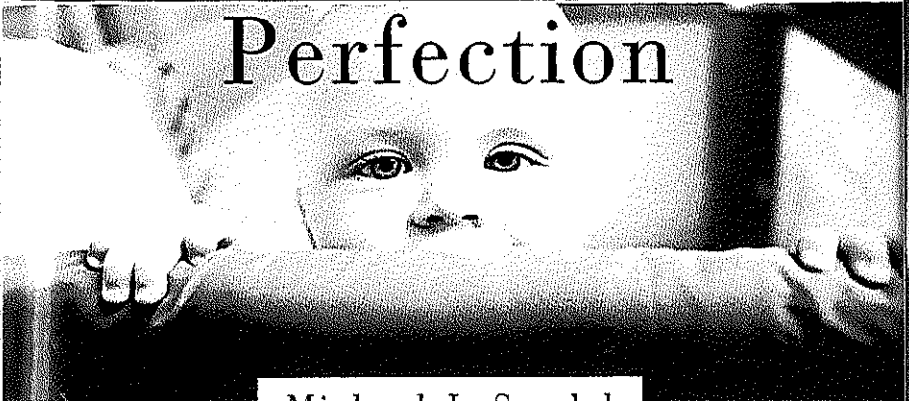


# The Case against Perfection



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ETHICS IN THE AGE OF GENETIC ENGINEERING



## I

### The Ethics of Enhancement

A FEW YEARS AGO, a couple decided they wanted to have a child, preferably a deaf one. Both partners were deaf, and proudly so. Like others in the deaf-pride community, Sharon Duchesneau and Candy McCullough considered deafness a cultural identity, not a disability to be cured. “Being deaf is just a way of life,” said Duchesneau. “We feel whole as deaf people and we want to share the wonderful aspects of our deaf community—a sense of belonging and connectedness—with children. We truly feel we live rich lives as deaf people.”<sup>1</sup>

In hopes of conceiving a deaf child, they sought out a sperm donor with five generations of deafness in his family. And they succeeded. Their son Gauvin was born deaf.

The new parents were surprised when their story, which was reported in the *Washington Post*,

brought widespread condemnation. Most of the outrage focused on the charge that they had deliberately inflicted a disability on their child. Duchesneau and McCullough (who are lesbian partners) denied that deafness is a disability and argued that they had simply wanted a child like themselves. "We do not view what we did as very different from what many straight couples do when they have children," said Duchesneau.<sup>2</sup>

Is it wrong to make a child deaf by design? If so, what makes it wrong—the deafness or the design? Suppose, for the sake of argument, that deafness is not a disability but a distinctive identity. Is there still something wrong with the idea of parents picking and choosing the kind of child they will have? Or do parents do that all the time, in their choice of mate and, these days, in their use of new reproductive technologies?

Not long before the controversy over the deaf child, an ad appeared in the *Harvard Crimson* and other Ivy League student newspapers. An infertile couple was seeking an egg donor, but not just any egg donor. She had to be five feet, ten inches tall, athletic, without major family medical problems, and to have a combined SAT score of 1400 or above. In exchange for an egg from a donor meet-

ing this description, the ad offered payment of \$50,000.<sup>3</sup>

Perhaps the parents who offered the hefty sum for a premium egg simply wanted a child who resembled them. Or perhaps they were hoping to trade up, trying for a child who would be taller or smarter than they. Whatever the case, their extraordinary offer did not prompt the public outcry that met the parents who wanted a deaf child. No one objected that height, intelligence, and athletic prowess are disabilities that children should be spared. And yet something about the ad leaves a lingering moral qualm. Even if no harm is involved, isn't there something troubling about parents ordering up a child with certain genetic traits?

Some defend the attempt to conceive a deaf child, or one who will have high SAT scores, as similar to natural procreation in one crucial respect: whatever these parents did to increase the odds, they were not guaranteed the outcome they sought. Both attempts were still subject to the vagaries of the genetic lottery. This defense raises an intriguing question. Why does some element of unpredictability seem to make a moral difference? Suppose biotechnology could remove the uncer-

tainty and allow us to design the genetic traits of our children?

While pondering this question, put aside children for a moment and consider pets. About a year after the furor over the deliberately deaf child, a Texas woman named Julie (she declined to give her last name) was mourning the death of her beloved cat Nicky. "He was very beautiful," Julie said. "He was exceptionally intelligent. He knew eleven commands." She had read of a company in California that offered a cat cloning service—Genetic Savings & Clone. In 2001 the company had succeeded in creating the first cloned cat (named CC, for Carbon Copy). Julie sent the company a genetic sample of Nicky, along with the required fee of \$50,000. A few months later, to her great delight, she received Little Nicky, a genetically identical cat. "He is identical," Julie proclaimed. "I have not been able to see one difference."<sup>4</sup>

The company's Web site has since announced a price reduction for cat cloning, which now costs a mere \$32,000. If the price still seems steep, it comes with a money-back guarantee: "If you feel that your kitten doesn't sufficiently resemble the genetic donor, we'll refund your money in full with no questions asked." Meanwhile, the company's

scientists are working to develop a new product line—cloned dogs. Since dogs are harder to clone than cats, the company plans to charge \$100,000 or more.<sup>5</sup>

Many people find something odd about the commercial cloning of cats and dogs. Some complain that, with thousands of strays in need of good homes, it is unconscionable to spend a small fortune to create a custom-made pet. Others worry about the number of animals lost during pregnancy in the attempt to create a successful clone. But suppose these problems could be overcome. Would the cloning of cats and dogs still give us pause? What about the cloning of human beings?

#### ARTICULATING OUR UNEASE

Breakthroughs in genetics present us with a promise and a predicament. The promise is that we may soon be able to treat and prevent a host of debilitating diseases. The predicament is that our newfound genetic knowledge may also enable us to manipulate our own nature—to enhance our muscles, memories, and moods; to choose the sex, height, and other genetic traits of our children; to improve our physical and cognitive capacities; to

make ourselves "better than well."<sup>6</sup> Most people find at least some forms of genetic engineering disquieting. But it is not easy to articulate the source of our unease. The familiar terms of moral and political discourse make it difficult to say what is wrong with reengineering our nature.

Consider again the question of cloning. The birth of Dolly the cloned sheep in 1997 brought a torrent of worry about the prospect of cloned human beings. There are good medical reasons to worry. Most scientists agree that cloning is unsafe and likely to produce offspring with serious abnormalities and birth defects. (Dolly died a premature death.) But suppose cloning technology improves to the point where the risks are no greater than with natural pregnancy. Would human cloning still be objectionable? What exactly is wrong with creating a child who is a genetic twin of his or her parent, or of an older sibling who has tragically died, or, for that matter, of an admired scientist, sports star, or celebrity?

Some say cloning is wrong because it violates the child's right to autonomy. By choosing in advance the genetic makeup of the child, the parents consign her to a life in the shadow of someone who

has gone before, and so deprive the child of her right to an open future. The autonomy objection can be raised not only against cloning but also against any form of bioengineering that allows parents to choose their child's genetic characteristics. According to this objection, the problem with genetic engineering is that "designer children" are not fully free; even favorable genetic enhancements (for musical talent, say, or athletic prowess) would point children toward particular life choices, impairing their autonomy and violating their right to choose their life plan for themselves.

At first glance, the autonomy argument seems to capture what is troubling about human cloning and other forms of genetic engineering. But it is not persuasive, for two reasons. First, it wrongly implies that, absent a designing parent, children are free to choose their physical characteristics for themselves. But none of us chooses our own genetic inheritance. The alternative to a cloned or genetically enhanced child is not one whose future is unbiased and unbound by particular talents, but a child at the mercy of the genetic lottery.

Second, even if a concern for autonomy explains some of our worries about made-to-order children,

it cannot explain our moral hesitation about people who seek genetic enhancements for themselves. Not all genetic interventions are passed down the generations. Gene therapy on nonreproductive (or somatic) cells, such as muscle cells or brain cells, works by repairing or replacing defective genes. The moral quandary arises when people use such therapy not to cure a disease but to reach beyond health, to enhance their physical or cognitive capacities, to lift themselves above the norm.

This moral quandary has nothing to do with impairing autonomy. Only germline genetic interventions, which target eggs, sperm, or embryos, affect subsequent generations. An athlete who genetically enhances his muscles does not confer on his progeny his added speed and strength; he cannot be charged with foisting talents on his children that may push them toward an athletic career. And yet there is still something unsettling about the prospect of genetically altered athletes.

Like cosmetic surgery, genetic enhancement employs medical means for nonmedical ends—ends unrelated to curing or preventing disease, repairing injury, or restoring health. But unlike cosmetic surgery, genetic enhancement is not merely

cosmetic. It is more than skin deep. Even somatic enhancements, which would not reach our children and grandchildren, raise hard moral questions. If we are ambivalent about plastic surgery and Botox injections for sagging chins and furrowed brows, we are all the more troubled by genetic engineering for stronger bodies, sharper memories, greater intelligence, and happier moods. The question is whether we are right to be troubled—and if so, on what grounds?

When science moves faster than moral understanding, as it does today, men and women struggle to articulate their unease. In liberal societies, they reach first for the language of autonomy, fairness, and individual rights. But this part of our moral vocabulary does not equip us to address the hardest questions posed by cloning, designer children, and genetic engineering. That is why the genomic revolution has induced a kind of moral vertigo. To grapple with the ethics of enhancement, we need to confront questions largely lost from view in the modern world—questions about the moral status of nature, and about the proper stance of human beings toward the given world. Since these questions verge on theology, modern philosophers and

political theorists tend to shrink from them. But our new powers of biotechnology make them unavoidable.

#### GENETIC ENGINEERING

To see how this is so, consider four examples of bio-engineering already on the horizon: muscle enhancement, memory enhancement, height enhancement, and sex selection. In each case, what began as an attempt to treat a disease or prevent a genetic disorder now beckons as an instrument of improvement and consumer choice.

##### *Muscles*

Everyone would welcome a gene therapy to alleviate muscular dystrophy and to reverse the debilitating muscle loss that comes with old age. But what if the same therapy were used to produce genetically altered athletes? Researchers have developed a synthetic gene that, when injected into the muscle cells of mice, makes muscles grow and prevents them from deteriorating with age. The success bodes well for human applications. Dr. H. Lee Sweeney, who leads the research, hopes his discovery will cure the immobility that afflicts the elderly.

But Dr. Sweeney's bulked-up mice have already attracted the attention of athletes seeking a competitive edge.<sup>7</sup> The gene not only repairs injured muscles but also strengthens healthy ones. Although the therapy is not yet approved for human use, the prospect of genetically enhanced weight lifters, home-run sluggers, linebackers, and sprinters is easy to imagine. The widespread use of steroids and other performance-enhancing drugs in professional sports suggests that many athletes will be eager to avail themselves of genetic enhancement. The International Olympic Committee has already begun to worry about the fact that, unlike drugs, altered genes cannot be detected in urine or blood tests.<sup>8</sup>

The prospect of genetically altered athletes offers a good illustration of the ethical quandaries surrounding enhancement. Should the IOC and professional sports leagues ban genetically enhanced athletes, and if so, on what grounds? The two most obvious reasons for banning drugs in sports are safety and fairness: Steroids have harmful side effects, and to allow some to boost their performance by incurring serious health risks would put their competitors at an unfair disadvantage. But suppose, for the sake of argument, that muscle-enhancing gene therapy turned out to be

safe, or at least no riskier than a rigorous weight-training regime. Would there still be a reason to ban its use in sports? There is something unsettling about the specter of genetically altered athletes lifting SUVs or hitting 650-foot home runs or running a three-minute mile. But what exactly is troubling about these scenarios? Is it simply that we find such superhuman spectacles too bizarre to contemplate, or does our unease point to something of ethical significance?

The distinction between curing and improving seems to make a moral difference, but it is not obvious what the difference consists in. Consider: If it is all right for an injured athlete to repair a muscle tear with the help of genetic therapy, why is it wrong for him to extend the therapy to improve the muscle, and then to return to the lineup better than before? It might be argued that a genetically enhanced athlete would have an unfair advantage over his unenhanced competitors. But the fairness argument against enhancement has a fatal flaw. It has always been the case that some athletes are better endowed, genetically, than others. And yet we do not consider the natural inequality of genetic endowments to undermine the fairness of competitive sports. From the standpoint of fairness,

enhanced genetic differences are no worse than natural ones. Moreover, assuming they are safe, genetic enhancements could be made available to all. If genetic enhancement in sports is morally objectionable, it must be for reasons other than fairness.

#### Memory

Genetic enhancement is possible for brains as well as brawn. In the mid-1990s scientists managed to manipulate a memory-linked gene in fruit flies, creating flies with photographic memories. More recently researchers produced smart mice by inserting extra copies of a memory-related gene into mouse embryos. The altered mice learn more quickly and remember things longer than normal mice. For example, they are better able to recognize objects they have seen before, and to remember that a certain sound leads to an electric shock. The gene the scientists tweaked in mouse embryos is present in human beings as well, and becomes less active as people age. The extra copies installed in the mice were programmed to remain active even in old age, and the improvement was passed on to their offspring.<sup>9</sup>

Of course human memory is more complicated

than recalling simple associations. But biotech companies with names like Memory Pharmaceuticals are in hot pursuit of memory-enhancing drugs, or "cognition enhancers," for human beings. One obvious market for such drugs consists of those who suffer from serious memory disorders, such as Alzheimer's and dementia. But the companies also have their sights on a bigger market: the 76 million baby boomers over fifty who are beginning to encounter the natural memory loss that comes with age.<sup>10</sup> A drug that reversed age-related memory loss would be a bonanza for the pharmaceuticals industry, a "Viagra for the brain."

Such use would straddle the distinction between remedy and enhancement. Unlike a treatment for Alzheimer's, it would cure no disease. But insofar as it restored capacities a person once possessed, it would have a remedial aspect. It could also have purely nonmedical uses: for example, by a lawyer cramming to memorize facts for an upcoming trial, or by a business executive eager to learn Mandarin on the eve of his departure for Shanghai.

It might be argued, against the project of memory enhancement, that there are some things we would rather forget. For the drug companies, however, the desire to forget represents not an objec-

tion to the memory business but another market segment. Those who want to blunt the impact of traumatic or painful memories may soon be able to take a drug that prevents horrific events from being etched too vividly in memory. Victims of a sexual assault, soldiers exposed to the carnage of war, or rescue workers forced to face the aftermath of a terrorist attack would be able to take a memory-suppressing drug to dull the trauma that might otherwise plague them for a lifetime. If the use of such drugs became widely accepted, they might one day be administered routinely in emergency rooms and military field hospitals.<sup>11</sup>

Some who worry about the ethics of cognitive enhancement point to the danger of creating two classes of human beings—those with access to enhancement technologies, and those who must make do with an unaltered memory that fades with age. And if the enhancements can be passed down the generations, the two classes may eventually become subspecies of human beings—the enhanced and the merely natural. But the worry about access begs the question of the moral status of enhancement itself. Is the scenario troubling because the unenhanced poor are denied the benefits of bioengineering, or because the enhanced affluent are