

A CROSS SECTION OF CONTEMPORARY ETHICAL DEBATE ABOUT ALTERING THE HUMAN BODY

ENHANCEMENT



Sarah Glazer

At The Hastings Center, we believe moral problems can be clarified through reasoned debate and an honest attempt to find common ground. Our work is characterized by its openness to differing perspectives. We use a process of assertion, analysis, critique, and response. While we may never reach full consensus, we have successfully used this process, time and again, to narrow differences, eliminate misunderstandings, and develop tolerance and trust.

This publication is the first in a series that will capture cross sections of the contemporary debates about topics of long-standing interest in medicine and the life sciences. Some of that debate takes place within The Hastings Center, but it also goes on in our homes, in hospitals and doctor's offices, in academic institutions and journals, and in government.

The series is intended to provide clarity about medical and scientific facts, about matters of law, about ethical standards, and about the underlying values that inform those standards. We hope to point out where genuine controversy over facts or policies exists—and where it does not.

Founded in 1969 in Hastings-on-Hudson, NY, The Hastings Center was the first bioethics research institute in the world. Some of the enduring topics we will address in this series received their earliest consideration in research conducted at the Center during the 1970s and 1980s.

Today, The Hastings Center confronts ethical issues in genetics and biotechnology, health care and health policy, and medical research. Privacy and confidentiality, fair allocation of scarce health care resources, protection of human research subjects, medical error and forgiveness, and the ingredients of human flourishing are core themes throughout our work.

Please visit www.thehastingscenter.org for more information about the Center, our publications, and our research programs.



Introduction

Like many patients with lymphoma, a blood cancer, 83-year-old Miranda Wallace* often suffered from severe anemia, leaving her too exhausted to rise from her bed. But a weekly shot of erythropoietin (EPO), a drug that stimulates the bone marrow to produce the red blood cells lacking in anemic patients, “brought me back to life,” she says.

Bodybuilders seeking ever-bigger muscles also take EPO to boost stamina, but since it is only approved as a prescription drug for medical conditions like anemia, they purchase it on a thriving black market along with illegal anabolic steroids. With EPO, “You can train day and night and not get tired,” explains Thomas Jakob, who coaches bodybuilders in Manhattan.

Jakob, 38, has used illegal steroids ever since he began competitive bodybuilding in his early twenties, reaching a level of rippling muscularity he says would have been unachievable with weightlifting alone. Jakob stopped taking steroids, after he suffered a heart attack his doctors attributed to elevated blood cholesterol from steroids. But he doubts his experience will persuade fellow bodybuilders to stop using substances that are practically a requirement of the sport. “The world of competitive bodybuilding is chemical warfare,” he explains.

To most people, there’s a clear dividing line between treating patients with a drug for a medical condition and using it to enhance one’s physique or performance. Indeed, many people find it morally repugnant to take drugs as enhancements—especially when, like steroids, they may give a competitive edge in athletics and cause long-term damage to the body.

How do we regulate such substances? The federal government currently bans over-the-counter sales of anabolic steroids and EPO because of their dangerous side effects. Sports organizations forbid their use in competition for both their physical risks and the unfair advantage they provide.

But what if a substance can benefit all of us—healthy and disabled alike—with minimal side effects? For example, Ritalin, a prescription amphetamine drug approved for treating attention deficit disorders, also helps people with normal attention spans to focus better on intellectual tasks—as the growing number of college students who take it before exams shows.

Some scientists predict we may one day be able to achieve the effects of drugs, without their troublesome side effects, by beefing up our brains genetically. Doctors have already treated some genetic diseases by injecting healthy genes into individuals with immune disorders, although the practice has proved risky and successes have been rare. What if parents could tweak an embryo in the petri dish to endow a child with musical talent? Already parents employing in vitro fertilization can test embryos for genetic diseases or sex and decide which embryo is to be implanted on the basis of that information. What if they could also select for IQ or muscle strength?

* The name of this interviewee has been changed at her request in order to protect her privacy.

Research at The Hastings Center

These questions are the subject of vigorous debate in the sports world, the scientific research community, government, the popular press, and a variety of academic disciplines. Enthusiasts see such possibilities as part of a long tradition of human scientific advances in conquering disease and increasing the average life span. Critics worry about what pursuing enhancement will do to individuals, children, families, and societies. The contest between these views has become one of the most prominent and challenging debates at The Hastings Center, a research institute devoted to the study of issues in bioethics—that is, of the ethical questions raised by the biological and medical sciences.



Hastings Center scholar
Erik Parens

Replacing mere contest with thoughtful debate requires that one take a step back from social conventions and gut reactions and try to unveil the underlying philosophical and moral issues. Despite the debate's highly polarized nature, most people share values from both camps because both aspects are part of our understanding of what it means to be human, writes Hastings Center senior research scholar Erik Parens in a recent article, "Authenticity and Ambivalence: Toward Understanding the Enhancement Debate," which appeared in the *Hastings Center Report*. "As one side emphasizes our obligation to remember that life is a gift and that we need to learn to let things be, the other emphasizes our obligation to transform that gift and to exhibit our creativity," he observes. But, he argues, "most of us can be comfortable in both frameworks, even if most of us are considerably more comfortable in one framework than the other."

The work of The Hastings Center has anticipated the current debate over enhancement. More than twenty years ago, the Center brought leaders in science, medicine, law, and policy together with ethicists to discuss the moral, legal, and social issues posed by nontherapeutic drug use. The participants' papers were published in the 1984 volume *Feeling Good and Doing Better: Ethics and Nontherapeutic Drug Use*. In 1993, when psychiatrist Peter Kramer's *Listening to Prozac* shot to the top of the *New York Times* bestseller list, researchers at The Hastings Center were already asking the question he posed: Why might one worry about a drug that made some individuals feel, in the words of one of Kramer's patients, "better than well"? That year, The Hastings Center also kicked off a series of four research meetings to ask the basic question, "Will there ever be good reasons to worry about new biotechnologies aimed at the enhancement of human capacities?" The papers were published in 1998 as the book *Enhancing Human Traits: Ethical and Social Implications*.

More recently, The Hastings Center has concluded a two-year project, "Ethical, Conceptual, and Scientific Issues in the Use of Performance-Enhancing Technologies in Sports," funded by the U.S. Anti-Doping Agency (USADA). Three major research meetings examining the rationales for classifying certain enhancement technologies as either ethical or unethical will culminate in a book comprising the major papers commissioned for this project. A subsequent project over 2006 and 2007, also funded by USADA, will look specifically at "gene doping"—techniques for inserting genes into an athlete in order to enhance the athlete's abilities.

THE CONCEPT

What Is Enhancement and Why Is It So Difficult To Define?

The term “enhancement” is often used to mark off moral boundaries in medicine, distinguishing some optional or even frivolous improvement from that which is considered “medically necessary.” For example, a physician may be obligated to prescribe a beta-blocker to a patient with heart disease (as recommended by the guidelines of established medical groups), but not to an actor who seeks the drug’s heart-slowing effect to calm his stage fright. Today, health insurers also recognize this distinction and will pay for only what is considered medically necessary.

But it’s not always that simple. “Calling something an enhancement tells us little about what our moral attitude toward the intervention should be,” cautions Hastings Center president Thomas Murray. For example, vaccines can be seen as a form of enhancement because they do not cure a disease; they stimulate a healthy person’s immune system to

mount a response against an infectious agent. Yet, he points out, most people do not consider vaccination morally frivolous.

Normalization versus Enhancement

The proper use of synthetic human growth hormone, which has been called (misleadingly) “Miracle-Gro for children,” raises puzzling questions about what we consider normal and when it is proper to treat people who fall short of society’s standard. The hormone has been approved by the Food and Drug Administration (FDA) for children unable to make their own growth hormone. But it’s also been approved for children with normal hormone production who fall in the lowest 1.2 percent on the standard pediatric growth chart. “What started out as medicine has in effect become a lifestyle drug,” observed Stephen S. Hall—a noted science writer and contributor to the *Hastings Center Report*—in a recent article in the *New York Times Magazine*.

Why should naturally short children be given a drug? The argument for it is that short kids will be stigmatized and might suffer in their careers and relationships. But several recent studies have found that being short has minimal impact on a child’s social standing among his schoolmates. Other studies show that taller adults do have an advantage in life—they earn more money than short people.

The common notion that the world can be divided starkly into those who are normal and those who are sick is overly simplistic, certain bioethicists argue. Some diseases are simply the extreme end of a continuum starting with the normal. For example, Alzheimer’s disease is the extreme end of a natural aging process that often starts with middle-aged lapses in short-term memory, argues Hastings fellow Eric Juengst, director of the Center for Genetic Research Ethics and Law at Case Western Reserve University.

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Recently, some medical experts in the field of aging have argued that milder stages of memory loss and slowed intellectual processing deserve their own label—“mild cognitive impairment.” These experts think the condition, which is common to many people in old age, should be treated with drugs to prevent a more serious impairment like Alzheimer’s. If this “mild” condition becomes widely recognized in medicine as a genuine disorder—especially if it is eventually paid for by insurance—most people will see it as falling on the “disease” side of the dividing line. What was once viewed as a natural aspect of aging will have become an illness, and that raises new problems, Juengst suggests. This new label may stigmatize ordinary aspects of living and may legitimize medical attention for behavior once viewed as normal.

This argument is not new. In 1971, when the “test tube baby” was not yet a reality, many in medicine mocked researchers who described it as a humane medical treatment for desperate infertile couples. How could it be a “treatment” when it cured nothing? While a child might be brought forth, the “test tube” mother remained as infertile as before. The researcher under attack at the time, Robert Edwards, answered that medicine often involves corrective steps—such as eyeglasses, false teeth, and insulin—that fall short of being cures. Today, when more than a million babies have been born this way, it’s hard to understand the fears and passion that the phrase “test tube baby” once inspired.

Moral Boundaries and Moral Red Flags

Even if the issue of enhancement as a whole does not draw a clear moral line, ethicists like Juengst say, the use of some technologies should at least raise red flags before we embrace them. As a general moral guideline, he suggests, any time “we’re using biotechnology simply to reinforce oppressive practices from other parts of life,” we should be cautious. For example, if we “use enhancements in ways that reinforce or exacerbate racial tensions, so that we all go in for extra skin lightening or darkening in order to visibly draw these social lines around ourselves,” there would clearly be an ethical problem, he observes.

Ronald Bailey suggests a ban on steroids in sports may be fruitless: “Sports are arbitrary, rules are made up; there’s nothing pure about them.”

Or take ambitious stage mothers who try to channel their children into competitive performance careers regardless of the child’s wishes. Similar concerns may be raised about parents who decide to inject their normal but short children with human growth hormone because “their ambitions are to produce athletes taller than normal or because of their perception that it will help them succeed in life,” he says.

But it’s not always possible to see the red flags because many new enhancements, such as repairing middle-aged memory loss, are presented as prevention of more serious medical conditions like Alzheimer’s. The prevention message is often supported in advertising and in public relations campaigns by pharmaceutical companies that stand to make money from the use of a patented drug for this purpose.

“My worry [about prevention marketing],” says Juengst, “is that it’s a way of sidestepping the obvious moral red flags. . . . We have to decide whether they’re the sorts of interventions we want to make in ourselves and whether they will sustain our commitment to treating all people as equals”—particularly, he adds, if such enhancements can only be afforded by the wealthy.

In order to legally market prescription drugs in the United States, their safety and effectiveness must be approved for specific medical conditions by the FDA. However, once a drug is approved, physicians have wide latitude to prescribe it “off-label” for other conditions they consider appropriate.

Eric Juengst has urged medical societies to set guidelines that distinguish between drugs used for treatment and those used for enhancement. But the profession has been “reluctant to do that for the same reason off-label prescribing is perfectly legal,” he says—“the autonomy we’ve given individual physicians to use their own clinical judgment.” Except for the realm of athletics, the doctor’s independent judgment rules when it comes to the availability of most enhancements.



CURRENT PRACTICES AND PROHIBITIONS

Beta-Blockers

Beta-blockers (such as the drug propranolol, trade-named Inderal) are normally prescribed to treat high blood pressure or prevent recurring heart attacks, but a doctor can legally prescribe them off-label for a concert musician who wants to cure a case of stage fright. Beta-blockers work by blocking certain nervous system receptors that get activated in the “fight or flight response,” which often produces a racing heart and sweating palms. In one early study from the mid-1970s, British researchers found that string players trembled less and played better when they were given beta-blockers. Other studies have shown similar results for public speaking.

Anecdotal evidence suggests use of beta-blockers among musicians is common. However, beta-blockers are considered more suspect in athletics. They are prohibited during Olympic competition for sports such as archery because, by lengthening the heartbeat, they unfairly steady a competitor’s hand.

Anabolic Steroids

Anabolic steroids are synthetic versions of the male hormone testosterone, often taken to increase muscle mass. More recently, athletes have taken to using so-called “designer steroids.” These drugs are anabolic steroid precursors that turn into testosterone and estrogen in the body. They are preferable to many athletes because they are so difficult to detect through standard drug tests, and their use has only lately become illegal. In 2004, President George W. Bush signed into law the Anabolic Steroid Control Act, which updated the list of illegal substances to include anabolic steroid precursors. Prior to this law, they were marketed over the counter as dietary supplements, but now, like other steroids, they cannot be sold in the United States without a prescription.

Thomas Murray disagrees. “If the Olympics were to declare all drugs fair game, sport would be dominated by the athlete with the largest medicine cabinet.”

Professional sports leagues in the United States vary in how strictly they test and penalize for the use of substances like steroids. Spurred by reports of illegal drug use among baseball stars and by concern that testing has been too lax, members of Congress have introduced several bills to impose federal standards for testing and stricter penalties. Reacting to Congressional pressure, Major League Baseball announced in 2005 that it would toughen the penalties for steroid use and test for amphetamines, which have been described by sports analysts as a “pick me up” for players, for the first time. After baseball players in the major leagues were tested in 2003, the *New York Times* reported that 5-7 percent showed positive results for steroid use.

Efforts to control steroid use in athletes are not confined to the United States. Continuing controversies about the use of steroids in sports in the 1990s led the International Olympic Committee to adopt the World Anti-Doping Code in 1999. This created the World Anti-Doping Agency (WADA) to combat the use of performance-enhancing drugs in international sports. The Olympic list of prohibited substances is enforced through the testing of blood and urine samples in athletes, although authorities have had trouble developing effective tests for steroid precursors.

According to the FDA, steroids are quite dangerous: they can stunt growth, lead to cancer, ruin the liver, and create enlarged breasts in boys and masculine traits in girls. They can also cause cholesterol blood levels to rise, increasing the risk of heart disease and stroke later in life. Despite these risks and the measures taken to outlaw their use, many steroids are sold on the black market and can be easily obtained on the Internet.

Erythropoietin

This genetically engineered protein, which stimulates production of red blood cells to boost stamina, is approved for use as a prescription drug for anemia in the United States. However, it is banned under the World Anti-Doping Code for use in the Olympics. Injected erythropoietin (EPO) can lead to kidney damage, jaundice, and blood clots. Several recent heart attacks among elite cyclists have raised concerns that EPO may have played a role in their deaths.

Antidoping authorities have long struggled to develop an accurate test for detecting EPO in the blood. The first EPO test was used at the Sydney Olympic Games in 2000. As a result of this testing, EPO was found in the blood of some cross-country skiers at the 2002 Salt Lake Olympics, which led to their being banned from the games. EPO was also one of the drugs cited when U.S. sprint champion Kelli White was banned from international competition in May 2004—a ban that cost her a bid for a medal in the Athens Olympics that year.

Human Growth Hormone

The first genetically engineered version of human growth hormone became available twenty years ago. Since then, sales of the drug have led to a \$2 billion world market. The drug is approved to treat children with hormone deficiency and several other disorders that lead to short stature. It was also approved—controversially—in July 2003 for children who fall into the bottom 1.2 percent on the standard growth chart, but don’t suffer from any disorder or hormone deficiency. In 2004, the first full year after the FDA approved expanded use,

Is There Wisdom in Repugnance?

In 1997, bioethicist Leon Kass justified his opposition to human cloning primarily on the grounds that he found it “repulsive.” His article in *The New Republic* was entitled “The Wisdom of Repugnance.”

“In crucial cases,” he wrote, “repugnance is the emotional expression of deep wisdom, beyond reason’s power to fully express it.” Our revulsion is what tells us that practices like incest, rape, and murder are ethically suspect.

The way emotional reactions contribute to moral judgements points to some of the difficult theoretical issues underlying the enhancement debate.

As Kass wrote in his article, “we have become accustomed” to practices like in vitro fertilization (IVF) and surrogate pregnancy that just a few years before had been viewed by the public (including Kass) with distaste.

“It seems hard to believe today when the procedure is so routine . . . that in vitro fertilization was thought by some to threaten the very fabric of civilization”—including marriage, fidelity, the essence of family, and what it means to be human, writes Robin Henig in her history of IVF, *Pandora’s Baby*.

That change in societal views shows “how adaptable we are,” says Hastings fellow Eric Juengst. Today, he notes, “We’re able to fit in vitro fertilization into a context of family values and our understanding of family life.”

Sometimes, our initial aversion is overcome by an appeal to common values. For example, transgender surgery originally struck Hastings scholar Erik Parens as “a very bad idea” because of his view that “we should let bodies be, not mutilate them,” he wrote in the *Hastings Center Report* in May-June 2005. But Parens changed his mind after reading the memoir of a woman who had surgery to become a man because she said it made genuine relationships possible for the first time.

Or, maybe, repugnance sometimes informs our common values. “‘Repugnance’ is a two-sided coin,” urges Daniel Callahan, founder of The Hastings Center and now director of its international program. “Repugnance sometimes turns out to be wrong, but sometimes it is right.” Callahan cites repugnance about slavery and the treatment of women as examples of this process. “Repugnance is an important flag of something worth attending to.”

drug company sales of the hormone rose by double-digit rates. Expressing discomfort with the new label, one medical journal noted in an editorial, “This may be the only circumstance in which treatment of one group of children creates illness in another previously healthy group.”

Unlike most other drugs, which doctors may legally prescribe off-label, federal law makes distributing human growth hormone for any condition that has not been specifically approved by the FDA a crime punishable by up to five years in prison. However, the law has rarely been enforced. In fact, the *Journal of the American Medical Association* reports that an estimated one-third of prescriptions for human growth hormone in the United States are for uses not approved by the FDA—mainly athletic enhancement and to battle the effects of age (something human growth hormone is not proven to do).

Stimulants for Children and Young Adults

The use of drugs to treat attention-deficit hyperactivity disorder (ADHD) has skyrocketed in recent years. Between 1990 and 2000, yearly U.S. production of the stimulant drug Ritalin—considered the drug of choice to treat ADHD—increased 730 percent. This has raised concerns about whether children are being overdiagnosed. An estimated three to

four million children are treated for the disorder, the President's Council on Bioethics reported in 2003.

According to Lawrence Diller, too many children are being referred for treatment merely because they have a "Tom Sawyer or Pippi Longstocking" personality. Diller is a behavioral developmental pediatrician in Walnut Creek, California, who has written for the *Hastings Center Report* on pediatric use of "psychopharmaceuticals" and participated in the Center's groundbreaking project on enhancement in the 1990s. He suspects teachers often refer children because they are rambunctious in the classroom, and that parents bring their children in because of anxiety about how they are performing on tests. "I treat many children who I don't feel have serious impairment at all," he is quoted as saying in *Beyond Therapy*, the 2003 report of the President's Council on Bioethics.

However, other experts estimate that many more children suffer from ADHD than have so far been diagnosed. In 1998, an American Medical Association task force pointed out that the range of behavior considered to qualify as ADHD had broadened. It found no evidence of overdiagnosis and attributed the surging prescriptions to doctors' increased knowledge about the disorder and decreasing concerns about Ritalin's risks.

The same task force also stated that adults were taking stimulants designed to treat ADHD to help their concentration. Ritalin is reportedly widely used on college campuses, especially at exam time. A recent study found that 14 percent of students at a Midwestern liberal arts college said they had borrowed or bought prescription stimulants, and 44 percent knew someone who had used them.

Because of their addictive effects in adults, stimulants like Ritalin are classified as schedule II controlled substances, and their production is strictly regulated. But as the President's Council on Bioethics noted, "Closer to the ground of action, their prescription and actual use by pediatricians and other physicians are unregulated, and there is no scrutiny of off-label uses."

Antidepressants

Similar concerns have been expressed by some critics about the rise in the use of antidepressants, not just for clinical depression, but for other psychiatric disorders first defined in the 1980s and 1990s including social phobia, panic disorder, and obsessive-compulsive disorder.

With the advent of a new class of antidepressants known as selective serotonin reuptake inhibitors (SSRIs), which have fewer side effects than the antidepressants of the 1960s, the notion of clinical depression "has expanded tremendously to include many people who might once have been called melancholic, anxious or alienated," charges Carl Elliott, another participant in the Center's enhancement project who teaches bioethics at the University of Minnesota.

In his book *Better than Well*, Elliott writes that 70 percent of SSRI prescriptions are written by primary-care physicians for a wide range of disorders once considered rare or nonexistent. For example, social phobia is now considered the third most common mental disorder in the United States after depression and drug

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abuse. Fifteen years ago, social phobia was seldom mentioned in the psychiatric literature. It was first included in the American Psychiatric Association's manual of mental disorders only in 1987, and it wasn't until the late 1990s, when GlaxoSmithKline won FDA approval for its drug Paxil to treat social phobia, that the diagnosis became widely known. Perhaps not coincidentally, this followed GlaxoSmithKline's \$91.8 million campaign advertising Paxil directly to consumers. Elliott finds this trend worrying. "We are medicalizing a personality trait called shyness," he writes, "which has been with us for quite a while but has not previously been called a mental disorder."

In the wake of the disclosure in 2004 that several drug companies suppressed results of clinical trials showing an increased risk of suicidal thoughts among adolescents who took antidepressants, doctors are apparently writing fewer prescriptions for them. However, according to a recent *New York Times* article by Amy Harmon, it is now standard for "a sizeable group of people in their 20s and 30s" to decide on their own what drugs to take—including stimulants, antidepressants, and anti-anxiety drugs. The generation that grew up on Ritalin obtains drugs illegally by buying them over the Internet, trading prescription drugs among themselves, or persuading doctors that they have the necessary symptoms to qualify for the drugs they seek.

Cosmetic Surgery

Cosmetic surgery is now more popular than at any time in American history, following big increases in its use in the 1990s. Breast augmentations grew more than fourfold during the 1990s, and liposuction, one of the riskiest procedures, grew tenfold. In 2004 alone, U.S. doctors performed a total of almost nine million cosmetic procedures.

"Survival of the fittest has been replaced by survival of the fakest," *New York Times* columnist Maureen Dowd recently quipped in her book, *Are Men Necessary?* By doing so, she joins the chorus of social critics who wonder why so many American women feel compelled to shape their bodies to a transient Hollywood fashion. Philosopher Margaret Olivia Little has written that to employ such procedures is to be "complicit with suspect norms" that fuel a vicious cycle: the more frequently breast enlargements are performed, the more entrenched society's preference for them becomes.

Cosmetic surgery is also growing in popularity among teenage girls. In 2004, more than four thousand teenagers aged eighteen or under had breast implants—even though the FDA has approved the procedure only for women eighteen or older—and about six thousand teenagers had liposuction.

The field is largely unregulated despite some highly publicized deaths. Any licensed physician can perform plastic surgery, and in some states even dentists are allowed to do it. Compared to prescription drugs, cosmetic surgery avoids the kind of ethical and regulatory oversight routine in most areas of medicine because a new surgical procedure doesn't have to undergo extensive research or get approval from an agency like the FDA.

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EMERGING TECHNOLOGIES

Life-Prolonging Technologies

Experimental research over the last two decades has suggested that sharp decreases in caloric intake and a variety of genetic interventions in animals can produce dramatic increases in longevity. These interventions can also affect most other aspects of aging, including memory loss, muscle loss, declining activity, and slowed immune-system response. “It seems increasingly likely,” concluded the President’s Council on Bioethics in *Beyond Therapy*, “that something like age-retardation is in fact possible.” University researchers and pharmaceutical companies are banking on it—they are pursuing the development of several drugs and therapies to prolong life. So far, most of these therapies have not been tested in humans.

On an even more futuristic level, some scientists predict that nanotechnology—the science of building minuscule machines from single atoms and molecules—will come to the forefront of medicine. In his recent book, *Liberation Biology*, Ronald Bailey, science correspondent for *Reason* magazine, writes of a future in which tiny nanorobots and nanomachines injected into the body will detect harmful disease organisms, fix damaged cells, remove plaque from arteries before it causes heart attacks, and replace infection-fighting white blood cells or oxygen-carrying red blood cells before they deteriorate.

Memory Enhancement

A number of biotech companies are trying to develop a pill that would treat age-related memory loss, aiming for the market of seventy million baby boomers who will soon begin to suffer from it. Such a pill also holds out the possibility of enhancing normal memory. In December 2004, Helicon Therapeutics began clinical trials with a memory-enhancing compound. “If it proves safe and effective, it could ultimately be used by people who want to learn a language or a musical instrument or even in schools,” Bailey quotes Tim Tully, a professor of genetics at Cold Spring Harbor Laboratory in New York, as saying in *Liberation Biology*.

Genetic Manipulation and Gene Doping to Enhance Muscle

Genetic modification in humans has so far been limited primarily to efforts to correct or treat genetic diseases by introducing healthy versions of the disease-causing gene into target cells of the body. This technique is known as “gene transfer.” Since the first human gene transfer experiment in 1990, over four thousand subject volunteers have enrolled in clinical trials involving the technique.

Gene transfer has so far proved to be quite risky. Nevertheless, in the near future, athletes may be able to enhance their abilities through gene doping, according to the World Anti-Doping Agency. In 1998, University of Pennsylvania researcher Lee Sweeney announced

dramatic results in enhancing the skeletal muscle of mice by injecting the gene for insulin-like growth factor (IGF-1). Although the research is directed at treating muscle-wasting diseases like muscular dystrophy and repairing the loss of skeletal muscle in old age, athletes have been quick to see its possible advantages for bulking up and have been contacting gene researchers.

“Is it accessible to rogue scientists who want to make it available to athletes? We have no reports on abuse of those technologies, but it’s not impossible,” says Olivier Rabin, science director of the WADA, which in 2003 banned gene doping in the Olympics. According to the agency, gene therapy, once available, will be relatively simple to use, requiring only a standard laboratory.

“Designer Babies”

Yet more controversial, politically and ethically, is an emerging technique for changing the genetic makeup of human eggs, sperm, or embryos—a practice made possible through the now commonplace technology of in vitro fertilization. Experts disagree as to how soon this technique will become feasible, and federal agencies in the United States have discouraged scientists from exploring it further in humans.

The technique, known as “human germline genetic modification,” has been the subject of vigorous debate because of its potential to make permanent, heritable changes in humans. It involves manipulation of stem cells, eggs, sperm, or embryos in the laboratory, before they are introduced into a woman’s uterus. Scientists believe that one of its earliest feasible uses would be to prevent genetic diseases such as cystic fibrosis by eradicating the single-gene mutation that causes them.

No federal or state laws have been passed that explicitly address germline modification. However, a 1996 Congressional ban on funding any research in which an embryo is created or destroyed could limit some germline research involving human embryos to the private sector. In addition, several states have laws prohibiting research with human embryos, which could also limit human germline research.

Experts differ as to how close we are to being able to modify embryos in any way a parent might wish. The President’s Council on Bioethics has called germline modification purely speculative “for now and for the foreseeable future.” But Princeton molecular biologist Lee M. Silver, in his paper “Evolution and the Future of Humankind,” holds that eventually, due to recent scientific breakthroughs and increasing experience with the technology in animals, “Any gene imaginable and any number of genes could be modified in, or added to, an embryo.” In the future, he has written, the questions will not be ones of feasibility but of ethics: “Who decides which child will get the HIV resistance gene, which child will have the potential for a long life span and which one will have superior protection against cancer and heart disease?”

Arguing that it’s difficult to decide the morality of a technique according to whether it treats an illness, Thomas Murray suggests that it depends on the context. “Does the enhancement undermine what’s most admirable about the social practice, or does it support the practice?”



ETHICAL ARGUMENTS FOR AND AGAINST ENHANCEMENT

Should Healthy Individuals Be Free to Enhance Their Bodies?

Should there be limits—moral or governmental—on how far humans can go? “In therapy we have a limit set by the concept of health. With enhancement there is no limit set other than our desires. If you say there are no limits, then where do we get the moral guidance for how to make these decisions? Then it just depends on our desires, and our desires are endless,” says Gilbert Meilaender, a professor of Christian ethics at Valparaiso University and a Hastings Center fellow who serves on the President’s Council on Bioethics. He’s alarmed, for example, at the prospect of a drug that could make a man so cheerful he wouldn’t mourn his wife’s death. “It’s at least conceivable that in eliminating certain pain and suffering from human life we eliminate some good things as well.”

But the prospect of the government setting limits on how we enhance ourselves or our children alarms libertarians and technology enthusiasts. “Every time the government gets involved in these kinds of decisions, it screws it up,” Ronald Bailey writes. As an example, he cites past efforts to limit reproductive health, including state laws that once banned intermarriage between blacks and whites and outlawed the use of contraception.

People in both camps generally agree that government should have a role in limiting substances that are dangerous to one’s health. Indeed, Ronald Green, chair of the Bioethics Department at Dartmouth College, says that’s the main reason we ban enhancements—not because they’re morally wrong. “Nearly every American drinks several cups of mood-enhancing beverages every day: coffee, Coke, tea. Nobody thinks twice about it,” he says. “People routinely use plastic surgery to tuck a waddle here and there. The claim that medicine is involved only with therapy and not enhancement is contradicted by the routine use of cosmetic surgery and sports medicine. Enhancement is part of what it means to be a human being.”

Of course, some find even current laws banning unsafe substances overly paternalistic. Thomas Jakob probably speaks for many bodybuilders when he asks why there should be more legal restrictions on steroids than on alcohol and tobacco—substances that also carry long-term health risks. “If I want to use myself as a guinea pig, it’s my own body,” he says.

Bailey argues that this kind of attitude among athletes suggests a ban on steroids in sports may be fruitless: “Sports are arbitrary, rules are made up; there’s nothing pure about them.” But Thomas Murray disagrees. If the Olympics were to declare all drugs fair game, he points out, “sport would be dominated by the athlete with

In the future, writes biologist Lee Silver, “Who decides which child will get the HIV resistance gene, which child will have the potential for a long life span and which one will have superior protection against cancer and heart disease?”

the largest medicine cabinet.” Moreover, he says, “It undermines everything we value; it punishes the honest and rewards the cheaters.”

The debate over how sports should set rules illustrates a larger argument in the enhancement debate: Is it possible to draw a clear line between using a technique to treat a medical condition and using it to enhance oneself for personal advantage?

Princeton biologist Silver, an asthmatic, uses a steroid spray when his lungs tighten up in an attack. But the steroid improves the lung capacity of anyone who uses it. Initially, Olympic rowers were permitted to use it only if they were diagnosed with asthma; suddenly half the competitors claimed to be asthmatic. The problem Olympic officials faced, Silver says, is that there’s no clear line between asthmatic and nonasthmatic people. “That’s true for almost any condition. It eventually blurs into normalcy.”

Yet even if there’s a continuum, responds ethicist Eric Juengst, “Someone has to say this is where we’ll draw the line. That’s not simply a scientific decision. That’s something we have to make moral judgments about.” Today, health insurers are the ones who usually draw the line between medical necessity—which they’ll pay for—and enhancements, which they won’t. But, observes Juengst, insurers are looking at the interests of other policyholders and the bottom line. “Unless you really believe in the market, that doesn’t seem like the best way to make social policy.”

With each enhancement that gets introduced, whether drugs today or better genes tomorrow, individuals will feel increasing pressure to avail themselves of the technology in order to meet infinitely rising standards of performance, Erik Parens warns. What’s wrong with the office worker who says that he’s able to clean off his desk faster when he takes Prozac? Answers Parens, “The more we take these drugs to clean off our desk, the more work will be on our desks; because our boss will see how quickly we can do it. . . . We make a culture on steroids all the more hyper.”

Parens would like to see a broad, national conversation about the use of enhancement technologies. What should be the guiding ideas in that conversation? Arguing that it’s difficult to decide the morality of a technique according to whether it treats an illness, Murray suggests that it depends on the context. “Does the enhancement undermine what’s most admirable about the social practice, or does it support the practice?”

In the case of competitive sports, he says, “We’re trying to find out who has the finest combination of natural talents, dedication, and the virtuous perfection of those talents. The point of sport is to show those physical and moral gifts and reward them; the drug that affects those destroys that relation between the virtuous and physical.”

He suggests we consider the Olympic ban on beta-blockers and compare it with a different context. If a drug were developed that could steady the hand of a neurosurgeon operating on a loved one, would you feel morally obligated to pick a surgeon who didn’t use the drug? No, he answers, because “the point of neurosurgery is to heal,” rather than to showcase the performance of the surgeon.

But the prospect of the government setting limits on how we enhance ourselves or our children alarms libertarians and technology enthusiasts. “Every time the government gets involved in these kinds of decisions, it screws it up,” Ronald Bailey writes.

Is It Appropriate for Parents to Enhance Their Children Biologically?

Is giving children biological privileges—either through drugs or gene selection—any different from the other ways in which we help them? “What is the difference between Ritalin and the Kaplan SAT review?” asks Dartmouth neuroscientist Michael Gazzaniga, another member of the President’s Council on Bioethics, in its report, *Beyond Therapy*. “If both can boost SAT scores by, say, 120 points, I think it’s immaterial which way it’s done.”

Hastings scholar Parens says there is an important difference that can be found by examining the values attached to the method of choice. For example, some critics have suggested that increased classroom size has contributed to many children’s inability to pay attention in class. Giving a child Ritalin can emphasize the value of “efficiency” in that parents can expect a quick improvement in a child’s concentration, Parens says. But improving the teacher-student ratio “can emphasize the value of engagement” in that the teacher can spend more time with the child. “We need to realize that different means do emphasize different values.”

Pediatrician Diller is concerned that for some children, Ritalin is a shortcut to achievement that deprives them of important life lessons. Morally, “It’s not the same to take an amphetamine to improve your school performance versus studying harder and learning the discipline of studying.”

Ultimately, Parens maintains that an absolutist stand either for or against a body modification is not helpful. What’s most important is that we permit a child to flourish, and how we do that will depend on the child. There will be no one-size-fits-all recommendation. “If we are truly committed to allowing children to flourish, then we need to realize that some children are too distracted and impulsive to be able to function in any currently known form of schooling,” he recently wrote in a *Boston Globe* op-ed. For those children, Ritalin might be appropriate.

On the other hand, Parens urges that when making those decisions, a parent should also consider the arguments against drugs. “We might be quick to remind ourselves and our children’s teachers that distractedness and rambunctiousness are normal parts of growing up. After all, we want to let our children unfold and flourish in their own way. We don’t want a drug to make them conform to just one dominant way.”

One thing that distinguishes the debate about children, experts on both sides agree, is that children do not have the ability to grant consent or to weigh the risks and benefits of biological changes to their bodies. “With children, the stakes are higher,” writes David DeGrazia, a professor of philosophy at George Washington University who defends the right of individuals to choose enhancement in his recent book *Human Identity and Bioethics*. “I don’t have a moral obligation to promote my own best interest, but I do for my daughter; there’s less room for responsible risk-taking.”

Nonetheless, some argue that parents should have as much leeway with genetic enhancement as they do in childrearing. This debate came into sharp relief in the case of a deaf lesbian couple who sought out a deaf sperm donor to help them produce a baby through in vitro fertilization. The government should have the authority to stop a parent from engi-

“What is the difference between Ritalin and the Kaplan SAT review?” asks Dartmouth neuroscientist Michael Gazzaniga.

neering a deaf child because “that’s child abuse,” Lee Silver says. But he insists there is a line between handicapping and enhancing a child, and that true enhancement should not be off-limits to parents.

Disability advocates, however, have argued that it’s a slap in the face against the disabled to willfully remove a genetic disability. (Some deaf people don’t even consider deafness a disability.) Their worries came to the fore following the announcement in 2005 of a new prenatal test for Down syndrome that provides earlier, more reliable results for pregnant women of all ages. “The more people who think the condition is grounds for termination of a pregnancy, the more likely it will be that you’ll wind up with a society that doesn’t welcome those people once they’re here,” one father of a boy with Down syndrome told writer Amy Harmon in the *New York Times*. “It turns into a vicious cycle.”

Total design of a perfect baby, agrees Gilbert Meilaender, is “an extraordinary exercise of human power over the next generations that undermines our commitment to human equality.” When it comes to enhancing a child’s natural traits before birth, he is leery of giving parents broad latitude. “A parent should be able to say to a child, ‘It’s good that you exist.’ The more one requires a child to produce according to certain specifications, the harder it gets to understand that unconditional commitment.”

Take the father running down the soccer field yelling at his kid to make a goal. What makes us think this controlling parent will be any wiser when he can endow his child’s embryo with athletic prowess? “We’ve shoved those decisions off into private choices,” Meilaender observes. “But they are eugenic choices and may have unforeseen undesirable consequences down the road.” For example, if parents are able to choose the sex at the embryonic stage (as one method, involving in vitro fertilization, now permits with 85 percent certainty), the result could be a lopsided sex ratio in the population, much as China is currently experiencing.

Arguably, the problem with genetic enhancement may not be that it’s bad, but that it’s too good. Let’s say parents were able to genetically program their child to have a Ritalin-type concentration advantage—but at great expense. “There is reason to worry that parents who already purchase social advantages will be able in effect to purchase genetic capacities to use those advantages—thereby potentially increasing the gap between the haves and have-nots,” wrote Parens and his former Hastings Center colleague Lori P. Knowles in a Hastings Center special report on “reprogenetics”—the new techniques at the intersection of reproductive and genetic technologies. The fact that middle-class children already have superior access to drugs like Ritalin “is hardly an argument for permitting [genetic] means to achieve more of the same.”

Parens and Knowles recently noted that U.S. oversight of these kinds of issues is a regulatory patchwork riddled with gaps. They suggest that the “time may be right” for the nation to create a regulatory body like the United Kingdom’s, which licenses clinics involved in testing of embryos for in vitro fertilization. This new agency could have the power to permit, for example, testing of embryos for disease-related traits, but not for traits like height that are unrelated to disease.

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In seeking an overall ethical guideline, Murray suggests, “We need to ask what’s at the heart of the parent-child relation. What role does the enhancement play in human flourishing?” Almost everyone condemns parents who control children to the extent that they limit their future. “The more powerful enhancement technologies become, the more parents will try to do that,” Murray predicts.

In Vitro Fertilization—Will it Lead to a Market in “Designer Babies”?

Before the first test tube baby, Louise Brown, was born on July 25, 1978, ethicists and members of the public alike feared that in vitro fertilization would lead to treating babies like commodities.

Today, when over a million children have been born through this method, some would say those worries seem outdated. But others are not so sure. In an article in *The Atlantic*, Harvard political philosopher Michael J. Sandel cites the following examples as evidence that such a market already exists.

- Several Ivy League newspapers ran an ad years ago offering \$50,000 for an egg from a woman who was athletic, had no family medical problems, and had a combined SAT score of 1400 or above.

- A Web site claims to auction eggs from fashion models starting at \$15,000 to \$150,000.

- The California Cryobank, one of the world’s leading sperm banks, advertises for donors in campus newspapers at top colleges. For an extra fee, prospective customers can buy the results of a test that assesses the donor’s temperament and character type.

- Cryobank’s ideal sperm donor is six feet tall and has blond hair, dimples, and a college degree—the traits it says its customers want.

More sophisticated methods for testing embryos before implantation could exacerbate this trend, including:

- the ability to sort sperm by weight so as to select the sex of a child born through in vitro fer-

tilization (approximately 430 children have been born using this technique);

- the ability to test embryos to insure their cord blood is compatible with another child who may need frequent blood donations;

- the ability to inject healthy cytoplasm from the egg of a healthy woman into the egg of an infertile woman to permit her to have children; and

- the potential future use of cloning techniques to create healthy or “enhanced” embryos.

The worry is that “in a consumer culture such as ours, using technology to produce better children will drive us toward making the fundamental mistake of treating children—and the rest of us—as commodities rather than as persons,” Hastings scholar Erik Parens has written.

Many Americans share this sense of discomfort. In a recent national survey conducted by the Genetics and Public Policy Center, three-quarters agreed with the statement, “Technology will inevitably lead to genetic enhancement and designer babies.” Those surveyed made comments like, “We’re just inherently greedy people and it’s never going to be enough,” or predicted a slippery slope starting with preventing mental and physical deformities in embryos: “What’s next? We don’t like kids with blond hair?”

A majority of those surveyed supported prenatal testing and preimplantation genetic diagnosis of embryos for health reasons—including fatal childhood diseases, tissue matching, and adult onset diseases. Only a minority supported its use for traits like intelligence, strength, or hair and eye color.

Will Enhancement Technologies Lead to Social Problems?

In a future where only the privileged could afford genetically based enhancements, some see scary scenarios: a new master race emerging that does not mingle with the unenhanced human race, considers them inferior beings, and perhaps even treats them like slaves or seeks to kill them off. Such scenarios are dismissed as science fiction by others. But many see inequity as a real possibility and a tough moral problem. “What should we do about the fact [that] some people will have more access to these technologies than others?” asks Erik Parens. “Will this exacerbate the gap between the haves and the have-nots?”

One solution is to make it affordable for *everyone* to genetically enhance their children for an important trait—intelligence, for example. Would that be self-defeating, if everyone’s relative position in society remains the same? Not really, writes Ronald Bailey, because “the overall productivity and wealth of a society would increase considerably, making everyone better off.”

One of the major questions in the enhancement debate is contained in the statement: “What does being truly ‘better off’ mean?” Parens answers, “More productivity isn’t sufficient for a good life.” Indeed, he suggests that in subtle ways, our use of enhancements to become more productive—to work faster or do better on tests—is contributing to the stress many of us already feel in a hectic world.

Does the tendency to medicate also set a new norm for an outgoing, happy, workaholic personality that not everybody comes by naturally? In an essay written for the *Hastings Center Report’s* 1998 special report, *Enhancing Human Traits*, Carl Elliott asked if it’s appropriate to give Prozac to a man who suddenly asks existential questions about the meaning of his bland suburban existence. “There’s this American cultural ideal of cheerful optimism. To be unhappy is to commit a sin,” he observes.

Enhancement optimists ask why people can’t avoid personal suffering, even if society is to blame for it. “Why should people be denied relief just because some bioethicist says values must change?” asks Bailey.

Parens answers, “We can inadvertently produce more suffering—if by availing ourselves of drugs that help us live up to dominant norms, we increase the pressure on others to do the same and keep narrowing the range of what’s viewed as a normal-enough person in the world.” Imagine, he suggests, a genetic decision to give a child the white skin that ensures a measure of privilege according to current norms. “While we can understand why parents might want to protect their children, we might worry that using genetics to deal with discrimination leaves the unjust norms in place.”

Parents may feel they are conferring some benefit when they decide to give human growth hormone to their naturally short children. But, Murray points out, “The message you’ve given to this 12-year-old is ‘Being short is so bad that we’re going to inject you one thousand times,’” says Murray. “By doing that, we’ve exaggerated the social significance of height.”

Eric Juengst suggests, if we “use enhancements in ways that reinforce or exacerbate racial tensions, so that we all go in for extra skin lightening or darkening in order to visibly draw these social lines around ourselves,” there would clearly be an ethical problem.

Pie in the Sky Questions

To a large extent, the new technologies' availability and cost will be decided by the market and by health insurance companies. Maybe it's just "pie in the sky" to think, in the absence of national health insurance, that the nation as a whole will take a considered look at what enhancements it should pay for and how they'll affect the good life. Does that make today's ethical discussions irrelevant?

"The pie in the sky conversation was begun with Socrates," answers Parens. "Most religious traditions are founded on those questions." There's a tension in bioethics, he says. On the one hand, "We want to be relevant. On the other hand we want to ask the pie in the sky questions. . . . Those philosophical questions are increasingly difficult to ask in our culture because we're so impatient."

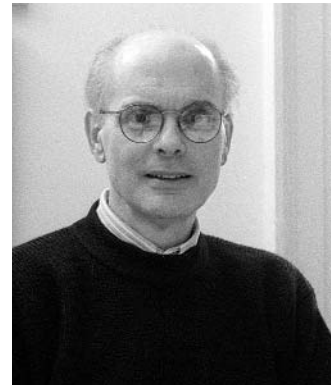
Evolving Field, Enduring Questions

Thirty years ago, The Hastings Center asked several leading thinkers for their reflections on the possibility of “designing our descendents.” That’s a typical Hastings Center question—multilayered, complex, challenging—posed in typical Hastings Center fashion to thoughtful scholars with a broad range of ethical, theological, and political views. And, typically enough, it has not gone away: new medical research and new discoveries have added new possibilities for designing descendents and new problems for any actual attempt at it.

The heart of The Hastings Center’s approach is the respectful confrontation of ideas from many, diverse, even clashing points of view. The debate over designing our descendents demonstrates the complexity of this exchange. Libertarians prize individual freedom above all and are happy, more or less, to leave to parents the decision about how much control to exert over a child’s characteristics. Ronald Bailey, whose opinions appear at several places in the preceding essay, is one of their intellectual descendents. Worries about the excesses of control are not the exclusive concern of conservatives (such as Gilbert Meilaender); liberals too can ask serious questions about the wisdom of the descendent-designing enterprise: Is it good for parents and children in the first place, and who has the wisdom to decide *which* characteristics to select? Erik Parens is one who brings this perspective to the debate.

Many of the most interesting and significant questions refuse to be sorted out along simple liberal-conservative or secular-religious dimensions. It helps to confront our preconceptions with facts. In the early 1980s, for example, The Hastings Center did the first sustained study of the ethics of performance-enhancing drugs in sport. In the course of that research, grand assertions about individual liberty to shape oneself however one chose crumbled under the weight of evidence that athletes felt coerced to use drugs to be able to keep up with their drug-using competitors. Like nations in an arms race, athletes in drug-infested sports were driving each other to take graver and graver risks: everyone was worse off.

We learned through these studies and others since then that coming to grips with biomedical enhancement is not easy. It will be a continuing and growing challenge to our wisdom, our laws, and our families. Biomedical technologies don’t respect our human distinctions between therapy and enhancement, or between the natural and the unnatural. As the powers of biomedicine multiply—and they will continue to do so with entirely novel repertoires such as nanobiology—new variations of these age-old questions will pop up. Doing them justice will require the same formula of careful attention to facts, respect for the full range of convictions, and thoughtful analysis that have been central to the Center’s work since Daniel Callahan, philosopher, and Willard Gaylin, psychiatrist, began a research institute in a spare bedroom in Hastings-on-Hudson, New York, in 1969. The questions are no less pressing, and only more complex, today.



*Hastings president
Thomas Murray*

—Thomas H. Murray

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