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Prenatal Screening and the Culture of Motherhood

by

LORI B. ANDREWS*

During the past two decades, physicians have been able to obtain an increasing amount of genetic information about fetuses before birth. The diagnostic techniques that physicians use do more than predict the future health of the developing fetus, however, they transform the culture of motherhood—society's expectations of pregnant women and women's expectations of themselves. Decisions to undergo genetic testing—and control or lack of control over dissemination of the results of such testing—affect a woman's self-image, her personal relationships, and how she is regarded by institutions such as insurers and employers. These impacts should be taken into consideration by health care providers and policymakers as they develop practices and policies for the use of prenatal testing.¹ Based on analyses of the potential impacts of prenatal testing, this article makes policy recommendations regarding the regulation of a new form of prenatal testing, fetal cell sorting (FCS).

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1. This type of policy analysis—grounded in empirical data about the actual impact on individuals—is rarely undertaken in law journals. However, there is a growing consensus that such an analysis is the most appropriate way to develop a policy response to the new reproductive technologies. See, for example, the articles of Dorothy Roberts and Michael Shapiro in this symposium. Other observers of genetic policy development have come to similar conclusions. Benjamin Wilfond and Kathleen Nolan, for example, have criticized what they label as the “extemporaneous” manner in which genetics policy has been made in the United States. They argue in favor of using an “evidentiary” approach incorporating evaluation of impacts and attention to underlying norms. Benjamin S. Wilfond & Kathleen Nolan, *National Policy Development for the Clinical Application of Genetic Diagnostic Technologies*, 270 JAMA 2948, 2949 (1993).

I. The Nature of Prenatal Diagnosis

A growing number of pregnant women receive genetic information about their fetus' well-being through fetal blood sampling, chorionic villi sampling, amniocentesis, maternal serum alphafetoprotein screening and other technologies.² However, such information is obtained at some risk to the fetus itself. Fetoscopy, in which blood is sampled from the fetus while it is *in utero*, is associated with a 3% to 6% risk of fetal death.³ Chorionic villi sampling, in which tissue surrounding the fetus is sampled and analyzed between eight and twelve weeks of gestation, is associated with a 2% to 3% spontaneous abortion rate.⁴ Amniocentesis, in which fluid from the amniotic sac is withdrawn and analyzed, causes spontaneous abortion in approximately one or two per thousand pregnancies.⁵ These procedures entail physical risks to pregnant women as well, particularly risks of infection.⁶ Some women choose to run these risks and undergo prenatal screening because they intend to terminate a pregnancy if the fetus is diagnosed as having a serious disorder.

There are currently hundreds of tests that can be performed on fetal tissue obtained through fetoscopy, chorionic villi sampling and amniocentesis,⁷ such as fetal testing to identify chromosomal disorders

2. In the state of New York alone, 25,000 women per year are screened for fetal genetic abnormalities. Kimberly Nobles, *Birthright or Life Sentence: Controlling the Threat of Genetic Testing*, 65 S. CAL. L. REV. 2081, 2086 (1992). Michael Malinowski notes that "[o]ne reason for our acceptance of extensive prenatal genetic screening is that it is being introduced to us through the health profession rather than through a social movement." Michael Malinowski, *Coming into Being: Law, Ethics, and the Practice of Prenatal Genetic Screening*, 45 HASTINGS L.J. 1435, 1453 (1994).

3. OFFICE OF TECHNOLOGY ASSESSMENT, HUMAN GENE THERAPY BACKGROUND PAPER 64 (1984).

4. *Id.* at 65. Moreover, there have been some reports of limb defects resulting from chorionic villi sampling undertaken prior to the tenth week of pregnancy. Barbara K. Burton, *Spectrum of Limb Disruption Defects Associated with Chorionic Villus Sampling*, 91 PEDIATRICS, 989, 989-90 (1993).

5. OFFICE OF TECHNOLOGY ASSESSMENT, HUMAN GENE THERAPY BACKGROUND PAPER 64 (1984). See also Mitchell S. Golbus et al., *Prenatal Genetic Diagnosis in 3000 Amniocenteses*, 300 NEW ENG. J. MED. 157, 162 (1979).

6. See Mark Deutchman & Ellen L. Sakornbut, *Diagnostic Ultrasound in Labor and Delivery*, 51 AM. FAM. PHYSICIAN 145, 151 (1995).

7. Fetuses can be tested for single-gene disorders, caused by a defect in a particular gene pair. These disorders are of two types—dominant or recessive. There are currently nearly 1500 diseases that are thought to be dominant single-gene disorders. These include achondroplasia (a type of dwarfism), some forms of chronic glaucoma (which causes blindness), Huntington's disease (which causes degeneration of the nervous system), and hypercholesterolemia (a high level of cholesterol in the blood that may lead to heart disease). With a dominant disorder, the parent who carries the gene is also at least somewhat affected by the disease. The affected parent has one normal gene and one faulty gene in

such as Down syndrome.⁸ And often, genetic information about the fetus provides genetic information about the mother.

Perhaps because the diagnostic techniques of fetoscopy, chorionic villi sampling and amniocentesis present physical risks, no state has adopted laws mandating their use. Moreover, the use of diagnostic techniques is generally limited to women whose fetuses are at greater-than-average risk of a genetic or chromosomal disorder, such as those over the age of thirty-five (who are at a greater-than-average risk of giving birth to a child with Down syndrome) or those who have family histories of or ethnic group experience with genetic disorders. In many instances, this means that the women who are offered prenatal testing have some knowledge of the disorders for which the fetus is tested. Most women are familiar with Down syndrome. Women who

the specific pair causing the disease, but because the defective gene is dominant, the normal gene cannot compensate for the problems caused in the faulty gene. Since the child inherits only one of the two genes in a pair from each parent, there is a 50/50 chance that the gene that that parent passes on to the child will be a faulty one and that the child, too, will suffer from the dominant genetic disorder. Sometimes, though, the problem will not manifest itself at birth but will appear much later in the child's life. The dominant single-gene disorder Huntington's disease, for example, does not generally appear until the affected person is in his or her late forties.

In the case of a recessive single-gene disorder, the person who has one faulty gene in a pair is not affected by the disease because the normal gene in the pair makes up for the faulty gene. That person is known as a carrier. If two carriers have a child together, there is a one-in-four chance that the child will inherit one faulty gene from each parent and thus have the recessive single-gene disease. There are about 1100 recessive single-gene disorders, including sickle cell anemia (a blood disorder that primarily affects African-Americans), cystic fibrosis (a disorder affecting the muscles and sweat glands), phenylketonuria, also known as PKU (a deficiency in an essential liver enzyme), galactosemia (an inability to metabolize milk sugar), thalassemia (a blood disorder that primarily affects people of Mediterranean ancestry) and Tay-Sachs disease (a disorder of the nervous system that primarily affects Eastern European Jews).

X-linked disorders, another type of genetic difficulty, affect males who inherit the defects from their mothers. In this situation, the defective gene occurs only on the X chromosome. Such defects are generally recessive. Since every woman has two X chromosomes, there is a 50% chance she will pass on her defective X to her children and a 50% chance she will pass on her healthy X. The daughter of a woman with an X-linked disorder is generally unaffected. Because she gets an X from her mother and an X from her father, even if she gets the defective X from her mother, its defects are made up for by the normal X that her father gives her. Since a son always gets a Y from his father, an X with a mutation from his mother will not be compensated for, and the son will suffer from the disease. Over 100 X-linked disorders are known. They include hemophilia (also known as bleeding disease), Duchenne's muscular dystrophy (involving muscle deterioration) and a mental retardation in boys known as Fragile X.

8. Down syndrome is caused by additional material of chromosome 21 which results in various malformations and mental retardation. See Committee on Genetics, American Academy of Pediatrics, *Health Supervision of Children with Down Syndrome*, 93 PEDIATRICS 855, 855 (1994).

have a family history of a disorder such as cystic fibrosis or sickle cell anemia may know an affected relative. And within ethnic groups that have a higher-than-average risk of certain genetic diseases (such as sickle cell anemia among African-Americans or Tay-Sachs disease among Ashkenazi Jews), there is often widespread community knowledge about those disorders.

Two developments, though, are changing the nature of prenatal diagnosis. The first is the advent of multiplex testing, in which numerous genetic tests can be performed on a single tissue sample.⁹ As a result, some women will be offered prenatal testing for a wide range of disorders about which they have little knowledge, and the description of the disorder given by health care providers may have undue influence on whether these women choose to undergo testing and abort based on the results. The range of tests offered is growing continually, due in large measure to concerted efforts by the Human Genome Project, a \$3 billion federally funded endeavor to map and sequence the complete set of genes in the human body. Prenatal testing is now possible not just for serious, life-threatening disorders¹⁰ but also for disorders that are treatable after birth, for disorders that do not manifest until later in life, such as breast cancer, and even for conditions not thought to be medical problems, such as homosexuality.

At the same time, a developing technology offers more women the option of prenatal testing. This technology, fetal cell sorting, provides fetal information without creating a physical risk to the fetus or the pregnant woman. A "simple" blood test is performed on the woman. In the laboratory, technicians use complex procedures to capture minute quantities of fetal blood cells circulating in the woman's blood.¹¹ Prenatal diagnosis is undertaken on those cells, to determine,

9. COMMITTEE ON ASSESSING GENETIC RISKS, NATIONAL ACADEMY OF SCIENCES, *ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY* 177 (Lori B. Andrews et al. eds., 1994).

10. An example of a disorder that most people consider to be serious is Tay-Sachs disease, which generally causes a painful death by age three.

11. For a description of the technology, see Sherman Elias et al., *First Trimester Prenatal Diagnosis of Trisomy 21 in Fetal Cells from Maternal Blood*, 340 *LANCET* 1033, 1033 (1992); see also Jane Chueh & Mitchell S. Golbus, *Prenatal Diagnosis Using Fetal Cells from the Maternal Circulation*, 159 *W.J. MED.* 308, 311 (1993); Richard Saltus, *Noninvasive Way is Cited to Deter Down Syndrome in Fetuses*, *BOSTON GLOBE*, Nov. 12, 1992, at 8.

for example, whether the fetus has Down syndrome, cystic fibrosis,¹² Tay-Sachs disease,¹³ or other disorders.

Researchers developing fetal cell sorting have pointed out that it could be used to screen large populations of women. One group of researchers has noted that,

because the . . . procedure requires sampling of maternal blood rather than amniotic fluid, it could make widespread screening in younger women feasible. . . . Widespread screening is desirable because the relatively large number of pregnancies in women below 35 years old means that they bear the majority of children with chromosomal abnormalities despite the relatively low risk of such abnormalities in pregnancies in this age group.¹⁴

The advent of fetal cell sorting raises an important policy issue regarding women's control of prenatal testing. Because the procedure does not create a *physical* risk to the fetus or the woman, there may be a trend toward undertaking such testing without the woman's consent. Blood is routinely drawn during pregnancy for a variety of legitimate purposes, and it would be simple to subject that blood to genetic testing without the woman's knowledge. Already, some obstetricians test pregnant African-American women for the sickle cell anemia gene without informing them in advance or asking for their consent. Only when results indicate that a particular woman is a sickle cell anemia carrier is she informed.¹⁵ The health care providers believe that the woman will want this information; they expect that a woman who finds out that she is a carrier will have her mate tested and, if he is a carrier as well, will have the fetus tested to determine if it has inher-

12. Cystic fibrosis is "[t]he most common potentially fatal genetic disease" among Caucasians; it is "caused by a disorder of exocrine glands. Individuals with cystic fibrosis have a variety of physical abnormalities, [the] most serious among them [being] chronic obstructive lung disease." OFFICE OF TECHNOLOGY ASSESSMENT, *HEALTHY CHILDREN: INVESTING IN THE FUTURE* 263 (1988).

13. Tay-Sachs disease is a fatal neurodegenerative disorder caused by a genetic mutation. It is very common among Ashkenazi Jews. See, e.g., Eleanor C. Landel et al., *Frequency of the Tay-Sachs Disease Splice and Insertion Mutations in the UK Ashkenazi Jewish Population*, 28 J. MED. GENETICS 177, 177 (1991).

14. Leonard A. Herzenberg et al., *Fetal Cells in the Blood of Pregnant Women: Detection and Enrichment by Fluorescence-Activated Cell Sorting*, 76 PROC. NAT'L ACAD. SCI. U.S. 1453, 1455 (1979).

15. For an example of a research protocol in which sickle cell anemia screening was undertaken without informed consent, see Peter T. Rowley et al., *Do Pregnant Women Benefit from Hemoglobinopathy Carrier Detection?* 565 ANNALS N.Y. ACAD. SCI. 152, 153 (1989).

ited a gene from both parents and thus will develop sickle cell anemia.¹⁶

Because fetal cell sorting presents fewer physical risks than existing prenatal diagnostic techniques, there is also a possibility that policymakers may mandate that women undergo the procedure. The ostensible purpose would be for couples to receive information that would help guide their reproductive decisions. However, since the genetic disorders being screened for are generally untreatable,¹⁷ the only reproductive option in most situations would be to abort an affected fetus. Thus, the underlying goal of such an approach would be to encourage the termination of affected fetuses, in order to save society the expense of caring for such children.

Currently, genetic testing of adults is not mandated by law in any circumstance. However, in five states, laws require that blood samples be taken from newborns and tested for genetic disorders such as phenylketonuria and congenital hypothyroidism.¹⁸ In forty other states, parents ostensibly have the right to refuse newborn screening,¹⁹ but since parents in most of those states are not told that they have such a right, testing is *de facto* mandatory there, too. The initial purpose of such laws was to detect certain diseases early enough for the infant to be treated in a timely fashion. For example, treatment of phenylketonuria shortly after birth can prevent mental retardation. However, some states have expanded their mandatory newborn screening programs so that more and more genetic diseases are evaluated in the single blood sample. In Pennsylvania,²⁰ for example, infants are tested for Duchenne muscular dystrophy,²¹ even though early detection will have no influence on the clinical course of the disease. Rather, the information generated is purportedly for the parents' benefit. If the infant has the disorder, the mother is a carrier; there is a 50% risk that any son she conceives will be affected. The

16. Physicians may be overestimating couples' interest in fetal testing. *See id.* In one study, physicians describe this involuntary testing as beneficial, even though in that study *none* of the couples who learned that the woman was carrying a fetus with sickle cell anemia took action on that information and underwent an abortion. *Id.*

17. For the disorders that are treatable after birth, such as phenylketonuria, there is no real advantage to screening during pregnancy as opposed to after birth.

18. LORI B. ANDREWS, *MEDICAL GENETICS: A LEGAL FRONTIER* 238 (1987).

19. *Id.*

20. COMMITTEE ON ASSESSING GENETIC RISKS, *supra* note 9, at 261.

21. Duchenne muscular dystrophy is a "[p]rogressive deterioration of muscles beginning in infancy and leading to death in [the] second or third decade. Inheritance is X-linked recessive." Committee on Genetics, American Academy of Pediatrics, *Newborn Screening Fact Sheet*, 83 *PEDIATRICS* 449, 457 (1989).

logic in screening an infant for Duchenne muscular dystrophy is that it will provide information that helps parents make future reproductive plans. Similar logic may be used to attempt to justify mandatory prenatal screening using fetal cell sorting.

A. Why a Simple Blood Test Isn't So Simple

The current practices surrounding prenatal screening seem to rely on an assumption that providing genetic information to women during pregnancy is an unquestionable benefit. This may lend support to the policy of state-mandated testing of pregnant women, particularly when the intervention entails minimal physical risk.²² This article argues against mandatory fetal cell sorting, however, in large measure because of the psychological, social, and financial risks it entails.

The information generated by genetic testing is powerful information. Genetic information can affect women's reproductive behavior—such as their willingness to conceive a child,²³ continue a pregnancy,²⁴ or use alternative reproduction technologies (such as gamete or embryo donation) or adoption to become a parent.²⁵ It can change the way women experience pregnancy and motherhood.²⁶ The existence of prenatal diagnostic technologies may also change ideas about what type of children are “normal” and worthy of a mother's unconditional love.²⁷

Much evidence indicates that receipt of genetic information can cause significant psychological, social, and financial risks to women.

22. As noted at pages 999 to 1002 *infra*, in various policy realms, interventions involving minimal physical risk have been viewed as permissible. For example, state-ordered blood testing in some Fourth Amendment contexts has been seen as permissible due to the fact that it entailed “minor intrusion.” See, e.g., *Schmerber v. California*, 384 U.S. 757, 772 (1966). Similarly, courts that have upheld a woman's right to refuse a forced Cesarean section have nonetheless indicated in dicta that they might consider imposing less intrusive interventions on a woman against her will. See, e.g., *Baby Boy Doe v. Doe*, 632 N.E.2d 326, 333 (Ill. App. Ct. 1994).

23. Nancy Wexler, *Clairvoyance and Caution: Repercussions from the Human Genome Project*, in *THE CODE OF CODES: SCIENTIFIC AND SOCIAL ISSUES IN THE HUMAN GENOME PROJECT* 211, 227 (Daniel J. Kevles & Leroy Hood eds., 1992).

24. Golbus et al., *supra* note 5, at 157.

25. Michael K. McCormack et al., *Attitudes Regarding Utilization of Artificial Insemination by Donor in Huntington Disease*, 14 *AM. J. MED. GENETICS* 5, 6 (1983).

26. Barbara Katz Rothman, *The Tentative Pregnancy: Then and Now*, 8 *FETAL DIAGNOSIS & THERAPY* 60, 60-61 (Supp. 1, 1993); Tjeerd Tymstra, *Prenatal Diagnosis, Prenatal Screening, and the Rise of the Tentative Pregnancy*, 7 *INT'L J. TECH. ASSESSMENT* 509, 514-15 (1991).

27. A recent poll suggested that 12% of Americans would consider aborting a fetus that is predisposed to obesity. Dorothy C. Wertz et al., *Attitudes Toward Abortion Among Parents of Children with Cystic Fibrosis*, 81(8) *AM. J. PUB. HEALTH* 992, 994 (1991).

Social scientific studies show that learning genetic information about oneself or one's fetus can have a negative impact on one's self-concept, can significantly change the way one experiences pregnancy, can change one's personal relationships and, if the information is shared with others, can lead to stigmatization and discrimination. These risks provide a policy rationale for recognizing a woman's right to refuse fetal cell sorting.

B. Overall Impact of Prenatal Screening

Many pregnant women who choose to undergo prenatal screening feel that it offers them an overall benefit by allowing them to make an informed choice about their pregnancies. A federal court has recognized the importance of this choice by indicating that the constitutional protections of the abortion decision logically "must also include the right to submit to a procedure designed to give information about that fetus which can then lead to a decision to abort."²⁸ The fact that many women undergo prenatal testing and make decisions based on that information, however, does not indicate that the process is an easy one for women.²⁹ The testing process generally provokes anxiety, whether or not a woman ultimately receives the comforting news that her fetus is not affected with the disorders for which it has been tested. The news that her fetus is affected with a disorder has even more profound consequences, since a woman must grapple with the decision to continue or terminate the pregnancy. Moreover, abortion of the wanted fetus because of its genetic profile often causes grief, sorrow and guilt. And, with impacts that last far longer than the pregnancy, the diagnosis that the fetus has a particular genetic disorder often provides the woman with information about her own genetic status. The woman will face varying degrees of difficulty in incorporating this information about herself into her self-concept, her personal relationships and her dealings with social institutions.

C. Impact on Psychological Well-Being and Self-Concept

Learning genetic information about oneself or one's fetus has an impact on a woman's emotional well-being and self-concept.³⁰ With

28. *Lifchez v. Hartigan*, 735 F. Supp. 1361, 1377 (N.D. Ill. 1990).

29. Genetic counselors point out that "[n]o matter how glad they are that they terminated the pregnancy or how much they love the health-impaired child they have, they still will be saddened by the loss of the child or the things the child cannot do." Malinowski, *supra* note 2, at 1467.

30. See, e.g., Mack Lipkin, Jr. et al., *Genetic Counseling of Asymptomatic Carriers in a Primary Care Setting*, 105 ANNALS INTERNAL MED. 115, 119-20 (1986). There are also

prenatal testing, diagnosis of the fetus generally reveals genetic information about the mother or father or both. If the fetus is affected with a recessive disorder, both the woman and her mate are carriers of the gene for the disorder.³¹ Although a woman's carrier status will have no effect on her health, and she may understand that fact, carriers as a whole have more negative feelings about their future health than do members of the general population.³² In addition, the information—which she would not have learned if she had not undertaken genetic testing in conjunction with reproduction—may change her view of herself. She may feel “defective” somehow. This has happened to women whose sons are mentally retarded due to the chromosomal abnormality of Fragile X.³³ Some feel that they have “failed” in the role for which society most values them—producing healthy sons.³⁴

Identification as a carrier of a recessive genetic disease generates anxiety,³⁵ which can have a lasting impact on the individual.³⁶ Women experience anxiety when they or their spouses are identified as carriers.³⁷ The impact of the test results on the spouse is related to the

speculative philosophical writings about how genetic technologies might change self-concept. See, e.g., Dan W. Brock, *The Human Genome Project and Human Identity*, 29 *Hous. L. Rev.* 7, 13 (1992).

31. The carriers of a gene for a recessive disorder do not themselves have the disorder. See *supra* note 7.

32. Theresa M. Marteau, *Psychological Implications of Genetic Screening*, in 28 *BIRTH DEFECTS: ORIGINAL ARTICLE SERIES* 185, 186 (1992) (although Tay-Sachs carriers viewed their current health status no differently from non-carriers, carriers' perception of future health and risk of illness was significantly more negative than non-carriers').

33. In that situation, the mother has passed on the mutant gene on the X chromosome; the father has passed on a Y chromosome. See *supra* note 7.

34. LORI B. ANDREWS, *NEW CONCEPTIONS: A CONSUMER'S GUIDE TO THE NEWEST INFERTILITY TREATMENTS, INCLUDING IN VITRO FERTILIZATION, ARTIFICIAL INSEMINATION, AND SURROGATE MOTHERHOOD* 79 (1985).

35. Barton Childs et al., *Tay-Sachs Screening: Social and Psychological Impact*, 28 *AM. J. HUM. GENETICS* 550, 550-51 (1976).

36. In a study of cystic fibrosis carrier testing, 27% of carriers remained slightly anxious over test results six months after testing. Eila K. Watson et al., *Psychological and Social Consequences of Community Carrier Screening Programme for Cystic Fibrosis*, 340 *LANCET* 217, 218 (1992). Similarly, in an eight year follow-up of individuals who had been screened for Tay-Sachs carrier status in high school, 46% recalled that they were worried at the time of their result. Nineteen percent remained worried eight years later. Susan Zeeman et al., *A Private View of Heterozygosity: Eight Year Follow-Up Study on Carriers of the Tay-Sachs Gene Detected by High School Screening in Montreal*, 18 *AM. J. MED. GENETICS* 769, 772 (1984).

37. Anxiety was most often associated with fears of children inheriting the disease, lack of understanding of the meaning of carrier status, and shock at “having been singled out.” Individuals experiencing the most anxiety were women who were identified as carriers and were pregnant. Childs et al., *supra* note 35, at 551.

gender of the spouse. Female partners of carriers more often experience heightened anxiety along with their husbands, whereas male partners of carriers less often experience anxiety with their wives.³⁸ This data indicates that female partners in couples where one or both learn their carrier status are more susceptible to heightened levels of anxiety, regardless of whether they or their partners are found to be carriers.

If a fetus is diagnosed as having a dominant disorder, for which the woman herself is at risk, the diagnosis of the fetus with the gene means that the mother has it as well. This occurs most strikingly in the case of Huntington's disease, a debilitating neurological disorder that generally does not begin to affect people until their late forties. Most people who have a parent with the disorder, and thus are at 50% risk of having the disorder themselves, decide not to get tested.³⁹ Since there is no treatment, they see no benefit in learning their status. Nancy Wexler observes that "if the test [of the fetus for Huntington's disease] is positive, two massive losses are suffered simultaneously. The child will most likely be aborted, or else the test would not have been taken initially. And the parent is immediately diagnosed as an obligate carrier."⁴⁰ If the disorder is a dominant late-onset disorder, at-risk parents "hear their own death knell with that of their child."⁴¹

The psychological impact of learning that one has the gene for an untreatable disorder such as Huntington's disease can be devastating. The suicide rate is four times higher among people with Huntington's disease than among the general population.⁴² Even when women are prepared for bad news as a result of testing, they may still be shocked by the reality of it. For example, a woman who said before predictive testing for Huntington's disease that she believed she would be found to have the faulty gene nonetheless stated after she received the results, "I feel like someone has died. Part of me has died, the hopeful

38. *Id.*

39. Less than 15% of at-risk individuals decide to be tested. Maurice Bloch et al., *Predictive Testing for Huntington Disease: II. Demographic Characteristics, Life-style Patterns, Attitudes, and Psychosocial Assessments of the First Fifty-One Test Candidates*, 32 AM. J. MED. GENETICS 217, 222 (1989) [hereinafter *Predictive Testing*]. See also David Craufurd et al., *Uptake of Presymptomatic Predictive Testing of Huntington's Disease*, 2 LANCET 603, 604 (1989).

40. Nancy S. Wexler, *Genetic Jeopardy and the New Clairvoyance*, 6 PROGRESS MED. GENETICS 277, 300 (1985).

41. *Id.*

42. Lindsay A. Farrer, *Suicide and Attempted Suicide in Huntington's Disease: Implications for Preclinical Testing of Persons at Risk*, 24 AM. J. MED. GENETICS 305, 305 (1986).

part."⁴³ The woman experienced depression which became increasingly problematic.⁴⁴

Even when the results of genetic testing reveal that a person does *not* have a genetic mutation, the results may cause psychological harm. Some people experience "survivor's guilt," similar to that of soldiers whose buddies have died in war, as they wonder why they have been spared when other family members tragically have inherited the gene.⁴⁵ Of people who undergo genetic testing for Huntington's disease and learn that they do not have the gene, 10% experience severe psychological problems as a result.⁴⁶ Many people whose parents have Huntington's disease assume that they have inherited the gene.⁴⁷ They may live their lives as if they will die of the disease in their fifties. They may choose not to pursue a particular career or relationship because they believe that they will get the disease. Learning that they do not have the gene radically changes their self-image.⁴⁸ One woman said, "If I'm not at risk—Who am I?"⁴⁹

Mandatory fetal cell sorting will force many women to learn genetic information about themselves against their will. The psychological risks of mandatory genetic testing may be exacerbated by the unlikelihood that the state will set aside sufficient funds to provide counseling for pregnant women and their mates. Various national advisory groups have suggested that patient education and genetic counseling must be an integral part of any genetic testing program.⁵⁰ Yet educational counseling is not a routine part of state-mandated new-

43. Maurice Bloch et al., *Predictive Testing for Huntington's Disease in Canada: The Experience of Those Receiving an Increased Risk*, 42 AM. J. MED. GENETICS 499, 504 (1992) [hereinafter *Huntington's Disease in Canada*].

44. *Id.*

45. Kimberly Quaid et al., *Knowledge, Attitude and the Decision to Be Tested for Huntington's Disease*, 36 CLINICAL GENETICS 431, 436-37 (1989); Wexler, *supra* note 40, at 298.

46. Marlene Huggins et al., *Predictive Testing for Huntington's Disease in Canada: Adverse Effects and Unexpected Results in Those Receiving a Decreased Risk*, 42 AM. J. MED. GENETICS 508, 508 (1992).

47. If one of their parents has the disorder, there is a 50% chance that they will inherit the genetic mutation and get the disorder themselves.

48. In one case, a man whose father had died of Huntington's disease assumed that he would get the disease as well. Despite being employed, he lived his life on the assumption that he would die early, therefore failing to plan for his future in financial and interpersonal areas. Upon learning that he did not have the disease, he had to re-evaluate his life. One result of this re-evaluation was that he embezzled from his company in order to overcome the substantial personal debt that he had accumulated due to his earlier assumptions about the disease. Huggins et al., *supra* note 46, at 511-12.

49. *Id.* at 510.

50. See, e.g., COMMITTEE ON ASSESSING GENETIC RISKS, *supra* note 9, at 14.

born screening programs. The harms that can result from genetic testing programs that are undertaken without appropriate education and counseling were well documented in the 1970s, when states mandated genetic testing of African-Americans for sickle cell carrier status without providing these support services.⁵¹

D. Effect on Relationships with Family Members

Genetic information also affects one's personal relationships. Individuals may withdraw from family activities and events in order to avoid having to face family members with whom they do not wish to share test results.⁵² In some families, siblings share a bond created by the fact that they are at risk for having a genetic mutation that runs in the family. When a woman learns that she has a mutation and her sibling does not (or vice-versa), this new information can alter the nature of their relationship significantly.

The impact on a sibling relationship can be even more profound when one sibling is actually affected with the disorder for which another is undergoing prenatal diagnosis. When a woman's brother or sister is affected with a recessive disorder such as cystic fibrosis, for example, she may not want to learn her own genetic status, believing that her risk for having the gene makes her closer to her affected sibling than she will be if she confirms that she does not have the gene.⁵³ Moreover, learning that her fetus is affected with a recessive disorder may strain her relationship with her affected sibling. The affected sibling may perceive the woman's consideration of terminating the pregnancy as a rejection of the sibling.

51. See, e.g., PHILIP REILLY, *GENETICS, LAW AND SOCIAL POLICY* 62 (1977). See also Louis J. Elsas II, *A Clinical Approach to Legal and Ethical Problems in Human Genetics*, 39 *EMORY L.J.* 811, 827-28 (1990) (when sickle cell screening programs were implemented without the public's being fully informed and without genetic counseling, one out of every 20 African-Americans was found to be a carrier and many were stigmatized and discriminated against). See also Leslie Roberts, *One Worked; The Other Didn't*, 247 *SCIENCE* 18, 18 (1990).

52. A Canadian group studying predictive testing in Huntington's disease reported a case study of a woman who received an increased risk result. Although the woman had informed her father of the results, she did not inform her siblings. Her siblings became aware of her test results because they recognized her voice on a radio show discussing Huntington's disease. Her sister confronted her and offered her support and now they freely discuss Huntington's. Her brother on the other hand is aware of the results, but the test participant is still unable to discuss the results with him; she avoids family functions and outings in order to avoid seeing him. Bloch et al., *Huntington's Disease in Canada*, *supra* note 43, at 501.

53. J.H. Fanos & J.P. Johnson, *CF Carrier Status: The Importance of Not Knowing*, 55(3) *AM. J. HUM. GENETICS* A292 (#1711) (1994).

E. Relationships with Spouses and Potential Spouses

Genetic information can also affect relationships with spouses and potential spouses. In one study, sickle cell anemia testing was introduced in Orchemenos, Greece.⁵⁴ People who are carriers of the gene are healthy themselves but, if they procreate with another carrier, there is a 25% chance that any child will have sickle cell anemia. The health care providers in this study thought that the testing they offered would decrease the number of affected children by causing people to make more "rational" reproductive decisions (since, if a carrier and a non-carrier have a child together, there is no chance that the child will be affected with the disorder). The actual result, though, was that carriers were stigmatized.⁵⁵ The birth rate of affected children did not decrease because, in many instances, only another carrier would marry a carrier.

A survey of 214 women attending OB/GYN clinics in Ohio found that 9% of respondents felt that cystic fibrosis carrier status was a good reason for a couple to avoid marriage.⁵⁶ Men are more likely than women to say that they would alter marriage plans if they learned that their fiancé was the carrier of a recessive genetic disorder. Eight years after participating in Tay-Sachs testing,⁵⁷ 95% of female carriers responded that they would not alter marriage plans upon discovering that their intended partner was also a carrier.⁵⁸ In contrast, only 69% of male carriers responded definitively that they would not alter marriage plans if their intended spouse was also a carrier.⁵⁹ Another study of Tay-Sachs testing⁶⁰ found that 25% of carriers and 6% of carriers' spouses felt that knowing their own or their spouse's carrier status would have affected their marriage decision.⁶¹

Sexual relationships, too, may be affected by genetic knowledge. A study of daughters of breast cancer patients found that satisfaction with sex within relationships was adversely affected by fears or wor-

54. George Stamatoyannopoulos, *Problems of Screening and Counseling in the Hemoglobinopathies*, in BIRTH DEFECTS: PROCEEDINGS OF THE FOURTH INTERNATIONAL CONFERENCE 268, 272 (Arno G. Motulsky & Widukind Lenz eds., 1974).

55. Seven percent of non-carriers avoided marrying a carrier and some broke off their engagement when they learned that the potential spouse possessed the sickle cell trait. *Id.* at 274.

56. Jeffrey R. Botkin & Sonia Alemagno, *Carrier Screening for Cystic Fibrosis: A Pilot Study of the Attitudes of Pregnant Women*, 82 AM. J. PUB. HEALTH 723, 725 (1992).

57. Zeesman et al., *supra* note 36, at 773.

58. *Id.*

59. *Id.*

60. Childs, *supra* note 35, at 550.

61. *Id.* at 552.

ries about breast cancer.⁶² When compared to matched controls, daughters of breast cancer patients reported less frequent sexual activity and less satisfaction with sexual encounters.⁶³ A similar reaction might occur in women whose awareness of increased risk results from learning genetic information about their fetuses rather than their mothers. A study assessing changes in relationships after predictive testing for Huntington's disease found that individuals who received an increased risk result indicated a significant decline in satisfaction with their primary relationship during the two-year follow-up period after receiving test results.⁶⁴

F. Impact on Pregnancy

The use of prenatal screening changes pregnant women's relationships with their fetuses. Instead of bonding with the fetuses early in the pregnancy, women who undergo prenatal testing delay bonding until they learn the results of the testing. They often do not tell friends or family members about the pregnancy. Overall, this results in what Barbara Katz Rothman has called "the tentative pregnancy."⁶⁵ Moreover, women are concerned about how their mates and others will judge the actions they take during pregnancy. A wo-

62. David K. Wellisch et al., *Psychological Functioning of Daughters of Breast Cancer Patients. I: Daughters and Comparison Subjects*, 32 *PSYCHOSOMATICS* 324, 334 (1991), cited in Caryn Lerman & Marc Schwartz, *Adherence and Psychological Adjustment Among Women at High Risk of Breast Cancer*, 28 *BREAST CANCER RES. & TREATMENT* 145, 149 (1993).

63. *Id.* Although this study was conducted on women with an increased risk of breast cancer, the data reported is useful in determining the effects of genetic testing. Genetic testing often can determine whether an individual will develop or is at an increased risk of developing disease, yet testing often falls short of identifying the severity of disease manifestation or time of disease onset. This uncertainty is very similar to the uncertainty experienced by individuals at high risk of disease because of family history. Many of the same thoughts and fears which affect the daily functioning of daughters of breast cancer patients may be present in individuals receiving genetic test results that leave uncertainties.

64. This Canadian study of 27 individuals assessed changes in relationships for individuals participating in predictive testing for Huntington's disease by administering questionnaires prior to receipt of test results and then again at 7 to 10 days, 6, 12, 18, and 24 months after test results. T. Copley et al., Canadian Collaborative Study for P.T., *Significant Changes in Social Relations After Predictive Testing for Huntington Disease*, 55(3) *AM. J. HUM. GENETICS* A291 (#1707) (1994). A U.S. study of individuals participating in predictive testing for Huntington's disease found similar results. Nineteen couples participated in testing. Five of the couples received increased risk results. All 5 couples reported higher levels of marital stress 12 months after receipt of test results than did individuals with decreased risk results. Kimberly A. Quaid & Melissa K. Wesson, *The Effects of Predictive Testing for Huntington's Disease on Intimate Relationships*, 55(3) *AM. J. HUM. GENETICS* A294 (#1728) (1994).

65. BARBARA KATZ ROTHMAN, *THE TENTATIVE PREGNANCY* 86, 98 (1986).

man may believe that the father of the fetus will blame her if something goes wrong with the pregnancy.⁶⁶

G. Impact of Abortion

A woman who learns that her fetus has a genetic mutation may feel compelled to abort (or even pressured by her physician to do so), particularly since, as Adrienne Asch points out, society portrays people with disabilities "as being permanently ill and in pain."⁶⁷ At the same time, a woman may feel that she will be judged too harshly by friends and relatives for aborting. Women who terminate an affected pregnancy after prenatal diagnosis often feel guilty.⁶⁸ In addition, they are very cautious in deciding whom to tell all the facts surrounding the termination of the pregnancy,⁶⁹ since they are concerned about the "value judgments" made by others who have never gone through the same experience.⁷⁰

Women who abort affected fetuses express anxiety over whether they should attempt to conceive again.⁷¹ A majority of women fear that they will have to undergo the same experience over again if they conceive.⁷² In fact, some women indicate that, even if prenatal testing in future pregnancies indicates that the fetus does not have the tested-for disorder, they will still be very anxious about the occurrence of defects that are not detectable by testing.⁷³

H. Impact on the Decision to Carry the Pregnancy to Term

Women may also feel guilty when they carry an affected pregnancy to term.⁷⁴ This is particularly true in the case of mothers who already have children with a genetic disorder and who give birth to additional children with the same disorder.⁷⁵ Society may make wo-

66. Elena A. Gates, *The Impact of Prenatal Genetic Testing on Quality of Life in Women*, 8 FETAL DIAGNOSIS & THERAPY 236, 240 (Supp. 1, 1993).

67. Adrienne Asch, *Reproductive Technology and Disability*, in REPRODUCTIVE LAWS FOR THE 1990s 69, 83 (Sherrill Cohen & Nadine Taub eds., 1989).

68. Audrey Heimler, *Group Counseling for Couples Who Have Terminated a Pregnancy Following Prenatal Diagnosis*, 26 BIRTH DEFECTS: ABSTRACTS OF SELECTED ARTICLES 161, 167 (1990).

69. *Id.* at 165.

70. *Id.*

71. *Id.* at 166.

72. *Id.*

73. *Id.*

74. Donna G. Olsen, *Parental Adjustment to a Child with Genetic Disease: One Parent's Reflections*, 23 J. OBSTETRIC GYNECOLOGIC NEONATAL NURSING 516, 516 (1994).

75. *Id.*

men feel guilty for continuing the pregnancy of a fetus with even a slight disability. This occurred in the case of Bree Walker, a California television anchorwoman affected with ectrodactyly, a mild genetic condition which fused the bones in her hand. When she decided to continue a pregnancy of a fetus diagnosed with the same condition, a radio talk show host and her audience attacked the decision as irresponsible and immoral.⁷⁶

Health care professionals are more likely to blame women for the birth of children with genetic conditions if the women refuse prenatal genetic testing.⁷⁷ This is particularly troubling since physicians may be less likely to help women who decline testing because "the outcome, giving birth to a child with a condition for which prenatal screening is available, is seen as preventable."⁷⁸

I. Effect on the Relationship with the Resulting Child

When a woman carries a pregnancy to term, the genetic information that she learns about the fetus through mandatory prenatal testing may affect how she treats the resulting child. Some women will learn that their fetuses will not be affected with a recessive disorder such as cystic fibrosis, Tay-Sachs disease, or sickle cell anemia but instead will be a carrier of the disorder. Despite the fact that carrier status will not affect the child's health, parents may nonetheless view the child as much at risk medically because of this genetic "abnormality"⁷⁹ and may be overprotective. Parents may also interfere unwarrantedly with the child's later choice of a mate or decision to reproduce. Genetic information can create a feeling of obligation about the reproductive plans of one's child. One study examining decision-making in families with cystic fibrosis found that 31% of mothers and 32% of fathers of children with cystic fibrosis believed that carrier testing was important to provide information pertaining to risk which would aid carriers in their decision-making concerning marriage and reproduction.⁸⁰ Twelve percent of mothers and 18% of fa-

76. See Jean Seligmann & Donna Foote, *Whose Baby is it Anyway?*, NEWSWEEK, Oct. 28, 1991, at 73; Charlotte Allen, *Boys Only: Pennsylvania's Anti-Abortion Law*, 206(10) NEW REPUBLIC 16, 18 (Mar. 9, 1992).

77. Theresa M. Marteau & Harriet Drake, *Attribution for Disability: The Influence of Genetic Screening*, 40 SOC. SCI. & MED. 1127, 1129 (1995).

78. *Id.* at 1130.

79. See Marteau, *supra* note 32 (describing how carriers view their own future health negatively).

80. Gerry Evers-Kiebooms, *Decision Making in Huntington's Disease and Cystic Fibrosis*, in 23(2) BIRTH DEFECTS: ORIGINAL ARTICLE SERIES 115, 143 (1987).

thers thought that carrier testing was important to avoid marriage of carrier couples and/or avoid children in couples where both partners are carriers.⁸¹ Fifteen percent of mothers and 14% of fathers indicated that testing was important to avoid the birth of individuals with cystic fibrosis.⁸²

The impact on the parents' relationship with the resulting child may be even greater when the fetus has been diagnosed as having a disorder which shortens his or her life expectancy. The parent may be less likely to devote emotional care and financial resources to a currently healthy child who, in ten, twenty, or even fifty years, will fall ill. A few years ago, a mother entered a Huntington's disease testing facility with her two young sons. "I'd like you to test my sons for the HD gene," she said. "I only have enough money to send one to Harvard."⁸³ That request and similar requests to test young girls for the breast cancer gene or to test other young children for carrier status for recessive genetic disorders raise enormous questions about whether parents' genetic knowledge about their children will cause them to treat those children differently. A variety of studies have suggested that there may be risks in giving parents such information.

Genetic test results will follow a child throughout life,⁸⁴ potentially "restricting the future" (and also the present) by shifting family resources away from a child with a positive diagnosis."⁸⁵ Such a child "can grow up in a world of limited horizons and may be psychologically harmed even if treatment is subsequently found for the disorder."⁸⁶

Because of the potential psychological and financial harm that genetic testing of children may cause, a growing number of commentators and advisory bodies are recommending that genetic testing not

81. *Id.* at 144.

82. *Id.*

83. Wexler, *supra* note 23, at 233.

84. Dorothy C. Wertz et al., *Genetic Testing for Children and Adolescents: Who Decides?*, 272 JAMA 875, 875 (1994).

85. *Id.* at 878.

86. *Id.* Similarly, the ASHG/ACMG Statement notes that:

[e]xpectations of others for education, social relationships and/or employment may be significantly altered when a child is found to carry a gene associated with a late-onset disease or susceptibility. Such individuals may not be encouraged to reach their full potential, or they may have difficulty obtaining education or employment if their risk for early death or disability is revealed.

American Society of Human Genetics & American College of Medical Genetics, *Points to Consider: Ethical, Legal, and Psychosocial Implications of Genetic Testing in Children and Adolescents*, 57 AM. J. HUM. GENETICS 1233, 1236 (1995).

be undertaken on minor children unless there is an immediate medical benefit to the child. For example, the Institute of Medicine Committee on Assessing Genetic Risks has recommended that "in the clinical setting, children generally be tested only for disorders for which a curative or preventive treatment exists and should be instituted at that early stage. Childhood screening is not appropriate for carrier status, untreatable childhood diseases, and late-onset diseases that cannot be prevented or forestalled by early treatment."⁸⁷ Yet, while testing an existing child for certain conditions might be considered improper, physicians and legislators may mandate fetal testing for those same conditions. For example, Huntington's disease testing is currently not undertaken on children. However, it might be done on a fetus with the thought that women would be likely to abort those fetuses afflicted with the disease. Since some women will not abort,⁸⁸ however, those women will have information about their children that it has been recommended that parents not have.

J. Impact on Subsequent Use of Genetic Services and Other Medical Services

The psychological impact of receiving genetic information through prenatal testing may be sufficiently troubling that it will lead some women to refuse future testing in situations in which the testing might be beneficial. In one cystic fibrosis carrier screening program, women were sufficiently troubled by the process that they refused subsequent prenatal testing for maternal serum alpha-fetoprotein.⁸⁹ In addition, two couples—who had previously consented to prenatal testing for Huntington's disease during two pregnancies and had terminated the pregnancies as a result—refused prenatal testing during their third pregnancies and carried to term.⁹⁰

The fear of undergoing involuntary genetic testing may deter women from seeking medical care during pregnancy, increasing physical

87. COMMITTEE ON ASSESSING GENETIC RISKS, *supra* note 9, at 276.

88. For example, some women whose fetuses are at risk for Huntington's disease reject prenatal testing because they believe that a cure will be found before the child develops the disease (since the age of onset is often in the fifties). Personal Communication with Nancy Wexler, President, Hereditary Disease Foundation, Sept. 27, 1996.

89. M.E. Mennie et al., *Prenatal Screening for Cystic Fibrosis: Psychological Effects on Carriers and Their Partners*, 30(7) J. MED. GENETICS 543, 547 (1993). Similarly, another couple found prenatal diagnosis for Huntington's disease (and subsequent abortion) in their first pregnancy so stressful that they refused testing in subsequent pregnancies. M.M. Burgess, *Ethical Issues in Prenatal Testing*, 27(2) CLINICAL BIOCHEMISTRY 87, 89 (1994).

90. S. Adam et al., *Five Year Study of Prenatal Testing for Huntington's Disease: Demand, Attitudes, and Psychological Assessment*, 30(7) J. MED. GENETICS 549, 552 (1993).

risks to them and their fetuses.⁹¹ In addition, a mother's stress from being tested against her will and learning information that she does not want may harm the fetus *in utero*.⁹²

K. Impact on Insurability and Employability

In addition to its effects on people's emotional well-being and self-concept, their relationships with other people, and their use of medical services, the availability of genetic testing can influence people's relationships with third parties such as insurers and employers. An April 1995 Harris Poll found that 86% of people are concerned about the prospect of employers and insurers using genetic tests before deciding whether to hire or insure someone.⁹³ Such a worry is well-founded. Recently conducted studies reveal contemporary examples of genetic insurance discrimination.⁹⁴ Among people in families with a known genetic condition, 31% have been denied health insurance coverage of some service or treatment because of their genetic status, whether or not they were sick.⁹⁵ When a pregnant woman underwent cystic fibrosis testing and her fetus was diagnosed as positive, for example, her health maintenance organization informed

91. As Dawn Johnsen notes, "in order to avoid being 'caught' by the authorities, she might not seek any prenatal care, thereby endangering both her own and her future child's health." Dawn Johnsen, *The Creation of Fetal Rights: Conflicts with Women's Constitutional Rights to Liberty, Privacy, and Equal Protection*, 95 YALE L.J. 577, 612 n.56 (1986).

92. Because the stress caused by coerced medical interventions during pregnancy may harm the fetus, Elizabeth Taylor suggests in her Note that a fetus may have a psychological and physical interest in his or her mother's autonomy. Elizabeth Taylor, Note, *Constitutional Limitations in State Intervention in Prenatal Care*, 67 VA. L. REV. 1051, 1066 (1981).

93. Fear of discrimination may deter people from undergoing testing. In one study of women's interest in genetic testing for breast cancer, 15% of women declining breast cancer testing indicated that they were refusing testing because of worry about losing insurance. Caryn Lerman et al., *Interest in Genetic Testing Among First-Degree Relatives of Breast Cancer Patients*, 57 AM. J. MED. GENETICS 385, 389 (1995). Similarly, in a cystic fibrosis carrier study directed by Dr. Wayne Grody at UCLA, 11% of the subjects experienced concern over what others would think if the test were positive and 30% said that they would refuse testing if they knew that the results would be available to insurers.

94. For information on how insurers have responded to information about people's genetic status, see Paul R. Billings et al., *Discrimination as a Consequence of Genetic Testing*, 50 AM. J. HUM. GENETICS 476 (1992); OFFICE OF TECHNOLOGY ASSESSMENT, CYSTIC FIBROSIS AND DNA TESTS: IMPLICATIONS OF CARRIER SCREENING 31 (1992). See also NEIL A. HOLTZMAN, PROCEED WITH CAUTION 195 (1989); Larry Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 AM. J.L. & MED. 109, 119 (1991).

95. E.V. Lapham & J. Weiss, Georgetown University and the Alliance of Support Groups, Human Genome Education Model Project, 1995 (preliminary results of a survey of genetic support groups). In one study, 14% of responding genetic counselors reported that their counselees had difficulty obtaining or retaining health insurance due to genetic testing results. COMMITTEE ON ASSESSING GENETIC RISKS, *supra* note 9, at 270.

her that it would not pay for the health care costs of the child if she chose not to abort; that decision was reversed after a public outcry.⁹⁶ A woman whose mother had breast cancer was told that she could obtain health care coverage but not for any treatment of breast cancer.⁹⁷ In another instance, a newborn was diagnosed with PKU and successfully treated. She was covered under her father's health insurance, but when he changed jobs when she was eight years old, she became ineligible for coverage under his new group plan because of her diagnosis, even though she was developmentally normal and healthy.⁹⁸ Some people who have participated in genetics research, including a man who had undergone screening for APC (adenomatous polyposis colon cancer) as part of a study at the Huntsman Cancer Center at the University of Utah, have lost their health insurance as a result of their participation. Since health insurance companies can exclude people with pre-existing disorders, genetic testing provides an enormous loophole whereby numerous diseases can be classified as pre-existing because they have their roots in our genes.

Insurance in the United States is based on the ideas of risk-spreading and risk-sharing. When most people's future health risks are unknown, the future health care costs of a group can be predicted on an aggregate actuarial basis and the costs spread across the whole group. As genetic technologies have begun to identify currently-healthy people who will later develop particular diseases, insurance companies have begun charging exorbitant amounts—or denying coverage entirely—to people predicted to be at genetic risk. At first glance, such policies seem reasonable, akin to charging higher rates to people who smoke. But, as dozens of genes are identified each week, the absurdity of this approach becomes apparent. Since each of us has between eight to twelve genetic defects, anyone could become uninsurable. Alternatively, if each of us were charged an amount equal to our future medical costs, insurance would entirely lose its risk-spreading benefits.

Just as insurance discrimination might occur based on genetic information, so might employment discrimination. In the early 1970s, employers discriminated against African-American employees and

96. See OFFICE OF TECHNOLOGY ASSESSMENT, *CYSTIC FIBROSIS AND DNA TESTS: IMPLICATIONS OF CARRIER SCREENING* (1992).

97. National Action Plan on Breast Cancer & NIH-DOE Working Group on Ethical, Legal, and Social Implications of Human Genome Research, *Conference on Genetic Discrimination and Health Insurance: A Case Study on Breast Cancer, Testimony of Mary Jo Ellis Kahn* (July 11, 1995).

98. Billings et al., *supra* note 94, at 478.

job applicants who were carriers of sickle cell anemia, even though carrier status had no relation to the individual's health or ability to perform the job.⁹⁹ The only significance of the sickle cell trait was that the carrier would have a 25% chance of having a child with sickle cell anemia if he or she procreated with another trait carrier.

More recently, a healthy carrier of Gaucher's disease was denied a government job based on his carrier status.¹⁰⁰ Another man was given restricted benefits and denied a promotion and job transfer because he and his son carry the gene for neurofibromatosis.¹⁰¹ Still another man had a job offer withdrawn based on the claim that he "lied" during a pre-employment physical. He had said he was not seriously ill. However, he had a genetic form of kidney disease, but without any symptoms.¹⁰²

According to a 1989 survey of companies by the Office of Technology Assessment of the U.S. Congress, one in twenty companies conducts genetic screening or monitoring in the workplace.¹⁰³ In September 1995, the San Francisco Legal Aid Office filed a class action lawsuit by employees of Lawrence Berkeley Laboratories at the University of California, Berkeley, a laboratory funded by the federal Department of Energy.¹⁰⁴ The suit alleged that the lab had tested African-American employees for the sickle cell gene without their knowledge or consent and had secretly maintained that information in their files. In the future, employers may assign workers to tasks, not on the basis of expressed interests or talents, but on the basis of the results of genetic testing.

If mandatory fetal cell sorting were in place, insurers and employers could base their decisions on genetic information in a woman's or

99. ANDREWS, *supra* note 18, at 18.

100. Billings et al., *supra* note 94, at 478. Gaucher's disease is "an autosomal recessive disease characterized by a deficiency of lysosomal acid-beta-glucosidase." B. Bembi et al., *Enzyme Replacement Treatment in Type 1 and Type 3 Gaucher's Disease*, 344 LANCET 1679, 1679 (1994).

101. Jon Matthews, *Bias Based on Genetic Testing Techniques*, SACRAMENTO BEE, May 7, 1995, at A3. Neurofibromatosis is a condition in which there are tumors of various sizes on particular nerves. TABER'S CYCLOPEDIA MEDICAL DICTIONARY 951 (14th ed. 1981). It has an extremely wide range of clinical manifestations, with some people being only mildly affected by the disorder.

102. Matthews, *supra* note 101, at A3.

103. OFFICE OF TECHNOLOGY ASSESSMENT, GENETIC MONITORING AND SCREENING IN THE WORKPLACE 22 (1990). The survey polled 1500 United States companies, the 50 largest utilities, and the 33 largest unions.

104. Norman-Bloodsaw v. Lawrence Berkeley Nat'l Lab., No. C95-03220 (N.D. Cal. filed Sept. 12, 1995).

a resulting child's medical record.¹⁰⁵ A survey of U.S. geneticists revealed that 24% would share the patient's genetic information with employers *without the patient's consent*.¹⁰⁶ Physicians are increasingly being placed into the role of "double agents"—with dual loyalties to the patient and to the patient's school, employer, potential insurer, relative, or child.¹⁰⁷

L. The Larger Impact of Genetic Information on Family Members' Own Risks

The rippling effects of genetic information spread beyond the nuclear family. Information about a particular individual reveals genetic risk information about his or her other relatives as well. A parent and a child have half their genes in common, as do siblings. Cousins share one-quarter of their genes, as do grandparents and grandchildren. When a pregnant woman is forced to learn genetic information about her fetus, that information indicates certain risks to relatives. For example, in a family at risk for Huntington's disease, the fetus' at-risk grandmother may be in her late forties and not yet know whether she will get the disease. The fetal diagnosis means that the grandmother, by necessity, has the genetic mutation and will get the disease. If a

105. In the United States, only a few states have laws banning genetic discrimination in employment; most of these laws are deficient in that they cover only a limited number of genetic conditions or in that they apply only to certain types of genetic information (such as that which is obtained using particular genetic tests). For example, the Louisiana law only protects sickle cell anemia carriers. LA. REV. STAT. ANN. § 23:1002(B) (West 1985). At the federal level, the Americans with Disabilities Act (ADA) prohibits employers with 15 or more employees from refusing to hire or otherwise discriminating against people with disabilities or who are regarded as having disabilities (unless the disability impedes an employee's ability to do the job in question). 42 U.S.C.A. § 12101 (West Supp. 1995). In its compliance manual, the Equal Employment Opportunity Commission (EEOC) provided guidance about how the ADA would apply to an individual who is presymptomatic for a genetic disease. The EEOC wrote that it is illegal for an employer to discriminate against a person based on genetic information relating to illness, disease, or other disorders. As an example, the EEOC indicated that an employer may not refuse to hire an individual just because the person's genetic profile reveals an increased susceptibility to colon cancer. EEOC Compl. Man. (BNA) § 902, at 47 (1995) (defining the term "Disability"). This interpretation may not go far enough, however, since it does not specifically address whether someone can be denied a job because he or she is a carrier of a recessive disorder such as cystic fibrosis and the potential employer does not want to pay the health care costs of potential future affected children.

106. John C. Fletcher & Dorothy C. Wertz, *Ethics, Law, and Medical Genetics: After the Human Genome is Mapped*, 39 EMORY L.J. 747, 807 (1990).

107. Dorothy Nelkin, *The Social Power of Genetic Information*, in THE CODE OF CODES: SCIENTIFIC AND SOCIAL ISSUES IN THE HUMAN GENOME PROJECT 177, 189 (Daniel J. Kevles & Leroy Hood eds., 1992).

pregnant woman learns that her fetus has cystic fibrosis, there is a 25% risk that her cousin is a carrier as well.

Even if a pregnant woman decides not to share the genetic information with relatives in order to spare them potential psychological, social, and financial risks, they may learn about it anyway. There is widespread willingness on the part of geneticists to breach a patient's confidentiality and disclose information to relatives. In response to a survey by Dorothy Wertz and John Fletcher, 58% of geneticists said that they would disclose the risk of Huntington's disease to a relative without the patient's permission.¹⁰⁸ This is despite the fact that Huntington's disease is untreatable and that less than 15% of individuals at risk for Huntington's disease decide to undergo testing to determine whether they have the disease.¹⁰⁹

M. Medical Pressure to Undergo Prenatal Testing

Prenatal testing presents serious psychological, social, and financial risks. Perhaps because such risks are relatively unique to genetics and infrequently discussed in the medical literature,¹¹⁰ however, many physicians view genetic tests as risk-free blood tests and pressure women to undergo them.¹¹¹ In some instances, physicians surreptitiously test pregnant women's blood for carrier status. In other instances, physicians mislead pregnant women into undergoing genetic testing. In those situations, even so-called voluntary testing may become mandatory in fact. In an innovative anthropological study, Nancy Press and Carol Browner observed physician visits in which physicians offered the maternal serum alphafetoprotein (MSAFP) test to pregnant women. A California regulation requires physicians to offer women the blood test, which measures the level of a fetus' alphafetoprotein that circulates in a woman's blood.¹¹² Press and

108. Fletcher & Wertz, *supra* note 106, at 770.

109. Bloch, et al., *Predictive Testing*, *supra* note 39, at 222.

110. Ellen Wright Clayton notes that "[p]atients' experiences almost never get into print." Ellen Wright Clayton, *Screening and Treatment of Newborns*, 29 Hous. L. REV. 85, 90 (1992).

111. For some women, the fact that a physician has recommended testing will be enough to make the women undergo it. Abby Lippman observes that "since an expert usually offers testing and careseekers are habituated to follow through with tests ordered by physicians, it is hardly surprising that they will perceive a need to be tested." Abby Lippman, *Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities*, 18 AM. J.L. & MED. 15, 28 (1991) (citations omitted). For some couples, the mere existence of a prenatal test makes them feel compelled to use it. Adam et al., *supra* note 90, at 555.

112. CAL. CODE REGS. tit. 17, § 6527 (1996).

Browner identified factors that caused physicians to pressure women to participate in so-called voluntary MSAFP programs.¹¹³ They found that the physicians did not obtain true informed consent. Physicians offering the testing to women did not reveal the significance of the testing to the women—that it might show that a fetus had spina bifida or anencephaly and that the women then would be faced with a decision about whether or not to abort. Instead, the test was routinely described as “a simple blood test” or as a test to show “how your baby is developing.” While testing was supposed to be voluntary, those women who refused testing were hounded by the physician until some consented to testing.

The gender of the physician or genetic counselor can also influence the amount of pressure put on women to undergo genetic testing.¹¹⁴ Female physicians and counselors tend to be less directive, more sensitive to personal autonomy issues and more concerned with the overall effect that testing may have on the family unit as a whole.¹¹⁵ The directiveness or nondirectiveness of a physician or genetic counselor may influence not only whether a woman undergoes prenatal diagnosis but also whether she terminates an affected pregnancy.¹¹⁶

There is no data on what proportion of American geneticists and genetic counselors direct women to abort affected fetuses, although I have encountered women whose physicians have so pressured them.¹¹⁷ The type of coercion that women may undergo is illustrated by the case of a woman whose physician discovered prenatally that

113. Nancy Press & Carol Browner, *Collective Fictions: Similarities in the Reasons for Accepting MSAFP Screening Among Women of Diverse Ethnic and Social Class Backgrounds*, 8 *FETAL DIAGNOSIS & THERAPY* 97, 100 (1993). The authors also note that health care professionals may push women into prenatal tests due to fear of malpractice liability. *Id.*; see also Malinowski, *supra* note 2, at 1493.

114. Dorothy C. Wertz, *Providers' Gender and Moral Reasoning*, 8 *FETAL DIAGNOSIS & THERAPY* 81, 82 (1993).

115. *Id.*

116. If a physician or genetic counselor expresses an opinion as to a course of action, a woman may view that opinion as a medical recommendation and may be reluctant to choose an alternative course that the counselor is not “recommending.” Gates, *supra* note 66, at 240.

117. Genetic counselors point out that physicians and counselors will “get directive, especially if they feel the diagnosis is extremely severe or extremely mild.” Malinowski, *supra* note 2, at 1468. According to Judy Norsigian of the Boston Women’s Health Book Collective, “when it comes to something like Down’s syndrome, most physicians have been extremely directive and even obnoxious. They will even say, ‘we’ll be scheduling an abortion for you.’ This happens even when the extent of the disability is very mild.” Allen, *supra* note 76, at 19.

she would deliver a child with anencephaly.¹¹⁸ “[T]hey (the doctors) said her baby would have more in common with a fish than a human. They said to expect the girl to be as smart as a baboon.”¹¹⁹ International surveys also suggest that physicians pressure women to abort. For example, in Portugal, 50% of geneticists advocate termination of a pregnancy in which the fetus has cystic fibrosis (as compared to 21% in the United Kingdom).¹²⁰ This occurs despite the fact that children with cystic fibrosis are of normal intelligence and, with treatment, can live until their forties.

There are no standards concerning appropriate prenatal testing. Some physicians may seek to obtain genetic information that the woman does not want to know about the fetus and does not want to know about herself. For example, some physicians want to test fetuses for the breast cancer gene even though there is professional disagreement about whether this is appropriate. The lack of consensus about what type of screening should be offered means that there is also no clear guidance for state policymakers adopting mandatory screening plans. Along those lines, state-initiated screening programs of newborns vary in the disorders for which they mandate testing. Some states mandate genetic testing of newborns for certain disorders even when national panels of medical experts recommend against testing for those disorders.¹²¹

N. Impact on Women in General and People with Disabilities

The mandating of genetic testing on pregnant women may have an overall negative social impact on women and on people with disabilities. The adoption of a law mandating fetal cell sorting would be in keeping with the long-standing culture of motherhood, which has portrayed women as guarantors of their offsprings' wellbeing. Early cases suggested that women should be forbidden to do certain types of work—including being lawyers—because such work might make them less fit to reproduce. And when courts upheld sexist employment laws

118. Anencephaly is a “[c]ongenital absence of brain and spinal cord, the cranium being open throughout its whole extent and the vertebral canal converted into a groove.” *TABER'S CYCLOPEDIA MEDICAL DICTIONARY* 78 (14th ed. 1981).

119. Bonnie Gangelhoff, *Tragedy Spurs Mother to Back Registry*, *Hous. Post*, July 11, 1993, at A1, A20, *quoted in* Malinowski, *supra* note 2, at 1522.

120. Theresa Marteau et al., *Counselling Following Diagnosis of Fetal Abnormality: A Comparison Between German, Portuguese, and U.K. Geneticists*, 2 *EUR. J. HUM. GENETICS* 96, 99 (1994).

121. COMMITTEE ON ASSESSING GENETIC RISKS, *supra* note 9, at 262-63 (discussing reasons why newborn screening should not be undertaken for cystic fibrosis).

that kept women from assuming employment that men were allowed to take, they used as a rationale women's childbearing role: "that her physical structure and a proper discharge of her maternal functions—having in view not merely her health, but the well-being of the race—justify legislation to protect her from the greed as well as the passion of man."¹²²

This sentiment expressed by the Court is also in keeping with the harsh stance taken in a 1927 U.S. Supreme Court case, *Buck v. Bell*.¹²³ In that case, the Court upheld a statute which allowed the involuntary sterilization of patients of state institutions who suffered from hereditary insanity or mental deficiency. Justice Holmes, otherwise a champion of individual rights, wrote the Court's opinion, stating:

[w]e have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices . . . in order to prevent our being swamped with incompetence. It is better for all the world if, instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind.¹²⁴

The premium put on healthy babies is also seen in cases in which courts have been willing to order Cesarean sections for unconsenting women based on a doctor's advice that the operation is necessary for the fetus. Psychiatrists have been willing to institutionalize pregnant women who behave in a manner considered harmful to the fetus. And legal commentators have proposed statutory systems that would hold a woman guilty for child abuse if she risked harm to the fetus by smoking or drinking during her pregnancy or by refusing to follow doctors' orders. Margery Shaw, for example, recommends that states adopt policies to prevent the birth of children with genetic diseases. She suggests that the prevention of genetic disease is so important that couples who decide to give birth to a child with a serious genetic disorder should be criminally liable for child abuse.¹²⁵ Other commentators advocate reducing the burden of genetic disease to improve the health of society.¹²⁶ Some advocate prevention of genetic disease us-

122. *Muller v. Oregon*, 208 U.S. 412, 422 (1908).

123. 274 U.S. 200 (1927).

124. *Id.* at 207.

125. Margery Shaw, *Conditional Prospective Rights of the Fetus*, 5 J. LEGAL MED. 63, 99 (1984).

126. See, e.g., Thomas Caskey, *Molecular Medicine: A Spin-Off From the Helix*, 15 JAMA 1986, 1990 (1993).

ing analogies to infectious disease,¹²⁷ even where the disorders are untreatable, such that "prevention" is directed toward contraception and abortion. The impropriety of allowing children with genetic disorders to be born is also implied in articles that point out the financial cost to society of genetic disorders by providing figures on the annual costs of care per patient.¹²⁸

There appears to be a growing interest in subjecting a woman's pregnancy to public control.¹²⁹ Arlene Zarembka and Katherine Franke describe this as the "publicization" of pregnancy.¹³⁰ Carol Beth Barnett observes that "[o]nce a woman becomes pregnant, her life, her lifestyle and her medical options become subject to public control and scrutiny. . . . From this perspective, a woman's womb is like 'quasi-public territory' and a woman's right to bodily integrity and autonomy receives minimal respect."¹³¹ Such an approach conveys the impression to women and to society that pregnant women are mere fetal containers.

Mandating fetal cell sorting also further stigmatizes people with disabilities in our society.¹³² Existing people who have particular disorders may be viewed as having slipped through the net of prenatal screening. The argument about the cost savings that could be gained if women aborted fetuses with disabilities after mandated testing may

127. Shaw, *supra* note 125, at 94.

128. See, e.g., Benjamin S. Wilfond & Norman Fost, *The Cystic Fibrosis Gene: Medical and Social Implications for Heterozygote Detection*, 263 JAMA 2777, 2781 (1990) (average annual cost \$7500; lifetime costs at least \$200,000); Peter T. Rowley et al., *Cystic Fibrosis Carrier Screening: Knowledge and Attitudes of Prenatal Care Providers*, 9 AM. J. PREV. MED. 261, 261 (1993) (average annual cost for CF patient \$10,000; total direct costs may be \$300,000,000).

129. This is evident, for example, in the prosecution of women who drink alcohol or use drugs during pregnancy. See, e.g., JANET DINSMORE, NATIONAL CENTER FOR PROSECUTION OF CHILD ABUSE, AMERICAN PROSECUTORS RESEARCH INSTITUTE, PREGNANT DRUG USERS: THE DEBATE OVER PROSECUTION (1992).

130. Arlene Zarembka & Katherine M. Franke, *Women in the AIDS Epidemic: A Portrait of Unmet Needs*, 9 ST. LOUIS U. L.J. 519, 526 (1990). I have similarly noted a trend toward "policing pregnancy." See Lori Andrews, *A Delicate Condition*, STUDENT LAWYER, May 1985, at 30.

131. Carol Beth Barnett, *The Forgotten and the Neglected*, 23 GOLDEN GATE U. L. REV. 863, 886-87 (1993) (citation omitted).

132. For perspectives on disability and genetic testing, see Marsha Saxton, *Disability Rights and Selective Abortion*, in THE FIFTY YEARS WAR: ABORTION POLITICS 1950 TO 2000 (Ricki Solinger ed., forthcoming 1996); Adrienne Asch, *The Human Genome Project and Disability Rights: Thoughts for Researchers and Advocates*, 7(3) DISABILITY STUD. Q., Summer 1993, at 3; Laura Hershey, *Choosing Disability*, Ms., July/Aug. 1994, at 26-32.

spill over and might make people with disabilities look like social pariahs based on their existence.¹³³

By compelling fetal cell sorting, the government would influence the type of children born in our society. This smacks of government-initiated eugenics. Government control of the traits of children is inappropriate, even if some characteristics of the population would arguably be upgraded.¹³⁴

II. Using the Data on Impacts to Guide Policy

The empirical data about the negative impacts of genetic testing on people's emotional well-being and self-concept, personal relationships, and relationships with insurers and employers (as well as its impact on the culture of motherhood and on society's perception of people with disabilities) argues against requiring people to find out their genotype against their will. This is especially true in the case of prenatal testing, where diagnosis of the fetus often reveals genetic information about the mother or father or both. In addition to the changes in self-concept a parent may undergo as a result of the revelation of the unwanted genetic information about himself or herself, the parent and the fetus may also be stigmatized. The genetic information generated in the course of fetal cell sorting may make the mother, father, resulting child, or even other relatives uninsurable and unemployable. The possibility of psychological, social and financial risks to a variety of parties raises a caution against mandatory prenatal screening, either through a *de jure* state program or a *de facto* medical practice.

Various blue ribbon panels of government, ethics organizations, and entities like the Institute of Medicine have already concluded that, due to the various psychological and social risks of genetic testing, genetics services should be voluntary. With respect to prenatal testing, the National Institutes of Health Workshop on Reproductive Genetic Testing: Impact Upon Women has recommended that "[r]eproductive genetic services should be *meticulously* voluntary."¹³⁵ Similarly, the Committee on Assessing Genetic Risks of the Institute

133. This problem would be exacerbated by the fact that few people have contact with individuals with a disability and consequently may overestimate their cost to society and underestimate their contribution to society.

134. See discussion *infra* text accompanying note 153 regarding parents' liberty interest in childrearing decisions affecting the traits of the children.

135. *NIH Workshop Statement*, 8 FETAL DIAGNOSIS & THERAPY 6, 7 (Supp. 1, 1993) (emphasis added).

of Medicine has recommended that "voluntariness should be the cornerstone of any genetic testing program. The committee [finds] no justification for a state-sponsored mandatory public health program involving genetic testing of adults, or for unconsented-to genetic testing of patients in the clinical setting."¹³⁶

Overriding autonomy by mandating fetal cell sorting clearly has the most impact on women. Women are the people subject to genetic testing on their fetuses' behalf, and the action that the state subtly may be trying to encourage is one that the women would have to take—abortion. Additionally, diagnosis of the fetus more often provides information about the mother than about the father. In the case of a recessive disease, an X-linked disease, and some instances of dominant diseases, the fetus' genetic status will provide information to the mother about her genetic status,¹³⁷ thus influencing her self-image, her personal relationships, and her relationships with third-party institutions.

Moreover, the intrusion on autonomy may be especially egregious to women, who, more than men, feel that doctors should keep out of reproductive decisions. A Swedish study assessing the attitudes of women and men towards prenatal diagnosis found that autonomy in the decision-making process was more important to women than to men.¹³⁸ In response to the question: "[W]ho should decide about prenatal diagnosis, the couple itself or somebody else?," 82% of women indicated the couple should make the decision, compared to 20% of the male partners.¹³⁹

The decision of a woman to undergo or refuse testing during pregnancy cannot be considered in isolation. Jean Sternlight suggests that a woman making a related decision—whether to have her infant tested for HIV infection—will consider 1) the *accuracy of the pro-*

136. COMMITTEE ON ASSESSING GENETIC RISKS, *supra* note 9, at 276.

137. Only in a small minority of cases will the fetus' status exclusively provide information about the father. This is the case only when the disorder is of the dominant type and the gene is transmitted by the father. In other instances of dominant disorders, it is the mother who contributes the gene. In the case of a recessive disorder, both parents pass on the gene. In the case of X-linked disorders, the mother passes on the gene and 50% of her sons are affected.

138. Berit Sjogren, *Future Use and Development of Prenatal Diagnosis, Consumers' Attitudes*, 12 *PRENATAL DIAGNOSIS* 1, 2 (1992).

139. No woman indicated that the couple should not be the ultimate decision maker, while 18% were uncertain. Forty percent of male partners believed that the couple should not be the decision maker in the use of prenatal diagnosis, and 40% were uncertain as to who should be the decision maker. The question proposed medical specialists or public authorities as alternative decision makers to the couple. *Id.* at 4.

posed test; 2) the availability of medical care for the child and the mother, not only in terms of medical technology but also in terms of budgetary constraints, and the practical feasibility of obtaining the necessary medical care; and 3) the *anti-discrimination and anti-stigmatization protection available to both mother and child*.¹⁴⁰ These are reasonable considerations. To the extent that the state cannot guarantee appropriate anti-discrimination and anti-stigmatization protections, a program of mandatory testing should not even be considered.

A. Legal Arguments Supporting Women's Refusal of Testing

The studies on the impact of genetic information can be used in attempts to persuade legislators and physicians not to mandate fetal cell sorting on pregnant women. Such studies may help in framing legal arguments to uphold a pregnant woman's right to refuse fetal cell sorting. Currently, the constitutional protections supporting a woman's right to refuse medical interventions during pregnancy are four-fold: privacy protection of certain personal information; protection against unreasonable searches and seizures; protection of bodily integrity; and protection of reproductive decision-making and decisions regarding child-rearing.¹⁴¹

1. Informational Privacy

Medical information is protected as private, in part because of the psychological, social and financial risks associated with its disclosure.¹⁴² Common law privacy protections exist for certain types of medical information,¹⁴³ as do federal constitutional protections.¹⁴⁴

140. Jean R. Sternlight, *Mandatory Non-Anonymous Testing of Newborns for HIV: Should It Ever Be Allowed?*, 27 J. MARSHALL L. REV. 373, 384 (1994).

141. Equal protection concerns might be raised as well. Such testing might be considered to be discrimination based on pregnancy or perhaps even sex discrimination. *Geduldig v. Aiello*, 417 U.S. 484, 500-01 (1974) (Brennan, J., dissenting).

142. *Doe v. Borough of Barrington*, 729 F. Supp. 376, 384 (D.N.J. 1990).

Society's moral judgment about the high-risk activities associated with the disease, including sexual relations and drug use, makes the information of the most personal kind. Also, the privacy interest in one's exposure to the AIDS virus is even greater than one's privacy interest in ordinary medical records because of the stigma that attaches with the disease.

Id. As has been noted in this article, genetic information raises similar risks of stigma and discrimination.

143. See ANDREWS, *supra* note 18, at 190-94 (1987) (discussing common law actions for breach of medical privacy including actions based on the tort of breach of privacy, breach of contract, malpractice, and breach of fiduciary duty).

144. *Whalen v. Roe*, 429 U.S. 589, 599-600 (1977); *Doe v. City of New York*, 15 F.3d 264 (2d Cir. 1994).

Just as "the sensitive nature of medical information about AIDS makes a compelling argument for keeping this information confidential,"¹⁴⁵ so too does the sensitive nature of genetic information. Since mandatory genetic testing would provide medical information about the woman or fetus to third parties (the laboratory personnel, the woman's physician), this could arguably be a breach of privacy.¹⁴⁶ Such testing would violate one's privacy right not to know medical information about oneself¹⁴⁷ and one's right to refuse medical information that is part of the right of informed consent in the health care setting.¹⁴⁸

2. Fourth Amendment Protections

A pregnant woman could assert a Fourth Amendment right to refuse the fetal cell sorting test.¹⁴⁹ Mandatory blood testing is considered a search and seizure that must comply with Fourth Amendment standards that balance the nature and quality of the intrusion against the strength of a given state interest.¹⁵⁰ Under such an analysis, for example, mandatory testing of an incarcerated individual for HIV infection absent a warrant has been found unconstitutional under the Fourth Amendment.¹⁵¹ Similarly, mandatory HIV testing of state employees working with developmentally disabled clients was enjoined as an unreasonable search and seizure under the Fourth Amendment,

145. *Doe v. Borough of Barrington*, 729 F. Supp. 376, 384 (D.N.J. 1990).

146. It has long been recognized that blood samples contain more medical information than does a traditional medical record. As Fred Bergmann of the National Institutes of Health has pointed out,

[t]he genetic counselor takes a history and puts it in the computer bank. He also takes a blood sample and puts it in the deep freeze. And from the point of view of confidentiality, I would suggest that there is much more information in the deep freeze than in the computer bank, and I think that point should be appreciated by the lawyers and everyone else.

Statement of F. Bergmann, in *ETHICAL ISSUES IN HUMAN GENETICS: GENETIC COUNSELING AND THE USE OF GENETIC KNOWLEDGE* 411 (B. Hilton et al. eds., 1973).

147. Michael L. Closen, *Mandatory Disclosure of HIV Blood Test Results to the Individual Tested: A Matter of Personal Choice Neglected*, 22 *LOY. U. CHI. L.J.* 445, 454-57 (1991); Martha A. Field, *Pregnancy and AIDS*, 52 *MD. L. REV.* 402, 409-13 (1993).

148. Lori B. Andrews, *Informed Consent Statutes and the Decisionmaking Process*, 5 *J. LEGAL MED.* 163, 215-16 (1984). See also *Cobbs v. Grant*, 502 P.2d 1, 12 (Cal. 1976).

149. According to the U.S. Supreme Court, "[t]he overriding function of the Fourth Amendment is to protect personal privacy and dignity against unwarranted intrusion by the State." *Schmerber v. California*, 384 U.S. 757, 767 (1966).

150. *Id.* at 771-72. The blood test in that case was permissible as a minor intrusion. *Id.* at 770.

151. *Barlow v. Ground*, 943 F.2d 1132, 1137-39 (9th Cir. 1991), *cert denied*, 505 U.S. 1206 (1992).

since the employees' privacy interests outweighed the state's interest in preventing the low risk of clients' contracting AIDS from employees.¹⁵² Such precedents would likewise apply to blood tests to obtain genetic information.

3. *Protection of Bodily Integrity, Reproductive Autonomy and Parenting Decisions*

Women could also argue that they have a right to refuse fetal cell sorting based on the common law¹⁵³ (and, in some cases, constitutional)¹⁵⁴ protections of an individual's bodily integrity, as well as on constitutional protections of reproductive autonomy.¹⁵⁵ Recent cases have begun to recognize a woman's right to refuse invasive interventions, such as Cesarean sections, during pregnancy.¹⁵⁶ In *In re A.C.*, the D.C. Court of Appeals held that the decision about whether a pregnant woman should undergo a Cesarean section should be controlled by the woman's wishes, articulated either through her informed consent or, if she is incompetent, through substituted judgment.¹⁵⁷ A similar result was reached in an Illinois case, *In re Baby Boy Doe*.¹⁵⁸ In that case, a woman refused a Cesarean section on religious grounds, and the state attorney brought suit to force her to undergo the operation. The court upheld the woman's right to refuse, recognizing her right to privacy and bodily integrity. The court held that a woman has no duty to guarantee the physical and mental health of her child and that a woman may refuse forced interventions even if the refusal would be harmful to the fetus.¹⁵⁹

152. *Glover v. Eastern Neb. Community Office of Retardation*, 867 F.2d 461, 464 (8th Cir.), *cert. denied*, 493 U.S. 932 (1989).

153. *See, e.g., Union Pac. Ry. Co. v. Botsford*, 141 U.S. 250, 251 (1891); *Fosmire v. Nicoleau*, 551 N.E.2d 77, 80-81 (N.Y. 1990).

154. *See, e.g., Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 278 (1990) ("[A] constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions."); *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 426 (Mass. 1977); *Matter of Quinlan*, 355 A.2d 647 (N.J.), *cert denied*, 429 U.S. 922 (1976).

155. *See, e.g., Roe v. Wade*, 410 U.S. 113, 121 (1973); *Planned Parenthood v. Casey*, 505 U.S. 833, 844 (1992); *Lifchez v. Hartigan*, 735 F. Supp. 1361, 1363 (N.D. Ill. 1990).

156. *See, e.g., In re A.C.*, 573 A.2d 1235, 1247 (D.C. Cir. 1990); *In re Baby Boy Doe*, 632 N.E.2d 326, 332 (Ill. App. Ct. 1994).

157. *In re A.C.*, 573 A.2d at 1252. *See also Rodney Halstead, A Pregnant Woman's Right to Refuse Medical Treatment—Is It Always Her Choice?*, 24 CREIGHTON L. REV. 1589, 1589 (1991).

158. *In re Baby Boy Doe*, 632 N.E.2d 326, 326 (Ill. App. Ct. 1994).

159. *Id.*

Parents also have a liberty interest in the type of children that they conceive and raise. In U.S. Supreme Court cases involving child-rearing decisions, the Court has held that the determination of a child's social traits is a matter for the parents to decide (even if state control arguably could produce a better child).¹⁶⁰ A strong argument similarly could be made that a child's genetic traits should be determined by the parents rather than the state. Similar reasoning was used in dicta in *Planned Parenthood v. Casey*, in which the U.S. Supreme Court said,

If indeed the woman's interest in deciding whether to bear and beget a child had not been recognized as in *Roe*, the State might as readily restrict a woman's right to choose to carry a pregnancy to term as to terminate it, to further asserted state interests in population control, or eugenics, for example. Yet *Roe* has been sensibly relied upon to counter any such suggestions.¹⁶¹

B. State Arguments to Uphold Mandatory Fetal Cell Sorting

1. Minimal Burden on Rights

One argument that a state may make in support of mandatory fetal cell sorting is that the process places only a minimal burden on the woman and thus should not be viewed as an infringement of her constitutional rights. Several Fourth Amendment cases view a blood test as creating minimal risk.¹⁶² Moreover, the cases holding that pregnant women have a right to refuse Cesarean sections turned, in part, on the fact that such operations are massively physically invasive. In *In re A.C.*, for example, the Court stated: "Our discussion of the

160. In the 1920s, states passed laws that forbade parents from sending their children to private schools and that prohibited schools from teaching a foreign language. The states argued that they knew better than parents how to create good citizens. In responding to this argument, the U.S. Supreme Court discussed Plato's suggestion that children be raised communally with no child knowing his parent. *Meyer v. Nebraska*, 262 U.S. 390, 401-02 (1923). The Court also described the Spartan approach of entrusting the education and training of boys to official guardians. *Id.* at 402. The Court commented that, although such ideas were proposed by "men of great genius," the concepts of "the relation between individual and State were wholly different from those upon which our institutions rest; and it will hardly be affirmed that any legislature could impose such restrictions upon the people of a State without doing violence to both letter and spirit of the Constitution." *Id.* In a related case, the Court stated that education for citizenship is part of the parents' role: "[t]he fundamental theory of liberty upon which all governments in this Union repose excludes any general power of the State to standardize its children." *Pierce v. Society of Sisters*, 268 U.S. 510, 535 (1925). In essence, the Court held that the determination of a child's social traits are a matter for the parents to decide. A strong argument could similarly be made that a child's genetic traits should likewise be determined by the parents.

161. *Casey*, 505 U.S. at 859 (citations omitted).

162. *See, e.g., Schmerber v. California*, 384 U.S. 757, 771-72 (1966).

circumstance, if any, in which the patient's wishes may be overridden presupposes a major bodily invasion. We express no opinion with regard to the circumstances, if any, in which lesser invasions might be permitted"¹⁶³

The recognition that some interventions are too insignificant to trigger constitutional scrutiny has been introduced into abortion law through the undue burden standard.¹⁶⁴ Prior to the recent *Casey* decision, a woman may have been able to refuse mandatory genetic testing under the decisions of *City of Akron v. Akron Center for Reproductive Health*¹⁶⁵ and *Thornburgh v. American College of Obstetricians and Gynecologists*.¹⁶⁶ These cases recognized that the provision of information is not a value-free act. People have a right to waive information; for example, they can decide to waive the presentation of health care information before they consent to treatment. In these cases, the U.S. Supreme Court recognized that the presentation of information in the context of reproductive decisions can coerce an individual to make a particular decision. Laws requiring women to be given information that tended to pressure them not to have abortions were struck down as unconstitutional. In *Akron*, the Court struck down statutory provisions that required physicians to give speculative information, such as the characteristics of the fetus, including its ability to feel pain, and provisions that required physicians to present "a 'parade of horrors,' intended to suggest that abortion is a particularly dangerous procedure."¹⁶⁷ In *Thornburgh*, the Court held that the required disclosure of even medically accurate and objective information could be unconstitutional because it tended to influence a person's reproductive decision.¹⁶⁸ The Court said: "The States are not free, under the guise of protecting maternal health or potential life, to intimidate women into continuing pregnancies."¹⁶⁹ Under the logic of these cases, giving women information about their fetuses' genetic status would have been impermissible as coercing some women toward abortion.

163. *In re A.C.*, 573 A.2d 1235, 1246 n.10 (D.C. Cir. 1990). See also *In re Baby Boy Doe*, 632 N.E.2d 326, 333 (Ill. App. Ct. 1994).

164. *Casey*, 505 U.S. at 874.

165. *City of Akron v. Akron Ctr. for Reprod. Health*, 462 U.S. 416 (1983).

166. *Thornburgh v. American College of Obstetricians & Gynecologists*, 476 U.S. 747 (1986).

167. 462 U.S. at 444 n.34, 445.

168. 476 U.S. at 762-63.

169. *Id.* at 759.

However, *Casey* introduced the test of whether a state statute creates an undue burden on the woman's decision. *Casey* upheld a requirement that physicians inform women of the nature of the abortion procedure, the health risks associated with the procedure and with childbirth, and the probable gestational age of the fetus.¹⁷⁰ The Court held that providing truthful information during pregnancy is compatible with the state's interest in protecting potential life throughout pregnancy.¹⁷¹

Nevertheless, one could argue that mandating fetal cell sorting infringes upon a woman's constitutional rights. Fetal cell sorting entails not just the provision of information (as in *Casey*), but an intervention—a blood test—to obtain that information. Although some courts have viewed blood tests as insignificant, genetic blood tests to determine genetic information may be treated differently. The federal government, for example, treats them as being different. While other blood tests used in federally funded research may be exempt from full Institutional Review Board review, since they are viewed as entailing “minimal risks,”¹⁷² the federal Office of Protection from Research Risks has indicated that genetic tests present greater than minimal risks due to psychological risks and social risks including “stigmatization, discrimination, labelling, and potential loss of or difficulty in obtaining employment or insurance.”¹⁷³ In addition, precedents such as *Casey* are inappropriate since most genetic disorders capable of being diagnosed during pregnancy are untreatable, and thus the impact of learning this information is not likely to result in the protection of potential life, but the termination of the pregnancy.

2. *The State's Interest*

With respect to constitutionally-protected fundamental rights, state restrictions have been upheld if they furthered a compelling state interest in the least restrictive manner possible. A federal district court, in *Lifchez v. Hartigan*, has held that a similar test should be employed with respect to state restrictions regarding prenatal genetic testing.¹⁷⁴ A state seeking to uphold a law mandating fetal cell sorting might claim that it has a compelling interest in furthering the birth of

170. *Casey*, 505 U.S. at 882-83.

171. *Id.*

172. See 45 C.F.R. § 46.110 (1991).

173. OFFICE FOR PROTECTION FROM RESEARCH RISKS, NATIONAL INSTITUTES OF HEALTH, PROTECTING HUMAN RESEARCH SUBJECTS: INSTITUTIONAL REVIEW BOARD GUIDEBOOK 5-45 (1993).

174. *Lifchez v. Hartigan*, 735 F. Supp. 1361, 1376 (N.D. Ill. 1990).

healthy children. But mandating prenatal screening does not further that interest. Since treatment for the screened-for disorders generally is not available, the effect of testing is to encourage abortion and to deter carriers from having further children, rather than to promote the birth of healthy children.¹⁷⁵ Because the state cannot show that the policy improves the health of potential children, the state is likely to have to fall back on the argument that such a policy advances a state interest in saving money by discouraging the birth of children with genetic disorders. However, a state interest in saving money should not override fundamental rights.¹⁷⁶ In particular, the burden on the state in caring for children has not been seen to be a compelling interest in other contexts. For example, in *People v. Dominguez*,¹⁷⁷ a pregnant, unmarried woman with two children was convicted of second-degree robbery. As a condition of her probation, the trial judge required that she not become pregnant without being married, so that state taxpayers would be spared the burden of caring for illegitimate children. The appellate court reversed, finding that while "[t]he burden upon the taxpayers to maintain illegitimate children at the public expense is a grave problem . . . a court cannot use its awesome power in imposing conditions of probation to vindicate the public interest in reducing the welfare rolls by applying unreasonable conditions of probation."¹⁷⁸ Moreover, it is unclear that the state could prove, in a cost-benefit analysis, that screening would actually save a sufficient amount of money to justify the infringement of individual choice. While aborting a fetus with cystic fibrosis, for example, may save society the costs of rearing that child, the overall costs of screening and providing necessary counseling and other services for all pregnant wo-

175. The outcome of the constitutional analysis would change very little even if treatment were available. If the disorder at issue could be treated after birth, then testing the newborn infant would be a less restrictive alternative with respect to the woman than prenatal testing. If the disorder needed to be treated while the fetus was in utero, the case for prenatal testing would be stronger but would still fail, since the treatment would likely be more intrusive than the blood test and would invade the woman's bodily integrity and interfere with her right to privacy. Since the woman would be able to refuse the treatment under *In re A.C.*, 573 A.2d 1235, 1261 (D.C. Cir. 1987), and *In re Baby Boy Doe*, 632 N.E.2d 326, 334 (Ill. App. Ct. 1994), the state could not show that the testing would accomplish the end of assuring that the fetus was treated.

176. In U.S. Supreme Court cases, the goal of protecting the public treasury has not been found to be superior to that of protecting individual rights. A person's right to travel is recognized as more important than the drain on the welfare system of the state to which he moves. See, e.g., *Edwards v. California*, 314 U.S. 160, 165 (1941).

177. 64 Cal. Rptr. 290 (Cal. Ct. App. 1967).

178. *Id.* at 294.

men might exceed the cost of rearing the few affected children whose birth the state seeks to prevent.¹⁷⁹

C. Protections Against De Facto Mandatory Testing

Even if the government does not adopt a law mandating fetal cell sorting, some physicians may undertake such testing on the woman without her voluntary, advance, informed consent. Despite the clear common law precedents giving competent adults the right to refuse medical intervention and protecting the privacy of medical information, some physicians currently undertake genetic tests on pregnant women's blood without their consent. At a recent meeting at an elite medical school, I asked the physicians why they engage in such a practice. In that instance, they indicated that they did not ask pregnant African-American women for their consent for sickle cell carrier screening using the women's blood because 1) the women "wouldn't understand;" 2) the testing was done for the women's benefit; and 3) other types of testing are performed without consent during pregnancy. Each of these reasons is open to challenge.

The rationale that the women would not understand ignores the fact that some people do have a high level of understanding about genetic testing or genetic disease because they have relatives affected with a genetic disorder or because they are members of an ethnic subpopulation in which genetic testing or genetic disease is common. For example, sickle cell anemia testing has been widely publicized and discussed within the African-American community; it would be unusual for an African American woman not to know someone who has been tested.

Although there is some evidence that members of the general public who have not had prior experience with genetic disease do not understand the significance of genetic tests, education through a brochure, video, health provider, or some combination can ensure that more individuals have an adequate understanding of the nature of a particular genetic disease, its pattern of inheritance and the meaning of test results.¹⁸⁰ The existing legal doctrine of informed consent would seem to require such an effort. There are also sound policy

179. With respect to cystic fibrosis, "[i]t has been estimated that if a national [carrier] screening program were introduced, it would cost \$2.2 million for each case of cystic fibrosis avoided." Benjamin R. Sachs & Bruce Korf, *The Human Genome Project: Implications for the Practicing Obstetrician*, 81 *OBSTETRICS & GYNECOLOGY* 458, 459 (1993).

180. Ellen Wright Clayton et al., *Teaching About Cystic Fibrosis Carrier Screening by Using Written and Video Information*, 57 *AM. J. HUM. GENETICS* 171, 177 (1995).

reasons to encourage the medical community to make efforts to ensure that patients are informed and do understand genetic testing. The massive efforts to map and sequence the human genome (financed with over \$3 billion of taxpayer money) will lead to an increasing array of genetic diagnostic tests. People will need to understand genetic information in order to decide whether to undergo such tests in order to make decisions about health care, reproduction, and lifestyle.¹⁸¹

Secondly, the fact that prenatal testing is ostensibly done for a woman's benefit does not obviate the need for informed consent. The case law is clear that people have a right to refuse medical intervention, even if such intervention will benefit them.¹⁸² Moreover, it is unclear exactly what the purported "benefit" to the woman is. If the woman is a carrier of sickle cell anemia, she is healthy herself. She has a one-in-four chance of having a child with sickle cell anemia if she reproduces with another carrier, and so it may be beneficial to let her know about the risk in case she would like to have her partner tested or have prenatal testing on the child and abort an affected fetus. But that is far from universally considered a benefit. In some instances, the woman may already know her partner's test results. If he is negative for the gene for sickle cell anemia or other hemoglobinopathies, there will be no chance that the fetus will be affected. And even if both partners are carriers, the one-in-four chance materializes, and the fetus is affected, the couple most likely will not want to abort. In a study where women's blood was analyzed for sickle cell carrier status without their consent, *none* of the couples aborted when they later underwent amniocentesis and learned that their fetus was affected.¹⁸³ So it is hard to see a definite "benefit."

Related to the argument that this involuntary testing benefits women is the argument that testing is routinely done on pregnant women without their consent. Putting aside the question of whether *any* intervention should be done in the pregnancy context without the woman's consent, there are reasons why traditional testing (such as that for gestational diabetes or placenta previa) is distinguishable from ge-

181. Certain genetic diseases will only manifest if a person with a particular gene comes into contact with certain environmental stimuli. In the future, some individuals may choose their foods, jobs, and the climate in which they live based on their genetic types.

182. See, e.g., *In re Osborne*, 294 A.2d 372, 375 (D.C. Cir. 1972). See also *In re Baby Boy Doe*, 632 N.E.2d 326, 330 (Ill. App. Ct. 1994) (holding that "the right to refuse treatment does not depend upon whether the treatment is perceived as risky or beneficial to the individual" and citing *In re Estate of Longeway*, 549 N.E.2d 292, 297 (1989)).

183. Rowley et al., *supra* note 15, at 157.

netic testing. Standard, nongenetic tests are often performed in order to plan treatment of the fetus. Genetic testing often reveals that the fetus is untreatable, so the "benefit" is the possibility of abortion. There is a much wider range of moral and personal opinion about the advisability of abortion than about treatment of fetuses or newborns. A woman understandably may not want information about her genetic status or the fetus' genetic status, because she does not intend to abort or she does not want to risk genetic discrimination against her or her future child.¹⁸⁴ Standard tests generally are also performed to identify transitional, pregnancy-related conditions, whereas genetic information revealed about a woman or her fetus is permanent and immutable in character. If a woman learns through unasked-for prenatal testing that she has a genetic defect, that information is now in her record. Her health insurance rates may go up, or the information may make her uninsurable or unemployable.¹⁸⁵

Just as the state should not mandate fetal cell sorting, neither should physicians mandate or coerce such testing. The profound impact of genetic information necessitates new policies to ensure that those women who undergo prenatal testing do so in a voluntary and informed way. Such testing should never be performed without the pregnant woman's advance, informed consent. Before testing, she should be informed of the disorders for which her fetus is being tested, whether they are treatable, whether she will be faced with a decision about whether to abort the fetus, and whether the test will reveal information about her partner as well. In addition, she should be informed of the potential psychological, social, and financial risks that can result from the identification of genetic information, and their implications for her, her partner, the resulting child, and other family members.

184. There are financial consequences as well. The women who are tested for sickle cell anemia without their knowledge are paying for a test that they may not want. One research study on the topic found that when women who were tested without their knowledge discovered that they were carriers and then learned, through further testing, that they were carrying a fetus with sickle cell anemia, not a single woman aborted her fetus. Rowley et al., *supra* note 15, at 157. Since no woman changed her reproductive behavior based on the test, each woman at least should have been asked whether she would find it useful *before* she was tested and charged for the service.

185. Such a concern was raised by a pregnant woman at a Cystic Fibrosis Association annual meeting I attended. She had participated in a free research protocol in which she was not informed in advance of the possibility that the study might identify her as having two mutant cystic fibrosis genes. When she was so diagnosed, she was concerned that she would lose her insurance.

Conclusion

Genetic tests are rapidly entering into medical practice, becoming part of the medical standard of care virtually overnight. The potential psychological, social, and financial risks of testing are rarely considered. When these risks are analyzed in detail, a strong argument can be made that even genetic tests such as fetal cell sorting, which entail minimal physical risks, should be performed only with the woman's voluntary informed consent.