

Book Reviews

Prescribing Our Future: Ethical Challenges in Genetic Counseling

Dianne M. Bartels, Bonnie S. LeRoy, and Arthur L. Caplan, editors

Aldine de Gruyter, Hawthorne, NY, 1993, 186 pp., \$37.95 (hardcover), \$18.95 (paperback)

THIS BOOK IS AN EXAMINATION OF THE history of genetic counseling, the present ethos of nondirectiveness and value neutrality in interactions with clients, and the challenges to that ethos now and in the future. Each chapter is an original paper by the editors or other contributors on some aspect of genetic counseling.

The major theme of *Prescribing Our Future* is that nondirectiveness and value neutrality will not be an adequate ethos for the future, chiefly because of new information that will result from the ongoing work of the Human Genome Project, the effort to determine the molecular structure of all the human chromosomes.

The first section of the book discusses the evolution of genetic counseling. The Eugenic Record Office, the first American "hereditary clinic," was established at Cold Spring Harbor, NY, in 1910. At first, persons with doctorates in genetics did basic scientific research and provided genetic counseling which had a preventive, eugenic focus. Gradually, counseling teams included persons with doctorates in genetics and physicians. Eventually, even these could not meet the demand for genetic counseling, so in the 1960s and 1970s master's degree training programs were established.

The goal of genetic counseling remained the prevention of genetic disorders, but gradually psychosocial skills were included in curricula so counselors could help families in ways that emphasized client autonomy. The shift toward

a communication-based model rather than a preventive or eugenic one came about as the world became aware of the Nazi atrocities and the unethical practices in the United States and other nations that were carried out in the name of eugenics. In 1955 Dr. Sheldon C. Reed, director of the Dight Institution for Human Genetics at the University of Minnesota (who introduced the term "genetic counseling"), called for a "deep respect for the sensitivities, attitudes, and reactions of the client."

There are now 21 master's-level programs in the United States that graduate more than 100 students annually. The National Society of Genetic Counselors, which was founded in 1979, developed a code of ethics in 1990. The code specifies that counselors "enable their clients to make informed, independent decisions, free of coercion, by providing or illuminating the necessary facts and clarifying the alternatives and anticipated consequences."

The workplace ideology of genetic counselors in the early 1980s was a nondirective ethos and a principled stance of value neutrality, limiting the role of the counselor to information giver or decision facilitator. In theory, physician counselors exerted no constraint over their clients' autonomy. However, an examination of actual practice in the field showed that it is possible to inadvertently or deliberately influence decision making by the selection of facts presented and by the manner of their presentation.

The second part of the book discusses social and policy issues in genetic counseling. As our knowledge expands and the Human Genome Project progresses, nondirective, value-neutral ideology is coming under pressure. Genetic counselors are challenged to prepare for change as more information becomes available and the demand for genetic services increases. As technological advances are made, families will face more difficult decisions, and counselors will

need skills in communication and psychosocial counseling. Well-informed consumers will refer themselves and make requests based on what they have learned through the media.

Walter E. Nance, Department of Human Genetics, Medical College of Virginia, Virginia Commonwealth University, says that by the time the Human Genome Project has been completed, perhaps by the end of the 1990s, we will have 10 to 20 times as much clinically relevant genetic information as we have today. More will be learned about conditions that are not classified as diseases today, such as short stature, and there will be requests for testing and counseling about them. There will also be pressure to contain healthcare costs by preventing the birth or compelling the treatment of those likely to have costly diseases. Public health policies will probably take a proactive and prophylactic stance toward disease prevention.

The third section of *Prescribing Our Future* discusses future directions and ethical challenges in genetic counseling. LeRoy Walters of the Kennedy Institute of Ethics at Georgetown University reports on the predominant ethos among genetic counselors. A survey of genetic counselors in the United States and abroad published in 1989 indicated a consensus that genetic counseling should be nondirective. But another survey found that many medical geneticists believed that in certain circumstances directive counseling may be appropriate, if done by wise and experienced counselors. They believed that principles of beneficence or justice may sometimes take primacy over respect for autonomy in the decision-making process. Between 1985 and 1987 a survey was done on the circumstances in which respect for autonomy might be called into question in current practice. Responses of 682 medical geneticists in the United States and 18 other countries showed diverse ideas of what should be done and why. Three questions posed the most difficulty:

- Prenatal diagnosis for the purpose of

sex selection, with the intention to abort the child if it is not the desired sex

- Confidentiality about a Huntington's disease patient when others in the family are at risk and the patient does not want them contacted

- Disclosure of false paternity to the wife alone, to the husband, to the couple together, or not at all

Arthur L. Caplan of the Center for Biomedical Ethics at the University of Minnesota points out that screening and counseling that has prevention as its goal is not always morally neutral. And eugenic goals have not completely disappeared from our practice today. For instance, when the state of California

offers to all pregnant women testing for serum alpha-fetoprotein, it hopes that some women whose fetuses have neural tube defects will choose not to bring them to term, thus saving the state the cost of their care. This is hardly morally neutral.

Caplan concludes that the time has come to abandon the pretense of moral neutrality, both in the clinical setting and in the public policy arena. He says that the central ethical question in the field now is how to *define* genetic disease in order to identify appropriate testing and counseling. The current value-neutral ethos of genetic counseling is, in his opinion, inadequate.

Prescribing Our Future will be of value to genetic counselors, even if they are already aware of the information presented. It draws together the mileposts in the development of the present ethos in the profession and the future challenges to it. The book will also be of value to anyone interested in biomedical ethics and its future development, especially in the light of the new information provided by the Human Genome Project.

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BOOK BRIEFS

Long-Term Care Administration Handbook

Seth B. Goldsmith, ed., Aspen Publishers, Gaithersburg, MD, 1993, 592 pp., \$79

More than 40 experts in long-term care share their analyses of the major issues facing the field. The first eight chapters cover background issues, such as medical directors' and nurses' roles, ethical decision making, and mental health. The next 15 chapters deal with long-term care management. Seven chapters examine support systems in long-term care, such as food service, social work, and chaplaincy services. And six final chapters look at the future of long-term care management.

Bioethics, ed. 4

Thomas A. Shannon, editor, Paulist Press, Mahwah, NJ, 1993, 542 pp., \$24.95 (paperback)

Authors of the book's 30 current articles from medical, ethical, philosophical, legal, and theological journals discuss topics such as gene therapy, advance

directives, and privacy and disclosure. The book's first eight articles focus on abortion and reproduction. Daniel Callahan, Rev. Richard A. McCormick, SJ, and Marc Lappé authored three of the articles. The second part of *Bioethics* discusses death and dying, with articles by authors such as Timothy E. Quill, and Albert R. Jonsen. Steven H. Miles, and Terrence F. Ackerman wrote two articles in the book's third section, which covers consent, therapy, and research. The final chapters address public policy issues, with contributions by Robert M. Veatch and Alexander Morgan Capron, among others.

AIDS and Community-based Drug Intervention Programs: Evaluation and Outreach

Dennis G. Fisher and Richard Needle, eds., Harrington Park Press, Binghamton, NY, 1993, 223 pp., \$17.95 (paperback)

These proceedings of the AIDS Prevention Symposium trace the conceptual, methodological, empirical, and policy-related programmatic developments of

the National AIDS Demonstration Research (NADR) project, sponsored by the National Institute on Drug Abuse, and the Cooperative Agreement (CA) project. Both NADR and CA were designed to support community-based interventions to prevent the spread of the HIV among injection drug users (IDUs), other drug users at high risk for HIV infection, and sexual partners of IDUs. In the book's 14 chapters, contributors cover topics such as the need to balance prevention research and service in demonstration programs, develop behavior-change strategies for high-risk women, and design quantitative and qualitative methods to assess behavioral change among IDUs.

BOOKS RECEIVED

Inquiries in Bioethics, Stephen G. Post, Georgetown University Press, Washington, DC, 1993

A Minister's Handbook of Mental Disorders, Joseph W. Ciarrocchi, Paulist Press, Mahwah, NJ, 1993