

## BOOK REVIEWS

# Human Germline Gene Therapy: Scientific, Moral and Political Issues

David B. Resnik, Holly B. Steinkraus, and Pamela J. Langer

*Austin, TX: R.G. Landes Co., 1999, 189 pp., U.S. \$99 (cloth). ISBN 1-57059-586-0. R.G. Landes Bioscience, 810 S. Church St., Georgetown, TX 78626-5938, USA.*

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Human germline gene therapy (HGLGT) was, until very recently, a taboo subject for serious policy discussion. In the past few years, however, a growing number of credible commentators—including, perhaps most prominently, the Nobel Prize-winning co-discoverer of DNA, James Watson—have raised the possibility of real-world applications of HGLGT. Like so many other biomedical advances before it—such as surrogate motherhood, in vitro fertilization, genetic screening of embryos, and now cloning—the public discourse on HGLGT has distinctly but subtly shifted from moral outrage and outright rejection to a more dispassionate debate on the pros and cons of the technology. It remains to be seen whether this transformation will continue along the path to experimentation, gradual acceptance, and finally widespread adoption, as it has for so many of the other biomedical advances over the past few decades.

David Resnik, Holly Steinkraus, and Pamela Langer have provided a timely and helpful contribution to the public debate on HGLGT by providing in one concise volume a primer on the scientific, moral, and political issues associated with HGLGT. The book sets for itself a lofty task, not only to review the broad range of technical, ethical, policy, and legal issues involved with HGLGT, but to do so in a way that is accessible to the nonexpert and yet credible and insightful to experts. The premise for this ambitious undertaking is that public policy on HGLGT must take ac-

count of a wide range of inputs and areas of expertise, yet most readers will only have expertise in at most one of the relevant areas. Each section of the book therefore starts with first principles, but efficiently brings the reader up to speed with the full complexity and richness of each of the relevant fields of science, ethics, and policy. Unlike many other books that ultimately fail by trying to cover too much, the strength of this book is that it generally succeeds in being accessible and instructive to the nonexpert while at the same time offering the expert an insightful and engaging analysis of the many issues presented by HGLGT.

The first part of the book examines in depth the formidable scientific and technical barriers to HGLGT. These scientific challenges include the problems of inserting the DNA into the germline cell (whether it be a zygote or gamete), incorporating the DNA into the host DNA at the appropriate destination in a stable configuration, achieving appropriate expression of the inserted DNA, and preventing any harm to the host cell. A critical factor is that for HGLGT to be feasible, each of these challenges must be resolved with both high efficiency and zero tolerance for error, because the supply of zygotes or gametes for treatment cells will be strictly limited, and any error could have catastrophic consequences because it will be propagated into every cell of the individual.

In the course of describing the technical challenges of HGLGT, the book compares and contrasts HGLGT with somatic gene therapy (SGT). While the two procedures have some overlap, and ongoing research and clinical trials with SGT will partially help to pave the road for HGLGT, there are also significant scientific and ethical differences between the two procedures. In some ways, it may be easier to genetically modify a germ cell than a somatic tissue, because only a single cell needs to be altered, and the zygote or gamete is easily isolated. On the

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other hand, HGLGT will be much less tolerant of any error or any imperfection, since any negative effects will be propagated in every cell of the individual and possibly to future generations. Thus, “the potential effects of an HGLGT procedure are incalculable and dramatically more significant than with SGT” (p. 72).

The technical challenges of HGLGT lead to the question of whether the procedure is intended to correct a genetic defect in the embryo (gene therapy), or to improve the genetic potential of the embryo by supplementing its existing genetic complement with genes that provide some beneficial trait, such as enhanced intelligence, height, or health (genetic enhancement). The authors emphasize that HGLGT will rarely be the recommended method for correcting an existing single-gene defect in an embryo. In vitro fertilization followed by pre-implantation genetic screening and selection of a healthy embryo will be a far simpler and more certain option than trying to correct a genetic defect in an embryo using HGLGT. There will be a few situations where HGLGT is necessary to produce an embryo without a genetic defect, such as when both parents are homozygous for a recessive disease gene, but such situations will be rare. Thus, the primary motivation for HGLGT will likely be genetic enhancement.

Contrary to some commentators who argue that there is no meaningful demarcation between therapy and enhancement, the authors argue that there is a biologically based distinction between germline therapy and germline enhancement based on the concept of disease (p. 88). Yet, despite the theoretical possibility of distinguishing therapy from enhancement, the authors caution that we need to go beyond this distinction in evaluating the morality of HGLGT, because it is too simple to adopt a bright-line categorical approach that therapy is good and enhancement is bad.

The remainder of the book then proceeds to examine the ethics of HGLGT. It first examines the possible benefits and harms of HGLGT, dividing such effects into four categories of medical, evolutionary, psychosocial, and economic benefits and harms. To evaluate these potential consequences, the authors employ a series of scenarios that test the sensitivity of the analysis for the different possible objectives, methods, and outcomes of HGLGT. The overriding conclusion from this exercise is that the major scientific, technical, social, moral, economic, and political uncertainties about HGLGT dominate the analysis of its benefits and harms.

The book then takes another cut at the ethics of HGLGT from the perspective of the moral rights and political rights of parents, potential children, and future generations. Here the authors conclude that application of traditional bioethics principles results in a fairly clear conclusion, although some tricky counterarguments are addressed along the way to the resolution. The primary conclusion reached is that the rights of parents are limited by a duty to avoid imposing unjustifiable risks on potential children, with the consequence that parents have a right to use HGLGT only in rare cases when

there is no other, less risky option for preventing the birth of children with serious genetic diseases. In contrast, the authors conclude that the rights of future generations should have minimal weight in evaluating the ethics of HGLGT.

Subsequent chapters undertake a deeper philosophical evaluation of the ethics of HGLGT, examining, for example, how HGLGT comports with various philosophical principles and formulations of justice and equality. More fundamental moral objections to tinkering with human nature are also examined, including an extensive discussion of the meaning of our “humanness” and how it might be affected by HGLGT. This discussion then delves into the concepts of natural law, the striving for human perfection, and “playing God” with human nature.

The final chapter of the book addresses public policy issues concerning HGLGT. This is the weakest part of the book, and almost appears as an afterthought that fails to provide the depth and fullness of analysis that characterizes the rest of the book. The principal recommendation of the authors is a mandatory moratorium on HGLGT research, but no real analysis of the questionable constitutionality of such research restrictions is provided. The authors briefly mention in the introduction to the book the “genetic tragedy of the commons,” whereby the attempt by a few individuals or some countries to produce children with “superior” genes may create a cascading effect of defections from a social consensus against HGLGT. Yet, the chapter on public policy fails to elaborate on the critical role that this incentive for individuals or countries to defect from a prohibition on HGLGT will have on the stability of any policy measure to limit HGLGT.<sup>1</sup>

This final chapter does include brief discussions of other relevant policy issues such as research funding, privacy, intellectual property, and international coordination, but again provides only the barest analysis of these important topics.

Overall, this book provides a very useful analysis and integration of the scientific and ethical aspects of HGLGT. The text is both concise and rich, and is supplemented with an extensive bibliography of the literature from each of the multiple disciplines covered by the book. It would be a useful addition to the bookshelf of anyone interested in human genetic engineering, and one that would be taken down and consulted often.

## Notes

1. See William Gardner, “Can Human Genetic Enhancement Be Prohibited?,” *Journal of Medicine and Philosophy* 20 (1995): 65-84.

# Third World Environmentalism: Case Studies from the Global South

N. Patrick Peritore

Gainesville, FL: University Press of Florida, 1999, 328 pp. US\$49.95 cloth. ISBN 0-8130-1688-6. University Press of Florida, 15 NW 15<sup>th</sup> Street, Gainesville, FL 32611-2079, USA.

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N. Patrick Peritore models the attitudes of key decision-makers in developing states on issues of environment and development in *Third World Environmentalism: Case Studies from the Global South*, arguably finding a high level of consensus amongst leaders in government, business, and environmental groups. Discounting political culture, he finds that elite decision-makers in seven different developing states hold generally the same postmodern attitude. This finding runs counter to Peritore's initial expectations, that each country would have a culturally unique approach to environmental protection. This finding also runs counter to applications of Ronald Inglehart's 1970s analysis of developed nations<sup>1</sup> (which in turn was drawn from Maslow's hierarchy of needs describing post-material values that fluctuate with economic swings), where conventional wisdom held that the South would not care about environmental problems until the states were suitably developed.<sup>2</sup> Peritore then concludes that this unexpected common approach demonstrates the extent to which the environment has become a "truly international issue" (p. ix), and that post-Fordism helps explain this status as it "predicts the rise of a new class of postmodern elites" who will maneuver this value shift (p. 44).

In this context, *Third World Environmentalism* provides another welcome strand in the growing collection of literature that attempts to outline the best paths towards sustainability, specifically the need for a fundamental value shift in the way states think about the relationship between environment and development. The text starts out on a cheerful note in its initial three introductory and method-

ological chapters. Peritore describes the emergence of a new politics to support more sustainable environmental policies, and points out that this new politics goes beyond the confrontational left-right politics of old. Yet Peritore also cautions against the dangers of the darker side to this new world, where the global economy shows few signs of ecological sensitivity; that is, free trade agreements such as NAFTA, WTO, and MAI often supercede environmental treaties. It is this omnipresent threat that provides the greatest challenge to Peritore's analysis as he himself admits that, while most Southern states have large, growing environmental movements, they are still beset by the three ominous developing state hurdles of debt, overpopulation, and corruption.<sup>3</sup> Only with both scientific and financial aid from the North can Southern states exploit their "postmodern" ecological consciousness, according to Peritore (p. 244).

Yet Peritore's analysis does not make it clear that Southern states have reached even the first requisite stage, that of postmodern ecological consciousness. In deriving his conclusion that a growing internationalism regarding the environment exists, the author examined five hypotheses outlined in his introductory chapter. The first four are (1) elites will not show postmodern values; (2) the three major sectors (environmental groups, government, big business) will employ distinct approaches; (3) the environment is a divisive issue with high levels of partisanship and social division; and (4) the closed nature of political systems in the Third World requires the creation of Green parties or mass movements to bring environmental issues before elites. Each of these is disconfirmed, according to Peritore. The one hypothesis that Peritore does confirm is the fifth and final one, which states that "transitions from modernism to post-modernism and Fordism to post-Fordism provide axes for a model on which the shift from old to new politics may be mapped" (p. 4). This hypothesis, of course, serves as the heart of Peritore's analysis and thus deserves emphasis in this review, but first a few points should be noted regarding the challenging methodology Peritore employs.

Peritore uses Q-sort methodology, a protocol that develops psychological modeling by applying the "presup-

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positions of quantum physics to the study of subjectivity” (p. 12). He applies it cross-nationally to 241 top leaders of government, business, and environmental groups in the seven case studies of India, Korea, Brazil, Mexico, Puerto Rico, Romania, and Iran, sequenced from most to least environmentally concerned. Based on nine years of fieldwork and writing, the study covers 23% of the world population, including Catholic, Orthodox, Protestant, Confucian, Hindu, Buddhist, Islamic, and shaman religions as well as capitalist, colonial, revolutionary, and post-socialist economies. From 36 statements inductively drawn from literature on environment and development and interviews in the field (Brazil, Mexico, Cuba, Nicaragua), Peritore establishes seven factorial attitude types that explain elite environmental attitudes in the Global South. These are Greens, Political Greens, Sustainable Developers, Postmodern Managers, Developmentalists, Bureaucratic Nationalists, and Cultural Traditionalists.

This established, Peritore offers a useful historical overview of post-Fordism and the emerging global economy in his second chapter (pp. 37-44) and makes numerous intriguing observations throughout the analysis. Just one of note is his observation that transnational corporations (TNCs) ignore the environmental costs of production because they “deal at arm’s length with their subcontractors” (p. 41). Future research might tackle the question of how elite opinions could help draw TNCs closer and thus encourage more sustainable behavior. When questions like this are raised, the chapters are quite useful. In general, the case studies would benefit from more judicious use of the actual quotes collected from the elites themselves. In particular, the text is missing a general story that ties the collection of historical data and methodological analysis together. Too often the case studies read like a listing of environmental statistics. Taking more advantage of the rich quotes Peritore uncovered would help avoid this handicap.<sup>4</sup> The text could also benefit from further integration of the case study chapters. In particular, it would be useful to hear more comparisons amongst the Global South as Peritore does when he notes that Puerto Rico’s cultural traditionalists are similar to the religious conservatives in Iran (p. 186). Perhaps the fact that two of the seven case studies were team-written may have hindered these sorts of comparisons.

As noted earlier, Peritore asserts that the major finding of the text is the value shift among Global South elites, yet this review contends that the full extent of such a shift remains debatable. Looking at Peritore’s graphing of “Third World Elite Environmental Attitudes Mapped on Postmodern/Modern and Post-Fordist/Fordist Axes” leads to this conclusion. Each case study chapter has a figure illustrating this axis, with all results then summarized in the concluding chapter. But it is not clear by the end of the text that a postmodern and post-Fordist culture has emerged in the Global South. In Figure 11.2, for instance, one finds

that sizable portions of Fordists still exist in the Third World (p. 240).<sup>5</sup> Explanations of the figure also need further refinement in that the cultural traditionalist outlier largely is neglected and the distance in space amongst Greens from India and Puerto Rico is not adequately explained. And finally, no distinction is made when one factorial group is larger than another. This is particularly evident in the individual case studies; for example, the case study on India includes ten “religious conservatives”<sup>6</sup> but only three “bureaucratic nationalists” (p. 225). While quantity of opinion is clearly not Peritore’s objective in this study, significant variation in size of these factorial types undoubtedly has an impact on any qualitative measure of the attitudes.

Peritore’s major contribution to the literature is, instead, to provide further evidence to dispel the myth linking environmental consciousness to high economic status, at least in the South. Peritore admirably discounts this prevailing thesis and adeptly connects his work to that of Riley Dunlap, who has shown that low-income countries often express more concern for environment than high-income countries (p. 33).<sup>7</sup> *Third World Environmentalism* will be of interest to Q-methodology enthusiasts or those needing background material on the relationship between the political history and contemporary environmental problems in the specific states examined. The general reader, however, should seek out other sources.

## Notes

1. Inglehart, Ronald. *The Silent Revolution*. Princeton, J.J.: Princeton University Press, 1977.
2. As Inglehart contended in the first of his two major hypotheses, the scarcity hypothesis, this follows the logic where prosperity leads to increased post-materialism and the ability to care about nonmaterial issues like the environment. The second hypothesis was known as the socialization hypothesis and stated that values reflect pre-adult experiences.
3. Peritore notes that in much of the Southern hemisphere corruption is so rampant that it is considered an expected business cost (p. 75).
4. For example, one elite describes India’s fundamental problem as poverty: “But poverty drives us to produce. The West produces for no reason, creates waste for consumerism. But in the Third World, poverty is the main cause of pollution” (p. 84).
5. For that matter, the states where post-Fordists hold considerable sway, Korea and Puerto Rico, are arguably not true Southern states.
6. Throughout the rest of the chapters, this factorial type is referred to as “Cultural Traditionalists.” The study would benefit from keeping this label standardized.
7. Ethnographic studies suggest that this relationship changes when foreigners begin to exploit the local environment for their own purposes; that is, tribal peoples behave unsustainably when outsiders begin enclosing their environment (p. 33).

# Sexing the Body: Gender Politics and the Construction of Sexuality

Anne Fausto-Sterling

New York: Basic Books, 2000, 488 pp. US\$35.00 cloth. ISBN 0465077137. US\$21.00 paper. ISBN 0465077145. Basic Books, 387 Park Ave S., New York, NY 10016, USA.

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Anne Fausto-Sterling's *Sexing the Body: Gender Politics and the Construction of Sexuality* is another example of her constructionist approach to science. It is based on the premise that science is a social construction in which "created truths" about sex and gender are imposed on individuals. Fausto-Sterling claims that not only do our bodies take in these "truths," they make them part of our physiology. In other words, "sexuality is a somatic fact created by a cultural effect" (p. 21). In a rather circular argument, Fausto-Sterling describes how studies on sexual differences in genetics, hormones, and the brain, as well as the medical practices used on intersexuals, are gender-biased. She then argues that these biased studies in turn created our understandings of these phenomena as well as ourselves. Unfortunately, Fausto-Sterling spends most of her time analyzing and criticizing past scientific approaches to human sexuality, leaving little intellectual energy for theory building.

*Sexing the Body's* most informative contribution is how the medical community treated intersexuals. Before the twentieth century, most Western countries recognized just the male and female sex, and those who fell between had to pick a gender and act according to the prevailing sexual standards. As the medical profession gained more authority and began declaring babies with ambiguous genitalia as abnormal, it began using advances in surgical techniques to "fix" these babies. Doctors decided the sex and gender based on a chromosomal diagnosis despite the state of the baby's genitalia. Although the doctors may have had good intentions, these intersexuals experienced repeated surgeries, loss of sexual function, and a lifetime of confusion. The accounts are heartbreaking.

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Fausto-Sterling argues that the medical community used the following unexamined assumptions in treating these patients: (1) there are only two sexes, (2) only heterosexuality is normal, and (3) particular gender roles define a psychologically healthy man or woman. Rather than viewing these individuals as having unusual physiology, Fausto-Sterling maintains that they are a different sex. She wants a system in which physiology does not determine one's gender; individuals should be free to decide how to express their gender. However, this argument fails to make sense because Fausto-Sterling admits that the body does emit signals through the course of one's sexual development, and this is why the radical surgeries and hormone therapies have caused suffering for intersexuals. Although Fausto-Sterling argues that society creates our understanding of human sexuality and sexuality itself, she nonetheless has to recognize that the body plays a definitive role in forming one's sexuality despite what the environment or society allegedly tries to impose.

Fausto-Sterling also examines how ideas about gender have influenced the study of hormones and their effects on the brain. She provides an overview of how scientists named testosterone and estrogen based on their ideas and assumptions that only males had testosterone and only females had estrogen. Over time, scientists realized that both sexes had both estrogen and testosterone, with each playing important roles in both sexes. Fausto-Sterling also shows how the studies of rodents' sexual development set the paradigm for studies of human development until the 1970s. For over two decades, scientists assumed that prenatal hormones organized an individual's central nervous system so that by puberty the hormones could activate sex-specific behavior. She argues that scientists have failed to properly examine the impact the environment has on hormone levels during sexual development. While this is accurate, Fausto-Sterling's narrow scope leaves out the ongoing work on hormones, sexuality, and the environment. Worthman (1995) provides an excellent overview of the research done on hormones and their relationship to sex and gender.<sup>1</sup> She and others using evolutionary perspectives recognize the ongoing impact hormones have on individuals throughout their lifespans. If

the general reader takes Fausto-Sterling at her word, he/she would think that the study of hormones has stalled since 1980.

Overall, Fausto-Sterling's criticisms of various studies on the brain, hormones, and sexual development provide interesting stories of how the studies were done, accepted by the scientific community, and later reassessed. However, this does little for building better theory, and indeed she is extremely selective in the material she draws on to provide a framework for understanding human sexuality. For example, in her final chapter, she proposes three basic principles for scientists to use when investigating sex and gender: (1) nature and nurture are indivisible; (2) organisms are active processes; and (3) no single discipline offers the best or "true" way to understand human sexuality. Now, many scholars would not necessarily disagree with her proposals. Most behavioral scientists agree that animal and human behaviors are influenced by both the environment and biology. For over twenty-five years scholars using evolutionary approaches have recognized this interaction (for example, Wilson, 1975; Hrdy, 1981, 1999; Gowaty, 1997), some of whom Fausto-Sterling (1985, 1992) has vehemently criticized in the past. Now, she conveniently neglects to mention evolutionary approaches at all in *Sexing the Body*.

Fausto-Sterling also states that sexuality is an ongoing developmental process deeply influenced by social relationships and the environment over one's lifetime. Again, Fausto-Sterling presents this point as if it is radically new. However, scholars have previously examined the impact of relationships and environmental stresses on individual development and reproductive behavior. For example, biological anthropologists use empirical research in the field and the laboratory to develop and apply biocultural models, examining the relationships between culture and biology in human evolution, ontogeny, behavior, and cognition (for example, Panter-Brick and Worthman, 1999). In addition, Fausto-Sterling does not mention life-history theory. Used too by anthropologists, it examines how individuals allocate time and energy among the demands of growth, maintenance, and reproduction as they pursue reproductive success (for example, Chisolm, 1993 or Morbeck, Galloway, and Zihlman, 1997).

Finally, in terms of offering a new perspective on human sexuality, Fausto-Sterling proposes a "dynamic developmental systems theory" that would avoid the distinction between the body and the environment. Although she mentions in passing various studies or perspectives that call for this integration, she is vague about how this approach works. She illustrates this theory in terms of Russian nesting dolls that represent her framework incorporating history, culture, relationships, body, psyche, and cell. She states that scientists "need to stop looking for universal causes of sexual behavior and gender acquisition" and instead learn more about (and from) individual difference (p. 246). Indeed,

Fausto-Sterling sees the developmental systems theory as a means to avoid discussions of "fundamental truths" about what is desirable, healthy, or natural in the context of sexual development and behavior. This explains why she avoids contemporary evolutionary science, because it begins with the premise that the function or purpose of sexual behavior is reproductive success. Many of her discussions focus on sexuality outside the context of reproduction.

In conclusion, *Sexing the Body* is disappointing because Fausto-Sterling has little to offer to her newfound developmental systems theory. She believes that society needs to create consensus about the nature of human sexuality before science analyzes it. For example, she states that "choosing a scientific path acceptable to most, and littering that path with agreed upon facts, is only possible once we have achieved social and cultural peace about gender equity" (p. 145). Isn't this also the social construction of sex and gender that Fausto-Sterling has been criticizing, except that she would agree with the science because it would then be based on her own *a priori* assumptions? In light of her past writings, Fausto-Sterling's biases against several disciplines using evolutionary perspectives leave out many studies that examine how both the body and the environment affect sexual development and behavior. Because she relies on constructionism as her intellectual framework, Fausto-Sterling limits her capacity for theory building. *Sexing the Body* can only criticize and not contribute much to a new approach to human sexuality.

## Notes

1. I find it fascinating that Fausto-Sterling does not even cite this article, even though it directly pertains to her discussion of gender, sex, and hormones.

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# Transplantation Ethics

Robert M. Veatch

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Georgetown University Press, 3700 O Street NW, Washington, DC 20007, USA.

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For three decades now, Robert Veatch has been thinking and writing about the complex and controversial issues of defining death and transplanting human organs. As a scholar at the Hastings Center and at Georgetown University's Kennedy Institute of Ethics, and a member of both the Washington Regional Transplant Consortium Board and the United Network for Organ Sharing's Ethics Committee, Veatch has played an active role in the ongoing moral and public policy debates over transplantation.

In *Transplantation Ethics*, he has collected and revised fifteen of his most important published writings on this topic and added ten new chapters on current and perennial questions. The result is a tour de force—a review and examination of ethical issues in transplantation that is at once well informed, clear, comprehensive, and challenging. Whether or not they agree with all of Veatch's conclusions, both transplantation scholars and newcomers to the topic can learn a great deal from this volume.

The book has a clear and congenial structure. After introductory chapters reviewing religious and philosophical views, the volume is divided into three major parts, "Defining Death," "Procuring Organs," and "Allocating Organs." In each part, Veatch examines key concepts and distinctions, basic policy options and their rationales, and specific controversial questions. Thus, the reader can gain an appreciation both for the general structure of the moral and policy debates and for Veatch's own substantive positions. To take just one example, the volume's careful description and analysis of the allocation of transplant organs to baseball great Mickey Mantle and to Pennsylvania governor Robert Casey dispels much of the mystery and suspicion surrounding those well-known cases.

Robert Veatch has not been shy in proposing and defending novel, sometimes unorthodox, approaches to bio-

ethical and transplant issues over the years, and *Transplantation Ethics* is no exception. Veatch reaffirms his well-known and long-standing support of higher brain criteria for determining death and of a conscience clause allowing dissenters to opt for death criteria other than the legal default definition. He also defends controversial positions on a variety of other issues, including requiring competent persons to state a position on donation of their own organs, using organs from HIV-positive patients for transplants, using xenografts despite the risk of viral transmission, giving priority to younger patients in organ allocation, and making a history of alcoholism a modest negative factor in liver transplant allocation. Veatch reserves his strongest criticism in *Transplantation Ethics* for the whole-brain concept of death, for presumed consent models of organ donation, and for utilitarian approaches to organ allocation. Let us review each of these issues in turn.

Regarding "whole-brain death," Veatch argues that current diagnostic criteria do not, in fact, accurately measure death of the whole brain, since some isolated brain cells may continue to survive and produce limited electrical activity. Even if diagnostic criteria did measure whole-brain death, Veatch argues that this is not the most appropriate measure of human death. It does not correspond closely with what Veatch identifies as the characteristic essential for human life, namely, capacity for consciousness or experience.

The claim that consent to donation can be presumed is misleading and false, Veatch notes, since a large percentage of patients and families do not, in fact, consent to the use of their or their loved ones' organs. A more appropriate term to describe a policy of using cadaver organs without consent, he points out, is not "presumed consent," but "routine salvaging." Such a policy of routine salvaging, Veatch argues, inappropriately gives greater authority to society than to the individual over the disposition of the body after death.

Veatch argues that utilitarian approaches to organ distribution fail to satisfy the claims in justice of many needy patients. He asserts a strongly egalitarian account of justice—"I am convinced that striving for opportunities for equality of well-being takes absolute priority over maximizing aggregate social utility..." (pp. 36-37). This is a robust egalitarian claim, too robust for many liberal schol-

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ars of justice, not to mention those of a more conservative bent. Veatch does not defend this position at length in *Transplantation Ethics*, though he has done so elsewhere (Veatch, 1986). Later in *Transplantation Ethics*, Veatch expresses a willingness to compromise regarding this position, at least in public policy formation, allowing the claims of utility and justice to have equal weight in organ allocation formulas (p. 305). Nevertheless, he relies heavily on his own egalitarian principle of justice in staking out positions on such topics as multi-organ and repeat transplants, local versus national organ sharing, and directed donation.

Given the length and breadth of discussion in *Transplantation Ethics*, very few topics of interest are not discussed. Only two issues that can claim some importance, in my view, were omitted. First, although the volume does include a thorough examination of xenotransplantation (the use of nonhuman animals as organ sources), it does not address a very new and promising research area, namely,

the bioengineering of human organs for transplantation (see e.g., Mooney and Mikos, 1999). Second, the volume mentions in passing, but does not explore, the complex issue of whether current organ allocation systems unfairly disadvantage minority patients (see e.g., Young and Gaston, 2000). Despite these few omissions, however, *Transplantation Ethics* is the most current, comprehensive, richly detailed, and clearly argued treatment of this topic in the bioethics and health policy literature. Given the complexity of the topic, it is likely to remain so for some time.

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# Toxic Terror: Assessing Terrorist Use of Chemical and Biological Weapons

Jonathan B. Tucker, ed.

Cambridge, Massachusetts: MIT Press, 2000, 303 pp. US\$24.00 paper. ISBN 0-262-70071-9. MIT Press, 5 Cambridge Ctr., Suite 4, Cambridge, MA 02142-1493, USA.

**Jennifer L. Brower** RAND Corporation, USA

Many books have described changing trends in terrorism, such as escalating violence, the emergence and danger of loosely affiliated terrorist groups, and the rise of apocalyptically focused organizations. Others have described the infinite vulnerabilities of society to chemical and biological weapons (CBW).<sup>1</sup> *Toxic Terror*, edited by Jonathan B. Tucker, is the first systematic attempt to examine the historical record of CBW use by terrorist groups in order to provide an empirical guide for policymakers. Because the technical challenges of producing and using CBW have been studied at length, the book focuses on motivations of terrorists, not the technical obstacles (p. 12). However, because some technical discussion is included in the introduction and the case studies, the book provides a significant bridge be-

tween the technical literature on required capabilities and the politics and motivations of terrorists willing to use these weapons.

*Toxic Terror* is valuable because it dispassionately examines twelve cases of acquisition or use of CBW, some of which have been consistently misreported in the past. It provides in-depth factual information for both beginners and experts studying CBW use by non-state actors. Because the absolute number of case studies is small and because some of the cases seem to be untrue, it is difficult to assess the absolute value of Tucker's conclusions, as the author himself acknowledges (p. 249). Importantly, the methodology lays down a useful analysis that can easily be enhanced by the study of additional cases, as Tucker has suggested (p. 268). In addition, the characteristics of terrorists likely to use CBW and the motivations enumerated by Tucker can be used by the intelligence and law enforcement communities to focus attention on current potential actors.

While CBW are often associated with "weapons of mass destruction" in the press and the academic literature, this book addresses all levels of CBW use. Of the twelve case studies, only three of the groups—Avenging Israel's Blood, the

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Rajneeshees, and Aum Shinrikyo—were able to use a chemical or biological weapon to achieve significant numbers of casualties.

In the first case study, a well-written piece by Ehud Sprinak and Idith Zertal, the authors describe an attack on Nazi war criminals held at prisoner-of-war camps in Germany. This particular attack has received relatively little attention in the popular literature on CBW (p. 18). *Avenging Israel's Blood* had initially planned to target the general German population. But because of a lack of support by conventional Israeli leaders, the arrest of the group's leader, and reservations about indiscriminate attacks, the attack was targeted on the prisoner-of-war camp. The attack reportedly killed hundreds and injured thousands (pp. 32-33).

In the second case study, John Parachini discusses an alleged attempt by the Weather Underground, a radical leftist Vietnam War-era organization, to acquire chemical weapons from a U.S. Army research center (p. 43). Parachini also examines one of the largest acts (in terms of bomb size) of terrorism on American soil in his chapter on the World Trade Center bombers (p. 186).

W. Seth Carus examines the case of R.I.S.E., a small group of ecoterrorists who believed that in order to save the earth the majority of the human race had to be destroyed (p. 58). R.I.S.E. planned, but lacked the technical expertise, to use biological weapons to achieve this aim, and the small-scale operation was aborted when one member's biological cultures were confiscated (p. 70). Carus also inspects the one documented use of biological weapons in the United States by the Rajneeshees, a religious cult in Oregon (p. 115).

Jeffrey D. Simon examines the case of Muharem Kurbegovic, the Alphabet Bomber, a troubled man who used conventional weapons and threatened the use of chemical weapons for personal revenge (p. 94). David Claridge uncovers the mistruths behind the accusation that the Baader-Meinhof Gang stole mustard gas from a U.S. military installation in West Germany (p. 95). Taylor and Trevan debunk the allegation that the left-wing terrorist group, the Red Army Faction, attempted to acquire biological weapons (p. 107).

Jessica Eve Stern demonstrates that the Covenant, the Sword, and the Arm of the Lord (CSA) possessed potassium cyanide when the authorities raided the CSA compound on April 20, 1985 (p. 150). She also discusses the group's plans (in concert with other groups participating in the Aryan Nations Congress) to poison urban water supplies (pp. 147, 151). In a second case study, Stern examines the actions and motivations of Larry Wayne Harris, a disturbed member of the Identity Christian movement.

Jonathan Tucker and Jason Pate describe the acquisition of ricin by the Minnesota Patriots Council, a tax resistance group (p. 159). David E. Kaplan depicts the most famous use of chemical weapons and attempted use of biological weapons in recent history by Aum Shinrikyo, a New Age apocalyptic religion.

This last case, Aum Shinrikyo's subway attack, arguably provided the momentum for much of the current focus on the use of CBW by terrorists. While this focus seemed appropriate in the years immediately following the attack, many experts now recognize that this event did not presage a host of similar attacks. *Toxic Terror* furthers the balanced study of the use of CBW by terrorist organizations. As the author concludes, because of both technical and motivational factors and because of potential detection by authorities, small-scale, amateur use of CBW remains the most likely (pp. 266-267).

Although most of the case studies are familiar to those who study chemical and biological terrorism, one of the greatest values of this volume is that it corrects common mistakes and misunderstandings perpetuated in the literature. The experts Tucker has gathered compile factual, in-depth studies using mostly primary sources. Each author includes a useful amount of background information so that readers unfamiliar with the particular groups or incidents can understand the context and substance of the cases.

Tucker concludes that groups who have tried to acquire or use biological and chemical weapons are diverse and operate with a variety of motivations; however, there are a number of common characteristics and patterns of behavior (p. 255). Tucker also discusses the operational, psychological, ideological, and quasi-mythological motivations that might encourage an individual or group to choose chemical or biological weapons. Examination of these motivations and common characteristics can further the ability of decision-makers to prevent and prepare for potential CBW use.

John Parachini stated during his 1999 testimony for the U.S. House of Representatives Committee on Government Reform Subcommittee on National Security, Veterans Affairs, and International Relations, "Simply pouring resources, no matter how plentiful, in directions policy makers believe are appropriate without undertaking a thorough, systematic review, may very likely lead us to just spend money, not spend it wisely."<sup>2</sup> This book is an important first step in the systematic review.

## Notes

1. For instance, see Richard A. Falkenrath, Robert D. Newman, and Bradley A. Thayer, *America's Achilles' Heel: Nuclear, Biological, and Chemical Terrorism and Covert Attack*. (Cambridge, MA: MIT Press, 1998); Bruce Hoffman, *Inside Terrorism* (New York: Columbia University Press, 1998); Sidney D. Drell, Abraham D. Sofaer, and George D. Wilson, eds., *The New Terror* (Stanford, CA: Hoover Institution Press, 1999); Ian O. Lesser, Bruce Hoffman, John Arquilla, David F. Ronfeldt, Michele Zanini, and Brian Michael Jenkins, *Countering the New Terrorism* (Santa Monica, CA: RAND, 1999); and Jessica Stern, *The Ultimate Terrorists* (Cambridge, MA: Harvard University Press, 2000).
2. "Assessing the Threat of Bio Terrorism," October 20, 1999, Washington, DC. Accessed at <http://www.chem-bio.com/resource/1999/parachini102099.html>.

# Conquering Nature: The Environmental Legacy of Socialism in Cuba

Sergio Diaz-Briquets and Jorge Perez-Lopez

Pittsburgh, PA: University of Pittsburgh Press. 2000. 328 pp. US\$22.95 paper. ISBN 0-8229-5721-3. University of Pittsburgh Press, 3400 Forbes Ave., Eureka Bldg., Fifth Floor, Pittsburgh, PA 15260, USA.

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This comprehensive and detailed study of the Cuban environment, based on documentary sources and testimony from emigrees, provides an even-handed account of the central issues: law and policy, agriculture, hydraulics, forestry, industry, nuclear power, the condition of the capital La Habana, and a discussion of the economic and environmental challenges subsequent to the post-1989 crisis.

The authors compare Cuba with other Soviet-style economies and with the pre-Revolutionary regime. They appear torn between blaming Cuba's environmental problems on the Socialist development model, and the realization that the model of extensive development used on the island was adopted from advanced capitalist countries. Thus, the model of hard-power industrial development, which the Soviets encouraged in Cuba, was derived from U.S. practices (and is fortunately going out of vogue in developed nations). Cuba followed this model with the consistency and lack of concern for externalities characteristic of centrally planned economies—and aggressive capitalist regimes—creating the same extensive environmental damage seen on the Mexican border or in São Paulo.

A small island of about 110,922 sq. km. and some 11 million people, Cuba has ten major soil groupings, twenty-nine soil types, and devotes 61.5 percent of its land to agriculture. Cuba has extensive coral reefs, and some twelve thousand animal species, with a high percentage of endemic (biologically unique) mammals, birds, insects, fish, and molluscs, perhaps as high a rate of endemism as found in the Amazon basin. There are 6,700 species of flora, half of which are endemic. Cuba's advanced medical system and public education led to early demographic transition, and population growth has steadily declined since the 1980s, while

median age (33 years in 2000) and life expectancy (75.3 years in 2000) have increased (Chap. 2, p. 34). Cuba has a broad range of environmental legislation, with Article 27 of the 1976 Constitution guaranteeing "sustainable economic and social development," and a number of enabling regulations and sanctions.

Environmental impact assessments, licensing, monitoring, and remediation are mandated in law and enforced by the Ministry of Science, Technology, and Environment (CITMA). Cuba has ratified a number of important environmental treaties.

However, Cuban law is not specific enough in its norms and rules for direct application; lines of authority are vague; and often productive units regulate their own environmental performance to the detriment of the latter. The 1989 cutoff of Russian aid led to a 35 percent economic contraction, so that current policy creating coops, private business, and joint ventures in tourism, mining, petroleum, agriculture, and biotechnology, severely limit environmental regulation (Chap. 3).

Cuba's agriculture is based on a range of rich soil types, but humid tropical soils (oxisols, utisols, alfisols) predominate. Sixty-one percent of the soil is cultivated, but thirty-seven percent is poorly drained and eleven percent suffers from salinization. Crop diversification and reforestation (a 4 percent increase in forest cover since 1950) are positives, but the industrialized agriculture-augmented trend toward rain-fed erosion, soil compaction from mechanization (24.5 percent of soils), and acidification are serious problems. Cuba used heavy imported pesticides and herbicides, many being dangerous organochlorine and organomercury compounds banned in the U.S., including dieldrin, and even DDT.

The September 1993 decree ended Soviet-style collectivization and inaugurated a change to cooperatives and private farms. The lack of imports led to use of animal traction and organic fertilizers, and to a drive for local food self-sufficiency and commercialization of surplus (Chap. 4). Cuba has extensive rainfall and aquifer storage, but the rivers run off rapidly to the sea from the central mountain spine, leading to an effort to create 200 dams, 800 microdams, and lagoons. About 50 percent of usable wa-

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ter potential is being withdrawn for use, leading to saltwater intrusion into aquifers as they are overdrawn. Planners considered water a free good until the 1989 crisis, when they began charging in order to promote conservation. Poorly planned irrigation has led to salinization and waterlogging. Chemical runoff from farming and industry has caused serious pollution of groundwater, rivers, and bays, affecting fishing and public health. Organics dumped into adjacent waters are equivalent to what one would expect from a population 50 percent greater than Cuba's (Chap. 5, p. 136).

Cuba has successfully reforested the island, but collective agriculture required large-scale land clearing and cultivation of marginal lands. The "special period" post-1989 has led to cutting for fuelwood and charcoal, "development" of mangrove forests, and cutting for construction needs. The reforestation efforts are under pressure from the economic crisis and may prove insufficient to compensate for the externalities (Chap. 6).

Cuba is sparsely industrialized, but its technology is outmoded and polluting, emitting 9.4 million tons of carbon dioxide into the atmosphere (p. 167). There are 836 state enterprises, of which the 138 largest, in electricity, mining, oil, chemicals, sugar, food, and textiles, provide the worst pollution. Some of this pollution is mitigated by planners' attempts to distribute industry around the island to areas where wind and rain could flush pollution away from population centers, and to control immigration to the large cities.

The large sugar industry emitted liquid wastes (molasses, bagasso, cachaza, filter mud) directly into rivers and the sea, and created soot and steam, until the mid-1990s when some controls were imposed. The pulp, paperboard, and newsprint industries produce the same dangerous chemicals and air pollution as in the United States, but with little control.

Cuba's nickel resources, about 5.3 percent of the world's, are generally strip-mined and processed in damaging and uncontrolled ways, destroying landscape and emitting acids, heavy metals, and toxics like arsenic, mercury, and cyanide. Little reclamation has been done. Canadian and Australian joint ventures may lead to better practices, but so far the ammonia-leaching process has been used, leaking hydrogen sulfide, sulfur, and sulfuric acid; generating high dust emissions and acid rain that causes caustic burns; and creating 12,000 cubic meters of slurry per day. The factory at Moa may be dredging coral sand to use the calcium carbonate, destroying a pristine coral reef. Cement factories and asbestos-cement (!) factories emit 15-mile dust plumes that pollute coastal waters, La Habana, and the Florida Straits with dangerous carcinogens.

The oil refining industry, which provides 60 percent of primary energy, is highly polluting, and lately has been opened to joint ventures with five OECD countries for offshore exploration and technical modernization. Production is about 1.6 metric tons per annum, but the oil has high viscosity and high-sulfur content. Three oil refineries dump 87.5 percent of their toxic wastes directly into the ocean, largely destroying Havana, Moa, and Santiago bays. Be-

cause of outmoded technology, Cuba uses three times more energy to produce a unit of GNP than developed nations (p. 194). Cuba's thermoelectric plants burn oil and gas to generate electricity, and create serious levels of air and water pollution and acid rain.

Transportation uses about 12 percent of oil output, and is also polluting. The fleet is small (38 cars per 1000), but it consists of U.S. cars from the 1950s and awful Eastern European trucks and buses. Twelve fertilizer plants provide their share of pollution, as do four chemical factories. Of the nation's 32 cubic kilometers of water reserves, 13 are contaminated with chemical residues (Chap. 7, p. 202).

Cuba's nuclear efforts were fortunately stopped by the economic crisis. The Juragua reactor, a pressurized water VVER-440 a generation above the Chernobyl plant, was poorly built, with no quality control, little backup or containment, and insufficient training. It was never completed and was permanently closed in 1992. However, there are two research centers and three waste depositories, the latter planned for deep deposition of nuclear and toxic wastes. A nuclear accident could have spread radioactivity to Texas and Mexico and, of course, devastated the island (Chap. 8).

The deterioration of La Habana is a tragic outcome of the successful policy of rural regional development, whereby health, educational, sanitary, and amenity differentials between town and country were strongly reduced. Migration to La Habana is balanced by emigration and lower birthrates. La Habana was neglected in order to develop rural towns, leading to serious decline in housing stock, infrastructure, and basic services. Half of the 560,000 dwellings are in a poor state; 60,000 are beyond repair and need demolition; and 75,000 are propped up by wooden beams. There are 188 shanty towns, with 76,000 migrants (pp. 239-240).

Cuba has provided drinking water and sanitation services to its population, but the recent crisis has led to power outages, water availability only during certain hours, and uncertain sanitary collection. The water and sewer infrastructures are relics of a bygone era, and poor maintenance, leakage, flooding, and groundwater pollution are serious problems. Two thousand out of 3,800 km. of water lines are in substandard condition, and 30 million gallons of water are lost daily. Landfills are already beyond capacity and are heavily polluting.

Half of the 100 industrial plants around La Habana are incapable of technological improvement and must be shut down to avoid health effects of pollution. Two hundred plants pollute the water, and the rivers and bay are considered biologically dead. The bay receives 300 tons of organic matter and 40 tons of oil products per day, much of it from one oil refinery. In 1998 a barrier was placed around this plant, and technology upgrades at a gas plant, cessation of alcohol fermentation in the area, and closure of a slaughterhouse have helped lower discharges. The authors note that the situation is comparable to other Third World capital cities, but it is alarming and requires extensive mediation, the cost of which is estimated at about US\$14 billion.

## The Nazi War on Cancer

Robert N. Proctor

Princeton, NJ: Princeton University Press, 1999, 380 pp. US\$16.95 paper. ISBN: 0-691-07051-2. Princeton University Press, 41 William St, Princeton, NJ 08540, USA.

David B. Resnik East Carolina University, USA

Robert Proctor's book *The Nazi War on Cancer* is an important contribution to the history and philosophy of science and medicine. It is interesting, well written, and well researched. As an historian, Proctor is not primarily interested in developing moral arguments or drawing moral conclusions, but his book provides evidence that has a direct bearing on current debates about health policy and bioethics. All of those who are concerned about moral and political issues in science and medicine will benefit from reading *The Nazi War on Cancer*.

From start to finish the book is a fascinating account of how Germany under the Nazi regime conducted scientifically sound research on cancer, smoking, tobacco, radiation exposure, asbestos, pesticides, food additives, workplace hazards, the human diet, alcoholism, and addiction. The book tells the story of how the Nazis enacted policies that many people would regard as socially responsible, such as smoking education and prevention programs, taxes on tobacco, laws against smoking in public places, alcoholism education and prevention, laws regulating carcinogenic and toxic substances in the workplace, and bans on carcinogenic pesticides. While Proctor clearly states

that he does not defend or downplay the morally abominable acts committed by the Nazis, his book paints a portrait of Nazi science, medicine, and culture that is much more complex than the simplistic images of the Nazis one finds in media or high school history books. Proctor shows us that "good" science and "progressive" social policies could exist in a culture some would view as pure evil:

The Nazi war on cancer shows that what many of us would consider "good" science can be pursued in the name of antidemocratic ideals. Public health initiatives were pursued not just *in spite* of fascism but also *in consequence* of fascism. (pp. 248-49)

Proctor has written other excellent books on cancer and Nazi science and medicine, including *Cancer Wars: How Politics Shapes What We Know and Don't Know about Cancer*, and *Racial Hygiene: Medicine Under the Nazis*. Given his expertise in these areas, *The War on Cancer* was an appropriate topic for him to pursue. The book retraces many familiar themes of Nazi Germany, including eugenics and the drive for racial purity, euthanasia and the extermination of "unfit" populations, the belief in the superiority of the Aryan race, and the "Jewish question." During this era, all types of cancer were increasing in Nazi Germany, including lung, mouth, and throat cancer, stomach cancer, colon cancer, and breast cancer. Cancer was (and still is) a baffling disease in that it did not fit "the germ theory" model and it was not easy to prevent or treat with a vaccine or drug. Cancer also provided the Nazis with a convenient metaphor for diseases within the body politic: just as doctors must rid the body of cancer, so also must German citizens rid the body politic of its undesirable or "diseased" members. So, the "Jewish question" was analogous to the "cancer question" in Nazi Germany.

Readers of Proctor's remarkable book will discover some of the following facts about Nazi Germany:

- German researchers established a causal link between smoking and lung cancer long before the rest of the world accepted this fact. German studies on smoking and cancer were based on pathological analysis of lung tissue as well as epidemiological data. The United States did not officially recognize the connection be-

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tween smoking and cancer, and many American and British epidemiologists viewed the Nazi research on smoking as based on insufficient evidence and weak research methods.

- Many German scientists and physicians advocated “clean” lifestyles: one should avoid smoking, drinking, excessively rich food, and other sins that would harm the mind and body.
- The Germans were very concerned about how one’s diet could affect one’s health. Many researchers and physicians advocated diets high in fruits, vegetables, and fiber and low in fat and protein. German researchers studied food contamination and preservation as well.
- Adolph Hitler’s lifestyle—he did not smoke or drink and only rarely ate meat—was held up as an example for other Germans to follow.
- The Germans were especially concerned about protecting pregnant women from substances that could harm the fetus, including tobacco, alcohol, and hazardous workplace materials.
- The Germans recognized the affects of alcohol consumption during pregnancy on the developing fetus decades before the rest of the world discovered Fetal Alcohol Syndrome.
- The Germans during the Nazi era sterilized chronic alcoholics and sent many of the worst cases to concentration camps.
- The Germans regulated tobacco advertising and forbade advertisements aimed at children or ads that glamorized smokers or ridiculed nonsmokers. They had a vigorous antismoking campaign that rivals today’s campaigns with regard to resourcefulness and creativity.
- The Germans during the Nazi era proved that asbestos causes lung diseases, including cancer, and they took steps to ban asbestos in the workplace.
- Many German researchers and physicians believed that cancer and other health problems are “diseases of civilization,” and they advocated a return to more “natural” living as well as “natural” medicine, such as homeopathy.
- Economic considerations played a prominent role in public health policies. One of the main reasons why many Germans opposed alcohol and tobacco is that they regarded these substances as wasteful. One antismoking campaign claimed that two million Volkswagens go up in smoke each year. The Germans also viewed public health programs as a means of keeping down the costs of health care.

It is often said that those who do not learn from the past are doomed to repeat it. What can we learn from this dark but important part of world history? As someone who writes about issues in bioethics and health policy, I am eager to learn whether Nazi Germany offers us any

important lessons relating to contemporary debates about euthanasia, assisted reproduction, science policy, and public health measures. Many arguments in bioethics and public policy appeal to “slippery slopes” and use Nazi Germany as a defining case. For example, one of the main arguments against euthanasia is that any form of euthanasia would lead us down a “slippery slope” toward euthanasia as practiced by the Nazis (a.k.a. murder, genocide). These arguments also point out that the Nazi euthanasia program became more aggressive, inclusive, and ambitious from the 1930s to 1945. The reply to this sort of argument is that we can draw clear and firm lines with respect to medical practice, law, and public policy in order to avoid sliding down this slope. The slippery slope can be avoided with appropriate safeguards, such as informed consent, certification of a patient’s status as terminally ill or in a persistent vegetative state, etc.

Although I think the “Nazi analogy” has been overused in bioethics and health care policy, it can help us become aware of important questions relating to “line-drawing” problems and the measures society needs to take to avoid immoral or unjust outcomes. Proctor’s book invites us to think about line-drawing problems and slippery slope concerns relating to public health. Many contemporary societies have adopted public health initiatives similar to the initiatives adopted by the Nazis. For example, the United States bans smoking in public places and some types of tobacco advertising, and places high taxes on tobacco; it has a strong antitobacco media campaign; and most schools in the United States sponsor drug, alcohol, and smoking-prevention programs. All states in the United States have mandatory genetic screening tests for newborns, required immunizations for children, and required reporting of sexually transmitted diseases as well as some other infectious diseases, such as tuberculosis. Many U.S. businesses have fetal protection policies, and some states have attempted to prosecute women who takes drugs or drink during pregnancy in order to protect the fetus. The United States also has many programs designed to promote nutrition and healthy diets.

Without a doubt, these policies advance the causes of health promotion and disease prevention. I do not deny that we should try to promote these values. On the other hand, in order to promote health and prevent disease we often must sacrifice (or at least de-emphasize) other important values, such as privacy and liberty. For example, mandatory reporting policies sacrifice privacy in order to promote public health, and mandatory immunizations sacrifice liberty for public health. I think most people accept the general idea that individual rights to privacy or liberty can be restricted in order to prevent harm or promote social goods. But where should we draw the line when it comes to health promotion and disease prevention? How much privacy or liberty should we sacrifice in the name of public health? Although our modern world is in many ways

different from Nazi Germany, it faces many of the same dilemmas that the Nazis faced relating to public health. The Nazis decided that it was acceptable to sacrifice a variety of individual rights for the common good. What rights should we sacrifice or refuse to sacrifice in the name of public health? These are timely and important issues that

Proctor's book forces us to contemplate. I close this review with a Nazi slogan Proctor quotes (p. 120):

Your body belongs to the nation!  
Your body belongs to the Fuhrer!  
You have the duty to be healthy!  
Food is not a private matter!

## Prenatal Testing and Disability Rights

Erik Parens and Adrienne Asch, eds.

Washington, DC: Georgetown University Press, 2000, 371 pp. US\$65.00 cloth. ISBN 0-878-40803-7. US\$19.16 paperback. ISBN 0-87840-803-7. Georgetown University Press, 3700 O St. NW, Washington, DC 20007, USA.

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*Prenatal Testing and Disability Rights*, the result of a two-year Hastings Center project, provides not only a comprehensive and balanced defense of the disability rights critique of prenatal testing but also some of the best responses to it. In a series of reflective and well-written essays, health care professionals, scholars (particularly bioethicists), and members of the disability community reflect on the implications of prenatal testing—for people with disabilities in particular, and for society in general.

In Part 1, medical geneticist Cynthia M. Powell provides a useful report on the state of prenatal testing in the United States, expressing concern that there are not enough trained geneticists and genetic counselors available. Complementing her essay is one by Adrienne Asch and Erik Parens, two scholars who present the three major arguments voiced in the debate on prenatal testing and disability.

According to the *expressivist argument*, selective abortion subsequent to prenatal testing reflects negative attitudes about people with disabilities. Critics of this argument have retorted that a distinction can be made between devaluing

*people with disabilities*, and devaluing *disabilities per se*. Although this distinction seems reasonable, I nonetheless wonder: is it any easier to separate the disabled person from her disability, than, for example, it is to separate the homosexual person from his homosexuality?

The second disability rights argument—the *parental attitude argument*—claims that using prenatal tests to select against “unhealthy” fetuses signals a problematic conception of parenthood. Here the disagreement reduces to a debate between those who propose unconditional acceptance as the standard of parenthood, and those who find this standard unrealistic, given the imperfect nature of most human relationships.

Finally, the *misinformation argument* notes that most people without disabilities are severely misinformed about the exigencies of life with a disability, presuming that such a life is necessarily a diminished one. Many members of the disability rights community aim to correct the myth that most people with disabilities do not experience their own lives as productive, meaningful, and happy.

Connected to this emotionally volatile issue is the question of whether disabilities are best understood as “abnormalities” or as neutral human variations, diversities, or differences. In Part 2, Deborah Kent, a woman blind from birth, discusses how she felt when, early on in her pregnancy, she discovered that her parents and husband feared that she would pass on her congenital blindness to her child. She poignantly describes her realization that others view her blindness as a *defect*—an assessment that she did not share.

In another intense essay, Mary Ann Bailey explains why she would have terminated her pregnancy had her fetus tested positive for a significant genetic disability. Bailey demands that people within the disability rights community respect

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and support *personal* decisions to *not have* a child with significant disabilities.

In the next essay, Philip M. Ferguson, Alan Gartner, and Dorothy K. Lipsky note that according to recent studies, many families who have a child with significant disabilities view their situation positively (p. 85). Why then, they wonder, do so many of the “experts” continue to stress the hardships of families coping with a significantly disabled member?

Two of the remaining three essays in Part 2 are attempts to offer the disability rights debate the olive branch of a both-and approach. William Ruddick argues that we can avoid both the “bugaboo” of the perfect child and the “romantic ideal” of the perfect mother by providing balanced information about the benefits as well as the burdens of rearing children with significant disabilities. Echoing Ruddick’s sentiments, Bonnie Steinbeck adds that “there is no reason why society cannot both attempt to prevent disability and to provide for the needs of those who are disabled” (p. 121). Lest Ruddick and Steinbeck leave us with the impression that we really can have our cake and eat it too, Bruce Jennings suggests that the story of prenatal testing may have an unhappy ending, after all. He observes that prospective parents’ “choices” are overly influenced by market forces, the dominance of science, and health care professionals’ views about providing one’s baby the best of everything, from conception onwards.

Part 3 returns to the expressivist argument. Marsha Saxton stresses that the goals of the disability rights movement are neither to ban prenatal testing nor to force prospective parents to have children with significant genetic disabilities. Rather, members of the movement aim to *educate* the public about the views of the disability community (p. 161). Eva Feder Kittay, a philosopher who has a severely mentally and physically disabled daughter, and Leo Kittay, her son, and also a philosopher, exchange a series of passionate letters about the rights and needs of people with disabilities and their families. Eva defends the position that parents who choose to abort fetuses with genetic disabilities are not necessarily wrong to do so. Leo stresses that a family should not be viewed as a “club” in which the members are selected based on one characteristic or another (p. 192).

In another moving essay, James Lindemann Nelson reveals that when he was voluntarily sterilized in 1982, he worried that his three children would misinterpret his action as somehow signifying regret for having procreated them. As it turned out, Nelson’s children understood his action properly, viewing it as indicative of a socially conscious, loving father. Nelson shares his experience to make the point that “selecting and aborting do not wear their meaning on their sleeves” (p. 211). On the contrary, their meaning is determined by the context in which they occur.

Agreeing with Nelson that context affects interpretation, Nancy Press observes that disability has “two faces” and

that a “NIMBY” attitude about people with disabilities prevails among the general public (p. 225). She makes a keen point: Special Olympics events are wonderful, unless one’s own child is a team member. Another concern Press reflects on is that genetic counselors are not as non-directive as they claim to be. Indeed, she fears that genetic counselors may be “unwittingly and unconsciously, handmaidens of the system—a sort of bioethical window dressing that actually allows what Troy Duster has called ‘a “backdoor” to eugenics’” (p. 230).

In the last essay in Part 3, Adrienne Asch defends the position that there is more wrong than right about the present practice of prenatal diagnosis and selective abortion, pointing out that the general public tends to reduce people with disabilities to their disabilities. Asch, who is blind, often feels that the initial and last thing people without disabilities realize about her is her blindness, and she laments that this limited impression prevents most from getting to fully know her.

Part 4 includes discussions of the kind of policies that should guide prenatal testing. Jeffrey R. Botkin, a pediatrician and bioethicist, thinks it is possible for health care professionals to draw lines between reasonable and unreasonable tests based on factors such as the severity of the genetic condition, time of onset, and the probability that it will manifest itself as disease. In contrast, Dorothy Wertz, a sociologist, argues that prospective parents, and to a lesser extent, the general public, should be put in charge of the task of drawing the lines for “good” and “bad” uses of prenatal testing and selective abortion (p. 286).

Pilar N. Ossario predicts that as more prenatal tests are offered to prospective parents, and as extensive tests become the standard for good medical practice, we will see more suits based on wrongful birth—and wrongful life—arguments. Steven J. Ralston, an obstetrician-gynecologist, modestly writes that he does not know how to handle the problems of genetic testing and selective abortion at the macro-level. However, he has decided to handle them at the micro-level by helping patients discover their own solutions to these difficult issues (p. 339). Finally, Barbara Bowles Biesecker and Lori Hamby add that it will fall to genetic counselors, more than any other group of health care professionals, to create an atmosphere that permits clients to reflectively choose what is in the best interest of themselves, their families, and their fetuses.

Books like this one are a must read for anyone with concerns about the ethical, legal, and social implications of the Human Genome Project, particularly those who work in the life sciences and in public policy-related fields. Although I still wonder whether our society can ever entirely fend off the ghosts of the old eugenics that plagued us at the beginning of the nineteenth century, as long as we are blessed with authors as thoughtful as the ones included in this volume, we may be safely grounded.