits, but barring parental genetic trait selection is not the means of avoiding such reduced support and accommodation.

I have sketched briefly two of a number of justice concerns regarding parental genetic trait selection. Those justice concerns must be addressed as parental genetic trait selection becomes more common. But those concerns, like the others surveyed, do not make all genetic trait selections ethically unacceptable. Parental genetic trait selection does raise concerns regarding making the child feel inauthentic or feel like he or she received a shortcut, but those concerns also arise in post-natal parental interventions and should be addressed in the same manner.

The "playing God" objection fails unless all interventions in conception and pregnancy are ethically unacceptable, and most people do not so hold. The risk of commodification of children through parental genetic trait selection is a concern, but no more so than the risk of commodification of children created through traditional means, and so must be addressed similarly rather than serving as a prohibition on parental genetic trait selection. Parental genetic trait selections would seldom change the identity of their child and even if they did, that would not necessarily make them objectionable.

In conclusion, so long as parents use parental genetic trait selection in the best interests of their children, by expanding their children's ranges of open futures, we should consider their actions ethically acceptable. But if they make parental genetic trait selections that restrict or differentially shift those ranges of open futures, we should consider their actions ethically unacceptable.

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ERIC B. SCHMIDT

EDUCATION

Ph.D., Philosophy and Bioethics	University of Washington, 2004 - Specializations in bioethics, medical ethics and philosophy of law. - Dissertation, "Expanding the Child's Range of Open Futures: A Proposed Basis for the Ethical Assessment of Parental Genetic Trait Selections." - Supervisory Committee: Ronald Moore, Ph.D., Wylie Burke, M.D., Ph.D., Nancy Jecker, Ph.D., Sara Goering, Ph.D., Andrea Woody, Ph.D.
M.A., Philosophy	University of Washington, 2000
J.D. *cum laude*	Seattle University School of Law (formerly University of Puget Sound School of Law), 1985 - Research and Technical Editor, University of Puget Sound Law Review, 1984-1985.
B.A., Kinesiology	University of Washington, 1980

TEACHING EXPERIENCE

2000 to Present	Adjunct Professor of Law Seattle University School of Law Seattle, Washington - Designed and taught courses in Bioethics and the Law (particularly reproductive issues, substituted judgment and end-of-life issues) and in Medical Liability (medical and hospital malpractice). - Taught course in Health Law (structure and financing of health care).
1989-1992	Instructor National Academy of Paralegal Studies Seattle, Washington

EMPLOYMENT

2002 to Present	Commissioner Washington State Court of Appeals, Division II Tacoma, Washington
1994 to 2002	Senior Health Law Judge Washington State Department of Health Olympia, Washington
1992-1994	Staff Attorney Washington State Department of Health Olympia, Washington
1990-1992	Staff Attorney Washington State Court of Appeals, Division II Tacoma, Washington
1989-1990	Law Clerk to Judges Marshall Forrest and Ward Williams Washington State Court of Appeals, Division I Seattle, Washington
1987-1988	Associate Attorney Gordon, Thomas, Honeywell, Malanca, Peterson and Daheim Tacoma and Seattle, Washington
1986-1987	Appellate Backlog Elimination Program Director Washington State Supreme Court & Court of Appeals Tacoma, Washington
1985-1986	Law Clerk to Judge John A. Petrich Washington State Court of Appeals, Division II Tacoma, Washington
1980-1984	Facilities Planning and Projects Department Manager (1983-1984) Security and Systems Administrator (1980-1983) Weyerhaeuser Company, Research and Development Division Federal Way, Washington

PUBLICATIONS

"Voting Patterns of the Washington State Supreme Court - Criminal Cases in the Discretionary Era," *Washington State Bar News*, July 1990, 8-13.

"Public Policy over Metaphysics: Wrongful Birth and Wrongful Life in Harbeson v. Parke-Davis, Inc.," 8 *U. Puget Sound L. Rev.* 511 (1985).

PRESENTATIONS

"How the Supreme Court and the Court of Appeals Process Your Case", Washington Courts Historical Society, 2003.

"Designing for Deafness: The Ethics of Deaf Parents Acting to Increase the Likelihood of Creating a Deaf Child," University of Washington Graduate Student Philosophy Conference, 2003.

"How to Write Findings of Fact and Conclusions of Law in Dependency and Termination Cases," Washington State Attorney General's Office, 2003.

"Can Boorse's Naturalistic Definition of Disease Provide a Ground for the Ethical Assessment of Genetic Trait Selection Decisions?" Northwest Philosophy Conference, 2002.

"A Short Guide to Filing an Appeal in the Court of Appeals," King County Law Library, 2002.

"Should the Lack of an Emotion Be Punishable? Is Increased Criminal Punishment for Offenders Who Have a 'Lack of Remorse' Legally or Morally Justifiable?" Northwest Philosophy Conference, 2001.

"The Law of Confidential Records," Washington Law Institute, 2000.

"Mediation in Administrative Proceedings," Government Lawyers Bar Association, 1999.

"Administrative Hearings: What Judges Really Want to Hear," Washington State Bar Association, 1998.

"Effective Practice Before Boards and Commissions," Government Lawyers Bar Association, 1995.

SERVICE

Ethics Committee, Children's Hospital and Medical Center, 2004 to present.

Hospice volunteer, Northwest Hospice, 1994 to 1996.

Admitted to practice law in Washington State and the Western District of Washington, 1985.

Arbitrator, King County Superior Court Mandatory Arbitration Program, 1996 to 2001.

Certified mediator since 1996.