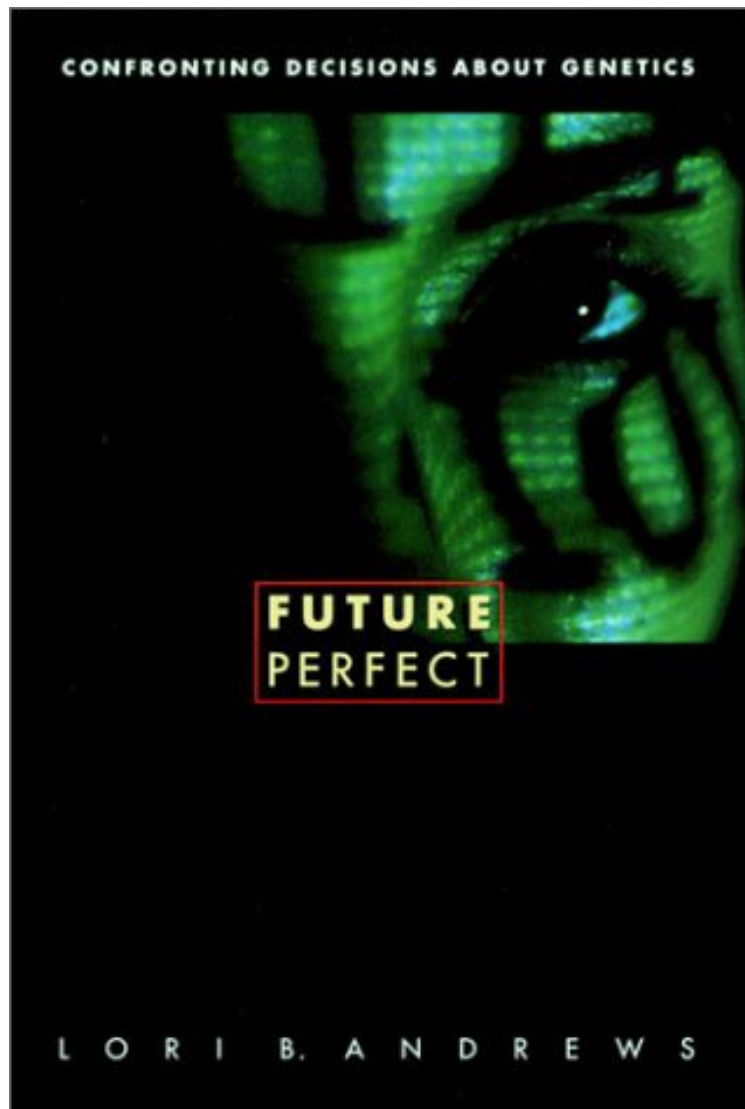


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## Future Perfect

*Lori B. Andrews*

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**Lori B. Andrews : Future Perfect** before purchasing it in order to gage whether or not it would be worth my time, and all praised Future Perfect:

0 of 0 people found the following review helpful. Half of an in-depth look at genetic testing and its implicationsBy Elizabeth A. RootIn this stilted, somewhat repetitive work, Lori Andrews tells us that we need to choose among three models for dealing with genetic testing: the medical model, the public health model, and the fundamental rights model. In truth, however, she seems to be arguing for a fourth model: no genetic testing at all. For Andrews, it appears that no good can come of it. I am left with the feeling that underlying the practical problems, she has an unacknowledged

philosophical objection to genetic testing and its medical implications. I would agree with her fundamental rights model because of its emphasis on voluntary decisions, but I fail to see how it necessarily produces better quality. This book is useful and laudable for a thorough examination of problems and issues to be considered if we are to use genetic testing and counseling. Some of them are frightening. Tests can be unreliable, more people will have worrisome knowledge that is not useful, or have bad psychological reactions of feeling stigmatized or unworthy. In some cases, Andrews seems to go a little far, arguing that aborting or averting the conception of children who will be disabled is a slap in the face to the living disabled. Perhaps she would like pregnant women to take thalidomide, or like us all to become voluntary quadriplegics so as to make disabilities the norm? There are already those who object to certain amelioration of disabilities, so as hearing aids and cochlear implants, on the grounds that it denies that identity of the disabled person and implies that the disability makes them less valuable. Some of the problems, like failures of medical confidentiality, denial of medical benefits, etc., are certainly serious problems, but they exist with or without genetic testing. And it is possible that if genetic testing made them more common, they would be viewed with more concern, and more effort made to deal with them. If we are going to make good decisions, we need to know the potential problems, but we cannot make an informed decision without knowing benefits as well as the present problems. Andrews apparently doesn't see any. Whenever she seems to be on the brink of something positive, she dismisses it or changes the subject as fast as possible. She tells us that ten percent of people who test negative for Huntingtons require psychological counseling, without discussing how many people, knowing that they have a fifty-fifty chance of inheriting the disease need help, let alone reflecting that ninety percent do not need help. She also does not consider, with some of her examples, that the reaction of the subjects might have been different if the test had been available earlier in their lives. Some people, not knowing, had lived their lives as if they had it; finding that they didn't require lifestyle adjustments or having regrets (over not having had children, for example.) But those seem likely to be the very people who might have chosen the test and so lived differently. Andrews worried, for example, about the problem of unwelcome knowledge within a family. If one person gets a test, and the results get out, other relatives will have the potentially unwelcome knowledge that they may have the same hereditary problem. That problem has existed ever since humanity noticed that some illnesses and conditions run in families. Guilt and resentment between relatives who do or do not have a condition, or inheritance of a hereditary problem existed long before genetic tests. Andrews cites the case of a couple who, finding that a fetus was going to have cystic fibrosis, called their family together to discuss the issue. Some relatives resented the possibility that the couple and their child might get an unfair amount of the family's resources. Would the situation have been different if the child had been born with the disease without forewarning? Andrews tells us that people may feel stigmatized, but again, this is not a new problem with genetic testing, only a more common one. And perhaps the very commonness would be a good thing, the realization that virtually everyone has genetic multiple genetic anomalies would make us more compassionate and supportive of one another. Andrews also does not really weigh whether or not particular problems can be dealt with. I am left with the feeling that she doesn't want solutions, since she apparently doesn't want testing at all. This book has very valuable insights into problems of genetic testing, but is by no means a thorough or adequate consideration of the subject.

2 of 2 people found the following review helpful. *Re-Thinking our Obsession with Genetics* By Erika VanNynatten I bought this book after hearing Lori speak at a forum at the University of Washington. While this is a book primarily about public policy (what our government should do about making laws covering genetic testing), it covers all aspects of genetics, from a history of genetic testing to the ways in which genetic testing information have been used and abused in our society. I came away worried about our future but hopeful that we could use the new information that genetic testing provides, without considering it the end of the line. Genetics are one piece of information that need to be considered along with ethics, other medical information, and personal beliefs.

1 of 1 people found the following review helpful. *Chapters cover all aspects of genetic issues* By Midwest Book Review Many books on genetics only address issues of interest to scientists or ethical studies programs: *Future Perfect* outlines some issues and solutions for individuals making decisions based on genetic testing and facts, providing the first insights into how such results can change self-images, relationships, and families. *Chapters cover all aspects of genetic issues; from business and employer concerns to family make-up and inherited traits.*

Genetic technologies have moved off the pages of science fiction and into our everyday lives. Internists now offer genetic testing for cancers and early coronary disease. Obstetricians make genetic predictions during pregnancy about a baby's future health. Even dentists are getting into the act, offering testing for a genetic propensity to periodontal disease. In this pathbreaking book, Lori Andrews provides the first detailed glimpse into how genetic testing can change your self-image, your relationships with loved ones, and your expectations about your children. She documents how ill prepared doctors are to deal with complex genetic issues. Andrews also uncovers the ways in which employers, insurers, schools, and courts have discriminated against people on the basis of their genetic make up. She traces the legal case history of genetics litigation and legislation and describes the ethical and social protections that need to be in place so that the Human Genome Project does not lead us directly toward Brave New World. In *Future Perfect*, Lori Andrews offers a new plan for making decisions as individuals and as a society based on emerging issues of ethics and

science. Who should have access to your personal genetic information? Should genetic treatments be used to enhance characteristics such as intelligence in "normal" individuals? Should gene therapy be undertaken on embryos, changing their genetic inheritance, as well as that of future generations? If a woman learns she has a genetic mutation predisposing her to breast cancer, does she have a moral or even a legal duty to share that information with an estranged relative? Andrews considers the answer to these and many other questions that have profound implications for health care providers, medical organizations, social institutions, legislatures, courts, and ordinary people.

From Publishers Weekly With the recently announced mapping of the human genome, the era of genetics is upon us. But how will this new information affect our decisions regarding genetic testing and treatment, especially if, as Andrews maintains, our ability to diagnose genetic diseases has outstripped both our ability to treat them and our related social policy? A scholar of science and law and an advisor to the National Institutes of Health, Andrews (*Body Bazaar*) offers a dry but insightful glimpse of the future, by examining three discrete policy models to determine which may be best suited for genetic testing. Andrews maintains that, currently, such decisions are being made by the "medical model," which stresses individual patient decisions but leaves patients too poorly informed to make good decisions. The "public health model," which is based on widespread educational campaigns or legally mandated acts such as vaccinations, is also inappropriate, because genetic diseases are not necessarily a public health problem. Moreover, mandatory screening could leave those who test positive discriminated against by employers and insurers. Instead, Andrews advocates a "fundamental rights model" that would empower the patient and ensure the high quality of health care services by requiring informed consent. Our goal now, she argues, should be to secure "an informed and knowledgeable health care provider base." The author then goes on to consider specific problems in genetic policy (e.g., the impact of negative test results, or the impact of genetic testing on minorities) under this plan. With its rather technical emphasis on how genetics will influence society and impact an individual psychologically, the book's primary audience will be policy makers, industry experts, physicians and public health officials. Copyright 2001 Cahners Business Information, Inc.

From Library Journal Andrews (law, Chicago-Kent Coll. of Law; *The Clone Age*), a world-renowned expert on genetic and reproductive technology, provides a fascinating look here at genetic screening. Rather than concentrate on the extreme possibilities that are often touted by the media, she aptly illustrates the subtle and very frightening ways that genetic screening is already affecting society, particularly women, ethnic groups, and persons with disabilities. The author contends that U.S. policymakers have not satisfactorily addressed the issues surrounding genetic technology and suggests a framework that will help to develop adequate protection for individuals and specific groups in these sensitive areas. Her extensive notes will provide useful background information for researchers. Although there are numerous publications about this broad topic, Andrews's legal insight and her ability to look beyond the superficial issues provide a breath of fresh air. Highly recommended for academic, medical, and legal collections. Tina Neville, Univ. of South Florida at St. Petersburg Lib. Copyright 2001 Reed Business Information, Inc.

From Booklist Andrews, a law professor, explores the implications and complications of advancements in genetics that potentially clash with our current values and expectations. What happens when science can identify genes associated with certain incurable diseases? What impact does that identification have on the abortion issue? What happens if your sibling is a carrier and it reflects that you are a carrier as well? What rights does a dead person have to his own DNA? Andrews shows the dangers associated with genetic studies that impact the individual's right to insurance, employment, and rights of privacy and the indirect impact on the rights of spouses, siblings, children, and family members. Andrews<sup>B</sup> points out current and potential bias associated with race and sex. In addition to raising such important questions, the author applies various conceptual models in addressing issues born<sup>B</sup> of genetic technologies, including a medical model, a public health model, and a fundamental rights model. However, such models and application reflect cultural values for which there is no consensus. Still, Andrews' book provides thoughtful insights to help address these issues. Vernon Ford Copyright American Library Association. All rights reserved