

## Introduction

### *Reversing Our Lenses*

Imagine that money is no object. Would it be a good thing if medical science developed – and if universal public insurance then paid for – sure-fire cures for blindness or deafness? What about an advanced generation of Prozac that could eradicate neurotic anxiety and mild depression? Or an advanced form of genetic engineering that would furnish every competitive runner with the same peak physical resources? How about a “Michael Jackson pill” that, “if taken by black people,” would “remove all vestiges of being black?”<sup>1</sup> Or new techniques of plastic surgery that would unerringly and permanently provide beautiful skin, lips, and noses? What about a fail-safe drug that cured obesity? Or anorexia? And what if none of these had any side effects?

Notwithstanding the protests of some analysts, who remind us that our financial resources are as limited as our technological hubris is boundless, questions such as these have assumed surpassing prominence in public debate.<sup>2</sup> Despite their futuristic aura, they address an intensely contemporary need to stake out the final limits to medicine, to locate the perimeters beyond which medicine would have no obligation to assist us – indeed, should not assist us – even if it could assist us.

Possibly, we treat these matters with urgency as much because of a sense of moral fallibility as technological hubris. It is often claimed that our scientific capacities continually outrun our moral ones, presenting us with new breakthroughs before we have had a chance to pave the moral way for them or ponder their ethical implications. True, the process of developing new generations of mood-altering or body-shaping or skin-rejuvenating or muscle-building drugs, especially if they are to be 100 percent effective and side effect free, will be long and error-ridden.

But, as those who engage in pitched contemporary debates about them note, so will be the process of thinking through their moral implications. We have every reason to begin asking now whether these are pursuits on which medicine should even embark or, if it does so embark, where it should stop. Put another way, it is precisely because the technologies for a super-Prozac or a side-effect-free steroid will take time to get right that their supporters, whether doctors, scientists, or potential patients, are so keen to broach them as possibilities right now. They want to begin dealing with the moral issues so as to get the scientific show on the road. Hence, we find ourselves today thinking about what medicine should do in a world without technological limits.

We also find ourselves thinking about what medicine should do in a world without financial limits. Of course, any given advocate for a super-Botox or a side-effect-free muscle-growth treatment will generally concede that in a world of limited medical budgets, they do not have the priority of, say, cardiac research or cancer care. Yet that same advocate can also insist, quite reasonably, that the cost of treating a condition should have nothing to do with the question of whether it is legitimately a medical one. “[D]ialysis machines and tomography units are enormously expensive,” Arthur L. Caplan notes, and even now we haven’t enough of them to help everyone in need. “But,” Caplan says, “these facts do not in any way change the disease status of . . . schizophrenia [or] kidney failure . . .”<sup>3</sup> Suppose that we are denied a particular medical treatment or that medical science opts not to pursue a cure for our particular condition. We are entitled to know whether, and we will reconcile ourselves differently to the decision according to whether, the reasons are financial, technological, or, instead, philosophical, having to do with medicine’s final limits.<sup>4</sup>

The eight questions that I pose in the opening paragraph – having to do with blindness and deafness, mild depression and slow running, black racial features and plain facial features, obesity and anorexia – have become, even in today’s world of limited resources and imperfect technology, principal lightning rods for debate over the final limits to medicine. They lend themselves, typically, to two approaches. According to bioethicists and others who adopt the first, it is the task of medicine to provide legitimate cures. Advanced performance boosters for competitive runners, however, or side-effect-free pharmaceuticals to lift people’s moods, or new-wave Botox for permanently youthful skin, raise the question as to whether they might not be mere “enhancements” instead of cures for real medical conditions. They provoke impassioned argument as to whether

they might not lie wholly beyond the province of medicine, even if we had the financial and technological wherewithal to provide them.

Those taking the second approach also affirm that the task of medicine is to furnish legitimate cures. The problem, however, is that treatments for conditions such as deafness, obesity, or anorexia may actually be a form of cultural genocide. People harboring conditions such as these, so the claim goes, have generated their own unique ways of life, historical traditions, means of understanding and interpreting the external world, or modes of expressing and communicating their inner beings: in short, their own irreplaceable and much-loved cultures. The notion of a cure for deafness, obesity, or anorexia, this line of argument concludes, is as offensive as would be a “cure” for being French or Hispanic.

These two endeavors – the attempts to make the cure/enhancement and the cure/cultural genocide “cuts” – are not inconsistent with each other, even though they are generally undertaken by different people, directed at different conditions, and advanced without much mutual recognition. But they have something important in common. Together, they comprise the contemporary attempt to draw the final limits to medicine, to say what it is that we shouldn’t treat medically even if we could: even if we had the resources and the technology. The two cuts are attractive in some ways. Each captures moral intuitions we have; and many of us, including myself, would want to draw final limits to medicine. Unfortunately, these two cuts, as they are typically advanced, fail to do that. In this book, I offer an alternative way of setting medicine’s final limits. But first: what’s wrong with the way the lines currently get drawn?

### Cure versus Enhancement

Bioethicists making a cut between cure and enhancement typically argue as follows: Cure, the proper function of medicine, restores or takes us to a social norm – think of plastic surgery to correct deviated septums – while enhancement, say plastic surgery to make ordinary noses more beautiful, takes us beyond the social norm.<sup>5</sup> Alternatively, by shifting from the social to the individual level, the cure/enhancement cut gets made in this way: If an individual whose pneumonia, say, has been cured by an antibiotic wins a race, then we should have no problem crediting the individual himself with that achievement. If, however, someone wins a race having taken steroids, then we can no longer be certain whether that individual himself is responsible for the accomplishment.<sup>6</sup> As a working paper for the President’s Council on Bioethics puts it, cure makes an individual “whole,

while enhancement alters the whole.”<sup>7</sup> Whether it flouts a social norm or some line demarcating the true individual, enhancement – unlike cure, which honors both – is to be resisted. Even assuming unlimited resources, we would have no obligation to pursue the development and fund the delivery of enhancement in the way we might for cure.

While these cuts between cure and enhancement hold intuitive appeal, they have not been successfully argued. The notion that medicine should be about bringing us to a social norm founders on the observation that the social norm is always moving: moving, in particular, in the direction of enhancement. Currently, half of all Americans over sixty-five have arthritis or a related form of chronic joint inflammation. It would, then, be considered socially normal, normal in our society, for an elderly person to suffer from arthritis. But if it’s medicine’s job merely to restore people to a state of social normality when they depart from it, wouldn’t the medical community be exceeding its bounds if it embarked on the research, and delivered the services, necessary to alter whatever the existing state of social normality happened to be? It would seem so. Yet few would define as beyond the legitimate purview of medicine the work of those rheumatologists who, refusing to take the social norm as given, are busy developing new therapies to palliate, delay, prevent, or cure arthritis and rheumatism in the elderly.

Some philosophers might reply that developing such an arthritis cure would be justified even on a “social norm” criterion, properly understood. What’s socially normal, Norman Daniels argues in his influential book *Just Health Care*, is whatever is necessary for human beings to pursue a great many “life plans” in a given society – lawyer, mountaineer, doctor, designer – as distinct from what’s necessary for the pursuit of only a few idiosyncratic life plans, such as the ability to play piano like Glenn Gould or hit a ball like Joe DiMaggio. Since healthy and pain-free joints are necessary for the pursuit of a societywide array of life plans, a cure will simply bring those suffering from arthritis to a state of social normality. Curing arthritis in the elderly, then, indeed falls within the bounds of medicine to provide.

This way of using the social norm criterion to justify a cure for later-life arthritis invites two alternative rejoinders. On the one hand, because of arthritis’s prevalence in those over sixty-five, the range of life plans in society does not, in fact, include the possibility of people continuing to practice law, climb mountains, drive trucks, or design clothes – free of joint pain – into their later years. Indeed, Norman Daniels allows that “for each age (stage of life), there is a normal opportunity range.”<sup>8</sup> Because

of arthritis's normality in later life, all life plans would in some way incorporate that fact. On the view that it's the task of medicine to bring people to the social norm, understood as the capacity to pursue a societywide range of life plans, there would be no call on medicine to deliver a cure for arthritis to those over age sixty-five.

On the other hand, suppose that the defender of the "socially normal" approach wants to insist that pain-free joints are socially normal, even for a person over sixty-five. After all, they would be necessary for people to continue pursuing a societywide array of life plans – lawyer, engineer, student of Russian literature, oil-rig worker – to the maximum possible. But then on the same argument, a pill that increased IQ to 300 – or life span to 200 – would be a cure, not an enhancement, since it too would be necessary for pursuing any number of life plans to the maximum. Few proponents of the social norm view, however, would want to deem such innovations as anything but enhancements. But if they are enhancements, then so is a cure for arthritis for those over sixty-five. And yet that's not what we want to think.

Georges Canguilhem, in his 1943 classic *The Normal and the Pathological* – a book that heavily influenced Michel Foucault's subsequent inquiries on similar themes – said that human beings are always "transcending the norm." Canguilhem's central insight was that the "momentarily normal [always itself includes] the possibility of tolerating infractions of the habitual norm and instituting new norms in new situations."<sup>9</sup> A philosophy that says that "cure is that which returns or takes us to normal" must, Canguilhem said, embrace the fact that it's normal for us always to be pushing the norm in the direction of enhancement.

It was a similar insight that led those advancing the social norm approach to reject (or modify) a competing alternative, the "biological norm" approach. According to the biological norm philosophers, the legitimate task of medicine is to restore a person to some notion of natural biological functioning. For example, it is the function of our legs to walk and run. So the notion of "legitimate" cure would embrace whatever restores or brings someone's legs to a point where they can execute that natural function. Yet as Dorothy Dinnerstein writes in refuting this claim, "[h]umans are by nature unnatural. We do not yet walk 'naturally' on our hind legs, for example: such ills as fallen arches, lower back pain and hernias testify that the [human] body has not yet adapted itself completely to the upright posture." To call an illness something "contrary to human biology is naïve," Dinnerstein says; "we are what we have made ourselves, and we must continue to make ourselves as long as we exist at all."<sup>10</sup>

Our biological functioning, in other words, is insufficient as a criterion for “cure.” Legs that walk, jog, run a mile in four minutes, or run a mile in three minutes are (or would be) all engaging in their biological functions. Indeed, one could argue that if our criterion is biological functioning, then the faster the legs the better the functioning. New steroid treatment that enabled running a two-minute mile should therefore be deemed a cure, not an enhancement, even on the biological functioning criterion. This is simply another way of saying that biological functioning, in and of itself, tells us little about the line between cure and enhancement. We have to take into account the social roles we need to fulfill. Those roles require us – contrary, as Dinnerstein says, to what may be deemed purely natural – to walk and run on two legs. Our social roles also require not just vision, but the vision to be able to drive at night; not just opposable thumbs, but the manual dexterity required to write.<sup>11</sup> Any medical cure that stopped short of enabling those and countless other social activities – on the grounds that our biological functioning didn’t strictly require it – would be deemed woefully inadequate. But once we acknowledge that social normality, not biological functioning or species normality, is the operative criterion, then we have to allow, somehow, for the inevitability that social norms will change and that medicine can legitimately be expected to play a role in such change.

Even the philosopher Christopher Boorse, who in a widely discussed 1975 article defined “disease” as a deviation from biological normality, then tightly circumscribed the relevance of that notion.<sup>12</sup> For he immediately went on to acknowledge that the role of medicine is in fact to cure not “disease” but “illness,” which he defined as a falling short of social norms that may go well beyond mere biological requirements. But “[w]hy,” as Lawrie Reznek asks, “draw a distinction between diseases and other negative medical conditions if no [practical distinction] is being picked out?”<sup>13</sup> And if we are going to acknowledge that medicine can legitimately take us beyond biological normality to social normality, we then have to confront the fact that we are always wanting, and legitimately so, to go beyond today’s social norms, too. And so we cannot use them, either, as the basis for dividing cure from enhancement. Even Leon Kass and Francis Fukuyama, chair and member of the President’s Council on Bioethics, respectively – though clearly drawn in principle to using a notion of social normality to draw the cure/enhancement cut – acknowledge how “fuzzy the boundary is.”<sup>14</sup>

We meet with no greater success in attempting to make the cure/enhancement cut at the individual instead of the social level. Drawing

a distinction between interventions that make the individual self whole (cure) and those that take the individual beyond whole (enhancement) is a vexing endeavor. For example, Erik Parens writes that “central to maintaining the idea of a self is the commitment to regard some of our actions and attitudes as justified by our reasons, not explained in mechanistic terms.”<sup>15</sup> The implication is that a mild depressive who undergoes psychotherapy engages her mind in an effort to overcome her condition; hence any resultant improvement represents growth in her personal wholeness, not a violation of it. Prozac, by contrast, would bypass these intellectual processes, bringing improvements that are artificial (“mechanistic,” and therefore enhancements), not real (appealing to reasons and therefore genuinely curative). But can we really equate the cut between making an individual whole and going beyond whole, on the one hand, with that between therapies that appeal to reason and those that work mechanistically, on the other? Prozac often cuts away neurotic encrustations on rational processes, while psychotherapy can frequently be mechanistic, subrational, in its workings.

Some commentators offer a different way of making the cut between cure – that which makes the individual whole – and enhancement, which takes him beyond whole. Such a distinction, they say, maps a deeper one between therapies that work externally and hence seem not to alter the individual – supportive shoes for runners, say – and those that operate internally and so seem to shift the shape of the self: steroids, for example. Yet we believe that whatever a student achieves on the Scholastic Aptitude Test (SAT) after having been tutored – thereby altering herself internally – is genuine, but whatever she might achieve by bringing a tutor, an external aid, into the test room with her would be artificial. We believe that whatever a baseball player achieves after having drunk coffee is genuine, but whatever he achieves after having taken steroids is artificial, although both operate on him internally. We believe that whatever a marathon runner achieves wearing air shoes is genuine, while whatever she achieves by taking a subway, as Rosie Ruiz famously did during the New York Marathon, is artificial, although both operate externally. As the psychiatrist Willard Gaylin has written, we must “re-examine the distinction between endogenous and exogenous” as a proxy for that “between artificial and natural.” And when we do so, we will find that we are “further undermining some of the fragile distinctions that have supported us in the past.”<sup>16</sup>

Listen, again, to Leon Kass thinking out loud during a 2002 President’s Bioethics Council meeting. Kass begins by drawing a line between the antibiotic that allows a runner to throw off her infection and win

a race – the achievement would genuinely be hers because she would have been made whole – and the steroids that would take her beyond whole, rendering her victory an artificial one. But he ends by arguing himself into acknowledging the incoherence of that very distinction: “[I]t’s not so clear that [a steroid-assisted victory] would be the achievement of the agent. There’s a certain line . . . where if you doped up several athletes . . . what you’d really be praising would be the chemists rather than the [runner]. And I know what’s coming next, because we’re just bags of chemicals and it’s very complicated.”<sup>17</sup>

### Cure versus Cultural Genocide

A second approach to the questions I pose in the opening paragraph would ask not “When does cure become enhancement?” but “When does cure become cultural genocide?” The idea here is that the deaf, or the obese, or the anorexic do not have medical conditions but rather are cultural groups. If they are so seen, then a cure could very well be a form of cultural genocide. As more and more deaf, obese, or anorexic people take cures, and as their numbers dwindle and then disappear, irreplaceable tiles in the multicultural mosaic will crumble. We will lose the culture of deafness, with its unique language; of obesity – would our culture not have been poorer without Falstaff, Fats Waller, Sydney Greenstreet, Santa Claus, or John Goodman?<sup>18</sup>; and of anorexia, which some anorexics describe as a religion and which others, anorexics and nonanorexics alike, have fashioned into the aesthetic of anorexic chic.<sup>19</sup>

Presumably, for a cure to amount to “cultural genocide,” there must be a legitimate culture at stake. Those making a cultural genocide argument against cure, accordingly, expend enormous energy trying to show how the art and experiences surrounding their particular condition rise to the level of a full-fledged culture. But here, too, we run into problems of line drawing. The enterprise of weighing different conditions on some kind of scale of cultural substance – three points for a language, two points for a literature, four for a history of vicious oppression – is a perilous one.

We might, for example, venture that obesity is less a culture than blindness, because blindness has its own quasi-language, Braille, which – although it doesn’t possess a unique grammar – does have its own singular symbology. Yet many obesity “activists [steadfastly] liken . . . medical efforts [against obesity] to genocide.”<sup>20</sup> As early as 1977, Hillel Schwartz reports in his history of overweight in America, “a member of the Los Angeles Fat Underground wrote in an open letter to a doctor: ‘You see fat as suicide, I



see weight loss as murder – genocide, to be precise.”<sup>21</sup> If “everyone who wanted to be thin could get thin by taking a pill,” Richard Klein writes in his celebrated 1996 book *EAT FAT*, then “[m]aybe in this decade, maybe in thirty years, a final fat solution will be found. To my mind, postmodern fat becomes a cultural problem at this moment . . . when it may be at the point of becoming extinct.”<sup>22</sup>

Or one might suggest that blindness has evolved less of a culture than deafness. After all, the deaf community has its own full-fledged language, with its own symbology *and* grammar: American Sign Language (ASL). That seems to be the view that Carol Padden and Tom Humphries take when they say that “[t]he term ‘disabled’ describes those who are blind or physically handicapped . . . not Deaf People.”<sup>23</sup> Deafness is “not a disability,” Edward Dolnick writes; “[i]nstead . . . deaf people . . . are a subculture like any other. They are simply a linguistic minority . . . and are no more in need of a cure for their condition than are Haitians or Hispanics.”<sup>24</sup> Deaf activists, the political scientist David Ingram notes, “have been maintaining for some time that ASL is the equal of any linguistic culture, its lack of literature notwithstanding”<sup>25</sup> (Ingram must be referring to written literature, since “the literature of American deaf culture, told in ASL, consists of history, tales, legends, fables, anecdotes, plays, jokes . . . and much more.”)<sup>26</sup> And so, on this reasoning, devices such as cochlear implants get viewed “as cultural genocide, an attempt to decrease the deaf population and ultimately eliminate it.”<sup>27</sup>

Yet in the eyes of others, “blindness,” too, seems to have all of the same “qualities of a subculture.”<sup>28</sup> Braille might not have its own grammar as does ASL, but then again, ASL hasn’t evolved a written literature. If we accept the project of classifying cure as cultural genocide by gauging the extent to which the particular condition in question has evolved the traits of a culture, then whatever protection the culture of deafness deserves, what blind activists have for decades called the “[c]ulture of blindness” merits the same.<sup>29</sup>

One might say that while deafness embraces a language, blacks have uniquely borne the burden of “systematic and organized discrimination” and that therefore “a practice of altering . . . skin colour is [particularly] disturbing.”<sup>30</sup> But there are members of the deaf community who claim that “[f]rom the deaf point of view, the notion that [cochlear] implants are beneficial ‘is both inappropriate and offensive – as if doctors and newspapers joyously announced advances in genetic engineering that might someday make it possible to turn black skin white.’”<sup>31</sup> Others argue that cosmetic “surgery to bring a woman’s body in line with prevailing

standards of female beauty – liposuction, cheekbone surgery, rib extraction, breast augmentation – is on a moral par with surgery to make a black person resemble a white one.”<sup>32</sup> And consider this statement: “I am . . . invisible . . . simply because people refuse to see me . . . . When they approach me, they see only my surroundings, themselves, or figments of their imagination – indeed, everything and anything except me . . . .’ So wrote renowned novelist Ralph Ellison about being black . . . But his eloquent description applies equally well to Fat Chicks.”<sup>33</sup>

Carl Elliott is quite right: “If stigma is a form of oppression, then in America no group has a monopoly on oppression.”<sup>34</sup> There is simply inveterate disagreement here, within and between groups harboring different conditions, but no overarching “intergroup” principle with which to draw the line between cure and cultural genocide. Are we going to say that a condition has generated a culture – and that cure therefore becomes cultural genocide – simply when some members harboring the condition say so? If not, what principles could we possibly use to decide – language? literature? a history of oppression? – given that each group seems to be asserting its own?

### Reversing Our Lenses

I believe that those who seek to draw cure/enhancement and cure/genocide cuts are pursuing the right projects. But each of the two endeavors suffers from lack of an ultimately persuasive argument on which to make the desired cuts and hence to draw the final limits to medicine. Nor have the two cuts been brought together under a common framework. In this book, I suggest a way of remedying this situation by exploring what might happen were the two debates to exchange focal points.

To explain: Philosophers of the cure/enhancement cut preoccupy themselves with both a societywide question – what is the social norm of noses, mental states, or body size, and what goes beyond the norm into enhancement? – and individual-level issues – how do we decide when we’ve made an individual whole, or when we’ve gone beyond whole into enhancement?<sup>35</sup> Difficulties arise because the social norm itself is always moving in the direction of enhancement. And trouble emerges because the criteria that we use to determine what makes an individual whole – and what goes beyond – are, as Gaylin says, “fragile”; they often fail to make the cut in ways that accord with our intuitions. But these are not