

# The New Genetics and Women

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**T**HE HUMAN GENOME PROJECT (HGP) IS A WORLD-WIDE effort to map and sequence all of the 100,000 or so genes that are found in the 47 chromosomes of human beings. Each gene comprises a sequence of four chemicals called nucleotides. These link together to form long, complex molecules of deoxyribonucleic acid, commonly known as DNA. The totality of genetic information in each organism is called its genome. To map the human genome means to locate each gene on a particular chromosome. To sequence the human genome means to determine the order in which the four nucleotides are arranged in each gene.

Specific genes, or combinations of genes, are associated with specific conditions: diseases and susceptibility to diseases, particular abilities, and distinguishing characteristics like eye color or height. Except for identical twins, each individual's genome is unique. Knowledge of our genetic makeup thus encompasses knowledge of what is personally unique about us. Information generated by the HGP will result in a greater

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understanding of genetic variation and disease, and has the potential to make available an increased number of genetic tests for screening and diagnosis of diseases, as well as other biological characteristics of humans.

Recognizing that the HGP raises fundamental issues of bioethics (Annas 1992), the U.S. Congress designated from 3 to 5 percent of the three billion dollars originally allotted to human genome research for studies of the ethical, legal, and social implications (ELSI) of the project and created a working group for this task (Roberts 1993). A novel aspect of the HGP is that it studies these issues alongside the scientific ones in the hope that problems can be anticipated and policy options developed. Three principal areas have been identified for initial study: privacy and confidentiality of genetic information; protection from discrimination based on genetics; and safe introduction of genetic tests into mainstream medical practice (Collins and Galas 1993).

Although all of these issues are relevant to individuals, families, and society at large, women, because of their central role in reproduction and caregiving, are affected not only differently but also more significantly than men by the information emerging from the HGP. Nonetheless, women have seldom been the focus of studies emerging from the ELSI program of the National Center for Human Genome Research. Accordingly, the goal of this article is to document the distinct impact of "the new genetics" on women. By identifying gender differences not only in research and clinical practice, but also in the psychosocial, legal, and ethical implications of the HGP, we hope both to evoke and to inform public discussion and policies that may be generated by these issues.

### A Typology of Gender Differences

Women are recipients of genetic services not only in their capacity as patients, but also as participants in prenatal diagnosis, treatment, research, and, frequently, as primary caregivers of those affected with genetic conditions. Women also predominate among health care providers for those who utilize genetic services; their predominance, however, is limited to those areas of health care that are held in less regard and are less remunerative than others (Weaver 1978). For example, only one-third of doctorally prepared medical geneticists are women, but 94

percent of master's-prepared genetic counselors are women (Wertz and Fletcher 1988a; Pencarinha et al. 1992).

The difference between male and female roles in reproduction accounts for the predominance of women as recipients of genetic services even when they are not personally affected by genetic conditions. Because some diseases are treatable in utero, pregnant women already undergo treatment for the sake of their fetuses. As gene therapies develop, they may be encouraged even more to participate in therapies for the sake of their offspring.

Political and social pressures are sometimes brought to bear on women who are carriers of genetic diseases, particularly those women who do not have independent financial resources to care for affected children. Such women may be challenged about becoming pregnant or criticized for continuing a pregnancy after prenatal diagnosis confirms the presence of fetal abnormality or genetic condition (Purdy 1978). Conversely, the ongoing controversy over abortion might lead to increased social criticism of women who wish to terminate affected pregnancies. Businesses may limit options of women in the workplace, and insurance companies may curtail their access to coverage based on genetic knowledge relevant to women's reproductive capacities. Admittedly, discriminatory practices affect men as well. In the past, however, discrimination based on reproductive capacity has mainly affected women (Annas 1991; Gostin 1991).

In spite of the unique ways in which women are differently affected, gender-neutral terminology continues to dominate considerations of ethical issues related to the HGP, even in discussions directly related to reproduction (Mahowald 1994; Watson 1990). It is crucial, however, to consider gender differences in order to formulate ethically justifiable clinical and policy decisions about reproduction and genetics. Such justification is usually linked with considerations of "justice" or "equality."

The concepts of "justice" and "equality" are often construed as requiring that all individuals be treated in the same way (Mahowald 1993). However, because men and women occupy empirically distinct roles, it is neither possible nor desirable to treat them in the same way with regard to reproduction, prenatal testing and diagnosis, and decisions about the continuation or termination of pregnancy. The differences that men and women embody as gendered individuals can be recognized and addressed without imputing inferiority to one or the

other on that basis (Mahowald 1994). Gender differences as such do not necessitate inequality or injustice toward members of either sex.

### Five Questions Based on Gender

To facilitate examination of ethical issues raised by gender differences in genetics, it is necessary to identify the differences that arise in research, the clinical applications of that research, and the nonmedical aspects of people's lives that are or may be affected by advances in genetics. This article addresses five empirical questions as a guide in that determination:

1. Of the genetic conditions that the HGP investigates, which ones mainly affect women and to what extent?
2. To what extent are women needed to fulfill the goals of the HGP, for example, by supplying genetic materials, undergoing preconception or prenatal testing or procedures, or by contributing to the process of research?
3. To what extent, if any, does availability of genetic information, including decisions about prenatal counseling and testing, influence women's decisions regarding reproduction and decisions to continue or terminate a pregnancy?
4. In what ways, and to what extent, have women been differentially affected through employment or insurance practices because of genetic information available to themselves or to others?
5. What impact does caregiving of those affected by genetic diseases have on the lives of women?

Studies addressing these issues were reviewed and summarized. Because of the breadth of the questions asked and the limitations of the available literature, our discussion of these issues cannot be regarded as conclusive or complete. By organizing a vast amount of material around a focus on women, however, we provide both an argument and an agenda for future empirical studies and ethical analyses of considerations that are particularly relevant to women in the new genetics.

*Genetic Conditions in Women*

Genetic conditions may be distinguished by their modes of inheritance; these include chromosomal, autosomal dominant, autosomal recessive, and X-linked recessive conditions (Jones 1989). Genetic conditions may also be distinguished by their different manifestations, which include physical impairments, mental retardation, chronic medical problems, reduced life span, and early or late onset of progressive symptoms. The same condition may fit into multiple categories (Jablonski 1991; McKusick 1992; Tierney et al. 1993). The genetic conditions associated with gender differences include: those affecting primarily one sex or affecting the sexes in unequal ratios; those determined by the sex of the transmitting parent; those affecting fertility differently in males and females; and those in which pregnancy poses risks to affected women or their fetuses. In table 1, we offer illustrations of how genetic diseases may have different physical effects and may be experienced differently by women than by men. For example, women transmit X-linked recessive conditions to their sons but not to their daughters (Laxova and Feldman 1992). Women with cystic fibrosis are fertile, whereas men are usually not; pregnancy, however, poses particular health risks to affected women (Canny, Corey, and Livingstone 1991).

The impact of gender-specific diseases is influenced by gender-based societal influences. Breast cancer, for example, is a disease whose impact is exacerbated in women because of social factors. Beyond its high incidence in women (one in eight, in contrast to its extremely low incidence in men), the extant treatment modalities of mastectomy and chemotherapy are generally disfiguring in ways that men treated similarly do not find as burdensome because society is less likely to attach importance to them for men. Hair loss, even though temporary, is embarrassing and sometimes humiliating for women, mainly because they are not expected to be bald; and breast removal entails for many the permanent loss of their womanly appearance. Prophylactic mastectomies for some patients who have a family history of the disease are particularly onerous because the disfigurement may not actually entail a compensating benefit.

Treatment of certain forms of gynecological cancer for which susceptibility tests are or will eventually be available may result in loss of the ability to conceive or bear a child. Men, of course, may be rendered

TABLE 1  
Types of Sex Differences in Genetic Diseases

*Examples of conditions affecting only or primarily one sex*

Most X-linked diseases (affected male, unaffected carrier female):

1. *Duchenne muscular dystrophy* (characterized by progressive muscle weakness, respiratory failure)
  2. *Hunter syndrome* (characterized by coarsening of facial features, defective bone formation, enlargement of the spleen and liver, lethality)
  3. *Hemophilia A* (characterized by bleeding diathesis in large joints) (Laxova & Feldman 1992)
- Sex-limited diseases (due to the nature of the disease itself):
1. Some forms of *breast and ovarian cancer* are inherited through autosomal dominant transmission, where the chance of inheriting the gene, BRCA1, is 50% (Biesecker et al. 1993). Female mutation carriers are estimated to have a 50% risk of developing *breast cancer* before age 50 and a 10% risk of inheriting *ovarian cancer* by age 60 (King et al. 1993). Recent discovery of another gene, BRCA2, increases the possibility of detection to at least 80% (Kolata 1995).
  2. Male carriers of BRCA1 are not thought to be at increased risk of developing *breast cancer* (although they will pass the gene on to 50% of their daughters); preliminary data suggest that they may have an increased incidence of *prostate cancer* (Arason et al. 1993).

*Examples of conditions affecting the sexes in unequal ratios*

Male > Female

*Fragile X syndrome*

Male live births: 1/1,000–1,500

Female live births: 1/2,000–2,500 (Turner et al. 1986)

Mental retardation in females is generally milder and only occurs in approximately 30% of carrier females (Webb 1989).

Female > Male

*Anencephaly*

The most severe defect, involving the whole neural tube, has a far more marked female excess than a defect restricted to the extreme anterior end. This is usually considered a polygene or multifactorial condition (Seller 1987).

*Examples of conditions determined by the sex or other characteristics of the transmitting parent*

## X-linked recessive conditions

The classic pattern of inheritance is from unaffected females to affected males. Unaffected males have not inherited the gene and therefore cannot transmit the disorder. All daughters of affected males are carriers, half the daughters of female carriers are also carriers, and half the sons of female carriers are affected (Laxova & Feldman 1992).

## Parental age effects

Women bearing children over the age of 35 are at increased risk for having infants born with chromosomal abnormalities (Laxova & Feldman 1992). Disease examples include *Down syndrome*, most often caused by the presence of an additional chromosome #21 and usually characterized by mild to severe mental retardation.

In contrast, older fathers are more likely to give birth to children with a new genetic condition in the family, including *achondroplastic dwarfism*, *Marfan syndrome*, and *myositis ossificans*, a disease of bony tissue (Angier 1994).

## Gender effect on disease severity

There can be a correlation between the sex of the transmitting parent and the severity of the inherited disease. Examples include *neurofibromatosis*, where the disease is more severe in patients born of an affected mother than in those born of an affected father (McKusick 1992).

## Mitochondrial inheritance

Diseases associated with mitochondrial inheritance are always transmitted through the mother; no paternal transmission has ever been documented. Examples include rare conditions like *myoclonic epilepsy* and *ragged red muscle fiber disease (MERRF)*, caused by a point mutation in mitochondrial DNA through maternal lineage and characterized by myopathy, hearing loss, and subclinical changes in EEG (Laxova & Feldman 1992).

*Examples of conditions affecting fertility in males and females*

## Cystic fibrosis

In the male patient, infertility is primarily caused by blockage or absence of the vas deferens and the distal half of the epididymis (Trezise et al. 1993). In women, cervical mucus may be dehydrated, presenting a formidable barrier to sperm penetration and contributing to reduced fertility.

*continued*

TABLE 1 continued

Congenital adrenal hyperplasia	A group of diseases caused by certain enzymatic defects in the formation of steroids produced by the adrenal cortex. Adrenal hyperplasia—the overproduction of adrenal androgens—is the result of these defects. The excess production of adrenal androgens causes prenatal masculinization of female fetuses. The genitalia of male fetuses are not affected prenatally (Zilberstein et al. 1992).
<i>Examples of conditions in which pregnancy poses additional risks for an affected woman</i>	
Cystic fibrosis	Women with <i>cystic fibrosis</i> can become pregnant, tolerate pregnancy, and have a positive fetal outcome. Women with poor respiratory status prior to pregnancy are at increased risk for life-threatening complications (Rossiter & Johnson 1992).
Sickle cell anemia	Individuals with <i>sickle cell disease</i> are at risk for exacerbation of clinical symptoms during pregnancy, including pneumonia, pulmonary emboli, retinal hemorrhages, and painful crises. The fetus is at an increased risk for spontaneous abortion, preterm delivery, and stillbirth (Perry & Morrison 1992).
Marfan syndrome	Pregnancy poses an increased risk in <i>Marfan syndrome</i> for patients with significant aortic problems (one of the characteristics of the syndrome). These patients are at high risk of life-threatening cardiovascular complications (Rossiter & Johnson 1992).



sterile through cancer treatment as well, but treatment of male infertility is often accomplished through women's bodies rather than through men's. Although men can store their sperm prior to treatment, no comparable option is currently available to women. Moreover, the fact that women can lose both their gestational and their genetic capability to have children may be viewed as doubling their potential losses.

### *Women Involved in Human Genome Research*

As outlined by Jordan (1992), the specific goals of the HGP are the following:

1. mapping and sequencing the human genome and the genomes of model organisms
2. research training
3. technology development and transfer
4. examination of ethical, legal, and social issues associated with the HGP

All of these goals appear gender neutral, neither disproportionately involving nor affecting one gender more than the other ( Jordan 1992; National Institutes of Health 1990). The genome to be sequenced is a composite of sequences from various sources, most from existing cell lines of healthy individuals of both sexes. DNA regions of particular interest (i.e., the genes involved in specific genetic conditions) are sequenced from many individuals of both sexes during the course of the research (National Institutes of Health 1990). HGP researchers have targeted diseases that are symptomatic in each sex, such as X-linked diseases in men and breast cancer in women (National Institutes of Health 1990). Although the National Center for Human Genome Research does not keep a summary of the number of men and women who are trained in skills necessary to complete the HGP, the numbers of men and women receiving grant awards have reflected the same proportion as those applying: approximately 23 percent are female (Muller 1992; Anderson 1992). In a 1995 estimate of grants and contracts awarded since the beginning of the ELSI program of the National Center for Human Genome Research, 48 of 103 proposals list women as their principal investigators and at least 12 projects explicitly consider the

implications of the HGP for women (Elizabeth J. Thomson, Acting Director of ELSI program: personal communication, December 21, 1995). Several additional projects focus on the role of genetic counselors and nurses, the majority of whom are women. While it may be argued that the nature of the information generated by the HGP requires greater attention to and consideration of gender-related issues, the funding of these proposals does demonstrate an awareness on the part of the ELSI working group of the importance of addressing the ways in which genetic information specifically affects women.

Because the goals of the HGP involve mapping and sequencing the human genome, and not detection of genetic diseases, the research itself does not differentially affect women. However, differential impact may occur with the use of the information generated by the HGP. Consideration of the ethical, legal, and social implications of the availability or generation of increased genetic information necessarily addresses advances in preconception screening, prenatal testing, and prenatal therapies for different genetic conditions (table 2). Additional studies are needed to determine the impact of this information on women in the context of their personal and social roles (table 3).

### Impact of Genetic Information on Women's Reproductive Decisions

The information derived from the HGP, such as the development of new or improved procedures for preconception screening, prenatal diagnosis, and prenatal therapies, will have a profound effect on decisions about reproduction and, therefore, on women's lives. Although the impact of such decisions on men cannot be discounted, the central role of women in reproduction and the direct impact of reproductive decisions on women's bodies point to a greater and more immediate effect. This differential impact has led to the enactment of laws that permit women alone to make decisions regarding initiation, termination, and continuation of pregnancy.

Reproductive technologies like prenatal testing are not gender neutral in societies where profound gender differences exist, particularly in societies where women are disadvantaged economically and socially and are thus more vulnerable or powerless (Lippman 1991a). Further, women

TABLE 2  
Nonmedical Factors Affecting Women in the New Genetics<sup>a</sup>

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*Material factors*

- Availability of institutions that provide genetic testing (Nsiah-Jefferson 1989, 1994; Rapp 1994; Wertz & Fletcher 1993)
- Required waiting periods for genetic services (Nsiah-Jefferson & Hall 1989)
- Limited availability of providers (Collins & Natapoff 1985; Remy 1985; Richert 1983)
- Transportation and child care problems (Poland et al. 1987)

*Psychosocial factors*

- Cultural differences (Nsiah-Jefferson & Hall 1989)
  - Ethnicity (Rapp 1988, 1990, 1994; Wertz & Fletcher 1988a)
  - Religious/moral beliefs (Nsiah-Jefferson 1989; Rapp 1994)
- Social influences
  - Societal pressures (Lippman 1991a; Kaplan 1993; Nsiah-Jefferson & Hall 1989; Paul 1994; Wertz & Fletcher 1993)
  - Laws governing pregnancy decisions (Clayton 1994)
  - Awareness/education of the possibility, benefits, and risks of genetic testing (Andrews 1992; Cowan 1993; Kassam et al. 1980; Smith & Miller 1990; Lippman 1991a; Marion et al. 1980; Rapp 1994; Wertz & Fletcher 1993)
  - Language barriers (Mittman 1990)
- Personal/psychological influences
  - Of the physician (Clarke 1991; Gallagher 1989; Gates 1994; Henifin, et al. 1989; Holtzman 1993; Sorenson 1993; Wertz & Fletcher 1993)
  - Of family members (Sorenson & Wertz 1986) and awareness of familial risk (Pryde et al. 1993)
- Personal anxiety (Abuelo et al. 1991; Black 1989, 1990, 1994; Caccia et al. 1991; Clarke 1991; Edwards et al. 1989; Evers-Kiebooms et al. 1988; Gates 1994; Marteau et al. 1992; Pryde et al. 1993; Rapp 1990; Rothman 1994)

*Economic factors*

- Availability of insurance coverage, government funding, or personal funds (Currie 1993; Nsiah-Jefferson 1994)
  - Ability to support a child with disabilities/genetic disease (Andrews 1987; Bianchi & Spain 1987; Billings et al. 1992; Gostin 1991; Jacobs & McDermott 1989; Lippman 1991a; Nsiah-Jefferson 1994; Wertz & Fletcher 1993)
  - Availability of funds for abortions (Charo & Rothenberg 1994; Curry 1989; Nsiah-Jefferson 1989, 1994; Nsiah-Jefferson & Hall 1989)
  - Limitation of employment options (Becker 1986; Billings et al. 1992)
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<sup>a</sup>Medical factors are indicated in tables 1, 4, and 5.

TABLE 3  
Some Issues Deserving Further Study

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*Cultural issues*

- Ethnic, cultural, and religious differences in women's attitudes toward genetic information

*Family issues*

- Impact of disclosure of misattributed paternity on the family unit
- Impact of a genetically affected child on marital and family stability
- Possible differences between women and men regarding importance of genetic tie to children

*Personal/psychological issues*

- Possibility of lasting effects on women of anxiety associated with prenatal testing when test results indicate no abnormality
- Influences on women's decisions to undergo prenatal testing and then either to terminate or to continue an affected pregnancy
- Effects of the delivery of genetic information to women by untrained genetic counselors
- Women's experience with genetic tests and interventions and how they cope with it
- Women's interest in prenatal testing for late onset disorders

*Economic issues*

- Extent to which new genetic tests are available to poor women
- Denial of health insurance for preexisting conditions to women or their children
- Disease-specific genetic discrimination against women in the workplace

*Caregiving issues*

- Costs and burdens to primary caregivers of genetically disabled or chronically ill relatives
  - Extent to which genetic information may reduce the caregiving responsibilities of women
- 

are frequently expected, and sometimes required, to fulfill norms and expectations regarding pregnancy and motherhood, including the responsibility for caregiving and children's health (King 1994; Lippman 1992). Determining the impact of genetic information on women calls for an examination of the variety of prenatal genetic services currently

available to them, along with the risks, burdens, and benefits associated with these services. It also calls for a determination of which women have access to prenatal genetic services, including abortion, and of the psychological impact of genetic counseling, testing, and termination of affected pregnancies.

Currently, a number of different procedures are available for detecting chromosomal abnormalities and other genetic conditions in utero (Verp, Simpson, and Ober 1993). These diagnostic procedures differ in their invasiveness, cost, accuracy, potential risks, and optimal time of performance. A brief description of each of the currently available prenatal diagnostic procedures is presented in table 4.

Prenatal treatment of fetal abnormalities is relatively new, and there are no known cures or treatments for the majority of conditions that can be diagnosed in utero (Elias and Annas 1992). Some recently developed or experimental prenatal therapies for fetal abnormalities are described in table 5. In general, however, pregnancy termination remains the only means for avoiding the birth of a child whose genetic anomaly has been discovered through prenatal testing. Preimplantation genetic diagnosis, described in table 4, is a means of avoiding pregnancy termination after diagnosis of an affected fetus, but this option is unlikely to be available to most because it generally requires in vitro fertilization, a costly procedure with a limited success rate (Carson and Buster 1994).

As information generated by the HGP escalates, the gap between our understanding of genetic diseases and effective treatment of these diseases has tended to increase rather than to narrow (Friedmann 1990). Further research into the development of gene therapies and other treatment modalities may alter this scenario. It cannot be denied, however, that the prenatal diagnostic procedures and therapies described in tables 4 and 5 offer benefits to many women and couples. For example, prenatal diagnosis provides important information to those who wish to avoid the birth of an offspring with a specific genetic condition. For women who do not choose to terminate affected pregnancies, advance knowledge in order to prepare psychologically, medically, and financially for the birth of an affected child has been viewed as desirable. Nonetheless, the burdens of prenatal diagnosis and therapy include physical risks to the fetus, to the woman carrying the pregnancy, or to both.

Although such medical risks are directly experienced by women but not men, the economic and emotional burdens may affect both partners. No data are available regarding the distinct financial and psychological

TABLE 4  
Procedures for Prenatal Testing and Diagnosis

Procedure	When performed	Method used and accuracy	Maternal risks	Fetal risks
Ultrasonography	Can be used as early as 5 weeks' gestation (Manning 1989).	Ultrasound, at a frequency greater than 20,000 kHz, emits wavelengths from a transducer in pulses that bounce off structures and return to the transducer. Return times are measured and used to determine locations of structures (Docker 1992). While sensitivity of ultrasound is low, routine screening leads to more frequent detection of major malformations before birth (Crane et al. 1994).	No physical risks (Docker 1992; Strassner 1992).	None detected (Docker 1992; Strassner 1992).
amniocentesis	Usually 14–20 weeks' gestation (Kerber & Held 1993); can also be done later (Verp 1992).	Insertion of spinal needle into uterus to aspirate 15–30 ml of amniotic fluid (Verp 1992). Amniocentesis has a false positive rate of less than 0.5% (CCCACTG 1989).	Vaginal bleeding, amniotic fluid leakage, infection (Verp 1992; MacLachlan 1992).	Fetal loss rate for midtrimester amniocentesis is 1% (Schemmer & Johnson 1993). Needle puncture, RH sensitization, umbilical cord hematoma and occlusion, cardiac arrest caused by fetal

contact with needle, inflammation of fetal membranes, premature labor (Verp 1992).

None.

Standard venipuncture risks.

Obtain a sample of maternal serum from patient and screen for alpha-fetoprotein, (AFP), estriol (uE3), and human chorionic gonadotropin (hCG) (Canick & Bowers 1991). Test performance for triple-marker screen shows a sensitivity and false positive rate of 90% and 6%, respectively (Cheng et al. 1993).

Most commonly performed 15-21 weeks' gestation (Hibbard & Verp 1992).

le screen  
AFP, MSuE3,  
MShCG)

Fetal loss rate using transcervical approach is 0.5%-1.0% over the general population risk (Verp 1992). No significant increases in preterm labor, or small-for-dates infants (Williams et al. 1987). There may be greater inci-

Vaginal bleeding for transcervical approach; infection for both approaches (Verp 1992). Acute amniotic fluid leakage is a rare occurrence (Schemmer & Johnson 1993).

Transcervical catheter or transabdominal needle insertion into placenta followed by tissue aspiration (Silberman & Wapner 1992). Studies of CVS accuracy have demonstrated a 99.6% diagnostic success rate (Ledbetter et al. 1990).

Most commonly performed 9-13 weeks' gestation (Verp 1992).

Chorionic villus  
sampling

*continued*

TABLE 4 continued

Percutaneous umbilical blood sampling	Eighteen weeks' gestation to term (Davis 1993).	A needle is guided by high resolution ultrasound equipment to the placental origin of the umbilical cord where fetal blood is aspirated (Wenstrom & Weiner 1992).	Bleeding in uterus and umbilical cord; infection; rupture of membranes, and premature labor (Weiner 1993).	Fetal loss rate is from 1% to 2% (Pryde et al. 1993). Bradycardia (slowness of heartbeat), fetal trauma, placenta abruption (Weiner 1993).
Fetal skin biopsy	At a gestational age compatible with the expression of the abnormal structure (Verp 1992).	Fetoscope or ultrasound guided technique is used to examine the fetus and to select area for biopsy. Forceps are used to obtain biopsy (Nicoloni & Rodeck 1992). Fetal skin biopsy to detect genetic skin disease can be used with a reasonably high level of confidence (Holbrook et al. 1993).	Bleeding in uterus and umbilical cord; infection; rupture of membranes and premature labor (Weiner 1993).	Fetal loss rate is estimated at 5%–7%, which is 1% to 2% over the miscarriage rate (Holbrook et al. 1993).



liver bi-	After week 17 of gestation (Nicoloni & Rodeck 1992).	Ultrasound guided technique locates an appropriate place for insertion of needle into fetal trunk and then into liver. Liver tissue is removed (Nicoloni & Rodeck 1992).	Bleeding in uterus and umbilical cord; infection; rupture of membranes and premature labor (Weiner 1993).	Fetal loss rate is estimated at 1%-2% (Nicoloni & Rodeck 1992).
mplantation tic testing	Analyses of cells from embryos after in vitro fertilization before implantation in the uterus. Analysis of cells prior to fertilization has also been performed (Carson & Buster 1994).	The cells can be analyzed for chromosome, biochemical, and DNA abnormalities, then implanted in the uterus (Trask 1991; Monk 1992; Handyside 1992). There is very little DNA to work with, but amplification by polymerase chain reaction makes prenatal diagnosis possible (Handyside et al. 1992).	Risks are related to oocyte recovery, IVF, and embryo transfer (Jackson 1991; Sauer et al. 1988).	No known risks; these techniques are relatively early in development and still experimental. Little is known about their technical and biological safety (Carson & Buster 1994).

TABLE 5  
Prenatal Treatment for Fetal Abnormality

Kind of therapy	Examples of when performed	Fetal abnormality	Fetal outcomes	Benefits
Fetal blood transfusion	Transfusion has occurred after 17 weeks' gestation (Socol 1992).	1. Isoimmunization 2. Anemia 3. Fetal hydrops (Nicoloni & Rodeck 1992; Socol 1992).	Fetal mortality rates for intravascular transfusions are between 4% and 9% (Barss et al. 1988; Berkowitz et al. 1988; Grannum et al. 1988; Ney et al. 1991). Can result in nonremediable prolonged fetal heart rate decelerations requiring cesarean section (Piolet et al. 1988).	Alleviates the effects of Rh isoimmunization; Rh antibodies can cross the placenta and destroy fetal red cells, resulting in anemia (Bowman 1989).
alsurgery	Ranging from 22-28 weeks' gestation (Adzick & Harrison 1994; Kuller & Golbus 1992; Rosner et al. 1989).	1. Urinary obstruction 2. Cystic adenomatoid malformation 3. Chylothorax 4. Diaphragmatic hernia 5. Sacrococcygeal teratoma 6. Twin-twin transfusion syndrome 7. Aque ductal stenosis 8. Pulmonary/aortic valve obstruction (Adzick & Harrison 1994).	In 1988, 8 surgeries were performed for urethral obstruction with 4 live births, and 3 babies presently living (Crombleholme et al. 1988). From 1989 to 1991, 14 surgeries were performed for diaphragmatic hernia with 4 babies surviving (Harrison et al. 1993). From 1989 to 1992, 9 surgeries were performed for cystic adenoma-	Cure or significant improvement of the congenital malformation (Adzick et al. 1993; Crombleholme et al. 1988; Harrison et al. 1993).

toid malformation of the lung, with 7 live births and 6 babies presently living (Adzick et al. 1993).  
 Maternal risks: uterine contractions, amniotic fluid leaks, infection, and required cesarean delivery with its risks (Adzick & Harrison 1994).

Cure or significant improvement of the inherited disease (Raudrant et al. 1992).

1. Fetus with BLS received transplant at 28 weeks' gestation. Child was born in 8/88 with reconstituted immunity.

2. Fetus with beta-thalassemia received transplant at 17 weeks' gestation. Fetal bradycardia occurred and fetus died. Fetus with beta-thalassemia received transplant at 12 weeks' gestation. Child born with partially improved thalassemia.  
 3. Fetus with combined immunodeficiency disease re-

1. Bare lymphocyte syndrome (BLS)
2. Beta-thalassemia major
3. Combined immunodeficiency disease (Raudrant et al. 1992).

Four fetuses have received fetal liver cell transplants, ranging from 12-28 weeks' gestation (Raudrant et al. 1992).

cell transplantation

*continued*

TABLE 5 *continued*

<p>roid treatment (dexamethasone)</p>	<p>Recommended to begin before week 9 of gestation and to continue until term (Karaviti et al. 1992)</p>	<p>Congenital adrenal hyperplasia (Karaviti et al. 1992).</p>	<p>ceived transplant at 26 weeks' gestation. Child was born 8/89; engraftment occurred. (Raudrant et al. 1992).</p>	<p>Prenatal treatment with dexamethasone to the mother prevented masculinization of fetal genitalia (Karaviti et al. 1992).</p>
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burden of prenatal tests on men. Because insurance coverage for such procedures is not universal (Nsiah-Jefferson and Hall 1989), however, the financial burden of prenatal diagnosis and therapy may fall on women with greater frequency than on their partners, depending on their insurance status and their partner's involvement. Similarly, the emotional burden of prenatal testing and decisions is different for women than for men. Studies suggest that the psychological burden of undergoing such procedures is great, even when, as is commonly the case, the results are normal (Rothman 1994).

Although new reproductive technologies may benefit some individuals and couples, the impact on women in general is a mixed picture (Nsiah-Jefferson 1994). In the context of a profoundly inequitable health care system, it is not surprising that some advocates for low-income women and women of color view new reproductive technologies with suspicion (Nsiah-Jefferson and Hall 1989), or that feminist critics consider the latest technologies as part of a larger history of women's loss of control over birth and the overuse of technology associated with it (Wertz and Wertz 1989; Wertz and Fletcher 1993). Some feminists and advocates for people with disabilities have argued that women are coerced into accepting prenatal diagnoses by social and cultural forces and by a medical system that follows the "technological imperative" of using prenatal diagnosis simply because it exists (Andrews 1987; Wertz and Fletcher 1993; Nsiah-Jefferson 1994). Despite the fact that women with lower incomes currently have less access to prenatal diagnosis than other women, there has been concern that pressure may intensify to require women without the resources for raising a disabled child to undergo prenatal diagnosis and to have an abortion if the child tests positive for a genetic condition (Nsiah-Jefferson 1994). Those most likely to lack such resources are minority women, many of whom are also single mothers (Andrews 1987; Bianchi and Spain 1987; Lippman 1991a).

Controversy surrounds the issue of whether prenatal testing and diagnosis is inherently beneficial or burdensome to women. It has been argued that women seek the options afforded by prenatal diagnosis, and exercise more power over their reproductive choices through prenatal diagnosis than through any other technologies associated with birth (Rapp 1990, 1991). But, as already suggested, many explicit and implicit pressures influence the decisions of women following the prenatal diagnosis of an affected pregnancy. The potential pressures include financial considerations, such as the loss of insurance or employment, and

social stigmas surrounding illness or disabilities (Billings et al. 1992; Gostin 1991; Lippman 1991a; Nsiah-Jefferson 1989; Nsiah-Jefferson and Hall 1989; Wertz and Fletcher 1993).

Ideally, prenatal testing and diagnosis should be offered after the woman or the couple has undergone genetic counseling, in which the primary nondirective goal is to help individuals and couples achieve their personally defined wishes (Wertz and Fletcher 1988a). However, the very offer of prenatal diagnosis by an obstetrician may be interpreted as a recommendation to accept testing, making it difficult for women to reject these medically sanctioned technologies (Clarke 1991; Gallagher 1989; Gates 1994; Henifin, Hubbard, and Norsigian 1989; Wertz and Fletcher 1993). Such pressures are most likely to be exerted in a climate where concerns about "fetal rights" and "prenatal abuse" are viewed as overriding the right of pregnant women to autonomous decisions about their lifestyle and medical treatment. Nonetheless, the fact that some women have refused prenatal diagnosis on moral grounds, even when tests are offered without charge through national or state health care systems, suggests that many women do exercise their autonomy. Women who have allegedly been "deprived of choice" have sued physicians on the grounds of "wrongful birth," stating that physicians failed to inform them of the availability of genetic testing and of their risks of giving birth to children with genetic defects (Andrews 1992).

The availability of prenatal genetic testing has increased third-party involvement in individual women's reproductive decision-making by family members, physicians, insurance agencies, and society (Gates 1994). This again raises concerns about possible constraints on women's autonomy. Research on agreement between men and women about the purposes of genetic services demonstrates that a substantial number of couples come to genetic counseling and testing for different reasons and with different reproductive plans. Disagreement between partners has not been diminished by genetic counseling (Sorenson and Wertz 1986). In light of the more significant burden of the decision on women, however, laws or policies affirm women's autonomy as paramount in situations of unresolvable conflict.

Contrasting views about the inherent value of prenatal diagnosis and testing may be influenced by the fact that the benefits and burdens are distributed most unevenly among women themselves. This maldistribution reflects social inequality and disparities in access to health care services in general (Nsiah-Jefferson 1994). Low-income women might

be pressured to abort because of perceived economic burdens on society of their disabled child (Lippman 1991a), but low-income women might also be denied full access to genetic technologies, leading to a disproportionate number of people with special needs from poor populations (Nsiah-Jefferson 1994).

Since amniocentesis first became available, utilization of prenatal diagnostic procedures by women has been strongly associated with socioeconomic status and education (Cowan 1993; Smith and Miller 1990; Lippman 1991a; Marion et al. 1980; Wertz and Fletcher 1993). Access to prenatal diagnosis is affected by access to general health care. Many low-income women are unable to avail themselves of prenatal testing because they begin prenatal care too late or receive none at all (Nsiah-Jefferson 1989; Wertz and Fletcher 1993). Low-income women must also depend on government funding of prenatal procedures because they lack medical coverage through employment-based insurance programs or cannot pay for these services privately. Medicaid provides funding for prenatal diagnosis procedures like amniocentesis or chorionic villus sampling, but reimbursement varies by state, with enormous gaps reported between reimbursements and charges. In essence, then, there is no guarantee of coverage (Nsiah-Jefferson 1994).

Access to abortion is also restricted for poor women. Medicaid fully supports the costs of abortion in 13 states; the other states fund abortions through Medicaid only in cases where the mother's life is in danger or the pregnancy results from rape or incest (Daley and Benson-Gold 1993). Access to sites for late abortions (those that occur after the first trimester, which is generally after prenatal diagnosis confirms the presence of a genetic anomaly) is even more restricted, and the financial costs more prohibitive (Nsiah-Jefferson 1994). Although some states fund abortions after the diagnosis of "severe" disability in the fetus, there is wide variability from state to state on what is considered a "severe defect" (Charo and Rothenberg 1994). Without equal access to abortion services, the autonomy of low-income women to make reproductive decisions is compromised (Charo and Rothenberg 1994).

Interestingly, socioeconomic disparity in the use of prenatal diagnosis also exists in Canada, where there is no direct charge for testing (Lippman-Hand 1981; Nsiah-Jefferson 1989). Other barriers to use of prenatal diagnostic services by women of lower socioeconomic status arise in communication difficulties between medical professionals and patients with less education, long waiting periods for services (which limit the

practicality of utilizing prenatal procedures), uneven geographic distribution of prenatal service sites, and lack of funding for abortions to terminate affected pregnancies (Curry 1989; Nsiah-Jefferson 1989, 1994; Nsiah-Jefferson and Hall 1989; Rapp 1994; Smith and Miller 1990; Wertz and Fletcher 1993).

The cultural values of specific ethnic groups play a role in their acceptance of, and interest in, prenatal testing and diagnosis (Rapp 1994). It has long been noted that white, middle-class patients are much more likely to undergo testing than poorer women from ethnic and racial minorities. This difference is probably influenced by disparities in access, familiarity with scientific and genetic information, attitudes toward the local health care establishments, and individual reproductive and life histories (Rapp 1994). Further, prenatal testing and diagnosis may seem pointless to women who would not terminate a pregnancy for cultural or religious reasons, or who have no access to funding for abortions if they should decide to terminate an affected pregnancy. Nonetheless, several studies have examined the acceptance of prenatal testing by low-income minority women and found that they are receptive to genetic services despite such influences or obstacles (Kassam et al. 1980; Marion et al. 1980; Rapp 1994). The acceptance by these women of reproductive technology suggests that they are not using prenatal diagnosis to make decisions regarding pregnancy termination, but rather to gain increased information about their children for personal or culturally mediated purposes (Rapp 1988, 1990).

For the many reasons listed above, prenatal screening and diagnosis appears much less likely to contribute to the reproductive choices of low-income women or women of color than other women. African Americans and Hispanics account for a greater proportion of births to women over 40 years of age (Wertz and Fletcher 1993). Because advanced maternal age is a strong risk factor for birth of children with genetic anomalies, genetic services may not be available to, or utilized by, the women who have the greatest need of them. As women of higher socioeconomic status continue to utilize prenatal diagnosis and selective abortion at greater rates, the number of children with genetic conditions born to minority and lower-income women potentially increases (Nsiah-Jefferson 1994; Wertz and Fletcher 1993). At present, the fear that lower-income women or single mothers may be differentially influenced by health professionals to use prenatal diagnosis and to abort affected pregnancies seems unfounded. Women who might be criticized for car-



rying fetuses with genetic anomalies to term because they lack the resources to care for them also generally lack the resources to pay for prenatal diagnosis.

The availability of increased genetic information may confer emotional or psychological burdens on women through the impact of the information itself and through their experience of prenatal testing and termination of affected pregnancies (Abuelo et al. 1991; Black 1989, 1990, 1994; Caccia et al. 1991; Clarke 1991; Edwards, Rothstein, and Young 1989; Marteau et al. 1992; Rothman 1994). Women's widely varying social and psychological experience of prenatal testing and diagnosis has mainly been discussed anecdotally. Little consideration has been given to the experience of the male partner as a separate participant. Despite the absence of conclusive data, proponents of testing have presented prenatal testing and diagnosis as a means of giving women increased control over their reproductive choices or reassurance in continuing their pregnancies; critics, on the other hand, have explored the implicit pressures that prevent women from exercising authentic choice (Lippman 1991a).

The possibility of obtaining unrequested information through genetic testing introduces another potential burden to consider. Occasionally, the disclosure of misattributed paternity has been withheld from the husband of a woman whose fetus is affected by a genetic disease. In situations of autosomal recessive disorders for which carrier testing is possible and accurate, Wertz and Fletcher (1988b) report that 94 percent of medical geneticists believe that protection of the mother's confidentiality overrides disclosure of misattributed paternity. Pencarinha and her colleagues (1992) found that 98.5 percent of genetic counselors would disclose the information to the mother alone. For both groups, the rationale most often offered for nondisclosure to the husband was preservation of the family unit.

That nondisclosure of misattributed paternity remains controversial is evident in the discrepant recommendations of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1983) and the Institute of Medicine's Committee on Assessing Genetic Risks (Andrews et al. 1994). The former maintains that counselors have an obligation to both partners as counselees. "Full disclosure," the commissioners wrote, "combined with careful counseling that goes well beyond information-giving, would seem most likely to fulfill the principles of autonomy and beneficence." In

contrast, the Institute of Medicine Committee recommends that information on misattributed paternity be communicated to the mother, but not volunteered to the woman's partner. Although the President's Commission supports nondisclosure if "disclosure would probably result in a serious and irreversible harm," whether disruption of the family unit would in fact occur and whether such disruption constitutes "serious and irreversible harm" are questions for which empirical evidence is lacking. Thus, while acknowledging that "this extremely sensitive issue is likely to become increasingly problematic as genetic testing expands," the Institute of Medicine committee concludes by recommending "research and evaluation of current policies and practices in genetic testing and screening related to identification of misattributed paternity" (see table 3).

Another issue that warrants further study is the weight that women place on having a genetic tie to their children. Among the infertile, some women regret that they do not or cannot experience gestation and childbirth more than they regret the absence of a genetic tie to their offspring. For example, in a study of 50 infertile women in England, the majority (28) said they would prefer to be birth mothers rather than genetic mothers if they could not be both (Thornton, McNamara, and Montague 1994). Because men can only be related biologically to their offspring through genetics, and not through gestation, they may place greater weight on genetics than women.

Women who choose to undergo prenatal testing procedures like amniocentesis or chorionic villus sampling (see table 4 for a description) tend to be concerned about the possibility of carrying a fetus with a genetic abnormality. Reasons for undergoing prenatal testing include maternal age, previous experience of an abnormal pregnancy or outcome, significant family history of genetic disease, and abnormal results on other screening tests like the maternal serum alpha-feto protein (MSAFP) test (see table 4 for a description) (Pryde et al. 1993). Such women are often particularly anxious about the risks of invasive testing and the possibility of abnormal results (Black 1994). Interestingly, one recent study suggests that women's perceptions of the increased risk of an abnormal pregnancy exceed the actual risk, and that their apprehensiveness does not diminish through counseling and education (Pryde et al. 1993). It is unclear that women experience lasting effects of this anxiety when test results indicate no abnormality (Black 1989; Caccia et al. 1991; Marteau et al. 1992). Some studies have demonstrated no

differences; others have demonstrated less anxiety among those who are tested than those who are not; and some studies have shown elevated anxiety throughout pregnancy even after normal results have been obtained (Evers-Kiebooms, Sweerts, and Van den Berghe 1988; Gates 1994; Rothman 1994). Finally, some commentators have suggested that an exclusive focus on "anxiety" as the main emotional burden conferred by prenatal testing and diagnosis leads to other powerful psychological burdens being overlooked (Rothman 1994).

After a test result indicates a genetic abnormality, a decision to terminate a pregnancy can have profound emotional and psychological consequences (Black 1994; Rothman 1994). Recent research has attempted to characterize the experience of elective termination of pregnancy after diagnosis of genetic anomaly for both women and men (Black 1994). The physical experience of pregnancy loss and the degree and duration of distress were felt to be critical gender differences (Black 1994; Rothman 1994). Although the response varies considerably, many women report profound feelings of grief and loss (Rothman 1994). Some evidence suggests that women who undergo abortions later in their pregnancies, who have had a number of prior miscarriages, or who have previously had a pregnancy in which the fetus was diagnosed with a genetic condition experience more difficult grief reactions than those whose abortions were not associated with these factors (Black 1994). Women who terminate affected pregnancies after prenatal diagnosis in the second trimester tend to experience psychological responses similar to those of patients who suffer second trimester miscarriages (Black 1994; Elders and Laurence 1991). Both experiences generally involve loss of a pregnancy that was both wanted and closely monitored, sometimes after having had the experience of seeing the fetus through ultrasound pictures, feeling fetal movement, and gaining information on fetal sex and chromosomal constitution (Fletcher and Evans 1983; Black 1989, 1994; Caccia et al. 1991; Rapp 1990; Rothman 1994). The process of prenatal testing and diagnosis, particularly the visual image of ultrasound, which presents the fetus as a real and separate entity, may actually strengthen the emotional tie between the woman and her fetus (Black 1989, 1994; Rapp 1990).

Black has provided one of the few rigorous empirical studies of the impact and consequences of the new genetic knowledge on reproductive decision-making and the social and psychological well-being of women. Many articles on this topic are reports of individual women's experi-

ences, which, while interesting and suggestive of future studies, are not conclusive (Rothman 1986); others are commentaries calling for increased attention to these issues (Lippman 1991b; Pryde et al. 1993). The existing studies tend to be limited by small sample sizes and uncontrolled study methodology. Empirical investigations like Black's are needed to test unproved assumptions about how women cope with and experience these issues (table 3).

The extent to which genetic information influences women's decisions on reproduction, including the decision to continue or terminate a pregnancy, is one of the most challenging issues emerging from the HGP. The use of genetic information in clinical practice continues to proliferate, as do the ongoing arguments about whether this will ultimately constitute a benefit or burden. There is as yet no clear picture of the factors that influence women's choice to undergo prenatal testing and then to terminate or continue an affected pregnancy (Pryde et al. 1993). It does seem, however, that specific subgroups of women are at increased risk of harm based either on the misuse of genetic information or lack of access to genetic information.

A final concern is the delivery of information on medical genetics to women by individuals who lack training in genetic counseling (Gates 1994). The HGP is certain to cause an influx of genetic information into mainstream medical practice. Counseling may become more directive and less accurate if provided by medical professionals who are not trained in techniques of genetic counseling (Holtzman 1993; Sorenson 1993). Training for primary caregivers and others involved in genetic counseling therefore is a critical step toward minimizing pressures and biases.

### *Impact of Genetic Information on Women's Employment and Insurance*

There is a wealth of information demonstrating that genetic discrimination (discrimination based solely on an apparent or perceived variation from the "normal" human genotype) already exists, particularly in social institutions like the workplace or in health and life insurance underwriting practices (Billings et al. 1992; Bowman 1991; Gostin 1991; Natowicz, Alper, and Alper 1992). Although the use of genetic screening, testing, or data is not yet widespread among employers or insurers, rising employee benefit costs, market forces, and technological

availability may create a powerful incentive for it to expand (Gostin 1991). Beyond issues of health care, women's workforce participation tends to cluster in low-paying, low-prestige occupations where they are already vulnerable to discrimination based on gender (Bielby and Baron 1986). Broader access to genetic information may thus increase the likelihood of genetic discrimination in the workplace.

Historically, employers have limited women's access to traditionally male-occupied, high-paying positions, often using health concerns as the basis for exclusion (Annas 1991; Norris 1991; Fischer 1987; Burstein 1989). Recently, employers have substituted concern about fetal health for concern about women's health as an argument for limiting women's job opportunities (Annas 1991; Flaherty 1991; Gostin 1991; Noble 1993; Norris 1991). In 1991, however, the U.S. Supreme Court affirmed that federal law prohibits employers from excluding women from job categories on the grounds that they are or might become pregnant. The justices unanimously decided that the "fetal protection policy" adopted by Johnson Controls to restrict jobs in the manufacture of batteries to men and sterile women was a violation of law prohibiting discrimination solely on the basis of possible or actual pregnancy.<sup>1</sup>

The Johnson Controls case nonetheless demonstrates that women may face discrimination because of their reproductive capacity, regardless of whether they are pregnant or intend to become so. Although male exposure to lead used in battery manufacture might also cause genetic anomalies in fetuses, only women were targeted by this policy. In addition to Johnson Controls, companies like General Motors, DuPont, Union Carbide, and other major corporations have prohibited fertile women from working in high-level, high-paying jobs involving substantial exposure to lead. Such fetal protection policies have barred women from as many as 20-million jobs (Becker 1986; Norris 1991).

At present, there are few reports of disease-specific discrimination affecting women. However, the history of disease or other preexisting conditions has often been used as a reason to deny health insurance to many individuals of either sex, and all genetic diseases may be considered "preexisting conditions." Whether this is a practice that affects women more often than men, or whether the loss of health insurance is generally more disastrous for women than men, is unclear. The increas-

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<sup>1</sup>111 S. Ct. 1196. 1991. *International Union, United Automobile, Aerospace, and Agricultural Implement Workers of America, UAW et al., Petitioners, v. Johnson Controls, Inc.*

ing number of female-headed households suggests that a greater number of women are responsible for coverage of affected relatives. More studies are needed to address this issue (see table 3).

Information regarding genetic discrimination in employment and insurance includes not only documentation of the practice, but also recommendations for avoiding or reducing such discrimination (Gostin 1991; Billings et al. 1992; Kass 1992; Natowicz et al. 1992; Murray 1992; Ostrer et al. 1993). Studies indicate that employers are less likely to offer common nonwage benefits like health coverage and disability to women (Currie 1993). There is, however, little documentation of gender-related genetic discrimination in employment and insurance, and little court litigation to date has focused on the burden of genetic testing on women (Gostin 1991). The use of genetic prognosis for employment decisions is generally a gender-neutral and race-neutral policy. Any Title VII litigation to remedy genetic discrimination is likely, therefore, to be based upon "disparate impact theory": the rationale that consideration of genetic traits or conditions in employment decisions disqualifies proportionately more women (Gostin 1991). The evidence of previous and current employment discrimination based on gender or reproductive potential supports the claim that the potential harm of rendering human beings virtually unemployable through genetic prognosis is likely to fall disproportionately on women.

### *Women Who Care for the Genetically Disabled*

The economic and social costs of bearing children, whether healthy or disabled, are greater for women than ever before because of their increased workforce participation (Bianchi and Spain 1987). Both formally as hired caregivers and informally as unpaid caregivers of family members, friends, and relatives, women are the main providers of care to children, the sick, the disabled, and the elderly (Thompson and Walker 1989; U.S. Bureau of the Census 1988; Wertz and Fletcher 1993). Moreover, the recent rise in divorces and numbers of births to single women has led to a predominance of women as sole caregivers of children, with or without genetic conditions (Bianchi and Spain 1987). Few studies have been undertaken on the costs and burdens of caregiving to disabled or chronically ill children, and these may be flawed by poor methodology in survey methods, limited use of variables to explain cost variations, and unstandardized mea-

asures in assessing the costs of caregiving. However, even these limited results suggest an enormous economic and social burden for family caregivers, who are usually women, in caring for disabled or chronically ill children (Jacobs and McDermott 1989; Marcenko and Meyers 1991; McCollum 1971; Wertz and Fletcher 1993).

Costs of caregiving include both objective and subjective costs, including money expended on therapies, medications, nursing care, hospital stays and medical equipment, as well as stress, time, and chronic fatigue (Breslau 1983; Eiser 1990; Parks and Pilisuk 1991). The costs of caring for chronically ill and disabled children extends long beyond the period of children's normal dependence (Jacobs and McDermott 1989; Wertz and Fletcher 1993). Added to the persistent economic costs is the physical and psychological toll on the part of the primary caregiver, which includes ill health, guilt, and anger (Parks and Pilisuk 1991). The symptoms of mothers who are primary caregivers are strongly influenced by their perception of how severely disabled their child is, the severity of the child's disability, and their relationship with the child's father (Eiser 1990). Women who are primary caregivers are more likely to experience depression than their male counterparts (Eiser 1990).

Studies looking at the impact of a child's disability on the mother's paid and nonpaid work are mainly descriptive, based on data from small samples of families of disabled children. They do not generally distinguish between genetic and nongenetic conditions. They do suggest, however, that caring for disabled or chronically ill children restricts women's activities outside the home, including employment, while increasing their domestic burdens (Breslau 1983). Not surprisingly, these effects are felt more by low-income and minority women than by others. Breslau has examined the impact of caregiving on a mother's employment and household work. Although care of disabled children reduces the probability of employment and increases the domestic workload of married women in low-income and black families, the employment probability and household activities of single mothers are not significantly affected (Breslau, Salkever, and Staruch 1982; Breslau 1983). Single mothers may depend upon their own employment for family income and spend their time in nondiscretionary activities that allow little flexibility for allocating additional time to the extra needs of a disabled or chronically ill child (Breslau 1983). However, married women or women who can rely on the economic assistance of a partner also experience the economic and social costs of giving up paid employment

(Wertz and Fletcher 1993). Nor does the burden of caregiving end with the advancing age of children, who in previous times might have succumbed to their disease before reaching adulthood. Medicine has greatly extended the lives of people with disabilities, necessitating the long-term involvement of parents in caring for their adult children.

Most research on families with disabled or chronically ill children has focused on their disruptive influence on families and marriages (Eiser 1990). Many people believe that the presence of a disabled child will strain a marriage. However, divorce rates among parents of disabled children have been reported to be no greater than among parents of nondisabled children (Benson and Gross 1989; Perrin and McLean 1988). Although the stresses of caring for disabled or ill children may exacerbate existing tensions or problems, some couples have indicated that working together to cope with a disabled or chronically ill child has enhanced their marital satisfaction (Benson and Gross 1989).

It is clear that women continue to serve as the primary caregivers of disabled and chronically ill children and are more likely to experience the burdens and costs associated with that task. However, the overall impact of the disabled child on the primary caregiver remains unclear because the methodological design of some studies addressing these issues is flawed, as is apparent in their lack of control groups, unstandardized measurements, and inadequate control of significant variables like disease severity (Benson and Gross 1989). More rigorous studies are required in order to characterize adequately the impact of caregiving on women and then to assess whether it meets standards of fairness in society (table 3). The HGP will not increase the number of disabled children born, and in all probability will reduce their numbers through advances in treatments or selective abortions.

## Conclusion

Tables 1, 4, and 5 provide concrete answers to our first and second questions. Regarding questions 3, 4, and 5, however, table 2 indicates only tentative findings about the particular impact of the HGP on women. For the most part, tables 1, 4, and 5 refer to gender differences derived from biological characteristics that are unchangeable; in contrast, most of those mentioned in table 2, which deal with differences related to employment, insurance, and caregiving, are changeable.



No conclusions have been reached about the ethical implications of either changeable or unchangeable gender differences. That would require a fuller and more theoretical analysis of "justice" and how such differences are to be handled in a "just" society (see, for example, Mahowald 1994, 1995). Nonetheless, cases where differences confer a greater burden or benefit to women have been noted, suggesting the need for policies to reduce disproportionate burdens and to distribute benefits more equitably. The recent report of the Institute of Medicine's Committee on Assessing Genetic Risks (Andrews et al. 1994) is a significant contribution in this regard. We believe, however, that adequate development of policies and legislation requires broader public input and greater participation of the groups most affected by the new genetics. A specific focus on women is more than justified by the data provided here.

Clearly, the most important set of gender differences as they relate to the HGP involves the increasing availability and use of genetic information for reproductive decisions. Information derived from the HGP will benefit some women by providing them with fuller information relevant to reproductive choices. For these women and others, however, the same information is likely to evoke pressures from others and to lead to greater physical risks and psychosocial burdens. Men are unable or less likely to experience most of these consequences of the new genetics. Moreover, unless current practice and politics shift drastically, the benefits of prenatal diagnosis and interventions will not be available to all women because those in lower-income brackets tend to have less access to these services.

It remains to be seen whether gender differences associated with the new genetics are just or justifiable. The data regarding current disparities between women and men, and between different groups of women, do not support the idealistic expectation that the new genetics is likely to be gender neutral in its impact. Yet the same data identify those areas of clinical and social practice that may be targeted now in order to reduce the potential for greater gender disparities in the future.

## References

- Abuelo, D.N., M.R. Hopmann, G. Barsel-Bowers, and A. Goldstein. 1991. Anxiety in Women with Low Maternal Serum Alpha Feto-protein Screening Results. *Prenatal Diagnosis* 11:381-5.

- Adzick, N.S., and M.R. Harrison. 1994. Fetal Surgical Therapy. *Lancet* 343:897-902. (Review)
- Adzick, N.S., M.R. Harrison, A.W. Flake, et al. 1993. Fetal Surgery for Cystic Adenomatoid Malformation of the Lung. *Journal of Pediatric Surgery* 28:806-12.
- Anderson, C. 1992. NIH Aims at "Glass Ceiling." *Nature* 356(March 5):6.
- Andrews, L.B. 1987. *Medical Genetics: A Legal Frontier*. Chicago: American Bar Association.
- . 1992. Torts and the Double Helix: Malpractice Liability for Failure to Warn of Genetic Risks. *Houston Law Review* 291 (spring):149-84.
- Andrews, L.B., J.E. Fullarton, N.H. Holtzman, and A.G. Motulsky. Eds. 1994. *Assessing Genetic Risks: Implications for Health and Social Policy*. Washington, D.C.: National Academy Press.
- Angier, N. 1994. Genetic Mutations Tied to Father in Most Cases. *New York Times* (May 17):C12.
- Annas, G.J. 1991. Fetal Protection and Employment Discrimination: The Johnson Controls Case. *New England Journal of Medicine* 325: 740-3.
- . 1992. The Human Genome Project as Social Policy: Implications for Clinical Medicine. *Bulletin of the New York Academy of Medicine* 681:126-34.
- Arason, B., R.B. Barkardottir, and V. Egilsson. 1993. Linkage Analysis of Chromosome 17q Markers and Breast-Ovarian Cancer in Icelandic Families and Possible Relationship to Prostatic Cancer. *American Journal of Human Genetics* 52:711-17.
- Barss, V.A., B.R. Benacerraf, and F.D. Frigoletto. 1988. Management of Isoimmunized Pregnancy by Use of Intravascular Techniques. *American Journal of Obstetrics and Gynecology* 159:932-7.
- Becker, M.E. 1986. From Muller v. Oregon to Fetal Vulnerability Policies. *University of Chicago Law Review* 53:1219-73.
- Benson, B.A., and A.M. Gross. 1989. The Effect of a Congenitally Handicapped Child Upon the Marital Dyad: A Review of the Literature. *Clinical Psychology Review* 9:747-58.
- Berkowitz, R.L., U. Chitkara, I.A. Wilkins, L. Lynch, H. Plosker, and H.H. Bernstein. 1988. Intravascular Monitoring and Management of Erythroblastosis Fetalis. *American Journal of Obstetrics and Gynecology* 158:783-95.
- Bianchi, S.M., and D. Spain. 1987. *American Women in Transition: A Census Monograph on the Population of the United States in the 1980's*. New York: Russell Sage Foundation/National Committee for Research on the Census.

- Bielby, W.T., and J.N. Baron. 1986. Men and Women at Work: Sex Segregation and Statistical Discrimination. *American Journal of Sociology* 91:759-99.
- Biesecker, B.B., M. Boehnke, K. Calzone, et al. 1993. Genetic Counseling for Families with Inherited Susceptibility to Breast and Ovarian Cancer. *Journal of the American Medical Association* 269:1970-4.
- Billings, P.R., M.A. Kohn, M. de Cuevas, J. Beckwith, J.S. Alper, and M.R. Natowicz. 1992. Discrimination as a Consequence of Genetic Testing. *American Journal of Human Genetics* 50:476-82.
- Black, R.B. 1989. A 1- and 6-Month Follow-Up of Prenatal Diagnosis Patient Who Lost Pregnancies. *Prenatal Diagnosis* 9:795-804.
- . 1990. Prenatal Diagnosis and Fetal Loss: Psychosocial Consequences and Professional Responsibility. *American Journal of Human Genetics* 35:586-7.
- . 1994. Reproductive Genetic Testing and Pregnancy Loss: The Experience of Women. In *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*, eds. K.H. Rothenberg and E.J. Thomson. Columbus: Ohio State University Press.
- Bowman, J.M. 1989. Hemolytic Disease (Erythroblastosis Fetalis). In *Maternal-Fetal Medicine: Principles and Practices*, 2d ed., eds. R.K. Creasy and R. Resnik. Philadelphia: W.B. Saunders.
- . 1991. Prenatal Screening for Hemoglobinopathies. *American Journal of Human Genetics* 48:433-8. (invited editorial)
- Breslau, N. 1983. Care of Disabled Children and Women's Time Use. *Medical Care* 216:620-9.
- Breslau, N., D. Salkever, and K. Staruch. 1982. Women's Labor Force Activity and Responsibilities for Disabled Dependents: A Study of a Family with Disabled Children. *Journal of Health and Social Behavior* 23:169.
- Burstein, P. 1989. Attacking Sex Discrimination in the Labor Market: A Study in Law and Politics. *Social Forces* 67(3):641-65.
- Caccia, N., J.M. Johnson, G.E. Robinson, and T. Barna. 1991. Impact of Prenatal Testing on Maternal-Fetal Bonding: Chorionic Villus Sampling vs. Amniocentesis. *American Journal of Obstetrics and Gynecology* 165:1122-5.
- Canadian Collaborative CVS-Amniocentesis Clinical Trial Group (CCCACTG). 1989. Multicentre Randomised Clinical Trial of Chorion Villus Sampling and Amniocentesis. *Lancet* 1-7.
- Canick, J.A., and G.B. Bowers. 1991. Enhanced Prenatal Screening for Down Syndrome Using Multiple Biochemical Markers. *Genetic Resource* 6(1):5-9.
- Canny, G.J., M. Corey, and R.A. Livingstone. 1991. Pregnancy and Cystic Fibrosis. *Obstetrics and Gynecology* 77:850.

- Carson, S.A., and J.B. Buster. 1994. Biopsy of Gametes and Preimplantation Embryos in Genetic Diagnosis. *Seminars in Reproductive Endocrinology* 12(3):184-95.
- Charo, R.A., and K.H. Rothenberg. 1994. "The Good Mother": The Limits of Reproductive Accountability and Genetic Choice. In *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*, eds. K.H. Rothenberg and E.J. Thomson. Columbus: Ohio State University Press.
- Cheng, E.Y., Luthy, D.A., and A.M. Zebelman, et al. 1993. A Prospective Evaluation of a Second-Trimester Screening Test for Fetal Down Syndrome Using Maternal Serum Alpha-Fetoprotein, hCG, and Unconjugated Estriol. *Obstetrics and Gynecology* 81:72-7.
- Clarke, A. 1991. Is Non-Directive Genetic Counseling Possible? *Lancet* 338:998-1001.
- Clayton, E.W. 1994. What the Law Says about Reproductive Genetic Testing and What It Doesn't. In *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*, eds. K.H. Rothenberg and E.J. Thomson. Columbus: Ohio State University Press.
- Collins, F. and D. Galas. 1993. A New Five Year Plan for the U.S. Human Genome Project. *Science* 262(October 1):43-6.
- Collins, M., and J. Natapoff. 1985. A Descriptive Analysis of Maternal and Infant Health Care in New York State. *Journal of New York State Nurses' Association* 16:11-17.
- Cowan, R.S. 1993. Aspects of the History of Prenatal Diagnosis. *Fetal Diagnosis and Therapy* 8(suppl. 1):10-17.
- Crane, J.P., M.L. LeFevre, and R.C. Winborn, et al. 1994. A Randomized Trial of Prenatal Ultrasonographic Screening: Impact on the Detection, Management, and Outcome of Anomalous Fetuses. *American Journal of Obstetrics and Gynecology* 171:392-9.
- Crombleholme, T.M., M.R. Harrison, and R.L. Anderson. 1988. Early Experience with Open Fetal Surgery for Congenital Hydronephrosis. *Journal of Pediatric Surgery* 23:1114-16.
- Currie, J. 1993. Gender Gaps in Benefit Coverage. NBER Working Paper No. 4265. New York: Center for Economic Analysis of Human Behavior and Social Institutions, National Bureau of Economic Research.
- Curry, M.A. 1989. Nonfinancial Barriers to Prenatal Care. *Women and Health* 15(3):85-99.
- Daley, D., and R. Benson-Gold. 1993. Public Funding for Contraception, Sterilization, and Abortion Services, Fiscal Year 1992. *Family Planning Perspectives* 25 (6).
- Davis, J.G. 1993. Reproductive Technologies for Prenatal Diagnosis. *Fetal Diagnosis and Therapy* 8(suppl. 1):28-38

- Docker, M.F. 1992. Ultrasound Imaging Techniques. In *Prenatal Diagnosis and Screening*, eds. D.J.H. Brock, C.H. Rodeck, and M.A. Ferguson-Smith, 69. Edinburgh, U.K.: Churchill-Livingstone.
- Edwards, J.G., W. Rothstein, and S.R. Young. 1989. Elective Termination of Chromosomally Abnormal Pregnancies: Psychosocial Effects and Experience in Genetic Counseling. *Loss, Grief, and Care* 3(3-4):21-36.
- Eiser, C. 1990. Psychological Effects of Chronic Disease. *Journal of Clinical Psychology and Psychiatry* 31(1):85-98.
- Elders, S.H., and K.M. Laurence. 1991. The Impact of Supportive Intervention after Second Trimester Termination of Pregnancy for Fetal Abnormality. *Prenatal Diagnosis* 11(1):47-54.
- Elias, S., and G.J. Annas. 1992. *Gene Mapping: Using Law and Ethics as Guides*. New York: Oxford University Press.
- Evers-Kiebooms, G., A. Sweerts, and H. Van den Berghe. 1988. Psychological Aspects of Amniocentesis. Anxiety Feelings in Three Different Risk Groups. *Clinical Genetics* 33:196-200.
- Fischer, C.C. 1987. Toward a More Complete Understanding of Occupational Sex Discrimination. *Journal of Economic Issues* 21(1):113-38.
- Flaherty, F. 1991. Who Decides What's Safe? *Commonweal* 118:713-15.
- Fletcher, J., and M. Evans. 1983. Maternal Bonding in Early Fetal Ultrasound Examination. *New England Journal of Medicine* 308: 392-3.
- Friedmann, T. 1990. The Human Genome Project: Some Implications of Extensive "Reverse Genetic" Medicine. *American Journal of Human Genetics* 46:407-14.
- Gallagher, J. 1989. Position Paper: Fetus as Patient. In *Reproductive Laws for the 1990s*, eds. S. Cohen and N. Taub. Clifton, N.J.: Humana Press.
- Gates, E.A. 1994. Does Testing Benefit Women. In *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*, eds. K.H. Rothenberg and E.J. Thomson. Columbus: Ohio State University Press.
- Gostin, L. 1991. Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers. *American Journal of Law and Medicine* 17(1-2):109-44.
- Grannum, P.A., J.A. Copel, and F.R. Moya. 1988. The Reversal of Hydrops Fetalis by Intravascular Intrauterine Transfusion in Severe Isoimmune Fetal Anemia. *American Journal of Obstetrics and Gynecology* 158:914.
- Handyside, A.H., J.G. Lesko, J.J. Tarin, R.M. Winston, and M.R. Hughes. 1992. Birth of a Normal Girl After in Vitro Fertilization and Preimplantation Diagnostic Testing for Cystic Fibrosis. *New England Journal of Medicine* 327:905-9.

- Harrison, M.R., N.S. Adzick, A.W. Flake, et al. 1993. Correction of Congenital Diaphragmatic Hernia in Utero. *Journal of Pediatric Surgery* 28:1411-18.
- Henifin, M.S., R. Hubbard, and J. Norsigian. 1989. Position Paper: Prenatal Screening. In *Reproductive Laws for the 1990s*, eds. S. Cohen and N. Taub. Clifton, N.J.: Humana Press.
- Hibbard, J.U., and M.S. Verp. 1992. Maternal Serum Screening for Detection of Fetal Abnormalities and Pregnancy Complications. In *The High Risk Fetus*, eds. C.C. Lin, M.S. Verp, and R.E. Sabbagha, 210. New York: Springer-Verlag.
- Holbrook, K.A., Smith, L.T., and S. Elias. 1993. Prenatal Diagnosis of Genetic Skin Disease Using Fetal Skin Biopsy Samples. *Archives of Dermatology* 129:1437-54.
- Holtzman, N.A. 1993. Primary Care Physicians As Providers of Front-line Genetic Services. *Fetal Diagnosis and Therapy* 8 (suppl. 1):213-19.
- Jablonski, S. 1991. *Dictionary of Syndromes and Eponymic Diseases*. New York: Krieger.
- Jackson, L. 1991. Practical Considerations in Preimplantation Diagnosis. In *Preimplantation Genetics*, eds. Y. Verlinksy and A. Kuliev, 182. New York: Plenum Press.
- Jacobs, P., and S. McDermott. 1989. Family Caregiver Costs of Chronically Ill and Handicapped Children: Method and Literature Review. *Public Health Reports* 104(2):158-63.
- Jones, O.W. 1989. Basic Genetics and Patterns of Inheritance. In *Maternal-Fetal Medicine: Principles and Practices*, 2d ed., eds. R.K. Creasy and R. Resnik. Philadelphia: W.B. Saunders.
- Jordan, E. 1992. The Human Genome Project: Where Did It Come From, Where Is It Going? *American Journal of Human Genetics* 51:1-6. (invited editorial)
- Kaplan, D. 1993. Prenatal Screening and Its Impact on Persons with Disabilities. *Fetal Diagnosis and Therapy* 8(suppl. 1):64-9.
- Karaviti, L.P., A.B. Mercado, M.B. Mercado, et al. 1992. Prenatal Diagnosis/Treatment in Families at Risk for Infants with Steroid 21 Hydroxylase Deficiency (Congenital Adrenal Hyperplasia). *Journal of Steroid Biochemistry and Molecular Biology* 41(3-8):445-51.
- Kass, N.E. 1992. Insurance for the Insurers: The Use of Genetic Tests. *Hastings Center Report* 22(6):6-11.
- Kassam, M.J., A. Fernhoff, K. Brantley, et al. 1980. Acceptance of Amniocentesis by Low-Income Patients in an Urban Hospital. *American Journal of Obstetrics and Gynecology* 138:11-15.
- Kerber, S., and K.R. Held. 1993. Early Genetic Amniocentesis: Four Year's Experience. *Prenatal Diagnosis* 13:21-7.

- King, M.C., S. Rowell, and S.M. Love. 1993. Inherited Breast and Ovarian Cancer. *Journal of the American Medical Association* 269:1975–80.
- King, P.A. 1994. Ethics and Reproductive Genetic Testing: The Need to Understand the Parent–Child Relationship. In *Women and Reproductive Testing: Facing the Challenges of Genetic Technology*, eds. K. Rothenberg and E.J. Thomson. Columbus: Ohio State University Press.
- Kolata, G. 1995. Scientists Speedily Locate a Gene That Causes Breast Cancer; Better Screening Is Seen. *New York Times* (December 21): A15.
- Kuller, J.A., and M.S. Golbus. 1992. Fetal Therapy. In *Prenatal Diagnosis and Screening*, eds. D.J.H. Brock, C.H. Rodeck, and M.A. Ferguson-Smith, 710. Edinburgh, U.K.: Churchill-Livingstone.
- Laxova, R., and P.F. Feldman. 1992. General Genetics Principles: Chromosomal, Mendelian, and Principles of Teratology. In *Principles and Practice of Medical Therapy in Pregnancy*, 2d ed., ed. N. Gleicher, 113–47. East Norwalk, Conn.: Appleton & Lange.
- Ledbetter, D.H., A.O. Martin, and Y. Verlinsky, et al. 1990. Cytogenetic Results of Chorionic Villus Sampling: High Success Rate and Diagnostic Accuracy in the United States Collaborative Study. *American Journal of Obstetrics and Gynecology* 162:495–501.
- Lippman, A. 1991a. Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities. *American Journal of Law and Medicine* 17(1 and 2):15–50.
- . 1991b. Research Studies in Applied Human Genetics: A Quantitative Analysis and Critical Review of Recent Literature. *American Journal of Medical Genetics*. 41:105–11.
- . 1992. Mother Matters: A Fresh Look at Prenatal Genetic Testing. *Issues in Reproductive and Genetic Engineering* 5(2):141–54.
- Lippman-Hand, A. 1981. Prenatal Diagnosis for the Detection of Down Syndrome: Why Are So Few Eligible Women Tested? *Prenatal Diagnosis* 249:250.
- MacLachlan, N.A. 1992. Amniocentesis. In *Prenatal Diagnosis and Screening*, eds. D.J.H. Brock, C.H. Rodeck, and M.A. Ferguson-Smith, 17. Edinburgh, U.K.: Churchill-Livingstone.
- Mahowald, M.B. 1993. *Women and Health Care: An Unequal Majority*. New York: Oxford University Press.
- . 1994. Reproductive Genetics and Gender Justice. In *Women and Reproductive Testing: Facing the Challenges of Genetic Technology*, eds. K. Rothenberg and E.J. Thomson, 67–86. Columbus: Ohio State University Press.
- . 1995. Gender Justice and Genetics. In *The Social Power of Ideas*, eds. Y. Hudson and W.C. Peden, 225–51. New York: Edwin Mellen Press.

- Manning, F.A. 1989. General Principles and Applications of Ultrasound. In *Maternal Fetal Medicine: Principles and Practice*, 2d ed., eds. R.K. Creasy and R. Resnik. Philadelphia: W.B. Saunders.
- Marcenko, M.D., and J.C. Meyers. 1991. Mothers of Children with Developmental Disabilities: Who Shares the Burden? *Family Relations* 40:186-90.
- Marion, J.P., G. Kazzam, P.M. Fernhoff, et al. 1980. Acceptance of Amniocentesis by Low-Income Patients in an Urban Hospital. *American Journal of Obstetrics and Gynecology* 138:11-15.
- Marteau, T.M., R. Cook, J. Kidd, et al. 1992. The Psychological Effects of False-Positive Results in Prenatal Screening for Fetal Abnormality: A Prospective Study. *Prenatal Diagnosis* 12:205-14.
- McCollum, A.T. 1971. Cystic Fibrosis: Economic Impact Upon the Family. *American Journal of Public Health* 61:1335-41.
- McKusick, V.A. 1992. *Mendelian Inheritance in Man* (vols. 1 and 2). Baltimore, Md.: Johns Hopkins University Press.
- Mittman, I. 1990. Immigration and the Provision of Genetic Services. In *Genetic Services for Underserved Populations*, eds. N. Paul and L. Kavanaugh. Washington, D.C.: National Center for Education in Maternal and Child Health.
- Monk, M. 1992. Preimplantation Diagnosis: A Comprehensive Review. In *Prenatal Diagnosis and Screening*, eds. D.J.H. Brock, C.H. Rodeck, and M.A. Ferguson-Smith, 627. Edinburgh, U.K.: Churchill-Livingstone.
- Muller, C.F. 1992. *Health Care and Gender*. New York: Russell Sage Foundation.
- Murray, T.H. 1992. Genetics and the Moral Mission of Health Insurance. *Hastings Center Report* 22(6):12-17.
- National Institutes of Health. 1990. *Understanding Our Genetic Inheritance. The U.S. Human Genome Project: The First Five Years, FY 1991-1995*. NIH pub. no. 90-1590. Bethesda, Md.
- Natowicz, M.R., J.K. Alper, and J.S. Alper. 1992. Genetic Discrimination and the Law. *American Journal of Human Genetics* 50:465-75.
- Ney, J.A., M.L. Socol, S.L. Dooley, S.N. MacGregor, R.K. Silver, and D.D. Millard. 1991. Perinatal Outcome Following Intravascular Transfusion in Severely Isoimmunized Fetuses. *International Journal of Gynecology and Obstetrics* 35:41-6.
- Nicoloni, U., and C.H. Rodeck. 1992. Fetal Blood and Tissue Sampling. In *Prenatal Diagnosis and Screening*, eds. D.J.H. Brock, C.H. Rodeck, and M.A. Ferguson-Smith, 44-8. Edinburgh, U.K.: Churchill-Livingstone.
- Noble, B.P. 1993. An Increase in Bias Is Seen against Pregnancy Workers. *New York Times* (January 2):A1, 15.



- Norris, R. 1991. Double Jeopardy. *American Health* 10(2):32-4.
- Nsiah-Jefferson, L. 1989. Reproductive Laws, Women of Color, and Low-Income Women. In *Reproductive Laws for the 1990s*, eds S. Cohen and N. Taub. Clifton, N.J.: Humana Press.
- . 1994. Reproductive Genetic Services for Low-Income Women and Women of Color: Access and Sociocultural Issues. In *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*, eds. K.H. Rothenberg and E.J. Thomson. Columbus: Ohio State University Press.
- Nsiah-Jefferson, L., and E.J. Hall. 1989. Reproductive Technology: Perspectives and Implications for Low-Income Women and Women of Color. In *Healing Technology: Feminist Perspectives*, eds. K.S. Ratcliff, M.M. Ferree, G.O. Mellow, et al. Ann Arbor: University of Michigan Press.
- Ostrer, H., W. Allen, L.A. Crandall, et al. 1993. Insurance and Genetic Testing: Where Are We Now? *American Journal of Human Genetics* 52:565-77.
- Parks, S.G., and M. Pilisuk. 1991. Caregiver Burden: Gender and the Psychological Costs of Caregiving. *American Journal of Orthopsychiatry* 61:501-9.
- Paul, D.B. 1994. Is Human Genetics Disguised Eugenics? In *Genes and Human Self-Knowledge*, eds. R.F. Weir, S.C. Lawrence, and E. Fales. Iowa City: University of Iowa Press.
- Pencarinha, D.F., H.K. Bell, J.G. Edwards, and R.G. Best. 1992. Ethical Issues in Genetic Counseling: A Comparison of M.S. Counselor and Medical Geneticist Perspective. *Journal of Genetic Counseling* 1 (1):19-30.
- Perrin, J.M., and W.E. McLean. 1988. Children with Chronic Illness: The Prevention of Dysfunction. *Pediatric Clinics of North America* 35: 1325-37.
- Perry, K.G., and J.C. Morrison. 1992. Hematologic Disorders in Pregnancy. *Obstetrics and Gynecology Clinics of North America* 19:783-99.
- Piolet, B.W., M.L. Socol, and S.N. MacGregor. 1988. Cordocentesis: An Appraisal of Risks. *American Journal of Obstetrics and Gynecology* 158: 1497.
- Poland, M., J. Ager, and J. Olson. 1987. Barriers to Receiving Adequate Prenatal Care. *American Journal of Obstetrics and Gynecology* 157:297-303.
- President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. 1983. *Screening and Counseling for Genetic Conditions*. Washington, D.C.
- Pryde, P.G., A. Drugan, M.P. Johnson, N.B. Isada, and M.I. Evans. 1993. Prenatal Diagnosis: Choices Women Make About Pursuing

- Testing and Acting on Abnormal Results. *Clinical Obstetrics and Gynecology* 36:496–509.
- Purdy, L. 1978. Genetic Diseases: Can Having Children Be Immoral? In *Genetics Now: Ethical Issues in Genetic Research*, ed. J.J. Buckley, Jr. Washington, D.C.: University Press of America.
- Rapp, R. 1988. Chromosomes and Communication: The Discourse of Genetic Counseling. *Medical Anthropology Quarterly* 2:143–57.
- . 1990. Constructing Amniocentesis: Maternal and Medical Discourses. In *Uncertain Terms: Negotiating Gender in American Culture*, eds. F.D. Ginsburg and A. Lowenhaupt-Tsing. Boston, Mass.: Beacon Press.
- . 1991. Reproduction and Gender Hierarchy: Amniocentesis in Contemporary America. In *Sex and Gender Hierarchies*, ed. B. Miller. Chicago, Ill.: University of Chicago Press.
- . 1994. Women's Responses to Prenatal Diagnosis: A Sociocultural Perspective on Diversity. In *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*, eds. K.H. Rothenberg and E.J. Thomson. Columbus: Ohio State University Press.
- Raudrant, D., J.L. Touraine, and A. Rebaud. 1992. In Utero Transplantation of Stem Cells in Humans: Technical Aspects and Clinical Experience during Pregnancy. *Bone Marrow Transplantation: Proceedings of the Symposium of Foetal and Neonatal Cell Transplantation and Retroviral Gene Therapy* 9 (suppl. 1):98–100.
- Remy, M. 1985. *A Report on Prenatal Care in Oregon*. Portland, Ore.: Oregon State Health Division.
- Richert, D. 1983. *Healthy Mothers and Babies: Pay Now or Pay Later*. Lexington, Ky.: Kentucky Coalition for Maternal and Child Health.
- Roberts, L. 1993. Taking Stock of the Genome Project. *Science* 262(October 1):20–2.
- Rosner, F., A. Bennet, and E. Cassell. 1989. Fetal Therapy and Surgery. *New York State Journal of Medicine* 89(2):80–4.
- Rossiter, J.P., and T.R. Johnson. 1992. Management of Genetic Disorders during Pregnancy. *Obstetrics and Gynecology Clinics of North America* 19:801–13.
- Rothman, B.K. 1986. *The Tentative Pregnancy*. New York: Penguin Books.
- Rothman, B.K. 1994. The Tentative Pregnancy: Then and Now. In *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*, eds. K.H. Rothenberg and E.J. Thomson. Columbus: Ohio State University Press.
- Sauer, M.B., M. Bustillo, M.J. Gorrill, J.A. Louw, J.R. Marshall, and J.E. Buster. 1988. An Instrument for the Recovery of Preimplantation Uterine Ova. *Obstetrics and Gynecology* 71:804–6.

- Schemmer, G., and A. Johnson. 1993. Genetic Amniocentesis and Chorionic Villus Sampling. *Obstetrics and Gynecology Clinics of North America* 20:497-521.
- Seller, M.J. 1987. Neural Tube Defects and Sex Ratios. *American Journal of Medical Genetics* 26:699-707.
- Silberman, N.S., and R.J. Wapner. 1992. Chorionic Villus Sampling. In *Prenatal Diagnosis and Screening*, eds. D.J.H. Brock, C.H. Rodeck, and M.A. Ferguson-Smith, 27-9. Edinburgh, U.K.: Churchill-Livingstone.
- Smith, S.C., and J. Miller. 1990. Prenatal Diagnosis Technology: Equal Access for all Women. In *Strategies in Genetic Counseling: Reproductive Genetics and New Technologies*, eds. B.A. Fine, E. Gettig, K. Green-dale, et al. Original Article Series. 26(3). White Plains, N.Y.: March of Dimes Birth Defect Foundation.
- Socol, M.L. 1992. Management of Blood Group Isoimmunization. In *Principles and Practice of Medical Therapy in Pregnancy*, 2d ed., ed. N. Gleicher, 1050. East Norwalk, Conn.: Appleton & Lange.
- Sorenson, J.R. 1993. Genetic Counseling: Values That Have Mattered. In *Prescribing Our Future: Ethical Challenges in Genetic Counseling*, eds. D.M. Bartels, B.S. LeRoy, and A.L. Caplan, 13. New York: Walter de Gruyeter.
- Sorenson, J.R., and D.C. Wertz. 1986. Couple Agreement before and after Genetic Counseling. *American Journal of Medical Genetics* 25:549-55.
- Strassner, H.T. 1992. Diagnostic Procedures. In *Principles and Practice of Medical Therapy in Pregnancy*, 2d ed., ed. N. Gleicher. East Norwalk, Conn.: Appleton & Lange.
- Thompson, L., and A.J. Walker. 1989. Gender in Families: Women and Men in Marriage, Work, and Parenthood. *Journal of Marriage and the Family* 51:845-71.
- Thornton, J.G., H.M. McNamara, and I.A. Montague. 1994. Would You Rather Be a Birth or a Genetic Mother? If So, How Much? *Journal of Medical Ethics* 20:87-92.
- Tierney, L.M., S.J. McPhee, M.A. Papadakis, and S.A. Schroeder (Eds.). 1993. *Current Medical Diagnosis and Treatment*. East Norwalk, Conn.: Appleton & Lange.
- Trask, B.J. 1991. Fluorescence in Situ Hybridization: Applications in Cytogenetics and Gene Mapping. *Trends in Genetics* 7(5):149-54.
- Treize, A.E., C.C. Linder, D. Grieger, et al. 1993. CFTR Expression Is Regulated during Both the Cycle of the Seminiferous Epithelium and the Oestrous Cycle of Rodents. *Nature Genetics* 3(February):157-65.

- Turner, G., H. Robinson, S. Laing, and S. Purvis-Smith. 1986. Preventive Screening for the Fragile X Syndrome. *New England Journal of Medicine* 315:607-9.
- U.S. Bureau of the Census. 1988. Who's Helping Out? Support Networks Among American Families. *Current Population Reports*. Series P-70. no. 13. Washington, D.C.
- Verp, M.S. 1992. Prenatal Diagnosis of Genetic Disorders. In *Principles and Practice of Medical Therapy in Pregnancy*, 2d ed., ed. N. Gleicher, 178. East Norwalk, Conn.: Appleton & Lange.
- Verp, M.S., J.L. Simpson, and C. Ober. 1993. Prenatal Diagnosis of Genetic Disorders. In *The High Risk Fetus*, eds. C.C. Lin, M.S. Verp, and R.E. Sabbagha. New York: Springer-Verlag.
- Watson, J.D. 1990. The Human Genome Project: Past, Present and Future. *Science* 248(April 6):44-8.
- Weaver, J. 1978. Sexism and Racism in the American Health Care Industry: A Comparative Analysis. *International Journal of Health Services* 8:677-700.
- Webb, T. 1989. The Epidemiology of the Fragile X Syndrome. In *The Fragile X Syndrome*, ed. K.E. Davies, 40-55. Oxford, England: Oxford University Press.
- Weiner, C.P. 1993. Percutaneous Umbilical Sampling. In *The High Risk Fetus*, eds. C.C. Lin, M.S. Verp, and R.E. Sabbagha, 354. New York: Springer-Verlag.
- Wenstrom, K.D., and C.P. Weiner. 1992. Diagnosis and Therapeutic Management of Fetal Disease. In *Principles and Practice of Medical Therapy in Pregnancy*, 2d ed., ed. N. Gleicher, 1317. East Norwalk, Conn.: Appleton & Lange.
- Wertz, D.C., and J.C. Fletcher. 1988a. Attitudes of Genetic Counselors: A Multinational Survey. *American Journal of Human Genetics* 42:592-600.
- . 1988b. Ethics and Medical Genetics in the United States: A National Survey. *American Journal of Medical Genetics* 29:815-27.
- . 1993. Feminist Criticism of Prenatal Diagnosis: A Response. *Clinical Obstetrics and Gynecology* 36:541-67.
- Wertz, R.W., and D.C. Wertz. 1989. *Lying-In: A History of Childbirth in America*. New Haven, Conn.: Yale University Press.
- Williams, J., A.L. Medearis, M.B. Bear, and M.M. Kaback. 1987. Chorionic Villus Sampling Is Associated with Normal Fetal Growth. *American Journal of Obstetrics and Gynecology* 157:708-12.
- Zilberstein, M.E., M. Feingood, and N. Gleicher. 1992. Adrenal Disorders. In *Principles and Practice of Medical Therapy in Pregnancy*, 2d ed., ed. N. Gleicher, 352. East Norwalk, Conn.: Appleton & Lange.

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