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Genetic Technologies and Their Implications for Women

MARY B. MAHOWALD[†]

Gender neutral language has been religiously observed by many people in recent years. I use it myself, and usually insist on it in my editorial work, to insure that the reader or listener does not interpret what is intended to apply to both genders as only applicable to one. This preference for gender neutral language embraces the avoidance of pronouns and nouns that may be intended to be generic but are often construed otherwise. To insure gender neutrality, the possibility of confusion between generic and gender specific language needs to be considered. Although clarifying constructions are sometimes more awkward than the supposedly generic ones, clarity is worth the price. In addition, the awkwardness may serve the strategic purpose of provoking some individuals to recognize inadvertent sexist tendencies in their interpretations of supposedly generic language.

Despite these points favoring gender neutral language, its use entails ethical pitfalls that need to be identified and avoided. The principal pitfall occurs when the gender neutrality obscures differences that are relevant to evaluative judgments. The aim of this Article is to overcome this pitfall with regard to genetic technologies by focusing on their implications for women. In the area of reproduction in which genetic technologies are often discussed, the tendency to use gender neutral language has become common, misleadingly masking significant sex and gender differences that must be examined if men and women are to be treated fairly as individuals.¹ Sex and gender differences

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1. See Mary B. Mahowald, et al, *The New Genetics and Women*, 74 *Milbank Q* 239

sometimes lead to disproportionate burdens and benefits for which laws and policies are needed to reduce inequities between women and men either as groups or as individuals.

In what follows, therefore, I begin by identifying empirical differences that occur in human genetics, medical genetics, and clinical genetics, and then track some of the psychosocial gender differences that occur in relation to genetic conditions. Psychosocial differences encompass not only relationships between individuals but also between employers and employees, insurance companies and potential customers, medical personnel and patients, government and citizens. Next, I consider some of the differences identified with regard to whether they are changeable, and whether they reflect disproportionate or inequitable impact on women. I isolate two categories of differences as necessary considerations in policies or laws intended to promote gender justice: those that involve inequity and are changeable, and those that involve inequity and are not changeable. For both categories I suggest a way of alleviating gender disparities. I do not call for the dissolution of gender inequity because I do not think that is possible. I do, however, argue for achieving the ideal of gender equality as fully as possible.

I

Victor McKusick, whose catalogue of human genetic conditions has become a classic in the field, provides some useful definitions with which to launch our analysis.² “*Genetics*,” he writes, is

[T]he science of biological variation; *human genetics*: the science of biological variation in humans; *medical genetics*: the science of biological variation as it relates to health and disease; and *clinical genetics*: the part of medical genetics concerned with health and disease in individuals and their families or the science and practice (art) of diagnosis, prevention, and management of genetic disorders.³

McKusick remarks that these definitions are nested in each other. They do not form a perfect nesting, however, because medical geneticists may study health and disease in nonhuman organisms or genetic conditions that are not related to health and disease, and clinical geneticists can and do provide diagnostic procedures that may be undertaken for reasons totally unrelated to health or disease, as in prenatal diagnosis for sex selection.

(1996) (exploring the use of gender neutral language by the Human Genome Project, obscuring its disproportionate effect on women because of their roles in reproduction and caregiving).

2. Victor A. McKusick, *Mendelian Inheritance in Man: A Catalog of Human Genes and Genetic Disorders* (Johns Hopkins 11th ed 1994).

3. Victor A. McKusick, *Medical Genetics: A 40-Year Perspective on the Evolution of a Medical Specialty From a Basic Science*, 270 JAMA 2351 (1993).

To identify sex differences that arise in the science and clinical practice of genetics, we may look at differences associated with various types of genetic conditions. These may be classified as follows:

- (a) those affecting primarily one sex
- (b) those determined by the sex of the transmitting parent
- (c) those affecting the sexes in unequal ratios
- (d) those affecting fertility differently in males and females
- (e) those in which pregnancy poses risks to affected women or their fetuses.⁴

Regarding (a), most X-linked diseases such as Duchenne muscular dystrophy and hemophilia affect males but not females.⁵ Females, however, are responsible for passing on the condition to their sons. Some diseases, such as breast cancer, affect women more than men because of the nature of the disease itself. Although men are not affected they may pass the susceptibility gene on to their daughters, affected mothers may of course do that as well.⁶

Regarding (b), the sex of the transmitting parent may determine whether a child is affected with a particular genetic condition. X-linked recessive conditions are transmitted by female parents only; maternal rather than paternal age accounts for the increased risk of Down syndrome and other chromosomal abnormalities in children conceived by women over 35 years of age.⁷ Diseases associated with mitochondrial inheritance, such as myoclonic epilepsy are also transmitted through mothers rather than fathers.⁸ In contrast, older men are more likely to father children with a new genetic condition in the family, such as achondroplasia or Marfan syndrome.⁹ The sex of the parent also affects the severity of some inherited diseases; neurofibromatosis, for example, is more severe in children whose mother is affected than in those whose father is affected.¹⁰

Regarding (c), although fragile X syndrome occurs in both sexes, it occurs less frequently and less severely in females.¹¹ The most lethal of all birth anomalies, however, anencephaly, occurs much more often in females than in males.¹² Regarding (d), some genetic conditions such as cystic fibrosis, entail

4. Mahowald, 74 Milbank Q at 242 (cited in note 1).

5. Renata Laxova and Paula F. Feldman, *General Genetics Principles: Chromosomal, Mendelian, and Principles of Teratology*, in Norbert Gleicher, et al, eds, *Principles and Practice of Medical Therapy in Pregnancy* 113, 138 (Appleton & Lange 1992).

6. See Mary-Claire King, Sarah Rowell, and Susan M. Love, *Inherited Breast and Ovarian Cancer: What are the Risks? What are the Choices?*, 269 JAMA 1975, 1976 (1993).

7. Laxova and Feldman, *General Genetics Principles* at 121 (cited in note 5).

8. Id at 141.

9. Natalie Angier, *Genetic Mutations Tied to Father in Most Cases*, NY Times C9 (May 17, 1994).

10. McKusick, 270 JAMA 2351 (cited in note 3).

11. Gillian Turner, et al, *Preventive Screening for the Fragile X Syndrome*, 315 New England J Med 607, 608 (1986).

12. Mary J. Seller, *Neural Tube Defects and Sex Ratios*, 26 Am J Med Genetics 699,

infertility for males but not for females. Congenital adrenal hyperplasia reverses that impact: women are rendered infertile but men are not.¹³

Regarding (e), only women are affected by the exacerbated risks that pregnancy entails for those with certain genetic conditions. Pregnant women who have sickle cell disease, for example, are at risk for exacerbations of their pain crises, pneumonia, pulmonary emboli and retinal hemorrhages; their fetuses are also at increased risk for spontaneous abortion, preterm delivery, and stillbirth.¹⁴ Pregnant women with cystic fibrosis may face life-threatening respiratory complications, while those with Marfan syndrome are at risk of life-threatening cardiovascular complications.¹⁵

This list of different kinds of sex-based differences, for which I have only offered a few examples, amply illustrates the necessity of dealing explicitly with the different implications for women and men of counseling, diagnosing, and treating individuals who are affected by, or are carriers of, genetic diseases, whether these are chromosomal disorders, single-gene disorders, polygenic, or multifactorial disorders. The range of differences also suggests that the burdens of specific conditions are greater for women than men in some instances and greater for men than women in other instances. While some men and some women may seem to be unfairly treated by their genetic fate, there is no compelling evidence that men or women as a group are being unfairly treated by that fate.

In one area, however, the different impact is obviously more burdensome for women as a group than for men as a group. That, of course, is pregnancy. The impact of pregnancy-related factors on women includes more than the fact that some genetic conditions make pregnancy especially risky for women; it extends importantly and undeniably to the fact that women rather than men undergo prenatal genetic tests and interventions undertaken in response to such tests, whether these be pregnancy terminations or fetal therapies. Even when either partner may be tested to determine whether their fetus is at risk of inheriting a genetic condition, women are more likely to be tested.

To appreciate more fully the impact of prenatal tests on women, consider the following forms that such tests or diagnostic procedures may take: ultrasonography, amniocentesis, triple screen, chorionic villus sampling, percutaneous umbilical blood sampling, fetal skin biopsy, fetal liver biopsy, pre-implantation

701 (1987).

13. Moshe E. Zilberstein, Michael Feingold, and Norbert Gleicher, *Adrenal Disorders*, in Norbert Gleicher, et al, eds, *Principles and Practice of Medical Therapy in Pregnancy* 345, 352-55 (Appleton & Lange 1992).

14. Kenneth G. Perry, Jr. and John C. Morrison, *Hematologic Disorders in Pregnancy*, 19 *Obstetrics and Gynecology Clinics of N Am* 783, 788-89 (1992).

15. See Lucille A. Lester, Amy Lemke, Dana Levinson, and Mary B. Mahowald, *The Human Genome Project and Women: Cystic Fibrosis, A Case Study*, 4 *J Women's Health* 623-35 (1995); and Judith Pratt Rossiter and Timothy R.B. Johnson, *Management of Genetic Disorders During Pregnancy*, 19 *Obstetrics and Gynecology Clinics of N Am* 801, 806-08 (1992).

genetic testing.¹⁶ The different procedures vary in terms of risk (to woman and fetus), cost, invasiveness, definitiveness of finding, and when they may be performed during gestation. Ultrasound, which involves no known risk to either the pregnant woman or her fetus, can be performed as early as five weeks gestation and may be used throughout pregnancy as well.¹⁷ Although its sensitivity is low, it is generally a cue to whether more sensitive but also more invasive procedures should be used to obtain a more definitive diagnosis.

Chorionic villus sampling (CVS) is commonly performed at 9-12 weeks gestation through aspiration of tissue obtained by insertion of a catheter or needle into the pregnant woman's placenta.¹⁸ Although the diagnostic accuracy of the procedure has been estimated at 99.7 percent, a greater than normal incidence of fetal limb defects has been reported when the procedure is performed prior to 9.5 weeks gestation.¹⁹ Amniocentesis, by which amniotic fluid is aspirated from the uterus under ultrasound guidance, is generally performed at 15-17 weeks.²⁰ The procedure entails risk of maternal infection and vaginal bleeding, along with a fetal injury rate of 1 percent.²¹ A newer test, called a "triple screen," samples blood from the pregnant woman to perform three different types of test at approximately the same period of gestation as amniocentesis; while less invasive, the procedure produces less definitive results.²²

From 18 weeks gestation to term, fetal blood may be aspirated by needle from the umbilical cord; this is called percutaneous umbilical blood sampling (PUBS).²³ The fetal loss rate of this procedure is 1-2 percent; it is also associated with uterine bleeding, infection, and premature labor.²⁴ Procedures used

16. Mahowald, 74 Milbank Q at 252-55 (cited in note 1).

17. M.F. Docker, *Ultrasound Imaging Techniques*, in David J.H. Brock, Charles H. Rodeck, and Malcom A. Ferguson-Smith, eds, *Prenatal Diagnosis and Screening* 69, 79 (Churchill Livingstone 1992).

18. See David H. Ledbetter, A.O. Martin, and Y. Verkinsky, et al, *Cytogenetic Results of Chorionic Villus Sampling: High Success Rate and Diagnostic Accuracy in the United States Collaborative Study*, 162 Am J Obstetrics and Gynecology 495-501 (1990). Marion S. Verp, *Prenatal Diagnosis of Genetic Disorders* in Norbert Gleicher, et al, eds, *Principles and Practice of Medical Therapy in Pregnancy*, 159, 160-61 (Appleton & Lange 1992).

19. Glenn Schemmer and Anthony Johnson, *Genetic Amniocentesis and Chorionic Villus Sampling*, 20 Obstetrics and Gynecology Clinics of N Am 497, 515-16 (1993).

20. Verp, *Prenatal Diagnosis of Genetic Disorders* at 159 (cited in note 18).

21. Schemmer and Johnson, *Genetic Amniocentesis and Chorionic Villus Sampling* at 502-504 (cited in note 19). However, "[t]his finding has not been substantiated by other controlled studies." Id at 503.

22. Judith V. Hibbard and Marion S. Verp, *Maternal Serum Screening for Detection of Fetal Abnormalities and Pregnancy Complications*, in C.C. Lin, M.S. Verp, and R.E. Sabbagha, eds, *The High-risk Fetus: Pathophysiology, Diagnosis, and Management* 210 (Springer-Verlag 1993).

23. Jessica G. Davis, *Reproductive Technologies for Prenatal Diagnosis*, 8 (Supp 1) Fetal Diagnosis and Therapy 28, 34 (1993).

24. Peter G. Pryde, et al, *Prenatal Diagnosis: Choices Women Make About Pursuing Testing and Acting on Abnormal Results*, 36 Clinical Obstetrics and Gynecology 496, 500 (1993).

much less often than the preceding involve biopsy or sampling of cells from the liver or skin of the fetus; these have the same maternal and fetal complications as PUBS, with a higher fetal loss rate (5-7 percent) for fetal skin biopsy.²⁵

Finally, a new experimental technique called preimplantation genetic testing involves analyses of cells taken from early embryos (sometimes called preembryos) that have been fertilized in vitro.²⁶ After the cells are examined for genetic abnormalities, the embryos that are affected may be frozen or discarded. The unaffected embryos may be transferred to a woman who will gestate and give birth to a (presumably) healthy offspring. In some people's minds, this procedure is a means of bypassing the emotional and ethical issues raised by abortion; the risks it raises are those related to oocyte recovery, in vitro fertilization, and embryo transfer.

Even when prenatal testing procedures are not performed on women directly, as in the case of preimplantation genetic diagnosis, the woman experiences physical risk and discomfort that her male counterpart does not experience. (In preimplantation genetic diagnosis, the woman undergoes ovulation stimulation and ova retrieval before fertilization occurs in the laboratory.) Beyond these testing procedures, however, women may also be subjected to fetal therapies prompted by prenatal diagnosis. Fetal blood transfusion for Rh immunization, fetal surgery for conditions such as diaphragmatic hernia and urethral obstruction, fetal cell transplants for conditions such as beta thalassemia major and combined immunodeficiency, and steroid treatment for congenital adrenal hyperplasia are examples in this regard.²⁷ As with prenatal tests, these treatments involve a range of invasiveness and risk to the woman and her fetus, and some, such as fetal surgery, remain highly experimental. Severe dietary restrictions, such as that required for pregnant women who were treated as infants for phenylketonuria, also impose demands on women that their male counterparts do not face.

Clearly, prenatal diagnostic procedures and therapies offer benefits to many women and couples, and can advantage women more than men to the extent that women have greater control over these measures. Prenatal diagnosis obviously provides important information to those who wish to avoid the birth

25. Umberto Nicoloni and Charles H. Rodeck, *Fetal Blood and Tissue Sampling*, in David J.H. Brock, Charles H. Rodeck, and Malcolm A. Ferguson-Smith, eds, *Prenatal Diagnosis and Screening* 46-49 (Churchill Livingstone 1992). C.P. Weiner, *Percutaneous Umbilical Sampling*, in C.C. Lin, M.S. Verp, and R.E. Sabbagha, eds, *The High-risk Fetus: Pathophysiology, Diagnosis, and Management* 354 (Springer-Verlag 1993).

26. See generally Sandra A. Carson and John E. Buster, *Biopsy of Gametes and Preimplantation Embryos in Genetic Diagnosis*, 12 *Seminars in Reproductive Endocrinology* 184 (1994). See also Alan H. Handyside, et al, *Birth of a Normal Girl After In Vitro Fertilization and Preimplantation Diagnostic Testing for Cystic Fibrosis*, 327 *New England J Med* 905 (1992).

27. See generally Nicolini and Rodeck, *Fetal Blood and Tissue Sampling* (cited in note 25). See also Michael R. Harrison, et al, *Correction of Congenital Diaphragmatic Hernia In Utero: VI. Hard-Earned Lessons*, 28 *J Pediatric Surgery* 1411 (1993).

of an offspring with a specific genetic condition. Even if women lack the means by which to act on that information, or if they choose to continue affected pregnancies, foreknowledge for the purpose of psychological, medical, and financial preparation may be desirable. However, despite the value of such information and the possibility that options may thereby be increased, biological differences associated with genetic testing and therapies inevitably entail greater burdens for women than for men.

II

In very fundamental ways, as Simone de Beauvoir observed decades ago, biology informs destiny for women.²⁸ Consider, however, a variety of factors not contingent on biology that affect women differently than men. Advances in genetics have generated knowledge and practices that support gender-based differences in material structures that provide genetic services and in societal, cultural, and economic influences that affect women's participation in those services.

Chief among the material factors that affect women significantly are those that limit the availability of genetic services. For those who can pay for their genetic tests, counseling, and follow-up, there are few genetic counselors, providers, and institutions to respond to present needs.²⁹ This gap between "supply and demand" is only going to be widened as new tests develop. Even now, however, among those who are unable pay for genetic services, the gap is great. When genetic services are free or covered by insurance, other factors such as transportation and child care problems, language barriers, and lack of education regarding the possibility, benefits, and risks of genetic testing often hinder the access of those who are socioeconomically disadvantaged.³⁰ Since the majority of the poor are women and their children, the number of women thus deprived of genetic services exceeds the number of men who are deprived of comparable services.

Some of the social factors that impact women more than men are inseparable from their biological differences. For example, required waiting periods at clinics for genetic services sometimes result in a pregnant woman not obtaining relevant information in time to act on it.³¹ If prenatal diagnosis is

28. Simone de Beauvoir, *The Second Sex* 33 (Knopf 1953).

29. M. Collins and J. Natapoff, *A Descriptive Analysis of Maternal and Infant Health Care in New York State*, 16 J NY St Nurses' Ass'n 11 (1985).

30. See Marilyn L. Poland, Joel W. Ager, and Jane M. Olson, *Barriers to Receiving Adequate Prenatal Care*, 157 Am J Obstetrics and Gynecology 297, 300 (1987); I. Mittman, *Immigration and the Provision of Genetic Services for Underserved Populations*, in Natalie Paul and Laura Kavanagh, eds, *Genetic Services for Underserved Populations: Proceedings of a National Symposium Held in Arlington, Virginia, May, 1989* (National Maternal and Child Health Clearinghouse 1990); A. Lippman, *Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities*, 17 Am J Law Med 15 (Penguin 1986).

31. Laurie Nsiah-Jefferson and Elaine J. Hall, *Reproductive Technology: Perspectives*

performed so late that the results are not available until the fetus is already viable or possibly viable, an abortion may not be legally or practically accessible. Here again, poor or uninsured women are less likely than other women to benefit from prenatal tests (even when they are available) because they cannot pay for abortions of affected fetuses.³² The legal right to abortion does not entail the legal right to have the cost of abortion covered by third parties.

Because of their financial inability to follow-through on test results, some poor women decline to avail themselves of genetic tests and counseling where the costs would be covered by others. Some women decline genetic tests because of moral, religious, or psychological qualms about abortion.³³ Even if test results are normal, as they usually are, the psychological burden of undergoing prenatal tests may be significant.³⁴ Neither legally nor physically can their male partners participate in these troublesome decisions for women. The difficulties women experience are exacerbated by the fact that genetic diagnoses are often made during the second trimester or later, when terminations are physically, psychologically, and economically more burdensome than first trimester terminations.

Despite the relative lack of access poor women have to abortion, some authors have commented on the probable increase in pressures on them to be tested for genetic abnormalities and to abort their fetuses if such abnormalities are identified.³⁵ We have already witnessed a kind of "eugenic persuasion" in efforts to dissuade or prevent women who suffer from anomalies such as mental retardation or epilepsy from having children. Recall Justice Oliver Wendell Holmes' infamous statement in *Buck v. Bell*, supporting compulsory sterilization of the retarded on grounds that "three generations of imbeciles are enough."³⁶ More recently, Laura Purdy has argued for the obligation of persons who are carriers for serious genetic disorders not to have children.³⁷

and Implications for Low-Income Women and Women of Color, in Kathryn Strother Ratcliff, et al, eds, *Healing Technology: Feminist Perspectives* 93, 100 (U Mich 4th ed 1992).

32. Id at 101. See also R. Alta Charo and Karen H. Rothenberg, "The Good Mother": *The Limits of Reproductive Accountability and Genetic Choice*, in Karen H. Rothenberg and Elizabeth J. Thomson, eds, *Women and Prenatal Testing: Facing the Challenges of Genetic Technology* 105, 108 (Ohio St U 1994).

33. Rita Beck Black, *A 1 and 6 Month Follow-up of Prenatal Diagnosis Patients Who Lost Pregnancies*, 9 *Prenatal Diagnosis* 797 (1989); Rayna Rapp, *Women's Responses to Prenatal Diagnosis: A Sociocultural Perspective on Diversity*, in Karen H. Rothenberg and Elizabeth J. Thomson, eds, *Women and Prenatal Testing: Facing the Challenges of Genetic Technology* 219, 222 (Ohio St U 1994).

34. See generally Barbara Katz Rothman, *The Tentative Pregnancy* (Penguin 1986).

35. See generally Lippman, 17 *Am J Law Med* 15 (cited in note 30).

36. *Buck v Bell*, 274 US 200, 207 (1927) (finding compulsory sterilization of the retarded constitutionally permissible).

37. See generally Laura Purdy, *Genetic Diseases: Can Having Children Be Immoral?*, in John J. Buckley, Jr., ed, *Genetics Now: Ethical Issues in Genetic Research* (U Press Am 1994).

Because women belong to different cultural, ethnic, and religious groups, they are influenced by the values that these groups represent.³⁸ In most cases, it is impossible to determine whether decisions made in the midst of such influences are truly autonomous. Of course, men are influenced by these factors as well, but the overall impact for men tends to be more beneficial than burdensome. Women, for example, are expected to be the main caregivers of children, whether healthy or ill. And whether expected or not, they do most of the caregiving of those who are disabled by genetic conditions, both formally and informally.³⁹ Men, on the other hand, are expected to leave these burdens to their wives; their main burden, stereotypically defined and culturally supported, is to earn the income necessary to pay for that care. While there is no good documentation that care for a genetically disabled child increases the possibility of divorce or family break-downs, this is commonly thought to be the case. Women are more likely than men to compromise their professional ambitions and to leave remunerative jobs to care for affected children.⁴⁰ Undoubtedly, parenting responsibilities for children with severe genetic anomalies involve extra tensions for families and couples.

In the context of a health care system that involves profound inequities, some advocates for low-income women and women of color view new means of genetic testing with suspicion.⁴¹ Feminist critics view the latest technologies as part of a larger history of women's loss of control over birth and overuse of the technology associated with birth.⁴² Some have argued that women are pressured into accepting prenatal diagnosis not only by social and cultural forces but also by a medical system which follows the "technological imperative" of using prenatal diagnosis simply because it exists.⁴³ Despite difficulties of access, pressures to use prenatal diagnosis with the possibility of abortion may be intensified for women who do not have the resources required to raise a disabled child. Those most likely to lack such resources are minority women, many of whom are also single mothers.⁴⁴

38. See Rapp, *Women's Responses to Prenatal Diagnosis: A Sociocultural Perspective on Diversity* at 222 (cited in note 33).

39. Mary B. Mahowald, *Reproductive Genetics and Gender Justice*, in Karen H. Rothenberg and Elizabeth J. Thomson, *Women and Prenatal Testing: Facing the Challenges of Genetic Technology* 67, 69 (Ohio St U 1994).

40. Naomi Breslau, David Salkever, and Kathleen S. Staruch, *Women's Labor Force Activity and Responsibilities for Disabled Dependents: A Study of Families with Disabled Children*, 23 *J Health and Social Behavior* 169, 179-80 (1982) (the pattern is most apparent in families with less than median income).

41. See generally Laurie Nsiah-Jefferson, *Reproductive Laws, Women of Color, and Low Income Women* in S. Cohen and N. Taub, eds, *Reproductive Laws for the 1990s* 23-35 (Humana 1989).

42. See generally Mahowald, *Reproductive Genetics and Gender Justice* (cited in note 39); Lippman, 17 *Am J Law Med* 15 (cited in note 30).

43. Lippman, 17 *Am J Law Med* 15 (cited in note 30).

44. See generally Diane Pearce, *The Feminization of Poverty: Women, Work and Welfare*, 11 *Urban & Social Change Rev* 28 (1978).

In addition to the social factors that influence women's experience of prenatal testing, such factors also influence their experience of particular diseases for which genetic susceptibility tests are now available. Breast cancer, for example, is a disease which results in an exacerbated impact for women because of social factors. Beyond its high incidence in women (1 in 8), 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.⁴⁵ Hair loss, even though temporary, is embarrassing and sometimes humiliating for women mainly because they are not expected to be bald; and breast removal, even if it is performed prophylactically, entails for many the permanent loss of their womanly appearance.

Treatment of gynecologic cancers for which susceptibility tests are or will eventually be available may result in loss of the ability to conceive or bear a child. Men may be rendered sterile through cancer treatment as well, but means of remediating this are less drastic, less costly, and more effective than they are for women. The fact that women can lose both their gestational and their genetic capability of having children doubles their potential losses with regard to reproduction. To many women, gestation is the more significant loss.⁴⁶

The economic and social costs of bearing children, whether healthy or disabled, are greater than ever before due to the increased workforce participation of women.⁴⁷ 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.⁴⁸ 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.⁴⁹ Few studies have been undertaken on the costs and burdens of caregiving to disabled or chronically ill children. Many of these are apparently flawed by poor methodology in survey methods, limited use of variables to explain cost variations, and unstandardized measures in assessing the costs of caregiving. However, even such imperfect data suggest an enormous burden for

45. Francis S. Collins, *BRCA1: Lots of Mutations, Lots of Dilemmas*, 334 *New England J Med* 186 (Jan 18, 1996) (citing statistics from the American Cancer Society reporting the incidence of breast cancer among women).

46. J.G. Thornton, H.M. McNamara, and I.A. Montague, *Would You Rather Be a 'Birth' or a 'Genetic' Mother? If So, How Much?* 20 *J Med Ethics* 87-9 (1994).

47. Laurie Nsiah-Jefferson and Elaine J. Hall, *Reproductive Technology: Perspectives and Implications for Low-Income Women and Women of Color*, in Kathryn Strother Ratcliff, et al, eds, *Healing Technology: Feminist Perspectives* 93 (U Mich 4th ed 1992).

48. Dorothy C. Wertz and John C. Fletcher, *A Critique of Some Feminist Challenges to Prenatal Diagnosis*, 2 *J Women's Health* 173, 175 (1993).

49. Susan Moller Okin, *Justice, Gender, and the Family* 160-67 (Basic Books 1989). See generally Suzanne M. Bianchi and Daphne Spain, *American Women in Transition: The Population of the United States in the 1980s* (Russell Sage 1986).

family caregivers, who are usually women, in caring for disabled or chronically ill children.⁵⁰

The costs of caregiving include both objective and subjective components, including money expended on therapies, medications, nursing care, hospital stays and medical equipment, as well as increased stress, time loss, and chronic fatigue.⁵¹ In addition to the persistence of economic costs, the physical and psychological tolls include ill health, guilt, and anger for the primary caregiver.⁵² Three factors strongly influence the symptoms of mothers who are primary caregivers: their perceptions of how severely disabled their child is, the actual severity of the disability, and their relationship with the father of the child. Women who are primary caregivers are also more likely to experience depression than their male counterparts.⁵³

Studies of the impact of a child's disability on a mother's paid and nonpaid work are mainly descriptive, based on data from small samples of families of disabled children. 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.⁵⁴ Not surprisingly, these impacts are felt more by low-income and minority women than by others.

Several scholars have examined the impact of caregiving on a mother's employment and household work. While 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. Single mothers may depend upon their own employment for family income and spend their time in nondiscretionary activities which allow little flexibility for allocat-

50. See Philip Jacobs and Suzanne McDermott, *Family Caregiver Costs of Chronically Ill and Handicapped Children: Method and Literature Review*, 104 Pub Health Rep 158, 162 (1989).

51. See generally Breslau, Salkever, and Staruch, 23 J Health and Social Behavior at 169 (cited in note 40). Susan Hillier Parks and Marc Pilisuk, *Caregiver Burden: Gender and the Psychological Costs of Caregiving*, 61 Am J Orthopsychiatry 501-09 (1991).

52. Parks and Pilisuk, 61 Am J Orthopsychiatry 501-09 (cited in note 51).

53. Because women in general experience depression more prevalently than men (21.3% vs. 12.7% lifetime risk), this would be true even if women did not predominate as principal caregivers. See R.C. Kessler, et al, *Lifetime and 12-Month Prevalence of DSM-III-R Psychiatric Disorders from the National Comorbidity Survey*, 51 Archives of General Psychiatry 8-19 (1994). Unfortunately, studies of the psychological impact of caregiving on those who care for the disabled seldom address gender differences, referring only to "parental" or "family" impact. When this impact is assessed, however, it is commonly acknowledged that mothers are the principal caregivers, and they are more often interviewed to obtain the relevant data. See for examples, A. Kathleen Barlew, Robert Evans, and Carlton Oler, *The Impact of a Child with Sickle Cell Disease on Family Dynamics*, 565 Annals of NY Academy of Sciences 162 (1989).

54. See generally Breslau, Salkever, and Staruch, 23 J Health and Social Behavior 169 (cited in note 40).

ing additional time to the extra needs of a disabled or chronically ill child.⁵⁵ 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.⁵⁶ 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.⁵⁷

Most research on the social milieu of disabled or chronically ill children has focused on their disruptive influence on families and marriages.⁵⁸ As already suggested, many people believe that the presence of a disabled child will strain a marriage. However, divorce rates among parents of disabled children have not been reported to be significantly greater than among parents of nondisabled children.⁵⁹ While the stresses of caring for disabled or ill children may exacerbate previously 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.

The overall impact of the disabled child on the primary caregiver remains unclear because of the poor methodological design of studies addressing these issues, including lack of control groups, unstandardized measurements, and inadequate control of significant variables, such as disease severity.⁶⁰ More rigorous studies are needed before the impact of caregiving on women can be adequately characterized and that knowledge used to assess whether the impact meets standards of fairness in society. The Human Genome Project will not increase the number of disabled children born in society and in all probability will reduce their numbers through advances in treatment or selective abortions.

Historically, employers have limited women's access to traditionally male, high-paying jobs, often using health concerns as the basis for exclusion. Recently, employers have substituted concern for fetal health for concern for women's health as an argument for limiting job opportunities for women.⁶¹ However, in 1991, the Supreme Court affirmed that federal law prohibits employers from excluding women from job categories on grounds that they are or might become pregnant in a work environment that might compromise the developing fetus. The justices held in an unanimous opinion that the "fetal

55. Id at 181.

56. Wertz and Fletcher, 2 J Women's Health at 175 (cited in note 48).

57. Id.

58. See generally C. Eiser, *Psychological Effects of Chronic Disease*, 31 J Clinical Psychology & Psychiatry 85 (1990).

59. Brooke A. Benson and Alan M. Gross, *The Effect of a Congenitally Handicapped Child Upon the Marital Dyad: A Review of the Literature*, 9 Clinical Psych Rev 747, 749-50 (1989).

60. Id at 747.

61. Mary E. Becker, *From Muller v. Oregon to Fetal Vulnerability Policies*, 53 U Chi L Rev 1219 (1986).

protection policy" adopted by Johnson Controls, Inc., to restrict jobs in the manufacture of batteries to men and sterile women was a violation of law because it discriminated solely on the basis of possible or actual pregnancy.⁶²

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 be pregnant. Although male exposure to lead might also cause genetic anomalies in fetuses, only women were targeted by the policy. Companies such as General Motors, DuPont, Union Carbide, and other major corporations have also prohibited fertile women from working in high-level high-paying jobs involving substantial exposure to lead. Such fetal protection policies have already barred women from as many as 20 million jobs.⁶³ Unless laws are introduced to prevent employers from obtaining and acting on genetic information, increased knowledge of the human genome may lead to more reduced employment opportunities for men and women, but especially for women of reproductive age.

The history of disease, or other preexisting conditions, has been used as a reason to deny health insurance to many individuals of either sex, and all genetic diseases may be considered "preexisting conditions."⁶⁴ 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. However, the increasing number of female-headed households suggests that a greater number of women are responsible for coverage of affected relatives.

Data regarding genetic discrimination in employment and insurance includes not only documentation of the practice, but recommendations for avoiding or reducing such discrimination. Studies indicate that women are less likely to be offered common non-wage benefits by employers, such as health coverage and disability.⁶⁵ However, there is 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.⁶⁶

62. *Automotive Workers v Johnson Controls, Inc.*, 499 US 187 (1991). Both concurrences to the majority opinion note, however, the possibility that sex-specific fetal protection policies might fall under the bona fide occupational qualification exception in another context. *Id.* at 211 (White, Rehnquist, and Kennedy concurring), 223 (Scalia concurring).

63. Becker, 53 U Chi L Rev at 1226 (cited in note 61) (estimating that the number of jobs which involve chemical exposure from which women might be excluded is possibly as high as 20 million). See also Rebecca Norris, *Double Jeopardy*, Second Opinion 32-34 (March 1991).

64. See Paul R. Billings, et al, *Discrimination as a Consequence of Genetic Testing*, 50 Am J Human Genetics 476, 481 (1992).

65. J. Currie, *Gender Gaps in Benefit Coverage*, NBER Working Paper 4265 (Center for Economic Analysis of Human Behavior and Social Institutions, National Bureau of Economic Research 1993).

66. Larry Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 Am J L & Medicine 109, 117-32, 137-141 (1991).

The use of genetic prognosis for employment decisions is generally a gender-neutral and race-neutral policy. 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 disproportionately more women.⁶⁷ 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 falls disproportionately on women.

III

The preceding account of the impact of genetic technologies on women includes not only biologically-based factors but also socially-determined factors. As a purely descriptive account, it entails no normative critique of the differences identified with regard to men and women. This final section, however, will address the normative question of whether these differences ought to prevail. If the answer is yes, then hooray for the status quo, and nothing need be done except to preserve it. If the answer is no, then two further questions need to be addressed: what type of situation should prevail, and how, if at all, can the present situation be changed to conform to it?

Since “ought” implies “can,” an affirmative answer to the question of whether sex and gender differences should prevail would be supported by the fact that these are inevitable or unavoidable. Such is the case for biologically based differences but not for socially determined ones. For either type of difference, the mere occurrence carries no ethical onus. Some differences among people enrich the lives of interacting individuals as well as society. In addition, such differences may make society more efficient, as one individual finds a niche that others are not suited for but need. Sex complementarity is a probable example of these positive effects, but so is the variety of talents that some individuals have and others can only benefit by or appreciate. When these are the types of differences considered, the answer to the question of whether they should prevail is surely *yes*. As the French might put it, *Vive la difference!*

For some differences, however, the answer to the question of whether they should prevail is clearly *no*. The negative response represents a normative judgment based on the proposition or assumption, for which I will not argue here, that human beings are equally human and deserve to be valued as such.⁶⁸ This does not imply that human beings are equal to one another in all respects. While every individual may be superior to every other in some respect, this means that every individual is inferior to others in some respect as well. Once we introduce this language of superiority and inferiority, we run

67. *Id.* at 137-38.

68. Mahowald, *Reproductive Genetics and Gender Justice* at 70-71 (cited in note 39).

the risk of interpreting differences as necessarily entailing inequities or inequality⁶⁹ among individuals or groups. That interpretation is, of course, a fallacy, but it seems to be fairly prevalent. In health care, for example, differences are often seen as divergences from "normality" that need to be corrected if possible. It is healthy or good to be normal; abnormalities put us in an inferior position, requiring intervention to restore normality. In genetics, mutations are abnormalities that evoke expectations of "bad outcomes." No matter that some abnormalities or mutations may have positive implications for individuals. A criterion for distinguishing between differences that ought to prevail and those that should not prevail is the determination of whether the differences are associated with avoidable inequalities.

Some differences *entail* actual inequalities; they believe that others are merely *associated* with them. For example, the health risk and discomfort experienced by women who provide gametes for reproduction are measurable, while men experience neither risk nor discomfort: this inequality is entailed or necessitated by one's being male or female. Aside from lactation, however, the unequal roles prevalently occupied by male and female parents, for example, in terms of time spent with children, are merely associated with their sex. The time spent by both parents could be the same, or the ratio could be reversed. With regard to prenatal genetic testing, women will continue to be the ones who undergo its risk and discomfort, even though the men who are the potential fathers of the fetuses thus tested may also benefit when these women undergo the procedure. This, of course, is an inequality necessitated by sex. But is it a necessary or merely an associated inequality that women are billed for such tests, while their partners are not? Health insurance may cover tests for one's spouse, but where this is not the case, the one tested is expected to pay.

What type of situation *should* prevail if differences result in inequality? If justice is a desirable social goal, the situation that should prevail is one in which reasonable efforts are made to reduce inequality. If gender justice is desirable, then efforts should be made to reduce inequalities occasioned by differences between the sexes. Where inequitable differences are not changeable, as in the different reproductive roles of men and women, measures can still be introduced to reduce the gap.⁷⁰ It may be argued, for example, that laws granting women alone the right to terminate a pregnancy are based on the realization that women's bodies and not men's are affected by those decisions. Where inequitable differences are changeable, then such changes should be

69. While recognizing the distinction developed by some authors, I use the terms "equality" and "equity" interchangeably because they often connote the same meaning in common parlance. In that context they typically represent a moral principle or value to be promoted in a democratic society. For a fuller development of this view see Mary B. Mahowald, *Women and Children in Health Care: An Unequal Majority* Ch 1 (Oxford 1993).

70. See generally Mahowald, *Reproductive Genetics and Gender Justice* (cited in note 39).

made, or at least attempted, on grounds of gender justice as a social goal. The conditions under which women, more than men, are likely to have their personal goals thwarted by the responsibility of caring for children affected by genetic conditions can be altered by establishing more effective means of support for principal caregivers and by incentives directed towards men to participate more actively in their children's care.

Inequality, even when validly established, is not necessarily unjust. It is not unjust, for example, that older people typically have a wider range of experiences and a more extended life span than younger people. Nor is it unjust that some people are more talented, more intelligent, more attractive, or more athletically gifted than others. In comparing unequal distributions of such factors among individuals, H. Tristram Engelhardt, Jr., suggests that such differences are due to failures of fortune rather than failures of fairness.⁷¹ It is unfortunate, then, that some people are disabled while others are fully abled, but it is not unfair that this is so. Engelhardt would probably not claim that it is unfortunate for women that they are not born male; yet such a statement would be empirically supportable on grounds that women are more likely than men to be poor and dependent on the health care system for themselves and others, and less likely than men to be well-educated or to find positions of power and prestige.

Engelhardt's distinction between what is unfortunate and what is unfair is based on the fact that inequality occurs naturally and, apparently, inevitably. But this alone says nothing to what is done or not done subsequently about such naturally occurring inequality. Different concepts of justice may be introduced to justify alternative means of responding to inequality. The alternatives range from procedure based libertarian theories such as Robert Nozick's, through theories that attempt to combine elements of both libertarian and egalitarian reasoning such as John Rawls', to idealistically egalitarian theories such as Karl Marx's.⁷² Each of these involves a different view of gender justice, and is thus relatable to different versions of feminism.

A libertarian theory of justice gives priority to the liberty of individuals in choosing procedural mechanisms for the distribution of goods. The economic system thus supported is capitalistic, individualistic, and rights-centered. Self-interest is the force that motivates individuals to freely enter, continue, and withdraw from socioeconomic arrangements whose rules they are bound, by virtue of their agreement, to observe. As Nozick paraphrases Marx, the libertarian criterion for decisions regarding distribution is: "From each as they choose, to each as they are chosen."⁷³ This concept of justice is essentially procedural rather than substantive. Depending on differences in the individuals whose liberty is equally respected under the aegis of the theory, the material

71. H. Tristram Engelhardt, Jr., *The Foundations of Bioethics* 340-41 (Oxford 1986).

72. See Mahowald, *Reproductive Genetics and Gender Justice* at 71 (cited in note 39). See also Robert Nozick, *Anarchy, State, and Utopia* (Basic Books 1974); John Rawls, *A Theory of Justice* (Belknap 1971); R. Tucker, ed, *The Marx-Engels Reader* (Norton 1972).

73. Nozick, *Anarchy, State, and Utopia* at 160 (cited in note 72).

gaps between them are inevitably widened through maximization of individual liberty in a laissez-faire environment. Nozick's dictum involves no restriction of the content of one's choices; it therefore permits racist, sexist, and classist choices as well as choices that are morally praiseworthy—so long as such choices are consistent with procedural fairness.

In genetics, both libertarian and liberal feminist arguments have been applied to specific issues. From a libertarian perspective such as Engelhardt's, for example, so long as women can pay for prenatal diagnosis and treatment, and are fully informed about the risks they freely undertake, genetic testing is ethically justified. Since the emphasis is on *individual* liberty, however, the tendency to treat these issues in the context of couples rather than individuals is inappropriate. Lori Andrews recognizes the inappropriateness when she argues that a feminist position on a woman's right to control the disposition of her own body is contradicted by feminists who oppose the rights of individual women to provide ova or gestation in exchange for money.⁷⁴

Liberalism and liberal feminism are also associated with an emphasis on individual liberty. However, liberal feminism defends an equality of opportunity that reduces the inequality that is theoretically justifiable in a libertarian system. Some of the implications of the liberal feminist position are clear, but some are not. It seems clear, for example, that women as well as men have a right to basic health care and to an environment that is free of contaminants that might damage their own or their offspring's health. It is not clear whether equality of opportunity requires access to prenatal counseling and intervention for all women. The extent to which society is obliged to pay for the health care of those who cannot pay for it themselves is a matter on which liberal feminists are likely to disagree. Some would support a minimal level of government subsidies, leaning closer to a libertarian approach; others would support a maximal level, with more egalitarian implications.

Rawls' theory of justice is an effort to combine liberal and egalitarian considerations. His first principle of justice incorporates the liberal's emphasis: individual liberty should be limited only to the extent that it is necessary to ensure the same liberty for others. Rawls' second principle of justice expresses the egalitarian component of his theory: social and economic inequalities should be arranged so that they benefit the least advantaged in a situation of equality of opportunity for all.⁷⁵ Susan Moller Okin endorses these principles of justice, but criticizes Rawls for assuming that families are just.⁷⁶ She develops a liberal feminist account that refutes this assumption through data illustrating that the inherently patriarchal structure of the family is unjust, and that injustice towards women is often triggered by family-related practices and attitudes.

74. Lori B. Andrews, *Feminism Revisited: Fallacies and Policies in the Surrogacy Debate*, 9 *Logos* 81-96 (1988).

75. Rawls, *A Theory of Justice* at 60-61 (cited in note 72).

76. Okin, *Justice, Gender, and the Family* at 93-109 (cited in note 49).

Okin's theoretical critique extends to "false gender neutrality" in language as well as action. She insists on paying attention to gender differences that might provoke injustice, even while arguing for an ideal of a "genderless family." Unlike most philosophers, she offers specific recommendations:

Because children are borne by women but can (and, I contend, should) be raised by both parents equally, policies relating to pregnancy and birth should be quite distinct from those relating to parenting. Pregnancy and childbirth, to whatever varying extent they require leave from work, should be regarded as temporarily disabling conditions like any others, and employers should be mandated to provide leave for all such conditions.⁷⁷

The same recommendations are applicable to issues that arise in genetic testing. For example, because men do not undergo the risk and discomfort of prenatal diagnosis, the time and cost of the procedures should not be borne by women alone but should be shared with men either directly (as couples paying for services) or indirectly (through employer or government coverage).

Critics of liberal feminism may focus either on its liberal component or its feminist component. The liberal component has been critiqued for its tendency to treat individuals atomistically, emphasizing rights rather than relationships and responsibilities for others as well as oneself.⁷⁸ The feminist component has been critiqued by feminists themselves for subscribing to an essentially male model of rationality and autonomy. One of the results of this subscription, according to Alison Jaggar, is a "normative dualism" with regard to our evaluation of the relationship between mind and body.⁷⁹ In a society that generally views activities of the mind as superior to those of the body, women are likely to be less esteemed because gestation, birth, and early nurturance of children tie them more to physical than to mental activities. Jaggar also maintains that a liberal feminist emphasis on individual autonomy provides an inadequate account of moral goodness.⁸⁰ Beyond respect for others' choices, the ends we pursue as individuals and as a society ought to promote human surviving and thriving.⁸¹

The normative dualism that Jaggar criticizes is apparent in attitudes and practices with regard to genetic diseases that are mainly associated with mental retardation. For example, the desire to avoid the birth of a child with Down syndrome is the most common reason for women to undergo prenatal testing. Although specific physical findings and other medical problems are often associated with Down syndrome, the principal problem the condition presents

77. Id at 176.

78. See Jean Bethke Elshtain, *Feminism, Family, and Community*, 29 *Dissent* 442, 445 (1982).

79. Alison M. Jaggar, *Feminist Politics and Human Nature* 46-47 (Rowman & Allanheld 1983).

80. Id at 48.

81. See generally Elshtain, 29 *Dissent* 442 (cited in note 78).

is mental retardation. Jaggar's insistence that other values besides respect for autonomy should be considered in our moral judgments is also applicable to genetics. The justification for nondirective counseling, for instance, is primarily based on respect for the client's autonomy. Jaggar and other socialist feminists would argue that considerations of beneficence and social justice are relevant to the counseling situation as well.⁸²

Socialist feminists are concerned not only about women's right to abortion but also about "the social pressures that may be exerted on couples, and especially on women, to terminate a pregnancy thought to be affected by a genetic disorder."⁸³ They would agree with Angus Clarke's concerns about the implications of prenatal diagnosis for "society as a whole, with long-term repercussions for the status of, and provision for, the mentally and physically handicapped."⁸⁴ Consideration of these repercussions through attention to differences between individuals as well as groups is crucial to the goal of social equality.

Communitarian or socialist thinkers are the principal critics of liberal feminism.⁸⁵ Communitarians tend to emphasize familial or affective relationships, while socialists emphasize political relationships and the importance of equality as a social goal. A communitarian ideology may be reinforced by the care models of moral reasoning that Carol Gilligan and Nel Noddings have developed.⁸⁶ Although both models are based on women's experience, some feminists are critical of them because they may promote exploitation of women's natural propensity to care for others.⁸⁷ Because women are usually the primary caregivers of persons affected by genetic conditions, possibilities for exploitation are evident in that context. If caring behavior were as esteemed and rewarded as behavior based on a justice model of reasoning, exploitation would be reduced if not eliminated.

Jaggar distinguishes between socialist and Marxist feminism on grounds of the primacy given to the oppression of women.⁸⁸ Marxist feminists, she claims, see women's oppression as an expression of the fundamental economic oppression that separates the bourgeoisie from the proletariat. As Marx put it, the degree of humanness that is evident in the relation between men and women is an indicator of the progress in humanness of the entire society.⁸⁹

82. Rosemarie Tong, *Feminist Thought: A Comprehensive Introduction* (Westview 1989).

83. Angus Clarke, *Is Non-Directive Genetic Counselling Possible?*, 338 *Lancet* 998, 1000 (1991).

84. *Id.* at 998.

85. See Tong, *Feminist Thought* (cited in note 82).

86. See generally Carol Gilligan, *In a Different Voice: Psychological Theory and Women's Development* (Harvard 2d ed 1993); and Nel Noddings, *Caring: A Feminine Approach to Ethics and Moral Education* 43, 79-81 (U Cal 1984).

87. S. Sherwin, *No Longer Patient: Feminist Ethics and Health Care* 49-50 (Temple 1992).

88. See Jaggar, *Feminist Politics and Human Nature* at 125-32 (cited in note 79).

89. See Tucker, *Marx-Engels Reader* (cited in note 72).

However, the goal of correcting injustice of inequality between men and women is subordinate to the goal of overcoming economic oppression between capitalists and workers. In contrast, socialist feminists see the oppression of women as the primordial social injustice; other forms of oppression stem from this. Overcoming gender inequality is thus central to the socialist feminist agenda.

From that standpoint, society and individuals alike should attempt to reduce the disproportionate impact of genetics on women and men. Minimizing the cost and risk of the procedures and maximizing access to them would constitute such an attempt. Requiring the partners of women who undergo prenatal diagnosis and pregnancy termination to pay for the procedure would be another way of reducing the gender gap. In general, the spread of the feminization of poverty must be checked in order to provide women with an equal balance of health prospects in comparison with men.

As more and more genetic information is obtained through the success of the Human Genome Project, the possibilities for discrimination increase. Socialist feminism rejects such practices through its critique of the capitalistic ideology that supports them. Without subscribing to a totalitarian system, it supports limitation of individual freedom to promote social equality. Lest this be construed as a radical proposal, it should be recognized that American society already endorses anti-capitalistic or socialistic measures such as a graduated income tax, government subsidies to farmers, and welfare payments for the poor. Government regulation intended to avoid genetic discrimination based on gender would also involve curtailment of liberty for the sake of equality. To be effective, however, such regulation needs to take explicit account of the gender-based differences that lead to discrimination. To the extent that the regulations limit liberty to promote equality, they are socialist in their orientation.

Although the term "socialist" has been in disrepute since the demise of the Soviet Union and other officially socialist states, the term itself is not a crucial label for the critique of individualism and liberalism that many feminists support. What is essential to that critique is that it starts with a concept of human beings not as isolated individuals but as individuals whose meaning and reality are definable and sustainable only in the context of their relationships to others. This emphasis on relationships is common to socialist feminism, communitarian versions of feminism, and to the ethics of care that Gilligan and Noddings have developed. Noddings claimed the relationship between mother and child as ethically paradigmatic, and argued for a broader application of the care embodied in that relationship.⁹⁰ Gilligan based her model of moral reasoning on studies of girls and women confronting ethical dilemmas in their own lives.⁹¹ Women, she found, typically reached their decisions

90. See Noddings, *Caring: A Feminine Approach to Ethics and Moral Education* (cited in note 86).

91. See generally Gilligan, *In a Different Voice* (cited in note 86).

through consideration of responsibilities derived from relationships to others rather than consideration of their own or others' rights as individuals. They were more likely than men to be influenced by concerns of justice towards those they did not know.

Recent studies have examined whether Gilligan's distinction between justice and care models of reasoning are applicable to providers of genetic counseling.⁹² The results suggest that women who do genetic counseling do not neatly fit into either of Gilligan's models of moral reasoning. Nonetheless, gender has been described as "the single most important determinant of ethical decision-making" among doctoral level medical geneticists from around the world.⁹³ In one study, although the majority of medical geneticists and genetic counselors were committed to nondirective counseling, the men were 2 to 13 times (depending on the country) more likely to be directive. The women (35 percent of the respondents) were also more likely than the men to emphasize client autonomy and to express concern about the families of their clients.⁹⁴ Their emphasis on the client's autonomy, often expressed in phrases like "the right to know" and "the right to decide," reflects the philosophical tradition of ethics that care-based thinkers generally reject. The concern about families, however, reflects the critique of individualism with which care-based thinkers agree. This critique is the point at which a care ethic and communitarian or socialist versions of feminism converge through their emphasis on relationships.

Another recent study compared the ethical decision making of masters-prepared genetic counselors and doctoral level (M.D. or Ph.D.) medical geneticists in the United States.⁹⁵ The genetic counselors, mostly women, primarily stressed the autonomy of their individual clients as their guiding ethical norm. They were even more likely than the medical geneticists, mostly men, to be nondirective, to respect client confidentiality even in cases where non-disclosure might threaten others' welfare, and to refer clients to another center for sex selection. To the extent that their respect for the autonomy of individual clients overrides concerns for other family members, genetic counselors depart from a care-based model of moral reasoning and illustrate traditional ethical (Kantian) reasoning. Attributing this priority to autonomy is consistent as well with liberal and libertarian versions of feminism.

Just as men and women are not necessarily incompatible or unequal because they are different, a care-based ethic and a justice ethic are not necessarily incompatible or unequally valid because they are different. Gilligan suggests that there are liabilities to either approach. The potential error of a

92. See Deborah F. Pencharinha, et al, *Ethical Issues in Genetic Counseling: A Comparison of M.S. Counselor and Medical Geneticist Perspectives*, 19 J Genetic Counseling 19 (1992). See also Dorothy C. Wertz, *Providers' Gender and Moral Reasoning: A Proposed Agenda for Research on Providers and Patients*, 8 (Supp 1) Fetal Diagnosis and Therapy 81, 85-86 (1993).

93. Wertz, 8 (Supp 1) Fetal Diagnosis and Therapy at 81 (cited in note 92).

94. Id at 82.

95. Pencharinha, 19 J Genetic Counseling at 19 (cited in note 92).

justice focus, she says, is "its latent egocentrism, the tendency to confuse one's perspective with an objective standpoint or truth, the temptation to define others in one's own terms by putting oneself in their place." The liability of a focus on care is that it tends "to forget that one has terms, creating a tendency to enter into another's perspective and to see oneself as 'selfless' by defining oneself in others' terms."⁹⁶ Historically, these liabilities have given rise to two common distortions of justice and care. In an ethic of justice the distortion is that human is equated with male; in an ethic of care the distortion is the equation of care with self-sacrifice. The liabilities are avoided and the distortions are corrected in an ethic that incorporates both justice and care. Women who do genetic counseling evidence elements of both justice and care.

Genetic counselors may be particularly inclined to emphasize client autonomy because they recognize that the lives of their clients, most of whom are women, are affected more significantly than their male partners by decisions involving genetics. They may be more inclined to recognize this gender difference because most of them are women. This practice is feminist to the extent that it promotes or is intended to promote gender justice.

To the extent that genetic counselors honor women's autonomy, they also support the reasons for which individual women make their reproductive decisions. If Gilligan is right, these reasons tend to be based on the complex set of caring relationships that each woman bears to others. Maximizing women's autonomy in decisions about genetics is thus a way of maximizing caring. Since women in our society are generally less economically powerful than men, maximizing women's autonomy is also a way of promoting equality or reducing inequality between them and men. Gender justice, implemented through support for the autonomy of those most affected by decisions in genetics, is a means, perhaps even an indispensable means, through which to realize an ethic based on caring.

While questioning whether either orientation is separably adequate from a moral point of view, Marilyn Friedman argues persuasively for the compatibility of care and justice.⁹⁷ If justice means giving people their due, it demands determination of what constitutes due care for each. The application of this concept to genetics is obvious: the practitioner must recognize and respond to different needs or interests on the part of each client. At times the needs of different clients are at odds with each other, as when the counselor learns that the assumed father of a child is not genetically related to him or her. Studies show that most genetic counselors believe that the confidentiality of the child's mother should be upheld in such situations.⁹⁸ Depending on the risk that not-

96. Carol Gilligan, *Moral Orientation and Moral Development*, in Eva Feder Kittany and Diana T. Meyers, eds, *Women and Moral Theory* 19, 31 (Rowman and Littlefield 1987).

97. See Marilyn Friedman, *Beyond Caring: The De-Moralizing of Gender* in Marsha Hanen and Kai Nielsen, eds, *Science, Morality, and Feminist Theory* 87, 98-100 (U Calgary 1987).

98. See Dorothy C. Wertz and John C. Fletcher, *Ethics and Medical Genetics in the*

knowing entails for others, however, non-disclosure may be morally unjust. A caring ethic is thus different from an ethic of health care that focuses solely on the client because it involves care for all of those affected by the caregiver's decisions. A *just* caring ethic requires efforts to distribute burdens and benefits fairly.

Although some men grasp and communicate the significance of women's role in genetics better than some women, women know better than men what women experience. Accordingly, some writers have argued for the necessity of a feminist standpoint in decisions and policies that particularly affect women. Sara Ruddick describes such a standpoint as "an engaged vision of the world opposed and superior to dominant ways of thinking."⁹⁹ The rationale for a feminist standpoint is both ethical and epistemological. In reproductive genetics, ethical arguments for a feminist standpoint are based on the fact that women's bodies and lives are generally more affected than men's by reproductive decisions. As abortion legislation illustrates, this gives them the more compelling right to determine the outcome in situations of conflict.

The epistemological argument for a feminist standpoint involves what Donna Haraway affirms as "the embodied nature of all vision."¹⁰⁰ Haraway regards the impartial standpoint of traditional ethics as neither feasible nor desirable. The alternative she proposes is "a doctrine of embodied objectivity" which involves "partial, locatable, critical knowledges sustaining the possibility of webs of connections called solidarity in politics and shared conversations in epistemology."¹⁰¹ Only through such partial perspectives, she claims, can we approach objectivity.

A feminist standpoint may draw on any of the diverse versions of feminism because all of these involve a remedial emphasis on women. In fact, the enrichment of perspectives that their inclusion involves can only be maximized by including representatives of diverse feminisms. Women are also distinguishable from one another by class, race, and sexual orientation, and by size, age, politics, religion, and profession. Thus, while we belong to the non-dominant group by gender, some of us belong to the dominant group by race or class or other criteria. Just as women have a privileged epistemological status vis-à-vis men, the same is true for women of color vis-à-vis white women, and clients or patients vis-à-vis the professionals who treat or counsel them. Moreover, because women as individuals are not definable through any collection of categorical designations, the rationale that underlies a feminist standpoint must be extended to a recognition of each woman as a unique individual. To promote gender justice for all women, individual differences as well as gender and other group-based differences must be taken into account.

United States: A National Survey, 29 *Am J Medical Genetics* 815, 820 (1988). See also Pencharinha, 19 *J Genetic Counseling* at 19 (cited in note 92).

99. Sara Ruddick, *Maternal Thinking: Toward a Politics of Peace* 129 (Beacon 1989).

100. Donna Haraway, *Situated Knowledges: The Science of Question in Feminism and the Privilege of Partial Perspective*, 14 *Feminist Studies* 575 (1988).

101. *Id.* at 584.

How, practically, can so many differences be fully considered in order to effect just policies and decision making in genetics? An honest answer to this question is "They can't." This does not imply, however, that it is useless to consider the differences and to attempt to minimize the inadequacy of their consideration. I wish to conclude, therefore, with the recommendation of a single, modest strategy that the preceding discussion suggests with regard to decisions and policies. It is simple, obvious, and demanding: Listen to women.

Beyond the fact that women may have a different moral voice than men, they have a different role, experience, and responsibility with regard to reproduction. The only way to adequately consider these differences is to learn about them from women themselves. Legislative and policy-making bodies that address issues in genetics need not only more but more diverse women in their ranks. Adequate *representation* of women may be an unachievable goal because of women's diversity as individuals and as participants in different groups. Nonetheless, their representation could surely be improved by specific measures intended to facilitate that. For example, if we valued the participation of poor women enough to ensure that their income would not be threatened by their participation in decision-making bodies, we might thereby increase our socioeconomic representation. If we were willing to challenge the political pragmatism or homophobia that has triggered the exclusion of lesbians and homosexuals from participation, we might also broaden our representation. Participation of more and more diverse women, as well as participation of non-dominant groups of men, is surely augmentable, though not without cost and effort.

If broader representation were implemented as a means of reducing the inevitable "nearsightedness" of the dominant class or classes, the different voices of women and minorities would certainly be heard in decisions and policies about genetics. They would be heard as practitioners and clients, as policy makers, and as teachers of those who belong to the dominant class. Such representation would also mean that tokenism, e.g., having one woman or African American serve on a policy-making committee, is not enough, particularly when the group's decisions disproportionately affect those who are not dominant. When a single individual represents several non-dominant groups, her voice and vote should count additionally for each of the groups represented.

Unfortunately, there are situations in which too few non-dominant persons are available to provide fair representation. For example, since very few of those trained as genetic counselors are persons of color,¹⁰² self-consciousness about their inevitable nearsightedness is demanded of the dominant individuals who render the representation disproportionate. With regard to gender differences, such self-consciousness involves acknowledgment of a possible sexist bias. A similar observation applies to groups distinguishable by race, class, mental or physical ability, and sexual orientation. Unfortunately, those who

102. Pencharinha, 19 *J Genetic Counseling* at 22 (cited in note 92).

assume that they are capable of total impartiality are unlikely to reduce their nearsightedness through inclusion of others' perspectives.

Listening to other women is as important for women as listening to women is for men. Such listening is often demanding because it requires the listener to suspend his or her own speech temporarily. It also requires psychological openness to new and critical ideas, that is, a kind of intellectual humility. At times, the learning that comes from listening changes our views of ourselves as well as others. Even as individuals grow through listening, so do women and men from diverse backgrounds and circumstances. A necessary means to continuing the growth is to keep on listening.

Listening to women, and learning from and acting on what we hear from women, is an indispensable means of promoting gender justice in genetics. Different versions of feminism support different degrees and concepts of social equality, but they concur about the importance of listening to women's different voices.

