

• 25 •

## Human Rights in a Post-human Future

*Marcy Darnovsky*

Most people are well aware that efforts to “improve the human gene pool” and “breed better people,” notoriously widespread from the end of the nineteenth century through the middle of the twentieth century, led to some of the most extreme violations of civil, political, and human rights in recent history. Nonetheless, five or six decades ago—before the structure of DNA had been deduced, before the modern environmental movement—most of the provisions of the Genetic Bill of Rights would have seemed nonsensical.

Even twenty-five years ago—before the development of genetic manipulation at the molecular level, legal doctrines that allow governments to grant patents on life, and DNA databases; before the advent and commercialization of in vitro fertilization and the screening of in vitro embryos; before the appearance of advertisements for social sex selection in mainstream U.S. publications—the document would have been widely considered an unwarranted over-reaction based on dystopian fantasy.

But here we are, at the beginning of the twenty-first century. Plants and animals are routinely genetically modified, patented, and brought to market by corporate enterprises. Genetic technologies are increasingly applied to human beings for forensic and medical purposes. The biotechnology industry, though it has lost over \$40 billion since its inception twenty-five years ago,<sup>1</sup> continues to attract large amounts of venture capital and generate glowing headlines.

As many have observed, public understanding of these trends is lagging far behind technical developments and commercial deployment. Many people feel daunted by their technical complexity, and therefore reluctant to make political or ethical judgments about them. Grappling with the social meaning of the various human genetic technologies has proven thorny even for those whose

210 *Marcy Darnovsky*

political commitments usually make them wary of corporate-dominated technological projects.

Though the environmental movement has gained at least a toe-hold for a precautionary approach to powerful new technologies, this principle is often disregarded when technical innovations are presented as medical advances. And that is a move that the biotechnology industry and its supporters have mastered. Their claims about the future of human genetic technologies are nothing if not ambitious. Revolutions in health care are invoked. Promises of imminent medical miracles proliferate. Technical fixes for global health inequities are proposed and funded. Senior researchers are unembarrassed to suggest that aging, even death, can be overcome through biotechnological engineering.<sup>2</sup>

#### REPRODUCTIVE GENETICS AND THE POST-HUMAN AGENDA

The most troubling of the human biotechnologies are those that involve reproduction. Currently, the procedure known as pre-implantation genetic diagnosis (PGD) allows the screening and selecting of embryos on the basis of sex and other traits. Many feminists and disability rights advocates are deeply uneasy about this practice. But for some enthusiasts, such crude forms of selection are just the beginning. More than a few observers predict that in vitro embryos will one day be manipulated and modified rather than merely screened and selected. They point out that the genetic technologies now being used routinely to alter mammalian species, if applied to humans, would permit the “redesign” of the traits of future children.

Some proponents of inheritable genetic modification (IGM) predict that within a generation “enhanced” babies will be born with increased resistance to diseases, optimized height and weight, and increased intelligence. Farther off, but within the lifetimes of today’s children, they foresee the ability to adjust personality, design new bodily forms, extend life expectancy, and endow hyper-intelligence.<sup>3</sup>

Eagerness to provide parents with the technical means to redesign their future offspring is often coupled with a larger social vision. Advocates of IGM point out that manipulating the genetic makeup of future generations amounts to “seizing control of human evolution.”<sup>4</sup> They correctly observe that coupling the techniques of inheritable genetic modification with existing social and market dynamics could trigger a self-reinforcing spiral of eugenic engineering, perhaps culminating in the abandonment of our common biological identity as human beings. Some anticipate a “post-human” future, called into existence through consumer choices in a market-based eugenics, and the subsequent emergence of “genetic castes.”<sup>5</sup>

Is such a future likely? Hopefully, scenarios like these will remain beyond technical reach. Notwithstanding the flesh-and-blood accomplishments of today's genetic scientists—glow-in-the-dark rabbits, goats that lactate spider silk, and the like—modified genes and artificial chromosomes may never work reliably. Transgenic designer babies may be too ridden with unpredictability or malfunction to ever become a popular option.

But both the trajectory of human biotechnology and the growing ideological influence of high-biotech libertarian futurism counsel that we take these visions seriously. After all, their purveyors are not limited to the marginal “cowboy cloners” and others on the far shore of credibility.<sup>6</sup> Also among those who eagerly anticipate a post-human future are congeries of biomedical researchers, biotech entrepreneurs, bioethicists, and other scholars. A disturbing number of them are respected figures working at prestigious institutions and wielding significant cultural influence. Also disquieting is the near silence of their scientific colleagues. Many of them must have qualms about the use of biotechnology in the service of a new eugenics, but few have publicly registered concern.<sup>7</sup>

#### A HUMAN RIGHTS FRAMEWORK FOR REPRODUCTIVE GENETICS

It is at this historical moment that a small U.S.-based non-governmental organization has written and proffered the Genetic Bill of Rights. Like other declarations of rights, this one makes bold claims about the social conditions that characterize our world, and about those that should. The Genetic Bill of Rights asserts the profound consequentiality of new knowledge in the genetic sciences and new techniques of biological manipulation, and of the legal and commercial contexts in which they are being developed and deployed. And it asserts the urgency of establishing a broad consensus about how the new knowledge and technologies should be governed.

In a landmark article titled “Protecting the Endangered Human Species: Toward an International Treaty Prohibiting Cloning and Inheritable Alterations,” published in the *American Journal of Law and Medicine*, George Annas, Lori Andrews, and Rosario Isasi argue that the human condition of belonging to a single biological species is “central to the meaning and enforcement of human rights.” Because reproductive cloning and inheritable genetic modification “can alter the essence of humanity itself,” they write, these techniques “threaten to change the foundation of human rights.” For this reason, the authors say, “cloning and inheritable genetic modification can be seen as crimes against humanity of a unique sort.”<sup>8</sup>

212 *Marcy Darnovsky*

In many parts of the world outside the United States, the technologies of human genetic redesign are commonly and comfortably viewed through the lens of human rights. These procedures would be easily and widely understood as violations of what the Genetic Bill of Rights calls “the right to have been conceived, gestated, and born without genetic manipulation.” Especially in light of the fact that neither reproductive cloning nor inheritable genetic modification has yet been applied to human beings, the strength of the sentiment for national and international bans on them is striking.

Some dozens of countries have already passed such bans, and several important multilateral instruments address these technologies under the rubric of human rights.<sup>9</sup> The Council of Europe, for example, prohibits both inheritable genetic modification and human reproductive cloning in its Convention on Human Rights and Biomedicine, which was opened for signatures in 1997 after several years of negotiations and preparations.<sup>10</sup> Similarly, UNESCO’s Universal Declaration on the Human Genome and Human Rights, though not a legally binding document, forbids the production of cloned human beings, and says that inheritable genetic modification “could be contrary to human dignity.”<sup>11</sup>

#### LIBERTY AND JUSTICE IN THE AGE OF GENETICS

In the United States, the claim of a right “to have been conceived, gestated, and born without genetic manipulation” resonates less strongly. We tend to think of “rights,” including “human rights,” as shielding individuals from the coercive power of the state. However, today commercial entities often have as much control over individuals’ life choices and destinies as do governments. If the biotechnology and assisted reproduction industries were to decide to develop “genetic enhancement” procedures and market them to prospective parents, the pressures to “provide the best start in life for your child” would be considerable. Health insurance companies would likely weigh in. Coercion of parents need not necessarily be enforced by governmental authority to be effective. And the children in question, of course, would have no protection—unless we establish that freedom from genetic manipulation is indeed a human right.

In the individualist culture of the United States, rights are usually meant first and foremost to protect and enlarge individual liberties. The discourse of human rights, by contrast, implies as well the imperative of safeguarding the collective conditions in which people and communities can flourish. In the United States, we tend also to characterize rights as applying to us as autonomous beings who choose our own values and chart our own lives, rather than as people unavoidably situated in complex and overlapping relationship

with each other. As autonomous individuals, we go it alone. As social beings necessarily dependent on each other in myriad fashion, we are obligated to struggle together toward shared understandings about the kind of world we want to build.

Finally, we in the United States often focus so sharply on individual rights and liberties that we blur our perception of the social conditions that foster or block their enjoyment. We sometimes forget, in other words, that rights are necessarily embedded in relations of power. But championing rights in the abstract, without considering the political and social inequities with which we live, can undermine our commitments to social justice and solidarity, and to the democratic principle that we can and ought to participate in decisions about the basic conditions of our polity and collective life.

In her investigation of the tension between individual liberty and social justice as it pertains to reproductive rights and racial equality, legal scholar Dorothy Roberts asserts that the “dominant view of liberty reserves most of its protection only for the most privileged members of society.” By contrast, she argues that “Reproductive freedom is a matter of social justice,” and that “procreation’s special status stems as much from its role in social structure and political relations as from its meaning to individuals.” She is appalled that advocates of the new eugenics can present themselves as champions of freedom even as they “dismiss the possibility that genetic enhancement might exacerbate race and class disparities.”<sup>12</sup>

Liberties and rights, no matter how loudly they are proclaimed to be “self-evident,” are always the results of social arrangements, often painfully arrived at, on matters of common concern. Most nations of the world have now abolished slavery. Many have criminalized marital rape and outlawed the selling and abuse of children. These are examples of widely accepted limits on practices once construed as rights.

In practice, the two conceptualizations of rights—call them the individual-choice-and-autonomy model and the social-justice-and-negotiation model—often co-exist in the same policy formulation. For example, the right not to be enslaved protects individuals from being subjected to involuntary servitude, yet the same right also bespeaks a socially negotiated—albeit once hotly contested—agreement that a world in which some have the power to enslave others is not a world in which we wish to live.

## GENETIC RIGHTS AND WRONGS

How does all this apply to the proposed “right to have been conceived, gestated, and born without genetic manipulation”? Advocates of market-based

eugenics, appealing to the widely accepted consumer-oriented norms of our society, and to the very high value it places on individual liberty, scientific freedom, and technological advance, argue that people have the right to select the traits of their future children. Often they present this as an extension of reproductive choice and “procreative liberty.”<sup>13</sup>

These assertions can be countered even from within the individual-choice-and-autonomy model of rights. Experience with cloned and transgenic animals demonstrates that such procedures would carry enormous risks for both the cloned or genetically modified child and for the child’s mother. As developmental biologist Stuart Newman points out, “no amount of data from laboratory animals will make the first human trials anything but experimental.” And since there is little medical justification for such procedures, they would represent a clear-cut case of unethical human experimentation.<sup>14</sup>

Furthermore, it would be impossible to obtain what bioethicists call “informed consent” from the person to be cloned or modified, since the procedure would have to be carried out well before birth. And reproductive cloning and inheritable genetic modification would arguably compromise the autonomy of the cloned or modified person, since his or her life would have been controlled in an unprecedented manner by the parents, fertility doctors, and biotech companies involved.

The social-justice-and-negotiation model of rights provides additional support for the proposed right to be born free of genetic manipulation. It attends with care to the likelihood that the commercial development of reproductive cloning and IGM would exacerbate existing inequalities and create new forms of discrimination and inequality. It heeds the dangers of granting novel forms of control over individuals’ lives, and over the genetic legacy of the human species, to any public or private entity.

The Genetic Bill of Rights, and the “right to have been conceived, gestated, and born without genetic manipulation” that it contains, is a statement of political will and moral intelligence. In an era that has witnessed dire consequences of technological grandiosity, it calls for extending the precautionary principle to our own biology. In an age of runaway elitism, it calls for affirming our common humanity as a minimal but crucial condition of solidarity and mutuality. In the face of efforts to inscribe inequality into the human genome, it insists that—like it or not—we’re all in this together.

## NOTES

1. David P. Hamilton, “Biotech’s Dismal Bottom Line: More Than \$40 Billion in Losses,” *Wall Street Journal*, May 20, 2004.

2. Stephen S. Hall, *Merchants of Immortality: Chasing the Dream of Human Life Extension* (Boston: Houghton Mifflin, 2003).

3. See LeRoy Walters and Julie Gage Palmer, *The Ethics of Human Gene Therapy* (New York: Oxford University Press, 1997); Gregory Stock and John Campbell, *Engineering the Human Germline: An Exploration of the Science and Ethics of Altering the Genes We Pass to Our Children* (New York: Oxford University Press, 2000).

4. Stock and Campbell, *Engineering the Human Germline*.

5. Perhaps the best-known statement of this vision in a lay book is Princeton biologist Lee M. Silver's *Remaking Eden: Cloning and Beyond in a Brave New World* (New York: Avon Books, 1998).

6. For a short account of claims by Severino Antinori, Panos Zavos, and the Raelians that they are actively trying to clone a human being, see [www.genetics-and-society.org/analysis/promodeveloping/cloning.html](http://www.genetics-and-society.org/analysis/promodeveloping/cloning.html).

7. Among senior genetic researchers, a rare exception is Whitehead Center for Genome Research Director Eric Lander's short essay, "In Wake of Genetic Revolution, Questions About Its Meaning," *New York Times*, September 12, 2000. "The hardest question is, To what extent will we decide to reshape the genes we pass to our children? Some of my close colleagues are already proposing ways to 're-engineer' what they view as an 'imperfect' human genome . . . by modifying the human germline. . . . I part company from some of my colleagues here. While I'm strongly opposed to laws limiting scientific investigation, I would support a ban on modifying the human germline."

8. George Annas, Lori Andrews, and Rosario Isasi, "Protecting the Endangered Human: Toward an International Treaty Prohibiting Cloning and Inheritable Alterations," *American Journal of Law and Medicine* 28(2/3) (2002): 151–78.

9. Countries that have banned reproductive cloning or IGM include Australia, Austria, Argentina, Belgium, Brazil, the Czech Republic, Costa Rica, Denmark, France, Germany, India, Israel, Italy, Japan, Lithuania, Mexico, the Netherlands, Norway, Peru, Portugal, Romania, Russia, Slovakia, South Africa, South Korea, Spain, Sweden, Switzerland, Trinidad and Tobago, and the United Kingdom. For a complete list, see [www.genetics-and-society.org/policies/other/index.html](http://www.genetics-and-society.org/policies/other/index.html).

10. Relevant passages are excerpted at [www.genetics-and-society.org/policies/international/council.html](http://www.genetics-and-society.org/policies/international/council.html). The Convention on Human Rights and Biomedicine, [conventions.coe.int/treaty/EN/searchsig.asp?NT=164](http://conventions.coe.int/treaty/EN/searchsig.asp?NT=164). The Additional Protocol [on human cloning], [conventions.coe.int/treaty/EN/searchsig.asp?NT=168](http://conventions.coe.int/treaty/EN/searchsig.asp?NT=168).

11. Relevant passages are excerpted at [www.genetics-and-society.org/policies/international/unesco.html](http://www.genetics-and-society.org/policies/international/unesco.html). The Universal Declaration on the Human Genome and Human Rights, [www.unesco.org/human\\_rights/hrbc.htm](http://www.unesco.org/human_rights/hrbc.htm).

12. Dorothy Roberts, *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty* (New York: Random House, 1997).

13. John Robertson, *Children of Choice: Freedom and the New Reproductive Technologies* (Princeton, NJ: Princeton University Press, 1994); Allen Buchanan et al., *From Chance to Choice: Genetics and Justice* (Cambridge: Cambridge University Press, 2002).

14. Stuart A. Newman, "The Hazards of Human Developmental Gene Modification," *GeneWatch* (July 2000), [www.gene-watch.org/newman.html](http://www.gene-watch.org/newman.html).