Book Review

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Human Genetics: Choice and Responsibility. By the British Medical Association. Oxford: Oxford University Press, 1998. Pp. 235. £7.99 (paper).

The product of a large and multifaceted committee, this excellent compendium provides no quick or easy answers. The British Medical Association (BMA) assembled a 17-member Steering Group to produce this guide to virtually any ethical problem that might present itself in medical genetics. These editors include the Bishop of Edinburgh, several geneticists and general practitioners, a genetic counselor, a consumer advocate, a social scientist, and two bioethicists. The book's great strengths are its balanced, even tone, its comprehensive approach, and its accessibility. Although aimed at health professionals—including general practitioners and nurses, as well as genetics specialists—it is purposely couched in terms understandable to laypeople, and so it avoids both biomedical jargon and the specialized terminology of academic philosophy.

The volume opens with brief definitions of harms, benefits, and disability, followed by a discussion of commonly held ethical principles that is presented in terms comprehensible to laypeople. A 10-page chapter on basic genetics follows. Succeeding chapters deal with prenatal diagnosis and screening and their societal implications, eugenics and respect for people with disabilities, carrier testing, presymptomatic testing, testing children, adoption, population screening, newborn screening, nondirectiveness in counseling, medical and social uses and misuses of genetic information, paternity testing, forensics, and gene therapy. A brief 7-page section deals with regulations, both in the United Kingdom and internationally. Summary statements are boxed for ease in skimming. Each chapter also includes a comprehensive, but not overwhelming, list of references.

Throughout the book, the editors' stated intentions are to present all reasonable sides of an issue, taking a definite stance only when the BMA has already taken a policy position on a related issue, or when other bodies—such as the Nuffield Council on Bioethics or the House of Commons Science and Technology Committee—have presented recommendations. The editors have done an excellent job of foreseeing the different possibilities and pitfalls in each situation, including many that may not seem immediately obvious. Their fundamental principle, which is shared by most American medical ethicists, is individual autonomy, but they acknowledge that individual rights are not absolute. They recognize the need for mutuality, especially toward family members who may be able to use genetic information about an individual to prevent harm to others. With admirable common sense, the editors note that the family is more likely than government or employers to seek an individual's genetic information. BMA recommendations for overriding confidentiality are similar to those of the ASHG's statement on Professional Disclosure of Familial Genetic Information (1998), but include considerations of the emotional effects of receiving unexpected, and possibly unwanted, information. Here, as elsewhere, the editors avoid proposing strict rules.

In general, the book takes the view that the embryo and fetus deserve some, but not absolute, respect. Although the BMA argues throughout this book that "enhancing individual choice rather than directive encouragement towards termination of an affected pregnancy must be seen as the principal objective" of prenatal diagnosis (PND) (p. 48), the editors recognize that many members of the British medical profession espouse more "preventive" views. Indeed, they point out a 1993 survey that found that one-third of British obstetricians require patients to commit to abortion before the procedure. The arguments recognize, with considerable sensitivity, the viewpoints of the disabled community, while balancing these viewpoints against families' rights to choose. The positions of the Genetic Interest Group (GIG), the United Kingdom's umbrella organization for genetic support groups, are represented throughout. The editors warn against discrimination against "expensive" or "uneconomic" patients, and they reject sex selection as a goal of medical intervention, regardless of whether the technique in question operates during the preconception, preimplantation, or prenatal period. Like many projects of this sort, this document does not define the "serious" disorders for which PND is ethically permissible or the "trivial" pursuits that should be kept outside presumed boundaries. Such definitions are perhaps impossible.

Unlike most discussions of PND in the United States, this book recommends caution in the use of PND procedures for adult-onset disorders, partly because if the fetus is carried to term, the resulting child will have received a presymptomatic test without consent. In a typical compromise position, the editors express concern about routine use, but agree that in some circumstances testing is appropriate. A balanced discussion of the issue leads them to discourage the testing of minors for carrier status or for disorders that occur later in life, but they urge a flexible approach that acknowledges the benefits, to both child and family, of testing in some cases.

The report leaves the door open to future attempts at germline gene therapy, provided that it is first proven safe and efficacious. Although all agree that there is still insufficient knowledge to evaluate risks and that, therefore, human research should not be undertaken, philosopher John Harris, a

member of the Project Steering Committee, argues that, in the future, there could actually be an ethical obligation to use germline therapy under the principle of avoiding harm.

The panel rejected all forms of human cloning, including splitting of embryos in in vitro fertilization, that would produce "identical" siblings, on the basis that, at present, the possible harms appear to outweigh the benefits. The report urges caution about premature legislation, however, and quotes a House of Commons report on the cloning of animals, to the effect that it is important to "keep such matters under review, as science develops and public attitudes shift, since it is possible, as in other areas of science and medicine, that developments which were originally considered objectionable may come to seem routine."

This compact paperback could serve as an excellent text for medical school courses in human genetics, especially since boxed summaries and brief sections of individual chapters could be pulled out for discussion. The book could also be useful for both general practitioners and experienced geneticists around the world, since it touches on most issues in clinical practice.

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