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### The Wonderful World of Genetics

George J. Annas

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#### ALWD 7th ed.

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#### APA 7th ed.

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#### Chicago 17th ed.

George J. Annas, "The Wonderful World of Genetics," *American Journal of Bioethics* 1, no. 4 (Fall 2001): 67-68

#### McGill Guide 9th ed.

George J. Annas, "The Wonderful World of Genetics" (2001) 1:4 Am J Bioethics 67.

#### AGLC 4th ed.

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#### MLA 9th ed.

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#### OSCOLA 4th ed.

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and 179–181 for his uncertainty over what to make of Caplan).

So here I am, among the mainly irrelevant few—for, like those whom Smith apparently likes but whom I've also thought wrong for strong reasons (mainly Kass). We who are not “insiders” can argue all we want and will yet suffer the fate of Paul Ramsey, who in Smith's view lost out to Joseph Fletcher and his ilk. So, then, why write a review when my long tenure in this field (since 1972) has been either ignored or, if I'm innocent of his charges, irrelevant? If I am not among the “highly ideological bioethics gurus” (219), why should I complain?—even if outside, at least, I'm not “ideological” and therefore not guilty.

However that might be, writing this review has given me the chance to say what I believe must be said—here

and elsewhere and constantly—by all of us in this difficult and compelling endeavor: There simply is no place for pundits whose practice is invariably to couch their so-called criticisms in easy abstractions and sly asides. Neither the good of vulnerable patients, the integrity of healthcare, nor the hard labor of thinking, rethinking, and speaking honestly about ethics and public morality are in any way well served by that. ■

#### References

- Hoffer, E. [1966] 1989. *True believer: thoughts on the nature of mass movements*. New York: HarperCollins.
- Neuhaus, R. J. 1990. *Guaranteeing the good life: medicine and the return of eugenics*. Grand Rapids: Eerdmans Publishing Co.

### The Wonderful World of Genetics

Lori B. Andrews. 2001. *Future Perfect: Confronting Decisions about Genetics*. New York: Columbia University Press. 264 pp.

Reviewed by George J. Annas, Boston University

Yes, yes, of course. Society is totally unprepared to deal with genetic testing. The prevailing view is that somehow it will all work out. Science is wonderful, the new genetics will make our lives better, and we will all successfully adapt. Yes we now worry about discrimination and stigmatization from genetic tests, but, as geneticist-lawyer-entrepreneur Phillip Reilly put it in his *Abraham Lincoln's DNA and Other Adventures in Genetics* (2000), “hopefully, over the next two or three years people will be gradually assured by the enactment of laws to ameliorate this fear” (233). Lori Andrews, professor of law at Chicago-Kent Law School and former chair of the federal Working Group on Ethical, Legal and Social Implications of the Human Genome Project (she resigned in protest in 1996 when the group's autonomy was undermined by Francis Collins), is not blinded by science. The future impact of the new genetics on real people she sees is anything but perfect.

Perhaps the major problem we have with the new genetics is that we don't know what to make of genetics. Where does genetics fit? Is it fundamentally new, or just more of the same? Will genetic medicine and pharmacogenetics completely displace current treatments, or is genetics familiar enough that we don't really need any new laws or rules for it, because they basically just do old-

fashioned diagnosis and treatment, only more effectively? All books on genetics at least implicitly adopt the premise that genetics is unique; and books like this one, funded by the National Human Genome Research Institute, are at least begun with the goal of having something specific to say about genetics.

Andrews lists several characteristics that make genetics different: DNA is immutable and knowledge of its content affects central aspects of our lives and thus our self-perception; people are likely to give insufficient advance consideration about the implications of genetic testing; the “therapeutic gap” means that predispositions to disease will be identifiable long before there is any treatment for them; genetic information affects a person's relatives; and genetics, especially eugenics, has a long and horrible history of abuse. This list won't convince everyone, but it reinforces my own conviction that viewing your DNA as your “future diary,” albeit one that is probabilistic and written in code, is still a good way to think about how simultaneously profound and private the predictive information disclosed by genetic testing can be.

Two of the experts Andrews quotes with approval might agree that genetics is unique, but they would still argue that we are putting far too much emphasis on it. Epidemiologist Abby Lippman asks,

Why do we construe childhood poverty as a “problem too big for ordinary mortals to tackle,” but consider mapping and sequencing all the 50,000 to 100,000 genes we have no big deal? Is children’s development disrupted more by genetic loci than by ghetto lead? Do guns or genes alone cause more premature deaths in North America? (149)

And sociologist Barbara Katz Rothman asks,

What if the earlier generation of public-health workers had spent their research money on figuring out which arm of which chromosome holds the “gene for” susceptibility to cholera? Do we want them to have figured out which people were most susceptible and what was wrong with them that made them so vulnerable. . . . I don’t care. I opt for a safe water supply. (149).

Andrews understands both the unique power of genetics and its simultaneous inability to confront most major human problems. Her discussion of genetic screening and its implications for reproduction, self-identity, insurance, and employment, for example, is careful, scholarly, and well referenced. And her insights about how genetic testing will primarily impact women, with emphasis on prenatal genetic screening and screening of newborns, are particularly strong. Since there is no treatment or prevention for the vast majority of genetic diseases, for example, prenatally discovered genetic predispositions can only be “treated” with abortion. This means that the primary short term result of the Human Genome Project will be an increase in the number of unnecessary abortions, something certainly not anticipated by the enthusiastic Congressional funders of the Project.

How should decisions about the appropriate uses of genetic testing be made? Andrews suggests that there are three possible models that we could adopt: the medical model, the public-health model, and the fundamental-rights model. Under the medical model, the one currently in use, people who can afford care come to physicians who act as the gatekeepers for medical technology. The doctrine of informed consent assures people (at least in theory) of an adequate amount of information on which to base their decision, and medical malpractice suits are available to help ensure quality. The public-health model attempts to prevent diseases through education and intervention on the population level. Since it is *public* health, the government is the central actor, and laws are often used to mandate certain interventions, including screening tests (such

as newborn screening) and vaccinations. The fundamental-rights model posits that decisions central to one’s personhood should be made by the person in a voluntary and informed setting. Reproductive decisions are fundamental decisions and should be made by individuals, not physicians or governments. I don’t think I am giving away the ending by disclosing that Andrews favors the fundamental-rights model because it “gives greater weight to individuals’ decisions about the use of healthcare services and provides greater assurances of quality.”

Given her three alternatives, this is certainly the best choice. But are those three really the only ones? The medical model can itself be divided in two: the market model (which Andrews denotes as the current medical model) in which genetics is sold as a product like hamburgers and fries to consumers who pay for it; and the medical-professional model, in which physicians actually set professional standards (such as which genetic tests should be performed prenatally) and follow them. Andrews may respond that the medical profession long abandoned its professionalism to managed care and the market, and that trying to resuscitate this almost dead corpse is futile.

More important, however, is the human rights and health model that can be seen as combining all three models into a powerful hybrid. In this model, disease is recognized as primarily a product of societal decisions rather than individual ones, and government and public health’s job is to help maximize the conditions in which health can flourish. These conditions, it turns out, involve not only basic public-health interventions, but, more important, protecting basic human rights to equality (especially gender equality), education, employment opportunity, and social justice, including poverty alleviation. The human rights environment is thus seen as much more important to health than an individual’s genetic code. Only, I think, a model like the human rights and health model, which recognizes the ecology of disease and protects the dignity of all human beings, can advance a constructive social-genetics agenda. My guess is that if there is a second edition of this book, Andrews will end it on a human rights and health note. ■

## References

Reilly, P. 2000. *Abraham Lincoln’s DNA and other adventures in genetics*. Cold Spring Harbor: Laboratory Press.