

Book Review

GENETICS AND PUBLIC HEALTH IN THE 21ST CENTURY.

By M.J. Khoury, W. Burke, and E. Thomson, Oxford University Press, New York, NY, 2000, 639 p.

Because public health professionals will increasingly use genetic technologies and information in research, policy and program development, the purpose of the book, as stated in the Preface, was to delineate a framework for the integration of advances in Human Genetics into Public Health practice. Even though the book was written by many contributors from various disciplines, the editors succeeded in keeping uniformity of the format, and the book represents a definite entity discussing many aspects of the subject.

The book is divided in six parts. The first part consists of an overview of the principles of human genetics in public health, and includes the presentation of a framework for the integration of human genetics into public health that was developed as part of the Center for Disease Control (CDC) strategic plan. The second part relates to public health assessment in genetics, in particular on various issues on surveillance of birth defects and genetic diseases and disorders with a genetic component. The third part of the book is devoted to public health evaluation of genetic testing, such as the quality assessment program for newborn screening. The last two parts of the book deal with some ethical and social issues, education, and information dissemination.

The main part of the book is on developing, implementing, and evaluating population interventions. Although there is one short chapter from the Netherlands, and another referring to developing countries, it would have been interesting to add experiences from other countries, in particular from Europe and the WHO program on Human Genetics. I was surprised to see that there are no chapters dedicated to carrier screening programs or to prenatal screening programs. I understand, however, that this was purposeful, as

stated on page 69 in a chapter for which one of the editors was an author: "...it is the authors' views that the goal of Public Health genetic screening programs should not be genotypic prevention, because the decision to undergo prenatal screening diagnosis and to consider pregnancy termination is intensively personal and should not be influenced by public health goals, professionals agencies or organizations. Although some geneticists have assessed prenatal testing programs on this basis, such goals can have eugenic implications." As a geneticist, I find this approach very disturbing, because the goals of prenatal genetic programs have never included the abortion of abnormal fetuses. The purpose of carrier screening programs is to give the individual or the couple, a choice to decide whether or not to have the test and whether or not to use it during a pregnancy. The programs for carrier detection of hemoglobinopathies in Mediterranean countries and the U.K., or of Tay Sachs disease among Ashkenazi Jews, have been very successful. A lot may be learned from these programs because millions of individuals have been screened and much of the experience gained should be used in future Public Health genetic screening programs, even if the aims are different. Similarly, the worldwide experience in the programs offering prenatal diagnosis for Down syndrome should have been discussed.

In each of the six parts of the books there are excellent chapters that give very good summaries of each of the respective subject. These chapters may serve as the basis for teaching relevant courses. It is my feeling that this book should become a reference to students and practitioners not only in the field of Public Health but also in the field of Medical Genetics.

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