INTRODUCTION

Women and Prenatal Testing:
An Introduction to the Issues

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Childbearing in the 1990s has brought with it new and expanding reproductive genetic testing options. These developments have led some to claim that now is an ideal time to be having children because the new procedures provide women with previously unavailable information about their pregnancies. Others maintain, however, that in the era prior to the advent of these options, reproductive ignorance was bliss. They contend that with fewer diagnostic interventions, fewer reproductive decisions were required of women. Today, some would claim that this increasing knowledge mandates increasing and perhaps unwarranted responsibility. While some women have greater knowledge about their pregnancies, so too do they face increasing pressure to do as much as is technologically possible to ensure the birth of a healthy child.

Along with these reproductive testing options have come obstacles that create new challenges. Reproductive genetic technologies are complex and difficult for many women to comprehend. Their purposes, benefits, risks, and limitations are not uniformly defined by providers nor fully understood by many women. Today, prenatal testing can disclose hundreds of disorders. Treatment or cure, however, is not possible for most of them. Some providers state that prenatal and perinatal care can sometimes be improved through increased prenatal knowledge. Yet in many cases there is nothing that can be done to improve
the outcome of the pregnancy, other than to terminate the pregnancy or prepare for the birth of a child with a disability.

In the majority of cases, especially when the disorder is perceived as serious, women choose to terminate the pregnancy. Some providers of reproductive genetic testing services do not provide the abortion services and, as a result, many women feel isolated and abandoned at this time in their pregnancy. Clearly, prenatal genetic knowledge does not necessarily guarantee successful treatment, cure, or care. Yet despite the lack of treatment or cure for diagnosed conditions, more women are being offered these services. Many women feel obliged to accept testing; they do not perceive that they have a choice. Ironically, many other women, because of little or no access to prenatal care, are also denied reproductive genetic testing services, even when they are desired.

As reproductive genetic technologies expand and provide more information about genetic diversity, so too does the complexity increase of the issues raised. For example, some proponents of first trimester prenatal diagnostic methods such as chorionic villi sampling (CVS) contend that early diagnosis will result in better care for women, especially for those in whose expected child a birth defect or genetic disorder is identified. Women who face the decision about whether to continue or terminate a pregnancy would thereby be allowed to make the decision in the first trimester rather than in the second. Although anecdotal reports exist, there is no scientific evidence supporting the assumption that first trimester fetal diagnosis actually makes prenatal diagnosis better for women. Whereas evidence exists that pregnancy termination is biologically safer in the first trimester, there is no corresponding evidence that it is psychologically easier. It may also be true that natural pregnancy loss would have resulted in a number of cases in which a genetic disorder was identified early and the pregnancy was intentionally terminated. Thus, it should be considered that one result of earlier prenatal testing may in fact yield a larger number of women faced with the decision of whether to continue or terminate a pregnancy. Additionally, because CVS does not provide information about one of the most common birth defects (spina bifida and other neural tube defects), women will be
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encouraged to undergo further testing for these conditions into the second trimester of pregnancy. What impact does such periodic testing have on women and their pregnancy experiences?

Advocates for the development of the noninvasive methods of prenatal diagnostic methods believe that eliminating the potential biological risks associated with prenatal testing will make the decision to have prenatal testing easier for women. Whether the development of noninvasive methods for prenatal testing will make women's decisions to have prenatal diagnosis more or less complicated is not known. Will there be some risk for increased directiveness on the part of providers to ensure that the testing is carried out? Will such noninvasive testing be moved further into the realm of routine testing that is carried out as a part of prenatal care? Will women feel even more obliged to accept testing when there are no biological risks associated with the procedure?

In order to begin responding to some of these issues, a workshop was held in the fall of 1991 on the campus of the National Institutes of Health. This meeting was cosponsored by the National Institute of Child Health and Human Development, the National Center for Human Genome Research, the National Center for Nursing Research, and the Office of Research on Women's Health. It was designed to provide a forum for dialogue among the basic scientists, providers of these services, social scientists, ethicists, and lawyers on how best to begin to address these issues. At the end of this book, in the appendix, is the Workshop Summary Statement highlighting some of the themes that emerged from the discussions of that meeting. The proceedings of the entire workshop were published in the journal, *Fetal Diagnosis and Therapy* (1993) Vol. 8, Suppl. 1.

This book is designed to focus primarily on the major women's issues surrounding the development and application of reproductive genetic testing. Although the literature is filled with articles addressing the biological safety and efficacy of these technologies, only a small amount of literature is devoted to the psychological, sociocultural, ethical, legal, or political impact of their application on women and their pregnancy experience. Following this brief introduction is a series of chapters designed to stimulate discussion on the complex issues being
raised by the increasing application of prenatal genetic technologies. Featured are the voices and questions of women coming from a variety of perspectives and experiences. A number of the authors have themselves been consumers of such services.

The book is divided into three main parts: The Context of Debate; Philosophical, Ethical, and Legal Perspectives; and Psychological and Sociocultural Issues. Part 1 provides the contextual framework through which the debate should be analyzed. Part 2 sets forth the philosophical foundations and complex ethical questions raised, as well as the types of legal issues that need to be addressed. Part 3 delineates a variety of perspectives on pertinent psychological and sociocultural issues.

Our goal is to examine reproductive genetic testing in the context of women's lives. Potentially, the major risk associated with reproductive genetic testing may come in not knowing how to cope with the information obtained from these procedures, rather than with the procedures themselves. Such knowledge may have a lasting impact on women, their families, and their pregnancy experiences. These and other issues will need to continue to be addressed in order to confirm or deny the anticipated benefits and risks of developing reproductive genetic technologies. It is our intention that this book will contribute to a further understanding of the issues.