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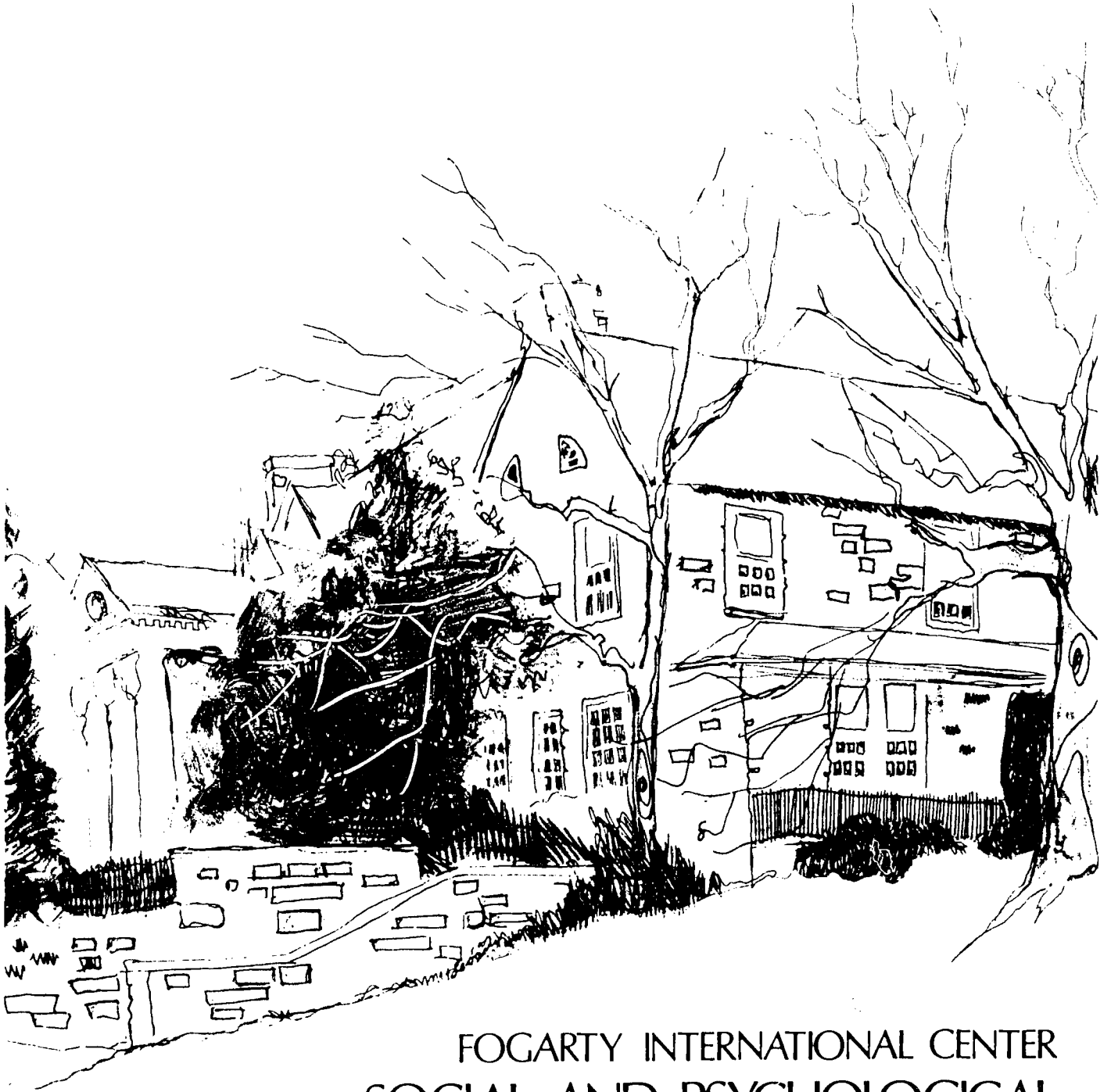
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ABSTRACT

This bibliography is a selective compilation of books and articles which focus on the psychological and social issues of applied human genetics. It is centered in particular around problems, issues, and discussions of genetic counseling, the primary mechanism by which human genetics has been applied to date. It includes those entries which, on the basis of information conveyed in the title, appear to be primarily concerned with social and psychological issues of applied human genetics in general, and genetic counseling in particular. The articles and books are arranged according to subject matter, usually on the basis of information given in the title, occasionally on the basis of bibliographical source subject-heading. Division of subjects was determined primarily by the number of articles that seemed to have a common area of concern. This bibliography should be especially useful to social and behavioral scientists conducting research in this area, to social workers, to genetic counselors interested in the problems and perspectives of practicing the art and science of genetic counseling, and to other allied health professionals engaged in applying human genetics. The publication of this bibliography was sponsored by the Fogarty International Center of the National Institutes of Health because of its interest in the social and ethical aspects of research in human genetics and in the application of these research advances to medical care. (Author/JM)



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INTRODUCTION

Within the past few decades, discoveries in basic science and developments in medical technology have significantly increased the role of human genetics in medical practice and daily life. Discovery of the genetic basis of an increasing array of bodily and mental disorders, as well as the development of a technology permitting *in utero* analysis of certain aspects of fetal bio-genetic health, are rapidly altering man's classically passive orientation to his genetic endowment. The development of mass screening for carriers of heritable derangements enables genetic and chromosomal health considerations to become important factors in mate selection and determination of the reproductive future of a couple. Even more frequently, procedures such as amniocentesis are permitting families to consciously determine, for the first time, the outcome of pregnancy on the basis of fetal, genetic and chromosomal characteristics.

Such developments raise an array of psychological and social issues for both the professionals administering these advances as well as for individuals with genetic problems. Our understanding of the meaning and significance of genetic disease for individuals and society and the problems encountered in the professional delivery of such knowledge is very meager compared to the battery of scientific and technical knowledge permitting increased control of genetic disease. For the wisest and most humane utilization of human genetics, it seems mandatory that we begin to explore the social and psychological aspects of applied human genetics as a means to develop an understanding of these issues commensurate with our understanding of the scientific-technical aspects of applied genetics.

For these reasons we have prepared this bibliography on the social aspects of applied human genetics. It should be especially useful to social and behavioral scientists conducting research in this area, to social workers, to genetic counselors interested in the problems and perspectives of practicing the art and science of genetic counseling, and to other allied health professionals engaged in applying human genetics.

This bibliography is a selective compilation of books and articles which focus on the psychological and social issues of applied human genetics. It is centered in particular around problems, issues, and discussions of genetic counseling, the primary mechanism by which human genetics has been applied to date. The bibliography is not exhaustive in its coverage, as it does not try to include those books and articles which deal with the ethical or proscriptive areas of human genetics. Rather, it includes those entries which, on the basis of information conveyed in the title, appear to be primarily concerned with social and

psychological issues of applied human genetics in general, and genetic counseling in particular.

Entries observe the following format: within a subject area, articles are listed first, alphabetically; then books are listed alphabetically. The title of a journal is followed by the number of the volume and the page numbers of its location. The number of the issue is generally omitted.

The articles and books are arranged according to subject matter, usually on the basis of information given in the title, occasionally on the basis of bibliographical source subject-heading. Division of subjects was determined primarily by the number of articles that seemed to have a common area of concern.

Bibliographical reference works searched for this bibliography include the following:

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This bibliography was compiled as part of a research project at Princeton University on the social aspects of applied human genetics and was directed by Professor James R. Sorenson. The funding for the bibliographic work was provided by the Russell Sage Foundation, 230 Park Avenue, New York City, New York. Assistance in the compilation was provided by Katherine Courant, Nancy Sorenson, and Camille Yinger.

The publication of this bibliography was sponsored by the Fogarty International Center of the National Institutes of Health because of its interest in the social and ethical aspects of research in human genetics and in the application of these research advances to medical care.

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