

## Genetic Manipulation in Humans as a Matter of Rawlsian Justice

### 1. Emerging Biotechnology Poses a New Problem for Justice

In the near future, advances in molecular biology, biochemistry, and genetics will make it possible to alter the genes of human beings and developing human embryos in predictable and extensive ways. This biotechnology presents society with a new moral problem concerning how best to apply the new knowledge to humans. As a way of addressing an extremely important aspect of this problem, this paper examines the issue of genetic alteration in humans as a matter of justice.

I focus on justice because of the central role justice plays in determining the basic structure of society as a whole and because of the fundamental challenges genetic intervention poses to established conceptions of justice. Theories of justice traditionally have regarded people's natural endowments as being fixed facts of the genetic lottery.<sup>1</sup> Some theorists, such as Robert Nozick, believe that we own our traits, talents, abilities, and genes even though they were endowed to us by chance.<sup>2</sup> Other theorists argue that the inequalities inherent in the natural distribution of talents and abilities place a moral obligation on us to compensate the less fortunate for their genetic disadvantages.<sup>3</sup>

The important point is that until now, theories of justice have regarded one's genetic endowment as a fixed fact of nature rather than as a matter of justice. The ability to control the genetic endowment of future generations calls for a rethinking of the traditional theories of justice. This paper aims to investigate how one such theory—John Rawls's—

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<sup>1</sup>George J. Agich, "Justice and Genetic Engineering," *Explorations in Medicine* 1 (1985): 22-38, p. 27.

<sup>2</sup>Robert Nozick, *Anarchy, State, and Utopia* (New York: Basic Books, 1974), p. 226: "Whether or not people's natural assets are arbitrary from a moral point of view, they are entitled to them, and to what flows from them."

<sup>3</sup>John Rawls endorses something like this view: "By accepting the difference principle, [we] view the greater abilities as a social asset to be used for the common advantage." Rawls, *A Theory of Justice* (Cambridge, Mass.: Harvard Univ. Press, 1971), p. 107.

might be modified to help us respond to this new moral problem in ways that reflect more completely our considered convictions about fairness and justice.

I argue that Rawls's theory as it stands does not give us satisfactory answers to questions about how to regulate genetic manipulation.<sup>4</sup> Rawls's failure to take natural primary goods into account in identifying the least advantaged leads him to counterintuitive conclusions about who in society is worst off. Similarly, worries about the inflexibility of social primary goods and the consequences these worries have for the instantiation of conditions of fair equality of opportunity are serious weaknesses in Rawls's theory of justice.

I explain how we can modify Rawls's theory into a framework that allows us to govern genetic manipulation in humans in ways that more fully accommodate the fixed points of our considered judgments about justice.<sup>5</sup> I go on to show how such a modified theory would instruct us to use technologies for genetic correction and enhancement. Assuming a safe, effective, and inexpensive means of genetic manipulation, the modified Rawlsian theory mandates certain kinds of genetic intervention while permitting or prohibiting others.

## 2. John Rawls's Theory of Justice

Rawls's theory of justice as fairness begins in the original position, the hypothetical standpoint from which we evaluate competing theories of

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<sup>4</sup>In one sense, this conclusion should come as no surprise, since Rawls explicitly ignores the possibility of genetic manipulation in humans. Rawls declares: "I have assumed so far that the distribution of natural assets is a fact of nature and that no attempt is made to change it, or even take it into account" (*Theory of Justice*, p. 107). Aside from the primitive state of genetic technology in 1971, Rawls eschews the issue of genetic endowment because of its intimate connection to an issue which Rawls tries desperately to avoid—the quagmire of health care. The prohibitive cost of compensating the severely unhealthy causes Rawls to limit his theory to normal, active, and fully cooperating members of a society over an entire life. Severely sick people due to natural ill fortune are essentially excluded from citizenship under Rawls's scheme of justice.

In his article, "Genetic Engineering and Social Justice: A Rawlsian Approach," *Social Theory and Practice* 23 (1997): 427-48, David B. Resnik states that Rawls's theory "would allow for genetic inequalities among individuals so long as those inequalities are (a) to everyone's advantage and (b) do not undermine fair equality of opportunity or equality of liberty" (p. 428). This statement cannot be true on its face, since Rawls explicitly refuses to address the distribution of genetic inequalities and instead focuses his theory on arranging social and economic inequalities so as to benefit the least advantaged members of society (defined as those with the least amount of income and wealth). As shown in more detail below, Rawls's theory requires modification before it can do the work Resnik and I want it to do.

<sup>5</sup>Cf. Rawls, *Theory of Justice*, pp. 19-22.

justice. People in the original position are situated behind a veil of ignorance that prevents them from knowing any facts about themselves that are irrelevant to justice, such as their place in society, social circumstances, and natural endowment. Each person conceives of himself as having some rational life plan, conception of the good, sense of justice, and desire to pursue and live by his chosen principles. Rawls argues that any rational person behind the veil of ignorance would choose his two principles of justice over utilitarian, intuitionist, and perfectionist alternatives. The two principles are defined as follows:

(1) “[E]ach person has an equal claim to a fully adequate scheme of equal basic rights and liberties, which scheme is compatible with the same scheme for all; and in this scheme the equal political liberties, and only those liberties, are to be guaranteed their fair value.”<sup>6</sup>

(2) “[S]ocial and economic inequalities are to satisfy two conditions: they must be (a) to the greatest benefit of the least advantaged members of society; and (b) attached to offices and positions open to all under conditions of fair equality of opportunity.”<sup>7</sup>

The principles are prioritized such that the first is lexically prior to the second. This lexical ordering prevents certain actions on the part of the subjects of justice. For example, no one may trade a liberty (by, say, becoming a slave) for the sake of greater economic efficiency or for the sake of more expansive opportunities. Within the second principle, part (b) prevails over part (a), the so-called difference principle. Economic gains can never justify the suspension of the conditions of fair equality of opportunity. Conversely, excessive accumulations of wealth by a minority of citizens which prevent the maintenance of the conditions of fair equality of opportunity are explicitly ruled out by this lexical ordering.<sup>8</sup>

The idea behind fair equality of opportunity is that every person should have a fair chance of attaining positions in society (careers, offices, positions of authority and responsibility). This notion is to be contrasted with the idea of formal equality of opportunity, which makes careers open to anyone with the talent to fill them, but would do nothing to ensure fair chances for everyone with similar talents. In contrast to formal equality of opportunity, which merely prohibits the exclusion of particular groups or individuals from careers, the concept of fair equality of opportunity specifies that “there should be roughly equal prospects of culture and achievement for everyone similarly motivated and en-

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<sup>6</sup>John Rawls, *Political Liberalism* (New York: Columbia Univ. Press, 1993), p. 5.

<sup>7</sup>John Rawls, “Social Unity and Primary Goods,” in A.K. Sen and B. Williams (eds.), *Utilitarianism and Beyond* (Cambridge: Cambridge Univ. Press, 1982); see pp. 161-62.

<sup>8</sup>Rawls, *Theory of Justice*, p. 302.

dowed.”<sup>9</sup> This principle attempts to minimize the effects of the morally arbitrary social and natural contingencies of birth such as class and inheritance. Significantly, the principle limits its guarantee of nearly equal life chances to those with approximately the same abilities and skills; this limitation has important consequences which I discuss below.

Against background conditions of equal liberties and fair equality of opportunity, the difference principle becomes the prominent feature of Rawls’s theory. Determining the least advantaged individual is a crucial step in enforcing the difference principle. Rawls makes the necessary interpersonal comparisons using certain necessary goods he defines as “primary goods”: things that any rational agent would desire no matter what his (thick) conception of the good.<sup>10</sup> The social primary goods include rights and liberties, powers and opportunities, income and wealth, and self-respect.<sup>11</sup> These social primary goods are contrasted with the natural primary goods of health and vigor, intelligence and imagination, and talents and abilities.

Without genetic technology, the distribution of natural primary goods is not directly “influenced by the basic structure” of society,<sup>12</sup> so Rawls excludes these goods from his index of interpersonal comparison. Instead, the least advantaged member of society is he who has the least amount of social primary goods. Rawls further simplifies his theory by taking income and wealth to be an approximation of all the social primary goods. This simplification is based on the facts that the distribution of most primary goods (basic liberties, freedoms, rights, opportunities) is fixed by the other principles and that the first principle and part (b) of the second principle are both lexically prior to the difference principle.<sup>13</sup>

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<sup>9</sup>*Ibid.*, p. 73.

<sup>10</sup>Rawls has a name for the idea that certain goods (the primary goods) are normally required in greater rather than lesser quantity by rational parties wishing to advance their aims; he calls it the thin theory of the good, and it “is to secure the premises about primary goods required to arrive at the principles of justice” (*Theory of Justice*, p. 396). The concept of a thin theory of the good is to be distinguished from an individual’s thick theory of the good, which includes one’s comprehensive moral doctrine, religious views, and other more specified notions of what is good. Everyone accepts the thin theory of the good, which establishes the mutually agreed-upon principles of justice. The principles of justice, in turn, establish the principles of right. In this way, the concept of right is prior to that of (any individual’s particular version of the thick) good. By excluding conceptions of the good that violate the principles of justice, the priority of the right over the good is one of the most indispensable features of Rawls’s theory of justice.

<sup>11</sup>Rawls, *Theory of Justice*, p. 62.

<sup>12</sup>*Ibid.*

<sup>13</sup>The distribution of powers and prerogatives and self-respect is ignored for the sake of simplicity. Rawls offers this simplified form of the difference principle as an example of how interpersonal comparisons under justice as fairness might differ from utilitarian conceptions. Presumably there are alternative (more complex) forms of the difference

On the traditional Rawlsian view, natural inequalities are seen as unavoidable. However, the morally arbitrary way in which the inequalities are distributed places a moral obligation on us to compensate the less fortunate for their genetic disadvantages. Rawls seeks to compensate natural inequalities with social primary goods by enforcing the difference principle. The next section explains how a strict Rawlsian interpretation of the principles of justice leads to unsatisfactory compensation for naturally disadvantaged individuals.

### 3. Two Problems with Rawls's Theory

Two problems arise for Rawls in his attempt to provide fair compensation for natural inequalities. First, his failure to take natural primary goods into account in his measurement of the least advantaged leads to distortions of who really is the worst off in society.<sup>14</sup> Second, even if natural primary goods could somehow be worked into the assessment of who is least well off, it seems as though no amount of compensation with social primary goods will make up for some physical disabilities.

As an example of the first problem, Will Kymlicka points out that Rawls is obligated to judge the genetically disabled person with more social primary goods to be better off than a genetically "normal" person with fewer social primary goods, even if the advantage in social primary goods is not enough to pay for the extra costs associated with the disability (medical bills, special equipment, psychological needs). Most of us, however, would not regard a person born without arms and legs who is receiving more wealth than a person with arms and legs as being the more advantaged of the two. Yet Rawls's method of interpersonal comparison would judge the quadriplegic to be more advantaged because of his greater total income and wealth. In cases like this, Rawls's exclusion of natural primary goods seems to lead to an inaccurate assessment of who really is least advantaged. Health and wealth should both be considered when assessing who is the worst off in society.<sup>15</sup>

The second and perhaps deeper worry concerns the Rawlsian approach to compensation. Our intuition tells us that the person without arms and legs does not want to be compensated with social primary

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principle, but it is difficult to see how these could be formulated without encountering the same insurmountable difficulties in interpersonal comparisons that plague the utilitarian doctrines. Although Rawls holds the social basis of self-respect to be the most important primary good, he believes it tracks well enough with income and wealth to be left out when measuring how well off one is.

<sup>14</sup>Will Kymlicka, *Contemporary Political Philosophy* (Oxford: Clarendon Press, 1990), p. 71.

<sup>15</sup>*Ibid.*

goods (income and wealth) as much as she wants arms and legs and the corresponding capabilities. Suppose there were an accurate way to measure the worth of arms and legs and that assessments of natural endowment were included in the determination of the worst off. There still seems to be something fundamentally unsatisfying about trying to compensate an individual for natural disadvantages by giving her more social primary goods. The person without arms and legs does not want money; she wants arms and legs. No amount of social primary goods will make up for lacking the capacity to do all the things someone with limbs can.

Amartya Sen argues that these two problems stem from an incorrect assumption about the flexibility of social primary goods. Depending on their capacities to function, different individuals may not be equally able to transform means (in this case social primary goods) into desired ends. As Joshua Cohen puts it, "the blind and the sighted are not equally advantaged by the same levels of income and wealth; people with and without phenylketonuria are not equally nourished by the same food."<sup>16</sup> A dollar for an individual who must pay thousands for special medical equipment to keep himself minimally functional is worth a lot less in terms of that individual's freedom to achieve desired ends than it is to a person who has no such medical needs. The case is even clearer for severely mentally disabled people who cannot even understand how to use money to satisfy desires they may not even be capable of forming.

Certainly we can compensate to a great extent for people's disabilities by giving them wheelchairs, access to buildings, and according them special protections against discrimination. It is also true that many disabilities and defects are disadvantageous only because of some feature of the environment (for example, the person afflicted with phenylketonuria in a phenylalanine-rich environment). However, there are limitations on how far certain naturally disadvantaged individuals can be compensated with social primary goods. A person without legs can never be given the ability to walk through compensation with social primary goods alone. Similarly, a blind person cannot be given sight, an individual with Huntington's disease cannot be given a disease-free adulthood, and a victim of Down's Syndrome cannot be given a mind that is capable of grasping a sense of justice. What we would really like to give these people is not more money, but a cure for their physiological ailments.

We are more interested in one's capability to function rather than simply the amount of social primary goods one has. Sen articulates this

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<sup>16</sup>Joshua Cohen, review of Amartya Sen, *Inequality Reexamined*, in *Journal of Philosophy* 92 (1995): 275-88, p. 281. Individuals afflicted with phenylketonuria (PKU) lack the enzyme necessary to break down the amino acid phenylalanine into safe components. If a PKU patient is not put on a special phenylalanine-free diet, this common amino acid can become toxic enough to cause mental retardation.



concern as the logical extension of his worries about the inflexibility of primary goods. "Neither primary goods nor resources, more broadly defined, can represent the capability a person actually enjoys."<sup>17</sup> The whole idea of the primary goods approach is to specify the things that all people need as a means to freedom. Sen argues that Rawls's primary goods approach puts too much emphasis on making sure people have sufficient means. By putting the primary focus on goods, the theory loses sight of what those goods are supposed to represent. The result is that those who have a harder time converting primary goods into actual freedom to achieve are mistakenly judged to be equal to other individuals when they have the same levels of primary goods, even when the other individuals are better at converting primary goods into freedom.

Since we care about freedom to pursue preferred life plans, our theory should base its interpersonal comparisons at least partly on people's capabilities rather than solely on the amount of primary goods they possess. Rawls himself admits that at least "when we attempt to deal with the problem of special medical and health needs, a different or a more comprehensive notion than that of primary goods will . . . be necessary."<sup>18</sup> He even suggests that Sen's focus on people's basic capabilities may be a more productive approach. An assessment of capabilities would appear to be a more accurate way of dealing with individuals with "special" medical needs, while a primary goods comparison will suffice for those individuals whose functioning is above a certain threshold.

Without providing an adequate level of functioning for people, Rawls's conditions of fair equality of opportunity become entirely unsatisfactory. If by fair equality of opportunity we mean simply equal chances for people with equal ability, those severely naturally disadvantaged will be left with a range (probably a narrow one) of occupational choices that do not ensure the possibility of "meaningful work that . . . can, with a straight face, [be] call[ed] a 'skillful and devoted exercise of public duties'."<sup>19</sup> The price we pay for ignoring natural disadvantages is the degradation of the worth of the conditions of fair equality of opportunity for at least that portion of the population that is functionally challenged. We need a way of resurrecting the validity of fair equality of opportunity.<sup>20</sup> In the following section, I propose two modifications to

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<sup>17</sup>Amartya Sen, "Justice: Means versus Freedoms," *Philosophy and Public Affairs* 19 (1990): 111-21, p. 116.

<sup>18</sup>Rawls, "Social Unity and Primary Goods," p. 168 n.

<sup>19</sup>Cohen, pp. 287-88.

<sup>20</sup>Resnik suggests that Rawls's principle of fair equality of opportunity is sufficient as written to suggest a scheme of genetic alteration in humans. Aside from the fact mentioned earlier that Rawls explicitly ignored the possibility of distributing natural assets, Rawls's "similarly talented and motivated" caveat prevents the theory from requiring the

Rawls's theory that strive towards that goal.

#### 4. Improving on Rawls: A More Satisfactory View

This section outlines two modifications to Rawls's theory designed to make it more ambition-sensitive and less endowment-sensitive.<sup>21</sup> Rawls's theory ignores individuals' varying abilities to convert primary goods into well-being. The main idea behind the modifications is to guarantee people some minimum, yet adequate, level of functioning whenever possible. Individuals whose genetic endowment places them below a minimum threshold of opportunity should be compensated in such a way as to give them the degree of functioning that corresponds to an adequate level of freedom to pursue preferred life plans. Without such a provision, even conditions of fair equality of opportunity will fail to give those severely disadvantaged (in terms of their capabilities) the fair life chances Rawls wants to provide for every subject of justice.

While it may be impossible in reality to accommodate our intuitions on these matters, we should at least acknowledge the desirability of doing so.<sup>22</sup> It may be that the state of genetic technology and the costs involved are such that it is just not possible in practice to improve on Rawls's theory. However, unless the theory can respond effectively to scientific advancements that make possible desired alterations in people's natural endowments, we will never get any closer to reaching our goal of a more endowment-insensitive and ambition-sensitive society.

The point is that Rawls's theory is insufficiently equipped to handle the coming revolution in genetic technology. In order to make the theory more true to the spirit of Rawls's endeavor,<sup>23</sup> I propose the following two modifications:

(A) In assessing who is the worst off, people's capacities for converting social primary goods into the freedom to achieve well-being are to be taken into account.

(B) The second principle's guarantee of conditions of fair equality of

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"genetic minimums" that Resnik and I both want (see Resnik, pp. 439-40). Hence the need to modify the theory.

<sup>21</sup>This phrase comes from Ronald Dworkin; cf. Kymlicka, pp. 76-85.

<sup>22</sup>Kymlicka, p. 73.

<sup>23</sup>Kymlicka characterizes this spirit as the tripartite aim of respecting the moral equality of persons, mitigating the effects of morally arbitrary disadvantages, and accepting responsibility for our choices (Kymlicka, p. 77). Furthermore, Rawls's sympathy for Amartya Sen's criticisms of his use of primary goods seems to indicate that Rawls would favor securing a higher level of functioning for people than that guaranteed by his theory (Rawls, "Social Unity and Primary Goods," p. 168).



opportunity is to carry the following addendum: Whenever it is possible to do so in accordance with the other principles of justice, individuals are to be provided with a minimally adequate range of opportunities.

The other principles of justice are to remain as originally written (see section 2).

Without (A), the theory is left with the type of unsatisfactory assessments of the least advantaged that were discussed above. (A) reflects the desire for a more comprehensive assessment of who is truly least well off. Even if nothing can be done to help the least well off, we should still acknowledge their status as (at least potential) moral equals by including them in the assessment of who is least advantaged. (A) without (B), however, would cheapen the fair value of equal opportunity. By relativizing equal opportunities to individuals' talents and motivations, Rawls's theory allows individuals unlucky in the genetic lottery to have insufficiently wide ranges of opportunities. The idea behind (B) is to make sure that people are brought up to a level of functioning that allows them to enjoy a minimally adequate range of opportunities. (B) helps widen the range of opportunities for the functionally worst off enough to guarantee every individual within the range a fair chance at a more decent life than would be the case if his functionings remained severely impaired.

Under Rawls's conception of equal opportunity, the "similarly talented and motivated" clause allows people with very minimal (abnormally low) capacities due to unfortunate genetic predispositions to exist without an adequately wide array of opportunities. As discussed in section 3, this undesirable loophole results from the dual faulty assumptions that (1) some aspects of talent and motivation in persons are fixed, irrevocable facts of nature, and (2) inequalities in opportunities that resulted from differences in genetic endowment could be compensated adequately by the social primary goods of income and wealth. The Rawlsian standard is amended with the modifications (A) and (B) to reflect our desire to correct those genetic defects that leave people with talents and motivations insufficient for securing an adequate range of opportunity.

Other followers of Rawls have failed to account for this fundamental feature of Rawls's principle of fair equality of opportunity. Norman Daniels notes that fair shares of the normal opportunity range will not be equal shares, but he follows Rawls in arguing that fair equality of opportunity requires only that opportunities be equal for persons who are similarly talented and motivated.<sup>24</sup> David Resnik argues that Daniels's

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<sup>24</sup>Norman Daniels, "Equality of What: Welfare, Resources, or Capabilities?" *Philosophy and Phenomenological Research* 50 (Fall Supplement, 1990), p. 281: "What is important here, however, is that impairment of normal functioning through disease and

health care approach would promote fair equality of opportunity. However, if Daniels's "health-care institutions are regulated by a fair equality of opportunity principle"<sup>25</sup> that relativizes fair equality of opportunity to those similarly endowed, genetically disadvantaged individuals will not be guaranteed a minimally adequate range of opportunities. Only the enforcement of a minimally wide array of opportunities for everyone can prevent Rawls's principle of fair equality of opportunity from being undermined by the proviso, "similarly talented and motivated."

To be sure, the argument for an adequate minimum array of opportunities for all persons above that guaranteed by the minimal threshold requirements of Rawlsian citizenship is not an argument for the absolute equality of genomes for all persons. To the degree that people's talents and abilities differ above the minimum required to guarantee an adequate opportunity range (or at least a chance at an adequate range, since other factors may come into play to deny this adequate set even given healthy genes),<sup>26</sup> it will still be the case that only those similarly talented and motivated will have equal opportunity ranges. Some people will have more opportunities than others in virtue of their greater natural abilities—but no one will be left with an inadequate opportunity set.

A word needs to be said about the "whenever it is possible to do so" clause in (B). Theoretical satisfaction aside, these revisions in Rawls's theory do us no good if they cannot be implemented. The first barrier to effective implementation is having the technology to alter people's genes in safe and effective ways. There are good reasons to believe that gene therapy will eventually be a safe and effective way of treating at least some genetic diseases. Until then, if compensation is not possible, modification (B) does not apply according to the "whenever possible" clause.

The second barrier to effecting (B) is the fact that society has finite resources. Society cannot allocate all of its resources to the compensation of the naturally disadvantaged without bankrupting itself. Rawls delegates the problem of how much of the society's resources to spend on compensating individuals with special health and medical needs to

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disability 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*" (emphasis added).

<sup>25</sup>Resnik, p. 435.

<sup>26</sup>In the case of the genetically disadvantaged man, the theory mandates that gene therapy be provided to raise his functionings to a level that allows him to have the minimally wide array of opportunities under conditions in which the principles of justice are being enforced. The caveat, "under conditions in which . . ." is designed to reflect the idea that a healthy set of genes does not guarantee one a minimally adequate level of opportunity. There are other obstacles to opportunity which must be avoided or overcome (social contingencies, misfortune, etc.). This point anticipates the rejection of genetic determinism, a conclusion that is evident throughout this paper.

the legislative stage rather than trying to work it out in the original position.<sup>27</sup> Modification (B) allows people in the original position to make better progress on this problem by invoking the minimally wide range of opportunities. The level of compensation (using social primary goods) paid to naturally disadvantaged individuals whose functionings cannot be medically restored should not be so great as to push below this minimum threshold of opportunity anyone who is already above it. Of course, the minimum range of opportunity is subject to alteration as agreed to by the citizens in the legislative stage, so the minimum could shift in response to a desire to compensate more naturally disadvantaged individuals. The point is that some standard can be agreed upon, and that standard can be used to measure the level of compensation that will be paid out to the naturally disadvantaged.

Similarly, if gene therapy can be used to restore functioning for individuals afflicted with given diseases, some account must be taken of the cost of those procedures. A cost-benefit analysis would need to be performed to decide exactly what levels of cost for what degree of benefits are acceptable. Again, fixing a minimally adequate range of opportunities below which no person already above it should be forced yields a workable standard whereby corrective costs can be contained.

The discussion of these barriers to implementation has shown that my modified Rawlsian theory is essentially the same in practice as Rawls's theory given today's nascent state of genetic technology. This fact is not surprising, since the quest for a better theory is being made in anticipation of revolutions in genetic technology that are only now just beginning. All that can be said for adopting the modified theory now is that it reflects in a more substantive way our desire to redress outcomes of the natural lottery that prevent individuals from having a minimally adequate array of opportunities. The effectiveness of my modifications is entirely contingent on there being a low-risk, cost-effective way of altering people's natural endowments by compensating them with components of normal human functioning.

The other point that should be made here is that these are not gross changes in Rawls's theory. Most of what Rawls says and how he intends to apply his theory is left unchanged. Again, this result is to be expected since the alterations in the theory are made in anticipation of very specific advances in technology. The task of this paper is not simply to show how the modified portion of Rawls's theory applies to questions of genetic alteration, but also to examine what the rest of Rawls's theory has to say on the matter.

Before going on to apply the theory to different types of genetic al-

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<sup>27</sup>Rawls, "Social Unity and Primary Goods," p. 168.

teration, I should address the criticism that what has been said so far about what range of opportunities will count as minimally adequate has been prohibitively vague. This vagueness also shows up in Sen's arguments for capabilities to function. For example, Sen maintains that one of the basic functionings all people should have is "avoiding preventable morbidity."<sup>28</sup> Even if we take morbidity to include genetic diseases, we are left with the problems of how to define disease and how far to go to prevent it. Similarly, Sen's call for a universal capability to avoid poverty, where poverty is defined as the inability to pursue well-being, leaves one wondering what constitutes well-being. Sen argues convincingly that people ought to have "minimally acceptable levels of capability," but what kinds of genetic defects would place a person below the minimum levels? If we are going to use this standard of a minimally adequate set of opportunities as a way of deciding how much the state should spend in subsidizing genetic alteration, it becomes even more critical to define what we mean by "minimum" in a non-circular way.

I say more on this topic in the discussion on restriction defects below. For now, note that the question of just how narrow an opportunity range will count as intolerably narrow need not be completely resolved at the theory's high level of abstraction. Rawls allows for this type of debate, deliberation, and even continual disagreement at the legislative stage. It is sufficient at this more abstract level to leave substantially open the question of what exactly a severe limitation on one's life chances would be. The important point is that all participants in the original position agree to a conception of justice that guarantees *some* (as yet unspecified) minimally wide array of opportunities to all people.<sup>29</sup>

To sum up what has been said so far, Rawls's impoverished conception of fair equality of opportunity limited to those who are similarly talented and motivated condones the fact that certain unlucky individuals are condemned to live with opportunity ranges which, under my revised conception of equal opportunity with a guaranteed minimum, would be considered unjustly restrictive. The merits of the modified theory become clearer in the next two sections which deal with what the theory tells us to do about regulating the correction of genetic defects and the enhancement of traits.

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<sup>28</sup>Amartya Sen, *Inequality Reexamined* (Cambridge, Mass.: Harvard Univ. Press, 1992), p. 110.

<sup>29</sup>See Amy Gutmann's *Democracy and Disagreement* for ideas on how this deliberative process might work under a Rawls-like framework of justice.

## 5. Responding to Different Defects

The modified Rawlsian theory provides a way of deciding what kinds of genetic alterations are permitted, what kinds are prohibited, and what kinds are mandatory (subject to the liberty constraints of the first principle).<sup>30</sup> I first ask what should be done for individuals whose DNA is defective. In section 6, I examine the issue of genetic enhancement.

Before outlining the different categories of genetic abnormalities, a word needs to be said about the definition of defect. There is great pressure for anyone writing in this field to attempt to answer the questions, "What is a defect, what is a disease, and how does one define normal and abnormal, healthy and sick?" The problems of defining these terms are in some ways insoluble. Sharp lines are impossible to draw between what counts as normal human variation and what counts as abnormal variation indicative of a disease. Many attempts have been made to elucidate these terms,<sup>31</sup> but problems remain. Nevertheless, although precise definitions are hard to formulate, useful distinctions can be drawn.

An indispensable step in applying the theory of justice to the correction of genetic defects is to recognize the variety of genetic damage that can occur. Different mutations affect one's level of functioning and one's opportunities differently. I distinguish three categories of defects to which my modified Rawlsian theory requires three different responses: (1) Sub-threshold defects are those so severe that they prevent a person from being able to cooperate and participate fully in society. These defects deny people the range of capacities Rawls requires all subjects of justice to have; (2) Restriction defects are those that are not

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<sup>30</sup>Throughout this paper, I will say that certain genetic alterations are mandatory. "Mandatory" in this context is to be understood as meaning "state-funded" for pre-natal treatments and "truly compulsory" for post-natal treatments. In cases where pre-natal gene therapy is required to prevent the irreversible onset of a debilitating genetic disease, there may arise a conflict between a mother's liberty to do what she pleases with her body and the (potential) child's "rights" to a minimally healthy set of genes as far as they are outlined by the modified theory. Cf. Gregory E. Pence, *Who's Afraid of Human Cloning?* (Lanham, Md.: Rowman & Littlefield, 1998), p. 113. Since freedom of the person is a liberty guaranteed by the lexically preeminent first principle, a compromise (although it won't save the babies that need early intervention) might be to provide state funding for pre-natal genetic interventions that are necessary to lift the child up to the level of functioning he needs to enjoy a minimally adequate range of opportunities. State-funded, as opposed to compulsory, intervention, would allow women with strong anti-interventionist beliefs to retain some degree of autonomy over their bodies while still providing others with the means to provide the most just outcome for the child.

<sup>31</sup>Cf. Evelyn Fox Keller, "Nature, Nurture, and the Human Genome Project," in Daniel J. Kevles and Leroy Hood (eds.), *Code of Codes* (Cambridge, Mass.: Harvard Univ. Press, 1992), pp. 294-99; Christopher Boorse, "On the Distinction Between Disease and Illness," *Philosophy and Public Affairs* 5 (1976): 49-68; and Christopher Boorse, "Health as a Theoretical Concept," *Philosophy of Science* 44 (1977): 542-73.

so severe as to prevent a person from participating in political life, but do severely limit a person's ability to pursue a preferred life plan; 3) Cosmetic defects are those that do not severely affect a person's ability to pursue a preferred life plan. I discuss the three types of defects in turn and examine what my modified Rawlsian theory has to say about each.

*Sub-threshold defects.* Rawls's theory of justice as fairness makes very few assumptions about the nature of persons. However, "Rawls's theory is idealized to apply to individuals who are 'normal, active, and fully cooperating members of society over the course of a complete life'."<sup>32</sup> This idealization requires Rawls to specify the two essential moral powers all citizens must possess in order to be free and equal subjects of justice: they are assumed to have a capacity for a sense of justice and a capacity for a conception of the good. Although Rawls seems safe in his assumption that the majority of humans share at least the necessary minimum of the moral powers, the difficulty is what to do about the people who fall below the threshold.

Any person lacking an ability fundamental to the requirements of free and equal citizenship is said to have a sub-threshold disability.<sup>33</sup> Rawls refers to these genetically most unfortunate individuals as non-ideal people (those not normal, active, fully cooperating participants in the community of justice), and he essentially leaves them out of his theory.<sup>34</sup> Rawls goes so far as to say that sentient creatures lacking the capacity for a sense of justice are owed duties of humanity and compassion even though they may not demand "strict justice" from free and equal citizens.<sup>35</sup> Together with Rawls's statement about each individual's interest in securing the best possible genetic endowment,<sup>36</sup> this acknowledgment is as close as Rawls gets to endorsing a policy of using genetic manipulation to treat those afflicted with sub-threshold defects.

Although Rawls's theory comes close to mandating genetic intervention for the correction of sub-threshold defects, it does not come close enough. Failures such as this one are precisely what motivated the modification in Rawls's theory. Giving aid to and permitting supererogatory acts towards the victims of sub-threshold defects is not the same thing as promoting their moral and political equality. The capacities lacking in non-ideal persons are essential for political personhood itself. If traits

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<sup>32</sup>Norman Daniels, *Just Health Care* (New York: Cambridge Univ. Press, 1985), p. 43.

<sup>33</sup>Although other ways in which people may become sub-threshold disabled are important (illness, accident, etc.), this paper concentrates on those people who are sub-threshold disabled as a result of genetic mutations.

<sup>34</sup>Rawls, *Political Liberalism*, p. 20; cf. Daniels, *Just Health Care*, p. 43.

<sup>35</sup>Rawls, *Theory of Justice*, p. 512.

<sup>36</sup>*Ibid.*, p. 108.



essential to personhood can be supplied by genetic engineering in a safe, effective, low-cost manner, it would be a travesty of justice to leave these distinctly disadvantaged members of our species out of any theory of justice. To do so would be to deny their personhood. The promise of genetic technology offers us a way of including these people that is consistent with the letter and the spirit of Rawls's original theory. As a consequence, my revised Rawlsian theory would obligate the state to pay for gene therapy procedures that corrected sub-threshold defects.

As mentioned above, society must decide how much of its resources it is willing to devote to the amelioration of sub-threshold defects. The principles of justice require that these defects be corrected as long as the cost of doing so does not push below the minimum threshold of opportunity anyone who is already above it. At some threshold range of cost, it actually becomes unjust to obligate the taxpayers to pay for the correction of sub-threshold defects because of the deleterious effect it would have upon the rest of society. In this situation, the "whenever it is possible to do so" clause in modification (B) kicks in to prevent society from destroying itself in its quest for justice.

One can imagine a day, however, when procedures to correct sub-threshold genetic defects might be as cost-effective and relatively risk-free as today's vaccinations against diseases. If we assume that the costs of correcting sub-threshold genetic defects are similar to the costs of vaccinating children against polio and smallpox, we can safely assert that such measures would be required by justice.

*Restriction defects.* Restriction defects are those that are not so severe as to prevent a person from participating in political life, but do severely limit one's range of opportunities to pursue a preferred life plan. Rawls's theory as written contains no provision for ensuring people a minimally adequate range of opportunities. Under his theory, people born with restriction defects are guaranteed fair equality of opportunity vis-à-vis people similarly talented and motivated. Consequently, Rawls's theory does not mandate correction of genetic abnormalities that amount to restriction defects because all people similarly afflicted will still have equal opportunities (although they will be severely limited). The modified Rawlsian theory offers a richer, more inclusive notion of equal opportunity by mandating the correction of restriction defects through genetic intervention whenever possible so as to provide everyone with a minimally adequate range of opportunities.

As noted at the end of section 4, the challenge lies in identifying what defects will count as *severe* limitations on opportunity. Defects that do not severely limit one's opportunities fall into the category of cosmetic defects. One way of distinguishing these two classes of defects is that while restriction defects leave one with an intolerably narrow opportu-

nity range, cosmetic defects do not. Interestingly, where the line is drawn between restriction defects and cosmetic defects determines the extent to which the modified Rawlsian theory improves upon Rawls's original theory. If we say that the pure Rawlsian theory is a strictly primary goods approach and that the modified Rawlsian theory is a capability approach for those individuals who fall below the line of minimally adequate range of opportunities, then "how close they will come depends on how the notion of severity is interpreted."<sup>37</sup>

An example involving height will help clarify how the concept of severity might work. A genotype predisposing an individual to a final adult height range of between 5'6" and 5'10" may restrict one's opportunity range to the extent that such occupations as "professional basketball player" will be closed to that individual. However, it would be odd to think of such a minor limitation on one's opportunity range as a severe restriction. What distinguishes this child's cosmetic defect from a restriction defect that predisposes another child to a final adult height of under 4'0" is that the restriction in opportunity range for the shorter child is intolerably great. The shorter child will be severely restricted in his ability to convert primary goods into freedom to achieve well-being. In contrast, the child predisposed for normal height still has an adequate array of opportunities from which to choose.

We must avoid defining restriction defects broadly enough to include things that do restrict opportunity but should not be thought of as "defects." Race and gender can (arguably) severely restrict one's opportunity range but should not be counted as restriction defects that ought to be "cured" through genetic manipulation. Such a policy would be blatantly opposed to the goal of maintaining a diverse and viable society.<sup>38</sup>

A Rawlsian might argue that in a well-ordered society, the enforcement of fair equality of opportunity would prevent differences in race and gender from limiting people's opportunity ranges. Therefore, the

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<sup>37</sup>Cohen, p. 285.

<sup>38</sup>This kind of over-broadness plagues Daniels's approach to disease, which he defines in terms of restrictions in the normal opportunity range (*Just Health Care*, p. 33). Daniels acknowledges the complications that ensue once principles of justice are relied upon to determine the distribution of health-care services, and he tries (unsuccessfully, I believe) to insulate his theory from charges of over-broadness by relying on what he calls "the biomedical model" (p. 31). In addition to being overinclusive, his biomedical construction of normal species functioning also seems intuitively unsatisfactory. For example, on Daniels's account, a cold would not seem to count as a disease, since it does not sufficiently restrict one's opportunity range. For a criticism of Daniels's model's ability to differentiate between enhancement and treatment, see Eric T. Juengst, "Can Enhancement Be Distinguished From Prevention in Genetic Medicine?" *The Journal of Medicine and Philosophy* 22 (1997): 125-42. These worries aside, Daniels's model does provide a useful baseline guide for policy makers at the legislative stage.

need to correct severe restrictions in opportunity caused by race and gender would not exist. Although true to the abstract nature of the theory, this move is somewhat unsatisfying, however much we would like to share the Rawlsian's vision of what society may someday be like. If we are ever to apply Rawls's ideas to society as we know it, we must include the fact that racial and gender inequality continues to restrict the opportunity range of disadvantaged minorities. This reality and the difficulty it poses deserve at least some discussion here.

One solution to this problem of over-inclusiveness might be to exclude from the definition of defect those aspects of a person that diminish that person's opportunities due to beliefs people in society happen to hold. These defects can be distinguished from those that restrict a person's opportunity range due to facts about the world. For example, a blind person cannot watch television because one needs eyesight in order to see things. Contrast this situation with that of the ugly person who is ugly because of the shared public conception of what is ugly that stems from individuals' beliefs about beauty.<sup>39</sup> The modified theory needs a way to limit the pool of restriction defects to those aspects of one's biomedical makeup that severely restrict one's opportunities due to facts about normal human functioning rather than expanding the notion to include genetically endowed aspects of one's person that cause one's opportunities to be restricted because of societal beliefs, prejudices, and biases.

Of course, a division between a restriction based on normal biomedical functioning alone and one based upon societal beliefs is not always clear. Chris Bobonich points out<sup>40</sup> that the role of technology in modern life poses interesting examples of how restrictions in opportunities can arise from the combination of societal beliefs and facts about species functioning. The way a product is designed is directly related to the designer's beliefs about the world. A computer may be designed in such a way as to prevent people who lack normally functioning hands from using it. However, a technician could also invent a computer that responded to voice commands so that people with defective hands could use the technology as well. In addition to having the potential to equalize access to technology for people of various levels of species functioning, technological innovation can also be used to open up entirely novel opportunities. The pervasiveness of these technologies changes societal beliefs about what types of biomedical defects are restrictive.

Even without the prospect of changing technology, complications

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<sup>39</sup>I am indebted to Debra Satz for coming up with the distinction between beliefs and facts about the world (personal communications, Stanford University, September 1996-May 1997).

<sup>40</sup>Personal communications, Stanford University, February 5 and March 17, 1997.

arise when the same genetic predisposition involves both biomedical facts and socially constructed beliefs that affect one's opportunities. One might argue that having dark skin is a disadvantage in today's society because of the socially constructed cultural prejudices against minorities.<sup>41</sup> On the distinction we want to make, genetically altering a person's skin color would not be allowed simply because of the beliefs some people have about race. Conversely, being darker skinned may be a biomedical advantage due to melanin's tendency to provide greater protection against skin cancer. Should we recommend that people's genes be altered to give them darker skin even though people with darker skin are disadvantaged because of the beliefs some others hold?

Examples like this, where the "defect" has divergent biomedical and cultural constructions, pose difficult challenges to policy makers at the legislative stage.<sup>42</sup> Another class of difficulties confronts legislators attempting to draw the line between restriction defects and cosmetic defects. Returning to the example of height, would a height of 4'9" place a severe restriction on an adult male's range of opportunities in the United States? In Japan?<sup>43</sup> The two difficulties have in common the possibility of being resolved by a functional theory of health and disease, a concept which has so far proved elusive. Eric T. Juengst attempts to save one such theory (Norman Daniels's)<sup>44</sup> by introducing a "robust concept of disease."<sup>45</sup> However, it is not clear that Juengst's concept of disease is any more precise or objective than Daniels's theory. Further, it may be impossible to construct a strictly medical model of health and disease that fits tightly onto the modified theory's more inclusive idea of a minimally adequate range of opportunities.

At the high level of abstraction at which Rawls's theory operates, it is impossible to make precise determinations about what kinds of defects will count as severe. Perhaps frequent debate and revision of the severity standards at the legislative level is the solution to this difficulty. The implementation of Rawls's theory in practice has always been a source of criticism; it is beyond the scope of this paper to address this issue fully.

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<sup>41</sup>I am indebted to Eddie Lee for providing me with the example of skin color (personal communication, Stanford University, April 1997).

<sup>42</sup>Some of these problems might be avoided by classifying race and gender as cosmetic traits. Of course, such a classification presupposes that these traits have a minimal effect on opportunity, an arguable premise.

<sup>43</sup>I thank the anonymous reviewer who pointed out this dimension of the problem.

<sup>44</sup>See above, n. 38.

<sup>45</sup>Juengst defines disease as "e.g., a biological process that moves from discoverable causes (genes, germs, or environmental insults) through a robustly confirmable process of pathogenesis that yields characteristic signs and symptoms that, in turn, reduce function below species-typical norms" (p. 138).

Putting aside the hard cases, the modified Rawlsian theory can be used to narrow down the notion of severe to come up with a policy for restriction defects. Take the case of the person genetically deprived of arms—an obvious restriction defect. The lack of arms represents an enormous obstacle she must overcome in converting social primary goods into freedom to pursue her desired ends. By invoking the modified Rawlsian theory, the implementation of a policy that mandated genetic corrections in these situations follows straightforwardly from the fact that this individual falls below the minimally adequate range of opportunities specified by society.

*Cosmetic defects.* Many “defects” people might want to correct will be cosmetic—those that do not severely affect a person’s opportunity range (e.g., a slight cleft lip, a missing toenail). Correction of cosmetic defects is permitted, but not mandated, under the modified theory because this type of correction does not significantly alter individuals’ levels of opportunity. While the state should be obligated to fund procedures parents wish to undertake to correct restriction and sub-threshold defects, the state should allow but not fund the correction of cosmetic defects.

One may object that allowing for the correction of cosmetic defects without providing state funding for the procedures will serve to exacerbate class divisions by adding a biological component to class. However, correcting cosmetic defects will not appreciably increase an individual’s life chances. Any class inequality due to permitting cosmetic corrections will probably be undetectable against the background of unfairness that already exists with the ability of the rich to have cosmetic surgery, buy fashionable clothes, and to exercise greater control over their appearance in general due to their increased purchasing power.

The idea behind the modified Rawlsian theory is that people who are severely disadvantaged should be helped if it is reasonable to do so. Our intuitions stem not from the belief that every lowering of life-prospects due to accident (morally arbitrary factors) requires redress. Rather, as Allen Buchanan reminds us, they flow from the idea “that, other things being equal, no person should be barred from the chance to have a minimally decent life as a result of undeserved natural (or social) deficits. In other words, the relevant concern here is with *deprivation*, not with inequality as such.” A deprivation is “a lack of some important constituent of a minimally decent or adequate human life.”<sup>46</sup> A deprivation caused by genetic defects (sub-threshold or restrictive) is exactly the sort of abnormality that ought to be corrected using state funds according to the modified Rawlsian theory. Cosmetic defects, on the other hand, are

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<sup>46</sup>Allen Buchanan, “Equal Opportunity and Genetic Intervention,” *Social Philosophy and Policy* 12 (1995): 105-35, p. 129.



not deprivations and do not warrant state funding for their correction.

We have seen how the modified Rawlsian theory might help us decide what to do in the case of genetic alterations designed to fix genetic damage. Most of these arguments jibe with our intuitions about the desirability of making sick people well. The next section considers genetic alterations that might be performed to enhance various traits such as immunity to disease, intelligence, and eye color.

## 6. Genetic Enhancement

A distinction is often drawn between correcting genetic defects and enhancing a person's genetic endowment. So far I have tried to draw a line between the practices of using genetic technology to correct defects and using it to enhance characteristics that would otherwise have been within the range of normal. In this section I investigate what the modified theory of justice has to say about regulating genetic enhancement.

Enhancing people's genomes seems appealing at first because of its potential to enhance people's life opportunities, health, and freedom. Yet talk of enhancing the human genome often arouses fears that the technology will be abused. These fears are not completely without a rational basis, but they should be put aside for the purposes of this analysis. The modified theory's recommendations concerning genetic enhancement derive from the principles of justice rather than independent judgments about the intrinsic rightness or wrongness of the genetic intervention.<sup>47</sup>

As I did with genetic defects, I divide genetic enhancements into three types that each demand separate consideration from the modified theory of justice: (1) Cosmetic enhancements are those in which genes are altered to enhance some cosmetic trait that would not have been con-

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<sup>47</sup>Space does not permit me to delve into the many arguments that have been made for and against genetic intervention, many of which purport to focus exclusively on genetic enhancement. For an argument that rejects the Daedalus effect and compares gene therapy to conventional medical treatments, see Nils Holtug, "Human Gene Therapy: Down the Slippery Slope?" *Bioethics* 7 (1993): 402-19; for discussion of the claim that unborn individuals have the right to an unaltered genome, see Maurice A.M. DeWachter, "Ethical Aspects of Human Germ-Line Gene Therapy," *Bioethics* 7 (1993): 166-77; for arguments for and against genetic intervention, see LeRoy Walters and Julie Gage Palmer, *The Ethics of Human Gene Therapy* (New York: Oxford Univ. Press, 1997), esp. pp. 80-86; 130-33; for an argument describing genetic engineering as a morally obligatory rescue, see E. Joshua Rosenkranz, "Custom Kids and the Moral Duty to Genetically Engineer Our Children," *High Technology Law Journal* 2 (1987): 1-53; for concerns about personal identity and future generations, see Jonathan Glover, *Causing Death and Saving Lives* (Harmondsworth: Penguin Books, 1977), David Heyd, *Genethics* (Berkeley: Univ. of California Press, 1992), and Derek Parfit, *Reasons and Persons* (Oxford: Clarendon Press, 1984).



sidered defective if no alterations had been made; (2) Health-related enhancements are those that enhance one's health (ability to resist disease, decreased tendency to get cancer, etc.) beyond what is normal in an unaltered member of the species; (3) Substantive enhancements are those that endow an individual with the potential for capabilities that enhance one's opportunity range in ways that threaten to upset the balance of the conditions of fair equality of opportunity and the fair value of liberty established by the principles of justice. I discuss each type of enhancement and the implications the modified theory of justice has for it.

*Cosmetic enhancements.* A cosmetic enhancement is defined as one that will not significantly affect an individual's opportunity range. Individual cosmetic traits such as eye color and belly-button configuration are examples of traits whose alteration will not significantly affect one's life chances.<sup>48</sup> Cosmetic genetic enhancements should be permissible (not state-funded) for persons who decide for themselves to have the enhancements. Parents should not be able to choose for their offspring which cosmetic enhancements they will receive.

With a slight difference, these conclusions accord for the most part with those drawn in the last section on cosmetic defects; traits whose enhancement does not result in greater opportunities may be permissibly enhanced without the state's having to provide funds. The difference is that parents are allowed to correct cosmetic defects, but they are not allowed to enhance their offspring cosmetically without the consent of those offspring (this restriction will effectively preclude pre-natal cosmetic genetic enhancement; post-natal gene therapy for a consenting adult would still be an option). The basis of my distinction here lies largely in the form of an intuition that correction of a defect can be permissibly chosen for another person, while unessential enhancements to one's appearance should be made by the individual who will have to live with the alteration. Decisions about whether to enhance cosmetically will hinge more on people's individual beliefs about what is beautiful than on concerns for justice. In short, nothing in the modified theory of justice prevents cosmetic genetic alterations.

*Health-related enhancements.* I subdivide health-related enhancements into two types: those that resemble vaccinations and those that resemble taking vitamins. The analogies are useful because they help us visualize the way in which the two subdivisions are separated on the basis of their

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<sup>48</sup>I specify "individual" here because combinations of cosmetic enhancements may yield a substantive increase in one's opportunity range. In these cases, the enhancement will no longer be considered cosmetic, but will instead be regarded as a substantive enhancement to be treated just like other substantive enhancements (see "Substantive enhancements," below).

relation to opportunity. In the 1950s, when polio was running rampant, being vaccinated against the disease represented a significant boost to one's capability and corresponding level of opportunity. Conversely, not being vaccinated represented a distinct disadvantage in terms of life chances. One can imagine that there could be a class of vaccine-like genetic enhancements. Everything from a fortified immune system to a decreased likelihood of contracting cancer may one day be available as a safe, effective, inexpensive gene therapy. If the day does come when such "genetic vaccines" can be provided in a cost-effective and safe manner, it seems as though they should be mandated for all individuals just as vaccines are today.

Vitamin-like health-related genetic enhancements will function essentially as genetic vitamins that are presumed to aid one's overall health in small ways. By vitamins I refer not to the actual daily requirements of vitamins that every person is supposed to get from his diet. Instead, I refer to those doses of vitamins that one takes in excess of what is required in those cases where such overdoses are not harmful (e.g., antioxidants, vitamin C, garlic pills). An example of a genetic vitamin would be a type of gene therapy that would give an individual extra copies of the genes that encode the enzymes responsible for the repair of DNA damage due to UV light. One might imagine a state of medical knowledge in which doctors and biochemists believed that a threshold level of copies of the genes encoding the repair enzymes was sufficient for providing one with a high level of protection from the sun but that higher doses of the gene might be even better.

Just as supplemental vitamins do not provide a substantial increase in one's health, genetic vitamins do not enhance one's health and corresponding level of opportunity range to a significant degree. In this way, they are similar to cosmetic enhancements. The difference is that the parents of the child are not able to make any cosmetic enhancements in their offspring, while they are freely permitted (at their own cost) to give their children whatever genetic vitamins they desire (just as they can give their children traditional vitamins).

Vaccine-like health-related enhancements are really a subset of substantive enhancements in that they increase an individual's opportunity range to a significant degree. By contrast, vitamin-like enhancements are neither substantive enhancements (they do not significantly increase an individual's opportunity range) nor cosmetic enhancements (because they are allowed to be chosen by parents). Instead, vitamin-like enhancements are their own unique category. Because vaccine-like health-related enhancements are substantive enhancements of which the modified theory of justice would always approve (given safe, effective, inexpensive gene therapeutic techniques), the arguments in the next section

regarding substantive enhancements apply equally well to this class of health-related enhancements.

*Substantive enhancements.* Substantive enhancements are those that endow one with a substantial increase in opportunity. As an initial observation, a policy making substantive enhancements merely permissible will cause problems of the sort modifications (A) and (B) are meant to prevent for the class of genetic repairs. Too wide a gap in opportunity ranges between the substantially enhanced and the non-enhanced could very well reduce the worth of fair equality of opportunity and the fair value of political liberty for the non-enhanced. The immediately obvious danger is that allowing enhancement for those who can pay for it will increase inequality by adding a genetic component to social inequalities. This arrangement would tend to widen the gap between rich and poor (or between those more free and less free to achieve well-being), even if the only inequalities that were allowed were those that improved the position of the least advantaged. Too wide a gap, Rawls warns, could jeopardize a society's ability to abide by the principles of justice.<sup>49</sup>

For example, if a few people are allowed to secure most of society's wealth, their superiority in that sphere easily could be translated into an inequality in the political sphere where fundraising and expensive media coverage is so critical. Closer to our focus, imagine a man genetically enhanced with a tall stature, booming voice, good looks, and keen intellect. It seems inevitable that these inequalities will translate into inequalities in opportunities in many spheres. Important offices in society will effectively be closed to those not genetically enhanced.

It may be that the presence of exceptionally talented individuals would make everyone better off. However, such an improvement at the expense of restricted access to offices and positions is explicitly prohibited by the principle guaranteeing fair equality of opportunity. It would be an injustice to allow any inequalities which prevented any group of individuals from "experiencing the realization of self which comes from a skillful and devoted exercise of social duties."<sup>50</sup>

Radical differences in natural assets due to genetic alteration might also increase discrimination against the genetically unaltered. The availability of enhancement and correction technology will make certain phenotypes rarer and thus more shocking. Children whose parents opt not to correct defects and those who acquire an abnormal phenotype through some accident or environmental circumstance may be stigmatized in

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<sup>49</sup>To borrow a concept from Michael Walzer, too great an inequality in one sphere of justice will inevitably spill over into other spheres. Michael Walzer, *Spheres of Justice* (New York: HarperCollins, 1983).

<sup>50</sup>Rawls, *Theory of Justice*, p. 84.

ways harmful to their ability to attain the primary good of self-respect.

The uncommonness of certain abnormalities may increase the marginalization of people with disabilities. A cost-benefit analysis might show that with the success of gene therapy, the smaller numbers of children with disabilities do not justify the huge expense of special education programs and special facilities necessary to bring these children up to a minimally adequate level of functioning. In other words, there would be great pressure to lower the minimally adequate level of opportunity for those rare children with phenotypes typically associated with genetic diseases that would be routinely corrected. Of course, the modified theory would ideally prohibit this, but one can easily imagine such a marginalization of the disabled considering how hard it has been to secure disabled rights in today's society with its estimated 49 million disabled members.<sup>51</sup>

All of these points reinforce the conclusion that substantive genetic enhancements should not be merely permissible. Now we must examine whether instead they should be mandatory or prohibited for everyone. The motivation behind mandating enhancement is captured by Rawls's intuition that rational members of society in the original position would want to ensure the best possible genetic endowment for their descendants, since better genes would help the descendants pursue preferred life plans. He concludes that "we might conjecture that in the long run, if there is an upper bound on ability, we would eventually reach a society with the greatest equal liberty the members of which enjoy the greatest equal talent."<sup>52</sup>

Rawls's claim that greater natural assets help one pursue a preferred life plan requires further examination. It is far from clear that a society in which everyone were, say, ten times smarter than they are now would be more just. Most traits confer an advantage because they are possessed to a greater degree by some individuals relative to others. That is, the advantage is a comparative one, not one that stems from possession of the trait itself. If everyone improves to the same degree, it is not clear in what sense we are better off. Perhaps with increased abilities, people would have a greater array of life plans from which to choose. This increase in choice might also increase the likelihood that one would be

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<sup>51</sup>Paul K. Longmore, "Disability and Human Identity," Lecture for "Bioethical Issues in Human Biology," Stanford University, March 11, 1997. Recall that the modified theory should not permit pushing anyone below the minimum level of opportunities who is already above it. However, one might argue that disabled people who were above the minimum level only in virtue of society's allocating them resources should not be protected from being pushed below the threshold when society decides at the legislative stage that an alternative distribution of resources is more desirable.

<sup>52</sup>Rawls, *Theory of Justice*, p. 108.

able to pursue a preferred life plan.

Assuming that substantive genetic enhancements did widen everyone's opportunity range, Rawls's original theory would still not necessarily mandate substantive genetic enhancement. The relevant concern for Rawls is fairly equalizing opportunity for those similarly talented and motivated. Further, as noted earlier, Rawls measures the least advantaged in terms of the social primary goods (income and wealth). Rawls's failure to take capacity to function into account in his measurement of the least advantaged person leads to the kind of unsatisfactory assessments of the least advantaged that motivated modification (A).

On the modified Rawlsian theory in which capacity to function is part of the measurement of the least advantaged, substantive enhancements would raise the position of the least advantaged simply in virtue of their increasing everyone's capacity to function. If our goal is to structure inequalities so as to maximize the position of the least advantaged, then it seems at first that enhancement would be required under the modified principles of justice. However, recall Sen's arguments that what we really care about is not one's level of natural primary goods, but one's freedom to achieve well-being. If our goal is increased freedom, it is not clear that substantive genetic enhancements will always be warranted.

My revision of Rawls's theory is designed to take capacity to function into account in the measurement of the least advantaged primarily for the case in which one's lack of capacities places one under some minimally adequate level of opportunity. Of course, the standard of what counts as a minimally adequate level of opportunity is based on norms that could, and would, change over time. As enhancement becomes a more viable option technologically and economically, the standard might rise. However, it might be that beyond enhancements that endowed one with genes that provided "maximum health," no more of a minimum in genes would be demanded. In this case, mandating additional enhancements of various genes would not make the society more just.

From a cost-benefit perspective, correction procedures should take priority over enhancement. Society should be more willing to underwrite the restoration of genetic health—with its corresponding minimally adequate level of opportunity—than the enhancement of normal traits. Given the choice between publicly funding the correction of restriction and sub-threshold defects or enhancements, where both treatments are equally priced and equally feasible (technically), the modified principles of justice demand that society subsidize the corrections first so as to guarantee more individuals a minimally adequate opportunity range. As Holtug puts it, this endorsement of correction is not an absolute condemnation of enhancement; it is simply an all-things-considered judgment that supporting enhancement is not the right thing to do given soci-



ety's priorities and limited resources.<sup>53</sup>

We will not have to consider what policies to adopt regarding genetic enhancement for a long time to come. One reason is the idea about limited resources put forth above. Another reason is that the Food and Drug Administration will not be in a position to approve gene therapy for non-life-threatening alterations until the risk is lowered tremendously. It is one thing to allow gene therapy on a patient with adenosine deaminase deficiency ("Boy in the Bubble disease") or cystic fibrosis whose life prospects are minimal; it is quite another to approve enhancement therapy for someone who would otherwise be perfectly healthy. The risks the FDA tolerates in trying to aid someone with a severe genetic disease are far greater than anything acceptable for already healthy patients.

Furthermore, the complexity of the traits for which genetic enhancements will most often be desired means that much more research must be conducted than will be needed for simple traits determined by a single locus. Simply by being multifactorial, the risks of the procedure will be higher because of the need to target several different sites. In addition, figuring out how all the different loci work together to yield the end phenotype will prove to be very difficult, time-consuming, and costly. Even when the risks are vastly reduced, there will always be some risk involved, just as there is with any surgical procedure. It does not seem likely that very many people would want to try out the new technology if doing so means risking the lives of their children.

If risk, cost, and limited resources ever cease to be significant barriers, society might consider making mandatory certain substantive genetic enhancements. In order to prevent the exacerbation of class divisions and the widening of the gap between rich and poor, state funding should be provided for safe and effective genetic enhancements that tend to give one an increased range of opportunity. If funding for these enhancements cannot be made available to everyone, then they should be outlawed. Our modified Rawlsian theory entails that there should be no permissible, unfunded genetic enhancements that confer an unfair advantage in opportunities to some and not all.

To summarize, the modified theory of justice allows adults to enhance themselves cosmetically but prohibits parents from cosmetically enhancing their offspring without their consent; substantive health-related enhancements are mandatory, while non-substantive health-related enhancements are merely permissible; finally, substantive enhancements cannot be merely permissible without jeopardizing the instantiation of the principles of justice. Instead, substantive genetic enhancements are either mandatory or prohibited depending on what soci-

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<sup>53</sup>Holtug, p. 414.



ety has agreed upon for each case. Far from being an absolute moral evil, genetic enhancement may one day be an integral part of our lives.

## 7. Prospects for the Future and the Now

This paper was written with three primary aims. The first was to show that Rawls's theory needed to be modified in order for it to yield satisfactory answers to the questions surrounding the regulation of genetic manipulation. Section 3 exposed two holes in Rawls's theory. First, by reducing the index of interpersonal comparison used to identify the least advantaged individual to a survey of income and wealth, Rawls's primary goods approach was shown to lead to unsatisfactory assessments of the least well off. Second, Rawls's primary goods approach was shown to be a worse way of assessing the position of the naturally disadvantaged than Sen's capability approach. We saw that Rawls's method of compensating natural disadvantages with social primary goods was unsatisfactory in cases of significant deprivations in human functioning. In addition, Rawls's principle of fair equality of opportunity relativized to those similarly talented and motivated permitted intolerably narrow ranges of opportunities for those severely genetically disadvantaged.

The second aim was to modify the theory in a way that made it responsive to the possibility of genetic manipulation in humans and that reflected our desire to redress more directly deficiencies in capabilities. Section 4 proposed two modifications to the original theory. Modification (A) instructs that account be taken of capabilities when determining the least well off. Modification (B) fixes a baseline level of opportunity below which no one is to fall unless it cannot be prevented in a way that avoids pushing below the minimum threshold those individuals who are currently above it. (B) prevents those genetically disadvantaged from falling too far through the cracks left by the "similarly talented and motivated" clause in Rawls's principle of fair equality of opportunity.

The third aim was to show how my modified Rawlsian theory would instruct us to use emerging biotechnology for the purposes of genetic correction and enhancement. Consistent with the first principle of justice, the modified theory mandates state funding for the correction of those genetic defects that burden an individual with a level of functioning insufficient to ensure a minimally adequate range of opportunity (sub-threshold and restriction defects). Correction of cosmetic defects and enhancement of cosmetic traits are both permissible, except that parents may not cosmetically enhance their children without their consent. Health-related enhancements that significantly boost one's range of opportunity are mandated as are all other substantive enhancements that society agrees are worthwhile. Health-related enhancements that have a

negligible impact on an individual's opportunity range are permitted. Substantive enhancements that society agrees not to endorse are prohibited for everyone.

This paper only begins the process of evaluating the imminent prospect of using genetic technology on humans. In many ways, the prospects for the future of medicine and human genetics seem scary. We will soon have the knowledge to carry out an entirely new form of positive eugenics. However, this knowledge will give us new ways to harm ourselves just as other emerging technologies have done throughout our history. Scientific discoveries in the field of genetics will not change our seemingly infinite capacity for harming ourselves. The hope is that the continual march of science will ease the strains on our lives that contribute to people's mutual mistreatment.

Moral disagreements will continue about how far society should go towards enforcing equality of opportunity and how society should "balance concern for those who are worst off with avoidance of society-wide losses in quality of life."<sup>54</sup> While a theory of justice will be instrumental in establishing a framework within which specific policy decisions can be made, much of the substantive work of drawing distinctions in the hard cases is left to be worked out at the legislative and judicial stages.<sup>55</sup> Public debate amongst competing conceptions of the good is the accepted procedure in liberal democracy; these kinds of ongoing peaceful disagreements actually serve to make more legitimate the forum of liberal democracy.

The key to a successful debate is the participants' knowledge of the relevant information. The best way to overcome our apprehension surrounding genetic manipulation is to talk about it, write about it, argue about it, and, most importantly, learn about it. We must insist upon educating the public honestly about issues of genetic innovation and the ethical problems it spawns. Only then will it be possible to make policies that truly capture our considered judgments on this important matter of justice.

**Jonathan S. Brown**

Boalt Hall School of Law  
University of California, Berkeley  
jbrownie@boalthall.berkeley.edu

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<sup>54</sup>Philip Kitcher, *The Lives To Come* (New York: Simon & Schuster, 1996), p. 318.

<sup>55</sup>As Michael Walzer observes, "It only remains to be worked out the details—but in everyday life, the details are everything." Walzer, p. 91.