Gene Therapies and the Pursuit of a Better Human

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As a philosopher interested in biomedical ethics, I find recent advances in genetic technologies both fascinating and frightening. Future technologies for genetic therapies and elimination of clearly deleterious genes offer us the ability to get rid of the cause of much human suffering, seemingly at its physiological root. But memories of past eugenics programs gone horribly awry (whether we speak of Hitler's program, California sterilization laws and practices of the 1920s, or even contemporary practices, such as attempts to work out deals that exchange sterilization for early prison release)[1] must make cautious our initial optimism for these generally well-intentioned programs. Most often the scientist proceeds in research with the best of intentions, but that does not make all scientific investigation worth pursuing.

Surely no one would dispute the claim that the aim of bettering humanity and/or our own children is morally acceptable. Indeed, most of us see as ideal a world in which every parent works toward improving the lot of his or her child, or the lot of all of our children. But while no one denies the importance of this quite general goal, we are still left with difficult issues about *how* we ought to proceed in addressing that goal. When we try to dodge diseases or disadvantages through genetic intervention, are we solving problems or just moving them to a different level? I want to briefly address two quite general questions in regard to this topic. First, what *means* should we take in trying to better our children? Second, how are we to decide what really counts as "bettering" them? I do not claim to solve these difficult issues here, but only to consider some ways we might approach the problems.

Consider the various ways in which we try to better our children. First and foremost, we try to educate them. That is, we provide public education for all children with the intention of teaching them not only how to read, write, and do arithmetic, but also how to function in this society and how to make important decisions in their lives. No one questions this means to bettering our children, unless they find fault with particular styles of teaching (for instance, they see the teacher as indoctrinating a particular view rather than presenting basic facts and promoting the child's own rational critical faculties in assessing those facts). Generally, as long as the education exercises the child's mind and allows the child some autonomy in regard to how he or she will understand the material, this means of bettering is considered morally acceptable and even required.

In addition to education, we find it morally acceptable to better children by giving them appropriate medical care. If a child needs surgery or a painful treatment to survive or to thrive, we allow ourselves room to do what is "best

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for the child" even if that may involve unavoidable pain that the child is not able to consent to. Furthermore, we often go beyond merely treating clearly defined diseases and actually allow enhancement of our children in the medical setting. We regularly give our children vitamin supplements, vaccinations, and dental enhancements (e.g., braces), and we generally do not blink at such interventions.[2] Thus we have no clear moral concern with imposing medical treatments paternalistically, so long as we are fairly certain that we are promoting the child's best interests.

There are no doubt numerous other ways that we try to make things better for our children and future generations. Many of them are indirect: we try to balance the national budget (or at least keep it under control); we try to pass legislation that will save the environment and preserve a fair quality of living for future generations; and we put federal and state money into exploratory research that is unlikely to produce immediate results but may lead to improvements in future lives. So whether we are trying to enhance children themselves or their environment, we are generally quite at ease with working toward improvements.

But how do genetic therapies fit into this classification? If we are speaking of somatic cell therapies (performed on the body cells of a fetus, infant, or adult, so that the genetic changes will not be passed on to the next generation), then we at least have an identifiable being who may be benefited by the changes; but if we speak of germline genetic therapies, performed pre-embryonically, then what is in question is who will come into existence, and we find ourselves in the Parfitian paradox of future generations.[3] Should we be compelled to try to make things better for unidentifiable future persons? What could the compelling reason be? Without wading through the vast literature debating this topic, I think it is safe to say that most of us are at least willing to admit that duties of beneficence and intuitions about morality suggest that we do care about these future people (whether or not we are required to do so by rules of justice). But in trying to work things out for future people (or even for young children who are not considered competent to decide for themselves), we must decide what kind of interventions are morally legitimate and most likely to be truly beneficial.

If we think that a genetic therapy will benefit a fetus or child, should we perform that therapy? The initial response might appear to be a resounding yes. This sort of treatment appears to get to the root of the problem and eliminates the need for any suffering from the disorder. Some common arguments posed against genetic interventions generally have been rather soundly disposed of in the relevant literature, e.g., arguments from playing God, from messing with nature, from the inevitability of slippery slopes.[4] But in a society that tends to overvalue the quick fix solution, we might do well to exercise some caution even here.

First, we might get unexpected results. If we perform genetic therapies to remove or change a clearly deleterious gene, then we might find that other important physical or psychological traits were also controlled by that gene (or by its influence on another gene or its expression). The commonest example here is the link between sickle cell trait and resistance to malaria. Another such link commonly discussed in the literature is that between creativity and various forms of mental illness.[5] Although we may be interested in relieving the suffering caused by the expression of certain genes, we are not yet certain what

else we may be removing or changing inadvertently. Although these are certainly reasonable worries, even with such possibilities, treating painful and restrictive genetic disorders (e.g., Tay-Sachs or cystic fibrosis) might be worth the risk, so long as traditional rules regarding informed consent for clinical trials are respected.[6]

Second, we might be losing something valuable if we are able genetically to engineer around our problems. Erik Parens, for instance, suggests that part of what we value about humanness is our fragility, and the capricious nature of our lives, which necessitate our taking care of one another in times of need.[7] If we are able to use genetic engineering to get rid of this fragility (or at least to change the kind of fragility or to make people less willing to feel sympathetic to one who is fragile), then we may inadvertently destroy something very valuable. This is not to say that we must keep people suffering so that we can be caring creatures, but only that we might lose part of what makes us really appreciate our lives.[8] Parens has tongue-in-cheek suggested that we might all vote to make it so that no one had to experience adolescence as we know it (it is painful to go through and it is painful to be around those who are going through it), but he also notes that most of us place value on the process of working through such a time, and that effort is part of what makes us appreciate our adult lives.[9] Thus he counsels caution in our eagerness for genetically eliminating *anything* that appears to cause pain or discomfort, and a deeper analysis of what it is that we receive from the experience of living with disadvantages and diseases.

This brings me to my second issue: How are we to decide what is to count as "bettering" children? Few of us would dispute the claim that eliminating Tay-Sachs disease or Lesch-Nyan syndrome or cystic fibrosis would count as an improvement for future generations. A future in which no one has to suffer from these debilitating diseases seems undeniably worth pursuing. On the other hand, disability rights advocates are quick to point out practical problems with holding this view without devaluing existing persons with those diseases.[10] Even if we can conceptually distinguish between the value of individuals with disabilities and the relative value of bringing such individuals into existence given other options,[11] in practice, public attitudes toward such individuals are likely to be prejudiced and will likely affect public financial support of the disabled.[12,13]

Even if we could reach agreement about the value of genetically intervening for clear cases of debilitating disorders, there are some physiologically or genetically based conditions that offer disadvantages to children in our society that might not so clearly be candidates for intervention. What about cases in which the real cause of the disadvantage is located in unjustified societal prejudices or values? For instance, children who are shorter than average (and grow into shorter than average adults) have a smaller statistical chance for success in classes and in athletics (and ultimately in the job market) because of the biased perception of them based on their inferior height.[14] Physicians who offer growth hormone treatments treat the physiological symptoms of shortness as a way of solving the social problem for the child. But the community is then allowed to continue its arbitrary preference for taller people. In this case, society is at fault for creating the disadvantage—solving the real problem seems to require addressing societal values, *not* just engineering a way around the problem. This may seem obvious, since when height is the feature in question, there is no absolute

advantage to be had, but only a relative advantage. There is no inherent value to being six feet tall, but it is advantageous if you are *taller* than others (within limits). But the same can be said of other features that do not rely on relative advantage, such as societal standards of beauty (having a symmetric face, hair in appropriate places and not in inappropriate places, etc.).[15] Some interventions that appear to be beneficial for the recipient may not be real benefits after all if they leave the root of the disadvantages unaddressed.

Another difficult case is deafness. Most hearing people consider deafness to be a defect, a physiological problem that deserves medical attention if and when it is available. But at least a segment of the Deaf community values their physiology as different but equal to that of hearing people, and they may argue that the only reason that deafness confers any disadvantage in society (when it does), is because of unfair societal discrimination and the fact that society is set up for the benefit of the hearing. Indeed, a 1994 publication of the Denver Ear Institute notes that many deaf people consider deafness "a birthright to a distinctive and rewarding way of life."[16] The Deaf community is rich and complex in terms of language, art, and social association.[17] Deaf community advocates suggest that the Deaf are more appropriately considered a cultural and linguistic minority (on par, for instance, with Hispanic-Americans) than a disabled group.[18,19] The availability of cochlear implants for deaf children has sparked the debate about the future of the Deaf community, and it will surely only be enflamed by the possibility of genetically engineering to avoid some forms of deafness. Segments of the dwarf community have made similar claims about the value of their genetic condition and problems with therapies that try to "rectify" it.[20] Is the elimination of deafness or dwarfism a benefit, or is it a systematic destruction of special minority communities?

We might also ask ourselves about the case of homosexuality. Simon LeVay's announcement in 1991 of a statistical difference in the sizes of a particular hypothalamic nucleus between heterosexual males and homosexual males evoked a loud public debate about the relevance of genetic or biology-based explanations for homosexual lifestyles.[21] If there is a genetic basis for homosexuality, then we must ask ourselves what to do about it. A homophobic parent might aspire to have this "defect" fixed, even though homosexuality itself does not bring about disadvantages; rather, homosexuals are often unfairly discriminated against by a society that arbitrarily devalues their lifestyle. Should we try to engineer a solution to this supposed "problem," or should we work to educate people that the only problem is within their unreasonable biases?

In general, then, it appears that we may not want to genetically treat (or eliminate) just any condition or trait that confers disadvantage to our children, especially when the disadvantages are not a direct result of the trait; rather, we need to find a reasonable decisionmaking process that will help to delineate what traits are acceptable candidates for genetic therapy or genetic engineering. The dominant paradigm in the literature for drawing this line has been a distinction between treatment and enhancement, based on standard medical practices. If we use the standard model of medical practice that relies on a principle of beneficence and is tied to a "normal" human capabilities model, then it seems justifiable (or perhaps even obligatory[22]) for us to treat defects or diseases. But nothing follows about the permissibility of using genetic intervention for the purpose of mere enhancement. This distinction is intuitively appealing to doctors, genetic scientists, and the general public, including many

medical ethicists,[23] but it has been rejected more recently by ethicists on the basis of its vagueness.

According to the medical model, the basis for pursuing any genetic therapies is the relief of pain and suffering. W. French Anderson argues that genetic diseases that "produce significant suffering and premature death"[24] (p. 690) ought to be the first candidates for genetic therapies, and then, if we succeed with those cases, we might be justified in extending genetic treatments to other diseases. He claims, however, that we should not undertake any genetic engineering for the purpose of enhancement. He offers two reasons why we should not engage in any enhancement engineering. First, he thinks that sort of engineering is "medically hazardous" because we are less sure about what "adding" a gene could do to the complex system compared to fixing an existing gene. Second, he believes that it is "morally precarious" because we don't have a clear way of determining what genes should be provided, who should receive them, and how to prevent discrimination against those who don't receive them.[25] His proposal involves the claim that it is problematical for us to determine the details of enhancement engineering, but not problematical, and in fact defensible, for us to employ treatment of disease as a clear category for use of genetic engineering. This proposal is sound only if there is indeed no clear line between acceptable improvements and problematic ones, and if there is a clear line between treatment and enhancement. But is such a view defensible?

How are we to define "disease," if that is what we are allowed to treat? If we look more closely at the concepts of health and disease, we discover that the label "disease" is not metaphysically pure. Indeed, while we often assume that a disease is an objectively identifiable state, in fact, the identification of something as a disease is dependent at least in part on evaluative judgments of the physician or general society.[26] Some commentators assume that the physiological conditions to be included under the label "disease" are ones that are identified either as abnormal or as dysfunctional relative to species norms. On this view, to be diseased is merely to exemplify a certain abnormal physiological state, whether or not it is disadvantageous or painful to the person. Anyone in any society could be objectively labeled as diseased simply by reference to his or her exemplification of the relevant physiological state. But this view does not stand up to difficult cases, as numerous commentators have pointed out. Disease is not simply a physiological state, but a physiological state that bears significantly on the functioning of the individual in his or her society. Color-blindness is not considered a significant disorder or disease in the United States, but in some places in Africa "in which the capacity to distinguish a great variety of shades of green is needed to function at a minimal level for survival" it is highly problematic.[27] As Harlan Lane notes, alcohol use, tobacco addiction, large body weights, the need for eyeglasses, and hookworm infestation are all considered diseases in certain societies and not in others. The American medical system has recently medicalized many conditions that were not previously considered appropriate for "treatment," including "contraception, fertility, pregnancy, childbirth, child development, hyperactivity in children, reading difficulty, learning problems, drug addiction, criminality, child abuse, physical disability, exercise, hygiene, sleeplessness, diet, breast and nose size, wrinkles, baldness, obesity, and shortness."[28] We view certain physical states as diseases because of our judgments about what is dysfunctional, and those judgments depend on our values and social norms, resources, and standard medical prac-

tices. These may differ across societies and across time periods, as well as within societies and time periods. Consider, for example, the fact that masturbation and homosexuality were both once identified as diseases.[29] When we realize that the definition of disease is norm based, then we find that "the intuitively attractive reply that 'If we stick to curing disease and promoting health, all will be well' begins to lose its attraction."[30] What counts as a disease depends on physiology but also on what the particular society values. Consequently, the line between treatment of disease and enhancement-directed engineering seems itself to rely on a rather fuzzy distinction.

There is also the further problem of defining when something is a disease in a society that agrees that a particular condition is not valuable. For instance, no one desires atherosclerosis and the heart attacks and strokes that often follow it. Evidence suggests that there is a gene that determines the body's ability to regulate blood cholesterol levels by production of low density lipoprotein (LDL) receptors on body cells. Inserting additional LDL receptor genes in otherwise normal individuals might reduce the probability for their developing atherosclerosis. But atherosclerosis is not so rigidly tied to genetic production of LDL receptors. Treatment could also take the form of reducing consumption of low density fat in the regular diet. Is genetic elimination of this "disposition" for heart disease rightly considered treatment or enhancement? Have we treated a condition that significantly contributes to much morbidity and mortality, or have we simply enhanced our systems so that we can be gluttonous, so that we can unrestrainedly eat according to our heart's desire rather than our body's needs? These difficult cases illustrate the difficulty of attempting to distinguish the treatment of disorder from creating enhancements. Given the problems with trying to force fit the genetic debate into these problematic categories, we ought to look for a new way to conceptualize the debate. What we care about is improving the lives of our children and future generations, but we are not certain what ought to clearly count as justifiable *genetic* improvement.

One possibility that I would like to propose involves using a famous sort of thought experiment in philosophy, proposed by John Rawls for devising a fair distributive justice scheme.[31] From behind the veil of ignorance (which obscures each individual's detailed knowledge of his or her own position in society), Rawls has rational creatures attempt to figure out what basic rules of justice would be fair for all society. Because no one is certain if he or she will be at the lowest rung of the social ladder or at the highest one, Rawls believes that people in this "original position" would opt for rules of justice that require equal basic liberties and a "maximin" policy that requires any changes in distribution of goods to benefit the worst off in society as well as the ones who have reason to cause the change to occur.

What if we were to put ourselves behind the veil of ignorance in respect to our children's genetic makeup? That is, what if we tried to determine what traits we would desire for them, and what traits we would prefer for them not to have if we did not know the details of our society (that is, if we did not know the particular patterns of racial/sexual/gender discrimination that we find in our own society, or we did not know what society we would find ourselves in)? The veil of ignorance, then, is a way to conceal from us the particular biases that our society has for traits that are otherwise not genuinely physically desirable. When we put on this veil of ignorance, we assume that we do not know which society we will be living in—we do not know physical or

social details about the majority class for instance. We then try to determine what physical traits would lead to clear advantages or disadvantages in *any* society. This test allows us to decide for our children and future generations what sorts of traits should *not* be genetically manipulated.

It seems that things like race and sexual preferences would be quickly eliminated as genetic engineering candidates, as well as cultural standards of beauty (including particular features as well as height) because they are only valued by particular societies. That is, if you live in a predominantly white society, having white skin would tend to confer advantages, but this would not be so in a predominantly black society. If there is no reason to prefer a particular trait from behind the veil of ignorance, then perhaps we should rule it out as a candidate for genetic engineering. Other things might be clear candidates for genetic intervention, because they would be disabilities (or bring disadvantages) for anyone in any society (e.g., conditions like Tay-Sachs or aminodeaminase deficiency).

Deafness would be more difficult—whether you need hearing depends on the social structure of society, and we can imagine a majority deaf society designed for the benefit of the deaf. Such societies are not completely imaginary. Although the deaf were not a majority, the history of Martha's Vineyard can be used as an illustration of what such a society might be like.[32] But there is an asymmetry. If you are deaf in a world in which the norm is nondeaf, then you are likely to experience significant disadvantages, both in terms of social goods and physical safety, because most communication, transportation, and warning systems are designed for the hearing. However, if you are nondeaf in a world where deaf is the norm, then you are not so clearly disadvantaged. (This claim is not without contention. You might be more easily distracted, and there is the possibility of experiencing some kind of schizophrenic symptoms, since you might respond to stimuli not perceived by others. This sort of experience is not, however, borne out by the early childhood stories of hearing children raised in deaf families.[33]) There is an asymmetric pattern of disability or disadvantage. The deaf individual might experience disadvantage in a hearing world, but the same might not be true (or at least not to the same extent) for the hearing person in a deaf world.

On the other hand, try height: the disability is symmetrical there. If you are tall in a short world, you hit your head often and cannot fit in cars or through doorways; if you are short in a tall world, you cannot reach the pedals or the countertops, etc. The feature of asymmetrical disadvantage might help to pick out factors that are worth changing genetically (or worth considering as candidates for genetic change). Perhaps changing the thing that "veiled" rational people agree would *always* be a detriment is permissible (or even required), as is changing what could not be a harm in *any* society (i.e., what involves asymmetrical conditions), but changing what finds its value only in the particular society should not be allowed.

While this suggestion is clearly susceptible to many of the criticisms of Rawls's work,[34] it may at least help to figure out a way to start the difficult process of distinguishing between legitimate genetic intervention and discriminatory or arbitrary intervention. Furthermore, given limitations on our imaginations (whether we are behind the veil of ignorance or not), I would certainly propose that those who make policies on genetic therapies should represent a wide variety of physical abilities and conditions (so that we do not hastily

presume, for instance, that deafness is a clear defect without first consulting with those who are deaf).[35] Thus we must surely bring a fair representative sample to the table to consider these possible interventions.[36] As Susan Wendell eloquently illustrates:

> The desire for perfection and control of the body, or for the elimination of differences that are feared, poorly understood, and widely considered to be marks of inferiority, easily masquerades as the compassionate desire to prevent or stop suffering. It is not only a matter of being deceived by others, but all too often a matter of deceiving ourselves. It is easy to make the leaps from imagining that I would not want to live in certain circumstances to believing that no one would want to live in those circumstances, to deciding to prevent people from being born into those circumstances, to supporting proposals "mercifully" to kill people living in those circumstances—all without ever consulting anyone who knows life in those circumstances from experience.[37]

To ensure that such experience is taken into account, the ideal decisionmaking procedure would bring together a number of differently abled individuals who would first openly discuss the benefits and harms, delights and difficulties of living with various physical conditions (as a way to inform the rest of the group about conditions they may only understand superficially or peripherally). Then, each representative would perform the thought experiment suggested by the veil-of-ignorance strategy. While I do not claim that this strategy would produce *unanimous* agreement on appropriate candidates for genetic engineering, I do believe that it is likely to bring us closer to agreement on what traits we should *not* be genetically engineering. Furthermore, it should help us to uncover some of our societal biases regarding genetic and/or physical traits and to stretch our imaginations regarding how we might address these biases through nongenetic means. If we work to imagine societies where being short or deaf or homosexual is not a disadvantage (as it unfortunately is in our present society), then we may be able to apply that thinking to social structures in our present society.

One interesting and fairly worrisome implication of this sort of analysis is that it does seem to leave open the possibility of tampering with intelligence.[38] Considering intelligence from behind the veil of ignorance results in an asymmetrical finding, like that of having hearing. Presumably, improving intellectual capabilities would be desirable in any society, and having more of it in a society that is less intelligent would not result in any significant disadvantage.[39] This implication of my analysis is a matter for concern and undoubtedly requires further investigation. One possible answer might be that we should be able to try to better our intellectual capabilities, but that doing so genetically is not really feasible. That is, we may all applaud programs like "Hooked on Phonics" if they do indeed provide a more efficient and effective means of teaching children language skills, but genetic alterations may never be able to produce that sort of change. A genetic intervention might increase the speed at which we can pick up or process information, but perhaps nothing more can be affected genetically. A child cannot be born *with* knowledge, but only with an improved ability to gain knowledge. But if we *could* improve intelligence via genetic enhancement, we might be tempted to do so. Although intelligence

might offer relative advantages (having more of it than another offers an advantage), it also seems to offer absolute advantages.[40] Even if we did desire to enhance intelligence and found that it was an acceptable candidate for genetic engineering, it might not be our first priority for funding, since other medical and/or social needs are more pressing. Still, this sort of difficulty deserves further consideration.

In conclusion, genetic enhancement is not clearly an evil deserving of outright prohibition. Rather, we need to make careful and reasoned decisions about what genetic and/or physical changes would truly constitute human improvement, and what changes would only serve to reproduce our societal biases. My decisionmaking proposal is a brief suggestion that requires further thought and consideration, but one that appears to take into account both what we are interested in preserving and what we are interested in changing. My main hope is that it will provoke further discussion.

Two final points require attention. First, leaving decisions about what traits we ought to genetically change to the market (as suggested, for instance, by Nozick[41]) is likely to be disastrous. Not only will it most likely increase the disparity between the "haves" and the "have nots," but even if we could ensure equal access to such therapies, we might move ourselves toward a highly homogenous society. Within a society, many people have similar values and desires (e.g., polls show that most American women would prefer to have a boy child first, followed by a girl[42]) and would probably prefer stereotyped masculine and feminine traits in their children as well. We need to consider what it is that we value about diversity, and how we can best promote that. We may be unintentionally drawn to a world where any difference is considered a disease.[43]

Second, we cannot be drawn back into an assumption of genetic determinism. Nature/nurture debates periodically come back into vogue, but we must continue to recognize that phenotypes and behavioral patterns are not wholly determined by genetic data, but by the interaction of the genetic information with the environment (both internal and external). Despite solid arguments against deterministic views,[44] the amount of time and attention given to books such as *The Bell Curve* ought not only to warn us of our ability to ignore the environmental influences when we so desire, but also of our need to take care to ensure that science is done properly. We should not expect genetic engineering to solve all of our problems, nor should we reduce anyone's identity and value to their genetics.

Notes

1. For a historical review of eugenic practices, see Kevles D. Eugenics and the Human Genome Project: is the past prologue? In: Murphy T, Lappé M, eds. *Justice and the Human Genome Project*. Berkeley: University of California Press, 1994:14–29.
2. Many of these noncontroversial interventions are discussed by Glenn McGee in his recent book *The Perfect Baby*. Lanham, Maryland: Rowman & Littlefield, 1997, esp. Chapter 7.
3. This problem was made famous by Derek Parfit in *Reasons and Persons*. Oxford: Oxford University Press, 1984.
4. For example, these issues are dealt with in Resnick D. Debunking the slippery slope argument against human germ-line gene therapy. *Journal of Medicine and Philosophy* 1994;19:23–40; Munson R, Davis L. Germ-line gene therapy and the medical imperative. *Kennedy Institute of Ethics*

Journal 1992;2(2):137–58; Boone K. Bad axioms in genetic engineering. *Hastings Center Report* 1988;18(4):9–13; Glover J. *What Sort of People Should There Be?* Harmondsworth, England: Penguin, 1984 (see also note 2, McGee 1997:ch. 4).

5. E.g., Beeman CA. *Just This Side of Madness: Creativity and the Drive to Create*. Conway AK: UCA Press, 1990. Beeman argues that while psychotic illnesses are not correctly construed as tied to creativity, the creative drive that exists to some degree in all humans is intensified in people who also inherit any of a range of affective disorders, especially manic depression or bipolar disorder. She believes that mental illness is a hindrance to creativity, but because those who inherit affective disorders often have an increased creative drive, they are often more artistic and creative until the illness overcomes them. She concludes that we ought to look to the social context to cure psychiatric disorders, rather than eliminating them genetically (which might eliminate the intense creative drive as well).
6. For a discussion of these rules, see McCormick R. Proxy consent in the experimentation situation. *Perspectives in Biology and Medicine* 1974;18(1):2–20.
7. Parens E. The goodness of fragility: on the prospect of genetic technologies aimed at the enhancement of human capacities. *Kennedy Institute of Ethics Journal* 1995;5(2):141–53.
8. As Ann Davis suggested to me, this argument bears striking similarities to philosophy of religion replies to the problem of evil, e.g., John Hick's soul-building theodicy, "soul-making and suffering." See Hick J. Evil and the god of love. In: Adams MM, Adams RM, eds. *The Problem of Evil*. New York: Oxford University Press, 1990: 6–88.
9. See note 7, Parens 1995.
10. Susan Wendell makes this point in her book *The Rejected Body: Feminist Philosophical Reflections on Disability*. New York: Routledge, 1996. She notes, "It sends a message to children and adults with disabilities, especially people who have genetic or prenatal disabilities, that 'We do not want any more like you.' Knowing that your society is doing everything possible to prevent people with bodies like yours from being born is bound to make you feel as though you are not valued and do not really belong" (p. 153).
11. See, for example, the argument in Glover J. *Ethics of New Reproductive Technologies*. Dekalb, Ill.: Northern Illinois Press, 1989:ch. 12, 13; and note 4, McGee, 1997. McGee claims "It is not insult to these people to suggest that serious genetic defects should be prevented—unless we equate the patient with the disease. Many patients would not resist the idea that the world would be a better place if they did not have to suffer and die from the disease. We can over-romanticize the courage of sufferers" (p. 59).
12. Murphy T. The genome project and the meaning of difference. In: Murphy T, Lappé M, eds. *Justice and the Human Genome Project*. Berkeley: University of California Press, 1994:1–13.
13. See note 10, Wendell 1996: 153–6.
14. See, e.g., Jackson L, Ervin K. Height stereotypes of women and men: the liabilities of shortness for both sexes. *Journal of Social Psychology* 1992;132(4):433–45; and Allen D, Fost N. Growth hormone therapy for short stature: panacea or Pandora's box? *Journal of Pediatrics* 1990;117(1):17–9.
15. See Landy D, Sigall H. Beauty is talent: task evaluation as a function of the performer's physical attractiveness. *Journal of Personality and Social Psychology* 1974;29(3):299–304; and Adams G. Physical attractiveness research: toward a developmental social psychology of beauty. *Human Development* 1977;20:217–39.
16. Boddie C. Debate heats up in the deaf community. *Denver Ear Institute Highlights* 1994;13(3):1–5.
17. For an interesting discussion of the deaf community's identity as a political and social group, as well as a distinctive culture, see Sacks O. *Seeing Voices*. Berkeley, Calif.: University of California Press, 1989.
18. Lane H. *The Mask of Benevolence: Disabling the Deaf Community*. New York: Alfred A. Knopf, 1992.
19. See Silvers A. "Defective" agents: equality, difference and the tyranny of the normal. *Journal of Social Philosophy*, 25th Anniversary Special Issue 1994;25:154–75. Silvers notes that "Deafness is not a natural disadvantage in interpersonal communication. Signing members of the deaf community communicate with one another as effectively as do hearing persons who speak to each other. That the majority of Americans know speech rather than sign may be thought of as simply another in a long list of practices imposed by the dominant group to suit its members while suppressing a minority whose practices are otherwise" (p. 164).
20. Berreby D. Up with people: dwarves meet identity politics. *New Republic* 1996;214(18):14–9.
21. LeVay S. A difference in hypothalamic structure between heterosexual and homosexual men. *Science* 1991;253:1034.

22. See Buchanan A. Equal opportunity and genetic intervention. *Social Philosophy & Policy* 1995;12(2): 105–35.
23. This kind of distinction is supported, for example, by Fletcher JC. Moral problems and ethical issues in prospective human gene therapy. *Virginia Law Review* 1983;69:515–46; Daniels N. The genome project, individual differences, and just health care. In: Murphy T, Lappé M, eds. *Justice and the Human Genome Project*. Berkeley, Calif.: University of California Press, 1994:110–32; and to a certain extent, Munson R, Davis L. Germ-line gene therapy and the medical imperative. *Kennedy Institute of Ethics Journal* 1192;2(2):137–158. W. French Anderson was one of its original proponents, and now accepts it with some exceptions (e.g., enhancement that may be considered preventive medicine, such as increasing LDL receptors to prevent atherosclerosis later in life). See Anderson WF. Human gene therapy: why draw a line? *Journal of Medicine and Philosophy* 1989;14:681–93. He is followed by many American and European scientists. Most of the proponents of the treatment-enhancement distinction recognize the difficulty of holding this line (due to its vague grounding), but conclude that it is the best alternative available.
24. See note 23, Anderson 1989.
25. See note 23, Anderson 1989:687. He argues that we can allow treatment for serious genetic diseases that everyone can agree are significant, but recognizes that we have no clear way of distinguishing "a serious disease from a minor disease from a cultural discomfort."
26. This popular debate of the 1970s pitted objectivists (e.g., Christopher Boorse, who believed that diseases and their diagnosis contained no judgments of value) against normativists (e.g., Tristram Englehardt or Thomas Szasz, who believed that the concept of disease and also diagnosis of diseases are necessary partially evaluative and thus relative to the prevailing views of the culture or society). See Boorse C. On the distinction between disease and illness. In: Caplan AL, Englehardt HT, McCartney JJ, eds. *Concepts of Health and Disease*. Addison-Wesley, 1981:545–60; Englehardt HT, Jr., The concepts of health and disease. In: Caplan AL, Englehardt HT, McCartney eds. *Concepts of Health and Disease*. Addison-Wesley, 1981:31–46; and Szasz T. *The Myth of Mental Illness*. New York: Harper, 1961.
27. See Cohen C."Give me children or I shall die!": new reproductive technologies and harm to children. *Hastings Center Report* 1996; 26(2):19–27.
28. See note 18, Lane 1992.
29. See note 26, Englehardt, 1981; and Green R. Homosexuality as a mental illness. In: Caplan AL, Englehardt HT, McCartney JJ, eds. *Concepts of Health and Disease*. Chicago: Addison-Wesley, 1981: 333–51.
30. Kitcher P. *The Lives to Come: The Genetic Revolution and Human Possibilities*. New York: Simon & Schuster, 1996:212.
31. Rawls J. *A Theory of Justice*. Cambridge, Mass.: Harvard University Press, 1971.
32. See Groce NE. *Everyone Here Spoke Sign Language: Hereditary Deafness on Martha's Vineyard*. Cambridge, Mass.: Harvard University Press, 1985.
33. These stories are contained in Carol Padden and Tom Humphries' book, *Deaf in America: Voices from a Culture*. Cambridge, Mass.: Harvard University Press, 1988.
34. For example, that it only works within a particular kind of liberal society; that it presumes that rational creatures can successfully abstract away from their individual realities when behind the veil of ignorance; that it is not sufficiently attentive to what exists in this society, etc. These are important objections, and I will no doubt have to assume some general conception of the human form (to avoid bizarre but possible genetic traits that might be beneficial in some imaginable societies, and not a harm in ours—like gills, or philosophers designed to sit for long periods of time reading and drinking port, with no ill results for health). (The latter suggestion was proposed in Englehardt HT, Jr.: Germ-line genetic engineering and moral diversity: moral controversies in a post-christian world. *Social Philosophy & Policy* 1996; 13(2):47–62), but I think that this strategy is still a useful one for assessing which physical traits are valued in our society for arbitrary or socially biased reasons, and which traits are genuinely physically beneficial.
35. It is important to recognize the particular limitations that able-bodied or "normal" people seem to have in regard to imagining themselves with disabilities. Anita Silvers comments, "the prospect of being so impaired seems to paralyze the normal imagination," resulting in a great number of people who report that they would "rather be dead than confined to a wheelchair." See note 19, Silvers 1994:158–9.
36. Here I draw from Susan Moller Okin's defenses of Rawls in Okin SM. *Justice, Gender and the Family*. New York: Basic Books, 1989. Again, this suggestion is clearly prone to objections raised in response to Okin's work, regarding how to decide on a fair representative sample, etc.

37. See note 10, Wendell 1996:156.
38. Not everyone agrees that it does leave this possibility open. See, for example, Ledley F. Distinguishing genetics and eugenics on the basis of fairness. *Journal of Medical Ethics* 1994; 20:157–64.
39. Except perhaps for the frustration of listening to illogical arguments—nothing that any teacher of an introduction to philosophy has not survived, or even found rather humorous.
40. Despite the frequent use of the phrase "ignorance is bliss," increases in intelligence through standard means in education are certainly not rejected outright, and are not considered mere attempts to seek relative advantage in the sense of "keeping up with the Joneses."
41. Nozick R. *Anarchy, State and Utopia*. New York: Basic Books, 1974.
42. See, e.g., Pebley A, Westhoff C. Women's sex preferences in the United States: 1970–1975. *Demography* 1982;19(2):177–89; and Coombs LC. Preferences for sex of children among U.S. couples. *Family Planning Perspectives* 1977;9(6):259–65.
43. Murphy T. The genome project and the meaning of difference. In: Murphy T, Lappé M, eds. *Justice and the Human Genome Project*. Berkeley, Calif.: University of California Press, 1994:1–13.
44. The best I have seen are offered by Philip Kitcher in Kitcher P. *The Lives to Come: The Genetic Revolution and Human Possibilities*. New York: Simon & Schuster, 1996; and in Lewontin R. *Biology as Ideology: The Doctrine of DNA*. New York: HarperCollins, 1992.