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GENETICS AND ETHICS IN GLOBAL PERSPECTIVE

by

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SPRINGER-SCIENCE+BUSINESS MEDIA, B.V.

A C.I.P. Catalogue record for this book is available from the Library of Congress.

ISBN 978-1-4020-2880-9 ISBN 978-94-007-0981-2 (eBook)

DOI 10.1007/978-94-007-0981-2

Printed on acid-free paper

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Originally published by Kluwer Academic Publishers in 2004

Softcover reprint of the hardcover 1st edition 2004

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PREFACE

Every book contains the story of how it came to be written. Over the years, many people have asked us how we arrived in the rather unusual position of doing social science surveys of ethics and human genetics. John Fletcher has already described his odyssey in the introduction to our previous book, *Ethics and Human Genetics: a Cross-Cultural Perspective* (1989): his deaf parents, his years in the Episcopal ministry, his founding of an interfaith theological seminary that provided pastoral training for Protestants, Catholics, and Jews, his research on families having prenatal diagnosis, which culminated in *Coping with Genetic Disorders: A Guide for Clergy and Parents* (1982), the first book of its kind, his 11 years as Chief and sole member of the Bioethics Program of the National Institutes of Health, followed by leadership of the Bioethics Program at the University of Virginia Medical School. Now it is time for me to tell my side of the story.

I was interdisciplinary from the beginning, a route that, for employment reasons, I always urge students not to take. At Radcliffe College/Harvard University I majored in Social Relations, an undergraduate program that combined Sociology, Social Psychology, and some Cultural Anthropology. I audited almost as many courses as I took for credit, mostly in Philosophy. After a rather unproductive year studying anthropology at the London School of Economics, I returned to Harvard to study existentialism, at the invitation of philosopher John Wild. As the Philosophy Department taught mainly logical positivism in the late 1950s, I had to enter an interdisciplinary program called History and Philosophy of Religion. After Wild left Harvard, I returned to my original interest in social science and specialized in Religion and Society, still under the same broad interdisciplinary committee. My thesis was on social conflict resolution in the fourteenth-century medieval morality plays; it taught me that writing a thesis and convincing a committee to accept it was more a work of salesmanship than scholarship. Harvard teaches its students to think independently and on their feet. Although several famous names appear on my oral examinations, including social psychologist Gordon Allport, sociologist Talcott Parsons, psychiatrist John P. Spiegel, and social ethicist James Luther Adams, I never had a mentor. Most women didn't in those days. Being a woman in religion was somewhat of an oddity. My first professional conference consisted of what seemed like 500 men and myself, the "invisible person." I quickly found out, on entering the job market, that most schools were not eager to hire women, especially in religion. Relying on my undergraduate major, I shifted to sociology, then a rapidly expanding field, and, over the course of 16 years at nine different colleges and universities, taught virtually every course in the sociology curriculum, plus a number in anthropology and psychology.

Along the way, I came to be co-author, with my husband Richard, of *Lying-In: A History of Childbirth in America* (1977, Expanded Edition 1989). The book emerged, not from our personal experience (we had no children), but from Dick's enduring interest in technology and society in American life, a course that he teaches to this day. In 1972, members of the Boston Women's Health Book Collective spoke in his history of medicine course at MIT and described the technologization of birth, which

should be a natural event requiring little intervention. I was then commuting from Boston to Connecticut to teach (an early example of commuter marriage), and Dick asked me to go to the Yale University library on my day off and see when episiotomies and routine forceps came into use. I returned so full of fascinating information that we decided to write an entire book on the history of birth in America, as an example of the complex interactions between culture, gender, and technology. As we progressed through our ten revisions of the manuscript, the emerging Women's Movement of the early 1970s played a greater role in our thinking.

In 1979, seeking an escape from undergraduate teaching and an opportunity to support myself by research and writing, I approached Boston University School of Public Health, book in hand, and asked if I could apply for a fellowship. The School of Public Health at B.U. was not doing anything related to birth at that time (they have since instituted an entire program in Maternal and Child Health); their closest area to my interest was a national survey of genetic counseling recently completed by sociologist James R. Sorenson, who agreed to act as my supervisor. After an initial false try (the reviewers did not like Jim's calling me "a lady and a scholar"), in 1981 I received three years of fellowships from the National Science Foundation, the longest-term stability in my career to that date. Jim taught me how to write articles for scientific journals (quite a different endeavor from writing a book), about how to approach a large data set, and how to present tables. Together we wrote a number of articles based on his genetic counseling survey, which remains the largest study of its kind. At the end of September, 1984, a month after my fellowship ran out, Jim received a call from John Fletcher, who had just returned from a six-month sabbatical visiting genetics centers in Europe. John was convinced that geneticists around the world were coming to a consensus about the resolution of ethical problems that occur in clinical practice, and wanted Jim's help in doing an international survey of geneticists to document this consensus. Jim, having little time available, enlisted my help and gradually turned the project over to me. There began a collaboration with John that has lasted 16 years.

In 1984–86, we did a survey of 683 geneticists in 19 nations, and found considerably less consensus than John had anticipated. We first presented the results at the 1986 International Congress of Human Genetics in Berlin and subsequently published them in *Ethics and Human Genetics: A Cross-cultural Perspective* (Berlin: Springer-Verlag, 1989).

As time went on, we were asked to share our findings with a variety of national and international ethics bodies. The Science Council of Canada invited me to participate in a project on ethical provision of genetics services. Subsequently, the Royal Commission on New Reproductive Technologies (Canada) commissioned me to write a paper on "Prenatal Diagnosis and Society." I became a member of the various ethics committees of the American Society of Human Genetics, Council of Regional Networks of Genetics Services, New England Regional Genetics Group, and finally, the international body of researchers, the Human Genome Organization (HUGO). Together with John, I was instrumental in developing three major documents on ethics and genetics for the World Health Organization.

Some geneticists thought that our survey should be repeated every 10 years, in order to identify trends. The first survey was supported by small grants from private foundations and a lot of volunteer labor. This time we resolved to do the work with

adequate support. Felix de la Cruz of the Mental Retardation and Developmental Disorders Branch of the National Institute of Child Health and Human Development (National Institutes of Health) encouraged us to negotiate a contract for the North American portion of the study. His staff members, Dorothy McKelvin and Harvey Shifrin, were attentive throughout the project. Eric Juengst of the Ethical, Legal, and Social Implications (ELSI) Branch of the National Human Genome Research Institute (NHGRI) helped with the international aspects of the project, under a peer-reviewed grant to the Eunice Kennedy Shriver Center for Mental Retardation in Waltham, MA.

This time we resolved to include United States primary care physicians in the study, because they will likely be doing much of the counseling and testing in the future. We also included US and Canadian patients, a group whose voices had been rarely heard. Internationally, we sought to include countries that had withdrawn from the earlier study, such as China and Russia, and also to include much of Latin America. In all, 36 nations participated. Unfortunately, we still failed to get adequate representation from the Muslim world.

Our purpose in doing surveys is not to “do ethics by the numbers.” Majorities, even large majorities, can be wrong from an ethical point of view. Our purpose is to present a basis for national and international discussion. People often think that they already know how their professional colleagues will respond to a situation, but they may have little basis for such suppositions. The survey responses – given by individuals privately, not in the public glare of a professional conference – have shocked many geneticists around the world. Usually people are most shocked by the responses from within their own country. Until these private ethics come before the public, it is difficult to have meaningful discussions of what really should occur.

Our questions are based mostly on clinical practice, not research. Since we completed the survey, a number of research issues have come to the forefront, including cloning, enhancement of intelligence, use of embryonic stem cells, and research use of collections of stored human cells. Although some of these issues have aroused media attention, none has yet affected clinical practice. Geneticists dislike answering hypothetical questions or questions about procedures that have not yet arrived; hence we omitted most hypotheticals, with the exceptions of pre-conception sex selection and testing for genetic predisposition to behavioral conditions such as alcoholism. If we were to do the survey today, we would include more questions of a research nature.

The first eight chapters describe the survey’s methods and results, in considerable detail. In order to spare the reader from verbal statistics, we have combined a largely non-numerical text with detailed tables. The text summarizes and comments on the tables and can be read independently by those who are interested in the general picture without a plethora of numbers. Those interested in seeing how a particular country responded, or how countries compare, can turn to the tables. We considered consolidating the responses of individual countries into “culture areas,” as for example, Latin America, an approach that would have considerably shortened the tables. However, there was so much difference between countries in a culture area (as for example, between Brazil and Chile, or Japan and China) that we think it would be misleading to try consolidation, except in the few instances where there was close agreement. International readers are usually interested in how a particular country responded, so that they can use the information in ethical and policy discussions. We consider the detail a strength of this report.

There follow sections on Genetic Services, Laws Affecting Genetics, and Geneticists Speak Out. The latter reports personal observations or pleas for change from our international authors. In the previous book we had a chapter written by a geneticist from each of the 19 countries surveyed. In this book, we could not do the same for 37 nations. Instead, we have selected what we consider the most interesting six chapters for inclusion, and have incorporated portions of the remainder into the three sections above.

The final two chapters describe some of the ethical complexities involved in the survey questions, in the context of varying economic, cultural, and religious backgrounds, and attempt to delineate what should be done in genetic services. The outline of the concluding chapter parallels that of the introductory chapters.

We would like to thank our international collaborators who distributed and collected the survey questionnaires, and whose names appear on page, our authors (who appear in the “About the Authors” section), and those who helped us to design the survey questions, including Betsy Anderson, Joan O. Weiss, Richard W. Erbe, Marvin Natowicz, Philip R. Reilly, Thaddeus E. Kelly, and the providers and consumers who participated in the field tests. This project could not have succeeded without the help of research assistants Wanda Hunt and Robin Gregg. Mary Jo Rosenblatt assisted with telephone follow-ups, and Lee Picard oversaw financial concerns. Leslie Cabral provided secretarial assistance in the early stages, and Donna Caira typed the final manuscript.

We hope that others will undertake similar pursuits in the future and that our efforts will serve to guide them.

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