Normal Functioning and the Treatment-Enhancement Distinction

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Treatment vs. Enhancement: Wide Use, Hard Cases, Strong Criticism

The treatment-enhancement distinction draws a line between services or interventions meant to prevent or cure (or otherwise ameliorate) conditions that we view as diseases or disabilities and interventions that improve a condition that we view as a normal function or feature of members of our species. The line drawn here is widely appealed to in medical practice and medical insurance contexts, as well as in our everyday thinking about the medical services we do and should assist people in obtaining.

In this paper I shall consider various objections to the treatment-enhancement distinction: that it is difficult to draw, that it does not give us the boundary between what is obligatory and nonobligatory in medical interventions, and that it leaves us with hard cases that make the distinction seem arbitrary. My qualified and limited defense of the treatment-enhancement distinction in this paper means it cannot provide a clear guide to the moral boundaries between what is obligatory and nonobligatory or between what is permissible and impermissible, though it has a useful, if modest, bearing on each.

Insurance Coverage and “Medical Necessity”

The treatment-enhancement distinction is closely related to the concept of “medical necessity” that appears in the legislation surrounding public insurance in both the United States and Canada, and in private insurance contracts. Medically necessary services are those that effectively treat physical or mental disease and disability or ameliorate conditions deriving from them.1 2 Some medical
services may effectively produce benefits for other conditions, but they do not count as medically necessary. For example, insurance coverage is provided by public and private schemes for growth hormone treatment for children projected to be very short, provided that there is an underlying disease condition, e.g., some diagnosable growth hormone deficiency. Insurers do not cover the treatment for children whose parents simply want them to be taller, regardless of how short they will be, if there is no underlying disease condition. Similarly, insurers will generally reimburse—and in some states, like Massachusetts, they are mandated to reimburse—reconstructive breast surgery following mastectomy or trauma. But they do not reimburse “cosmetic” surgery, however strongly a woman may feel that her life will be improved if her breasts are made larger or smaller.

The same distinction plays a role in coverage for mental health therapies. Consider the following cases illustrating coverage policy within the (then) Harvard Community Health Plan (HCHP), a staff-model health maintenance organization that serves over 550,000 people in New England. An adult patient with a history of bipolar disorder had been stabilized on lithium for some years. He remained shy, however, and was referred to an out-of-plan group therapy situation, from which he clearly benefited over a period of several years. In its original benefit structure, this long-term treatment could not have been covered by HCHP. HCHP revised its benefit structure, allowing an “extended benefit” that would cover protracted therapy of this sort without extensive copays, provided the treatment was for a serious condition. But does treatment for shyness count as treatment of a serious disorder? The psychiatrist managing the Shy Bipolar’s case believed that the shyness was the result of the onset of the bipolar disorder; had the disorder not interfered with the adolescent development of this man, who was normally outgoing before its onset, he would probably have been more outgoing. Consequently, the therapist reasoned, the “extended benefit” should be given. Had the shyness not been “diagnosed” as the result of the bipolar disorder, then even if it were comparably serious, there would have been no eligibility for an extended benefit.

The factor underlying this reasoning did not have to do with the degree of suffering involved in being shy; the reasoning depended on the etiology or explanation for the shyness. The point is illustrated by another case in which the clinician distinguished between treatment of illness and enhancement of well-being. An intelligent, professionally successful, married father of two children sought treatment because of severe unhappiness associated with marital distress. His wife suffered from a serious mental illness that made her very difficult to live with. The Unhappy Husband, we shall call him, was committed to maintaining the marriage. A V code diagnosis [“Conditions not attributable to a mental disorder that are a focus of treatment” (DSM-IIIR: 359)] (marital problem) was made. In 26 sessions of psychotherapy Unhappy Husband was able to clarify some of the pertinent dynamic issues in his marriage, and developed a number of adaptive strategies for lessening his distress. The 26 sessions were highly productive. Unhappy Husband wished that his treatment would be covered by insurance, but he agreed that he was not suffering from an illness and that it was fair to expect him to pay.

The Unhappy Husband is probably suffering more than many of the HMO members being treated for illnesses, and psychotherapy definitely enhanced his well-being. What possible rationale could there be for not covering his treat-
ment? The clinician’s decision hinged on the question of what the Unhappy Husband is suffering from. By the criteria set forth in DSM-III-R, the Unhappy Husband does not have an illness. His suffering arises from the fact that although his wife’s unchanging condition caused him great pain, his values precluded divorce. The clinician believed that under the prevailing agreements that govern insurance, individuals like the Unhappy Husband should be responsible for some or all of the cost of rectifying the unhappiness associated with an unfortunate existential situation. Paradoxically, if the Unhappy Husband expressed his suffering through somatic symptoms, and presented himself to an internist rather than a mental health clinician, insurance would typically cover medical investigation and treatment, which would probably be less effective but costlier than psychotherapy. A 1989 survey of medium and large firms showed that only 2% of insured employees have coverage for outpatient mental health services equivalent to other medical services.4

Hard Cases and the Expansion of Obligations

Unfortunately, if we look more closely at certain hard cases, we are harder pressed in attributing to the treatment-enhancement distinction the weight it is given in our medical practice, including our insurance schemes. For the sake of vividness, let us put names on the faces of the growth hormone treatment cases.

Johnny is a short 11-year-old boy with documented GH deficiency resulting from a brain tumor. His parents are of average height. His predicted adult height without GH treatment is approximately 160 cm (5 feet 3 inches).

Billy is a short 11-year-old boy with normal GH secretion according to current testing methods. However, his parents are extremely short, and he has a predicted adult height of 160 cm (5 feet 3 inches).5

These cases make the distinction seem arbitrary for several reasons. First, Johnny and Billy will suffer disadvantage equally if they are not treated. There is no reason to think the difference in the underlying causes of their shortness will lead people to treat them in ways that make one happier or more advantaged than the other. Second, although Johnny is short because of dysfunction whereas Billy is short because of his (normal) genotype, both are short through no choice or fault of their own. The shortness is in both cases the result of a biological “natural lottery.” Both thus seem to suffer undeserved disadvantages. Third, Billy’s preference for greater height, just like Johnny’s, is a preference that most people hold; it is not peculiar, idiosyncratic, or extravagant. Indeed, it is a response to a social prejudice, “heightism.” The prejudice is what we should condemn, not the fact that they both form an “expensive taste” in reaction to it.

If we return to the case of the Shy Bipolar, we could raise exactly the same points in comparing him to an equally shy but otherwise normal person, the Shy Normal. Shy Bipolar and Shy Normal will suffer the disadvantages of shyness equally. Both are shy through no fault of their own—assuming normal shyness is a feature that is significantly determined by temperament or by exposure to early learning situations that one did not choose to be in. And most people would prefer to be more outgoing and to enjoy the relationships we think come with such a posture toward others—that preference to change from being shy is not idiosyncratic or extravagant.

The Treatment-Enhancement Distinction
Cases like these raise the following question: Does the concept of disease underlying the treatment-enhancement distinction force us to treat relevantly similar cases in dissimilar ways? Are we violating the old Aristotelian requirement that justice requires treating like cases similarly? Is dissimilar treatment unfair or unjust? Any defense of the moral use to which we put the treatment-enhancement distinction in medical and insurance contexts must respond to this concern.

The Micro-Structure of the Normal and Moral Arbitrariness

Before responding, however, I would like to deepen the sense that there may be something morally arbitrary about the use to which the treatment-enhancement distinction is put and perhaps even about the distinction itself. To do so we appeal, at least hypothetically, to something we may learn from the human genome project and from the greater knowledge we get about how genes regulate growth. Suppose we learn that some particular pattern of genes explains the extreme shortness of Billy, the child who did not seem to be growth hormone deficient. Suppose we learn that some particular genes Billy has make some receptors to growth hormones slightly less responsive than the genes that would lead someone to be of average or above average height; perhaps there are fewer such receptors; or perhaps they shut down earlier than in those whose genotypes generally make them taller; or perhaps they slow down production of growth hormones sooner. We learn, that is, just which “losing numbers” in the natural lottery placed Billy in the bottom few percent of the normal distribution for height. Suppose, further, that we also identify the gene that disposes Johnny to develop the brain tumor that caused his growth hormone deficiency. We now have traced both Johnny and Billy’s shortness back to specific genes. Billy’s genes work directly to make him short; Johnny’s work indirectly to do so, through causing a tumor that disrupts hormone production. Why does having one set of genes give Johnny a claim on social resources necessary for growth hormone treatment but Billy no such claim?

Of course, this story really adds nothing new. We already knew that Johnny and Billy’s troubles were rooted in their biology. Adding the genetic detail only makes things seem more vivid. Still, if we can identify the specific genes that contribute to Billy’s shortness, we may be more tempted to think of them as “bad” genes: they lead to Billy’s unhappiness or disadvantage in a “heightist” world. We may be more tempted to think of them very much on the model of genetic defects or diseases, especially if they work through mechanisms that have some analogy to pathological defects. We will be tempted, that is, to medicalize what we have hitherto considered normal.

The hard cases thus pose this question: What justifies us in treating the normal but “bad” or disadvantageous genes differently from genes that lead to growth hormone deficiency or to receptor insensitivity to growth hormone? If we can remedy the effect of these genes with growth hormone treatment or other treatments, including genetic tampering, we might think it quite arbitrary to maintain the treatment-enhancement distinction.

Two Objections to the Treatment-Enhancement Distinction

The hard cases we have been considering raise two quite distinct kinds of objection to the treatment-enhancement distinction. One objection is that the
treatment-enhancement distinction, even assuming we can draw a persuasive
line between the treatment of disease and disability and the enhancement of
otherwise normal traits, does not have the moral import that is commonly
attributed to it, for example, in our insurance practices. Some nondisease con-
ditions seem to oblige us to provide assistance to people for the very kinds of
reasons that some disease or disabilities do. The treatment-enhancement dis-
tinction, then, does not map onto the boundary between morally obligatory
and nonobligatory services.

The second objection challenges the basis on which the treatment-enhancement
distinction itself is drawn. By implication, it then challenges whether we can
use it to draw further moral distinctions without some kind of circularity. On
this view, it is not because there is something biologically distinctive about
Johnny’s condition, as opposed to Billy’s, that has led us to describe Johnny as
having a disease and Billy not. (Although Johnny does have a tumor and Billy
does not.) Rather, our “social construction” of disease draws on a set of values
that happens to have singled out Johnny rather than Billy in this way. But if we
come to see that the values that lead us to consider Johnny’s tumor as a disease
condition—a condition that puts him at a certain kind of disadvantage through
no fault of his own—are arbitrary, then we should reconstruct our view of
disease to include Billy’s condition, for the same values apply to it. It is our
norms and values that define what counts as disease, not merely biologically
based characteristics of persons, and the arbitrariness in these hard cases comes
from inconsistently applying our values. Pointing to the line between treatment
and enhancement is not, then, pointing to a biologically drawn line but is an
indirect way of referring to valuations we make. We cannot point to such a line
as the grounds for or basis for drawing moral boundaries since we are only
pointing to a value-laden boundary we have constructed.

Are there reasonable replies to these objections? Can the treatment-
enhancement distinction do (at least most of) the work we commonly rely on it
to do?

A Limited Defense of the Treatment-Enhancement Distinction
and Its Circumscribed Use

Treatment-Enhancement and the Obligatory-Nonobligatory Boundary

No reasonable defense of the treatment-enhancement distinction is possible if
we expect too much of it. Specifically, we should not expect that distinction to map
unqualifiedly onto the moral boundary between obligatory and nonobligatory services,
even if it justifiably plays an important role in medical insurance coverage
decisions. There are good reasons why we are not obliged to provide all and
only treatments as opposed to enhancement. For the sake of argument in much
of this section, we shall assume that we can draw a plausible line between
treatments of disease and disability and we shall revisit the assumption at an
appropriate point.

There are two basic reasons why the treatment-enhancement distinction does
not coincide with the boundary between obligatory and nonobligatory services.
First, resources will be too limited to meet all of our needs for the treatment of
disease or disability. Justice then requires that we meet the most important
needs first, leaving people to fend for themselves in meeting less important medical needs. In other words, the class of beneficial treatments is broader than the class of services we are obliged to provide, given reasonable resource constraints. Being a treatment is thus not a sufficient condition for our being obliged to provide it to people.

Still, we might believe that being a reasonably effective treatment for a disease or disability is still a necessary condition, or an eligibility condition, for something being included in an insurance package or being thought to be a service we are obliged to provide to people. The second reason for limiting the role of appeal to the treatment-enhancement distinction also rules out this (unqualified) suggestion. We may—indeed we do—have certain moral or legal obligations to offer medical services that do not involve the treatment of disease. For example, I believe that our obligations to respect the equality of women compel us to make abortion a covered service in a national benefit package, just as it already is a covered service in most existing private insurance in the United States. But the reason for including it has nothing to do with treating a disease or disability, since an unwanted pregnancy is not a disease or disability but rather the result of normal functioning. Clinton’s proposed Health Security Act (1994) disguised the issue by including nontherapeutic abortions as “pregnancy related services.” Indeed, the reasons many have for excluding abortion also have nothing to do with the distinction between treatment and enhancement: some people are opposed to permitting abortions even when continued pregnancy involves a threat to the health or life of the mother and abortion is therefore “therapeutic” or “medically necessary.” If we are right that nontherapeutic abortion services should be included because of our concerns about the equality of women, then treatment of disease and disability does not capture the class of services we are obliged to provide once we consider all of our obligations. As we shall see, sometimes concerns about equality of opportunity might oblige us to provide some genetic interventions even when they too were not treatments of disease.

The Primary Rationale for Medical Obligations

Nevertheless, it may still be the case that the primary rationale for claiming that we are obligated to provide people with medical service is that it meets an important need for treatment of disease or disability. This may be the reason we typically agree on and justifiably cite when we think about the moral importance of healthcare services. If there is a plausible defense of the treatment-enhancement distinction, it will be in the limited role pointed to here. Our primary justification for considering a healthcare service something that we are obliged to offer people is that it is a reasonably effective treatment for a disease or disability. Other reasons may broaden our obligations, but the primary justification gives us the core.

This limited use of the treatment-enhancement distinction is elaborated in my (1985) widely cited (and challenged) account of justice and healthcare. On that view, disease and disability, both physical and mental, are construed as adverse departures from or impairments of species-typical normal functional organization or “normal functioning,” for short. The biomedical sciences for humans, like the veterinary sciences for animals, study both the variation in the functional organization typical for our species and the departures from normal
functioning that we call disease and disability. The line between disease and disability and normal functioning is thus drawn in the relatively objective and nonevaluative context provided by the biomedical sciences, broadly construed. What counts as disease or disability from the perspective of these sciences is largely free from controversy in the broad range of cases. Of course, sometimes value judgments, including prejudices, or errors intrude, and we get examples of conditions or behaviors that are improperly classified as disease or disability, e.g., the disease of masturbation. But just as whales are not fishes, though they were long classified as such, so too these conditions are not diseases.

We are not, however, just interested in categorizing disease and disability. Rather, we have an important interest in their effects, since they often cause pain and suffering, shorten life, and quite generally impair in varying degrees the range of opportunities open to us. On my view, the central moral importance, for purposes of justice, of treating disease and disability with effective healthcare services derives from the way in which protecting normal functioning contributes to protecting opportunity. Specifically, by keeping people close to normal functioning, healthcare protects an individual’s fair share of the range of opportunities reasonable people would choose in a given society. That fair share is defined by reference to the individual’s talents and skills. Accordingly, a principle assuring fair equality of opportunity should govern the design of healthcare systems. By keeping people functioning as close to normal as possible, within resource limits, we discharge part of our obligation to protect fair equality of opportunity.

We can distinguish the “normal functioning” and “level playing field” versions of equal opportunity. Rawls’s appeal to “fair” equality of opportunity eliminates socially induced disadvantages in the development of talents and skills that result from unfair social practices, such as racist or sexist practices, and from effects of family background, thus taking a partial step onto the level-playing field view. My extension of “fair” equality of opportunity to healthcare broadens the level playing field to include socially correctable departures from normal functioning. In doing so, it corrects both for some natural and some socially induced disadvantages. My account, however, stops short of leveling the field further by the redistributing of otherwise normal capabilities, and it is the justification for this stopping point that is at issue in the hard cases we have been examining.

The relative moral importance of treating different diseases and disabilities can in part be judged by reference to their impact on the range of opportunities open to us. Because this range of opportunities is itself socially relative, being affected by technology, education, wealth, and other cultural factors, judgments about the relative importance of treating different diseases and disabilities will have some social variability. For example, dyslexia is a cognitive disability in any society, but it is important to treat it only in literate societies. Within a society, relative to its normal range of opportunities, some diseases and disabilities are more important to treat than others, and this will affect our decisions about which treatments to offer when we cannot provide all the ones people need.

The appeal to a principle assuring fair equality of opportunity is an attempt to explain why we attribute special moral importance to treating disease and disability. If the particular interpretation of equal opportunity is acceptable, it explains the primary rationale for the provision of healthcare services. Aiming to maintain normal functioning makes a limited, but crucial, contribution to
protecting fair equality of opportunity. It leaves considerable room for social relativity about the importance of some treatments compared to others, but much less about what counts as a disease or disability. Still, it is critical to keep in mind that the treatment-enhancement distinction by itself does not specify the boundary between obligatory and nonobligatory medical services. Some obligations derive from considerations beyond the primary rationale, and the primary rationale includes a respect for reasonable resource constraints.

The Normal Function Model

The primary rationale rests on what we shall call a “normal functioning” interpretation of the requirements of fair equality of opportunity (Rawls 1971). Historically, our understanding of the requirements of opportunity has evolved. We have come to oppose allowing certain human traits—originally race and religion, later gender, age, disability, and sexual orientation—to serve as the basis for assigning people to jobs or offices. Rather, these traits are seen as “morally irrelevant,” and we believe people should be judged by their capabilities to perform in such jobs, offices, or educational settings. But we also recognize that past social practices may have distorted the development of people’s talents and skills, and that we may have to compensate people for the effects of those practices, for example, by special programs aimed at correcting for those distorting effects. Otherwise, expecting people to compete on the basis of the talents and skills they actually have may be expecting them to compete on an unfair basis. This was the idea behind the federal Operation Head Start, one of the most successful compensatory education programs attempted in the United States. Whereas “formal” equality of opportunity (the nondiscrimination view) simply requires us to eliminate reference to morally irrelevant traits, “fair” equality of opportunity (the level playing field view) requires us to correct where we can for the mis- or underdevelopment of talents and skills, that is, for effects of the social lottery.

The normal functioning interpretation of the requirements of equality of opportunity, whether in Rawls’s general account of distributive justice or in my extension of it to healthcare, assumes that there is a background inequality in the distribution of capabilities, an effect of the natural lottery. On the normal functioning interpretation, equal opportunity does not require assuring truly equal opportunity, which could result only if we eliminated this inequality in distribution of capabilities. The leveling of the playing field goes only so far. Applied to healthcare and construed as an account of the goals of medicine, the normal functioning interpretation of fair equality of opportunity principle thus ascribes to medicine the relatively modest and limited task of keeping people functioning as close to normally as possible. In effect, healthcare, like compensatory education programs, aims to produce “normal competitors” but not necessarily equal competitors. An unequal distribution of capabilities is left intact, once the distorting effects of past social practices and treatable disease and disability are addressed.

Why should we take the natural distribution of talents and skills as a baseline, as the normal functioning view does? If we can redistribute those talents and skills, why not alter the baseline? If we believe in leveling the playing field, and medical technology—whether genetic or not—allows us to redefine the baseline and produce more equal opportunity, are not we committed to doing so wherever we can?
A fundamental point to note is that our egalitarian concerns in general, and our concerns about equal opportunity in particular, form only part of our concerns about what justice requires. A theory of justice in general, or of justice for healthcare in particular, must combine concerns about equality with concerns about liberty, and both of these concerns must be reconciled with considerations about efficiency and the allocation of resources. Even if the fundamental intuition underlying our concerns about equality of opportunity pushed us toward thinking that we were obliged to take some steps toward the redistribution of capabilities such as talents and skills, rather than treating their “natural” distribution as a baseline, we must reconcile the pull of that concern with conflicting goals regarding liberty and efficiency. The presumption in favor of modifying the baseline, coming from the egalitarian pull of a concern about equality in opportunity, is defeasible in light of other key components of our concerns about justice.

In Rawls’s theory, this reconciliation takes place through the choice of principles that deliberators would make in the “original position,” Rawls’s social contract situation. Suppose that contractors knew that it was sometimes possible to alter the natural distribution of talents and skills and that doing so might make it possible to better promote equality of opportunity. They would still have to solve the more general problem of distributive justice posed by the fact that in general some unequal distribution of talents and skills can and must be taken as a baseline. For example, Rawls is quite explicit that environmental factors, including culture, family influence, and individual responsiveness to educational and compensatory educational measures, will unavoidably lead to some ineliminable inequality in the distribution of talents and skills. In the general case, it may be better for contractors, even for those who anticipate that they may turn out to be worst off with regard to marketable talents and skills, to mitigate the effects of inequalities by redistribution of other important goods than to insist on what may turn out to be a highly inefficient “equalizing” of the distribution of natural talents and skills. Insisting on such radical forms of equality might in fact make them worse off than they would otherwise be.

Rawls assumes that deliberators in his original position would make just such a reconciliation of competing concerns, requiring that the system as a whole be made to work to the advantage even of those worst off with regard to marketable talents and skills.

Interpreted in this way, there is no reason to think that Rawls’s account, or my extension of it to healthcare, would rule out our sometimes being obliged to use medical technologies to alter the distribution of talents and skills. The Rawlsian reconciliation, even if it captures the general case, will not justify treating the natural baseline as if it were an uncrossable boundary and that modification of it in the name of equal opportunity never falls within the scope of concerns of justice. However, what is made unlikely by Rawls’s and my accounts is that an individual who finds herself deficient in some particular capability thereby has a claim, based on equality of opportunity, to assistance to rectify that (perceived) deficit.21

Is the Treatment-Enhancement Distinction a Natural Baseline?

Throughout this section, I have assumed that the treatment-enhancement distinction can be drawn in a reasonably clear fashion, even though there may be
some gray areas and hard cases, and I have concentrated on its moral implications. I shall now revisit that assumption, which has been the focus of considerable controversy within the philosophy of medicine, but I shall limit the discussion rather severely. My concern is primarily with how the central debate affects the ethical implications of the distinction, not the fine details of debates in the philosophy of biology. I believe it is possible to set aside most of the actual controversy, at least for our purposes.

The central conceptual issue, and the focus of considerable controversy, is whether the concept of disease and disability, and the treatment-enhancement distinction that depends on it, can be drawn by reference to a “natural baseline,” such as departures from species-typical normal functioning, or whether the concepts of disease and disability are fundamentally evaluative. The extreme of the evaluative view is that a disease or disability is simply an unwanted condition. Earlier, I described the “social construction” view, which places the evaluation in the hands of some social agency, perhaps the medical profession or perhaps some broader interaction between the profession, patients, and other cultural and political institutions. Historically, of course, we can point to many instances in which conditions or behaviors were viewed as examples of disease or disability—masturbation or homosexuality, or the running-away disease of slaves— but these do not show us that disease and disabilities are just what society makes them out to be, given its values. We recognize the error in what was done; it is not simply a matter of social custom, like not shaking hands with the left hand. The real philosophical debate turns on whether one can characterize in the appropriate way, for purposes of theory, certain functions of individuals that are typical for members of that species and distinguish population variation in those functions from cases of disease and disability. It is this piece of the debate that I cannot enter into here.

Rather, some points I have already made about justice in a pluralist society have a bearing on what about this debate is relevant for us. The point behind appealing to a natural baseline that is not itself heavily value based is that people may agree that it forms a reasonable and relevant basis for public action, despite many other disagreements they may have about other issues of value. Despite many other sorts of comprehensive moral views, people may agree that maintaining normal functioning contributes in a reasonable and central way to protecting equality of opportunity. Depending on what other comprehensive moral views they hold, they may or may not agree that any inequality in capabilities or capability sets is a source of moral concern. Depending on what other comprehensive moral views they hold, they may or may not believe that individuals who are unhappy because of particular attitudes or beliefs they have acquired, through no choice of their own, are owed compensation for their unhappiness. Actually, we may find some disagreements about these matters, with many individuals wanting to hold people more directly responsible for their ends and others taking a more “compassionate” view. But this variation tends to show up outside the core area of agreement about the role of disease and disability.

The point that emerges here is that the natural baseline has no metaphysical importance: it is not that we must pay some special respect to what is natural, e.g., by maintaining or restoring it. Rather, the natural baseline has become a focal point for convergence in our public conception of what we owe each other by way of medical assistance or healthcare protection. To develop fair terms of
cooperation, we should not have to resolve our disputes about these comprehensive moral views. Nor should we have to settle an abstract issue in the philosophy of biology.

Suppose that the apparently natural baseline appealed to here does, in various ways, as it has in the past, contain hidden appeals to the values of special groups. Suppose it is a “social construct” after all and draws on some disguised comprehensive moral views. Then our only recourse is to hope that over time there are internal critical pressures within the biomedical sciences that work to expose the special role played by these valuations. Just as we have evidence over time that we have often snuck valuations into our categorization of disease, so too we have evidence that we have rooted them out over time. The optimistic view is that there are pressures here that tend to work against any values that are not at least widely shared. This is a partial recognition of the tendency of the sciences to be compatible with pluralism.

The position I am defending, then, does not insist that the natural baseline is completely natural and that no valuations incompatible with pluralism have emerged within it. But I do believe that our best hope of sustaining a point around which we can achieve social agreement is one that most assiduously avoids incorporating valuations into its definition of disease and disability, even if it cannot do so completely. The baseline that emerges over time is most likely one that is compatible with the demands of justice in a pluralist society.

Positive versus Negative Genetic Engineering and the Permissible-Impermissible Boundary

I have argued that the treatment-enhancement distinction is a useful one provided that we do not expect too much of it. Specifically, we should not expect that it coincides with the boundary between those healthcare services we are obliged to provide people, given all our obligations, and those that are non-obligatory. Still, it is a reasonable distinction for use within our primary rationale for including medical services in a healthcare benefit package. It remains a reasonable distinction even in light of expanded ability we may develop to enhance some otherwise normal traits. Dropping it in favor of more expansive views of our medical obligations has distinct disadvantages from a public policy perspective and no compelling arguments for it from a moral perspective.

Still, as I emphasized earlier, we may have other obligations, including those that derive from considerations of justice—such as our concern to promote equality of opportunity—that may compel us to offer some interventions that count as enhancements. Suppose we had a genetic technology that allowed us to enhance immune capabilities beyond those involved in normal functioning. Then like vaccinations—which have an analogous effect—we might well be obliged to provide this enhancement as part of a medical benefit package (costs and resource constraints permitting). Suppose we had an intervention that might allow us to improve reading or math skills, perhaps through an effect on short-term memory, attention, or some other component of cognitive processing capabilities. Suppose further that its effect is more pronounced for those who perform in the lower half of the normal performance distribution, so that it reduces variance in reading ability by pulling up the bottom. Then, just as we would consider it remiss if educational institutions did not incorporate a pedagogical technique that had the same effects or provide a nutritional supple-
ment that had the same effect, so too we might think medical institutions should provide the intervention, costs and resources permitting. Our arguments would turn on the effects on equality of opportunity and on considerations of social productivity. But providing the therapy for some would not be fair without providing it for all (or for all for whom it is reasonably effective).

We must now see if the treatment-enhancement distinction has any bearing at all on the moral boundary between permissible and impermissible germline or somatic cell genetic therapies. I shall argue that here too the distinction will be of some use, provided we do not expect too much of it.

**Negative and Positive and the Permissible-Impermissible Boundary**

Just as the treatment-enhancement distinction does not coincide with the obligatory-nonobligatory boundary, so too it does not coincide with the permissible-impermissible boundary. Not all treatments will be permissible and not all enhancements will be impermissible. As examples of permissible enhancements, Kitcher\(^23\) suggests an improvement to the immune system and possibly an intervention to prevent memory loss during aging. These enhancements might be highly beneficial without posing any significant risks. The strength of the immune system example comes from its close analogy to vaccinations, which exploit more fully our immune capabilities rather than extending them. The difference seems morally irrelevant. As Kitcher suggests, adapting an old argument from Hume, we are no more “playing God” by altering people genetically so that they have greater immunity than we are when we give them vaccinations.

Simply because a genetic intervention counts as an effective treatment does not mean we are obliged to include it in our repertoire of permissible medical treatments. Suppose we could treat a condition through somatic intervention, obtaining consent of the patient, or through germline intervention for which only consent of the parents were possible. If this were a case in which the germline intervention had no additional benefits to the patient (although it might have for her offspring), then we might prefer the direct consent of the patient to the proxy consent of the parents. Other moral constraints thus apply, and therefore being an effective treatment is not a sufficient condition for an intervention being permissible.

**Treatment-Enhancement and Moral Warning Flags**

Even if the treatment-enhancement distinction does not provide us with a simple criterion for deciding what genetic interventions are permissible and impermissible, there is good reason to think that many enhancements will pose serious problems not posed by treatments. For whole classes of cases, certain enhancements may be impermissible for reasons that are unlikely to arise for treatments or for reasons that can be more easily dealt with in the case of treatments. Knowing that something is an enhancement should thus raise a moral warning flag—this is the central implication for public policy.

Three types of warnings about enhancements that we do not encounter with treatments are worth noting here. First, there are public goods and other coordination problems that arise when all parents pursue a course intended to be “best” for their offspring. For example, gender selection to prevent genetic
disease or disability is pursued only by affected families and has no significant effect on gender ratios in subsequent generations. In contrast, gender selection for economic or religious reasons can modify gender ratios; not only is the gender selection for some of these reasons objectionable for reasons of justice, but the effect may be self-defeating. For example, parents seeking economic advantage for their male offspring may find that they contribute to an oversupply of male offspring, making each less valuable. Second, pursuit of “positional advantage” through enhancement of some traits, such as height, risks being either self-defeating or unfair. If all can do it, it may be self-defeating; no one gains a height advantage if everyone increases in height. If only the wealthiest can pursue enhancement, it seems unfair that advantages so ramify. In contrast, treatment of extreme shortness induced by disease will face neither objection. Third, we generally agree that eliminating disease and disability works to the advantage of those who end up functioning normally, but whether some enhancements constitute benefits or not will depend on the values the individuals hold, and parents’ values may not always coincide with the values of their offspring. So we may face problems determining what counts as a benefit and regarding who should decide that go beyond the problems faced by parents making proxy decisions about treatment of disease and disability.

Each of these warning flags requires more careful discussion. We must see if problems they flag warrant flags imposing restrictions on liberties, especially the liberty of parents to pursue the best for their children.

Notes

3. See note 2, cases are drawn from Sabin and Daniels 1994.
6. Using my (1985) account, described in this section, the importance of the need is explained by reference to its impact on an individual’s fair share of the normal opportunity range for his society. In an abstract way, this characterizes the expectation of disadvantage an individual may have relative to a baseline of talents and skills. Daniels N. Just Health Care. New York: Cambridge University Press, 1985.
7. Throughout this paper I equate an adverse departure from normal species functioning (or functional organization) with either disease or disability. I allow room for societally relative “construction” by noting that some disabilities (impairments) do not have enough impact on the individual’s share of the normal opportunity range for us to consider them morally important disabilities, just as some diseases may not warrant treatment because they have so little impact on us.
13. This discussion does not depend on a strong claim about the non-normativeness of judgments about disease of the sort made by Boorse (1976). (See note 9.) Such a claim depends on being able to distinguish genetic variation from disease, and more specifically, on specifying the range of environments taken as “natural” for the purpose of revealing dysfunction. The problem facing this strong claim is that some socially created environments should be counted as “natural” but others not. My discussion turns on a weaker claim. It is enough for our purposes that the line between disease and its absence is, for the general run of cases, uncontroversial and ascertainable through publicly acceptable methods, such as those of the biomedical sciences. It will not matter if what counts as a disease category is relative to some features of social roles in a given society, and thus to some normative judgment, provided the core of the notion of species-normal functioning is left intact. This qualification is made in note 6, Daniels 1985:30.


16. Rawls defines equal opportunity as follows: “those who are at the same level of talent and ability, and have the same willingness to use them, should have the same prospects of success regardless of their initial place in the social system.” (See note 14, Rawls 1971:73.) As Christiano has pointed out, this does not rule out using medicine to enhance the prospects of success of an individual by changing natural qualities of persons that are not directly related to the talents they have. The extension of Rawls’s account is thus not incompatible with its initial statement and may be less an extension than it appears. In any case Rawls seems to endorse the extension I propose. See note 15, Rawls 1993:184, note 14.

17. See note 6, Daniels 1985.

18. Some might object that the terminology is misleading: the principle actually supported does not really call for equality in opportunity, but only some adequate range of opportunities. Since protecting normal functioning while leaving a “natural” baseline of talents and skills in place leads to individuals having different “fair shares” of the normal opportunity range for their society, equality in opportunity does not, after all, assure strict equality of opportunity.


21. Should we think of the deficiency in capability as giving rise to a defeasible claim, if not ultimately a defensible claim? On the normal function model, if the deficiency falls within the normal range and is not itself produced by disease, disability, or unfair social practices, then we should ultimately recognize no claim here. Is this still a “defeasible” claim, one defeated by these etiological criteria, or should we say that defeasible claims arise only after these criteria are met? For example, reasonable resource limits might still defeat the claim that satisfied these criteria. I am inclined to say that defeasible claims arise only after the criteria that distinguish the theory are met. In From Chance to Choice, Chapter 4, the argument proceeds to show that more radical efforts to level the playing field do not, on close inspection, support eliminating the treatment-enhancement distinction in the way they might seem to at first.


23. See note 11, Kitcher 1996.