Making the Grade: Testing for Human Genetic Disorders

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The human applications of modern biotechnology are at once the most exciting and the most troubling uses of this new technology. Human gene therapy promises to be an important medical advance.¹ By manipulating the genes that are causally linked to disease, we will not only be able to treat diseases for which there is presently little or no means of treatment (e.g. sickle-cell anemia² and Lesch-Nyhan disease³), but we will also be able to prevent hereditary diseases from being transmitted to offspring.

There are two forms of human gene therapy aimed at the correction of a defect or disorder — somatic cell therapy and germ line therapy.⁴ In somatic cell therapy, only the cells causally connected to the disease of the affected individual are treated (for example, the bone marrow cells are treated if the disorder involves blood cells).⁵ In germ line therapy, the reproductive cells themselves are treated, thus preventing defective genes from being transmitted to an individual's offspring.⁶ While scientists are quick to point out that many technical problems must be resolved before even clinical trials on

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1. For a good overview, see OFFICE OF TECHNOLOGY ASSESSMENT, U.S. CONGRESS, HUMAN GENE THERAPY: BACKGROUND PAPER (1984) [hereinafter HUMAN GENE THERAPY].
2. Sickle-cell anemia is a recessive blood disorder that occurs most frequently in blacks, but also in people from the Mediterranean Basin. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, SCREENING AND COUNSELING FOR GENETIC CONDITIONS 13, 20-23 (1983) [hereinafter GENETIC SCREENING].
4. See HUMAN GENE THERAPY, supra note 1, at 6.
5. See id. at 55-59.
6. Id. at 59-61.
each of these proposed therapies could begin, one might nevertheless get the impression that human gene therapy is the goal of medical biotechnology.

Although human gene therapy might be the public’s hope for medical biotechnology, it also gives rise to some of the public’s deepest fears concerning this new technology. One of the most frequent concerns raised by critics is that gene therapy will lead to eugenics, where eugenics is understood to be the practice of improving the human race by giving those with superior qualities a better chance of reproducing. Once these gene therapy techniques are developed, they will not only enable us to deal with conditions that are universally recognized as diseases or disabilities, but they will also enable us to enhance other conditions not normally considered diseases. While enabling short people to have tall children hardly amounts to generating a race of supermen, it does raise some important issues. What are the moral constraints on the manipulation of the genetic endowment of future generations? If some genetic manipulations are wrong, on what basis can we distinguish them? Is the distinction between correction and enhancement a sharp one, or is it so vague that once the technology is in place, enhancement therapies of all sorts will be inevitable?

Despite the attention that has been given to these issues, human gene therapy may not be as significant an application of medical biotechnology as the discussions would lead one to believe. The technology of genetic testing is essential to germ line therapy, since a defective gene in an abnormal embryo or gamete cannot be corrected without first being identified. Moreover, as a report of the Office of Technology Assessment points out, “Germ line gene therapy may never be widely practiced because treatment of abnormal embryos and gametes offers little advantage over selection of normal ones.”

7. See, e.g., id. at 56.
8. See M. LAPPE, BROKEN CODE: THE EXPLOITATION OF DNA 122 (1984). Dr. James Wyngaarden, the Director of the National Institutes of Health (NIH), has noted that “exaggerated expectations as well as exaggerated fears are very common.” Id.
9. See, e.g., Proposal to Modify Section III-A-4 of the NIH Guidelines, 51 Fed. Reg. 23210, 23210-11 (1986) (proposed by Committee for Responsible Genetics). For a good history of eugenics, see D. KEVLES, IN THE NAME OF EUGENICS: GENETICS AND THE USES OF HUMAN HEREDITY (1985). Some commentators have redefined “eugenics” narrowly, such that the use of germ line therapy to confer enhancements need not always constitute eugenics. See, e.g., Anderson, supra note 3. The only apparent reason for this tantaduous redefinition is to distance enhancement therapy from the associations eugenics has had with the Nazi movement.
10. HUMAN GENE THERAPY, supra note 1, at 21.
In other words, gene therapy is likely to involve significant risks when practiced on embryos or gametes. As a result, a couple may choose to terminate a pregnancy and try again once a prenatal genetic disorder has been diagnosed, unless they have a fertility problem or consider abortion unacceptable.

If this assessment is correct, then the ethical and public policy issues surrounding genetic testing take on greater importance. The purpose of this Article is to point out the more distinctive and troubling ethical issues raised by genetic testing. The first of these issues are issues of knowledge — what information do these tests provide? The second are issues of access — who may have access to this information? The third are issues of actions — what actions ought to be based on this information? Of course, many of these issues are not unique to genetic testing. Genetic testing of humans is only one type of medical testing, which also includes blood, drug, and HIV antibodies testing. Consequently, several of the issues raised by genetic testing are also linked with more general phenomena and procedures. Some aspects of genetic testing, however, also raise issues unique to medical biotechnology.

I. ISSUES OF KNOWLEDGE

To begin with, the crucial issues concerning the reliability of genetic testing must be acknowledged. Enormous progress has been made in a relatively short period of time in developing techniques to read human genetic material and linking particular genes with various diseases. Nevertheless, these techniques are not flawless. It would be unrealistic to assume that any genetic test is guaranteed to be free of error — free of false positives or false negatives. The

11. Id. Risks involved in treating early embryos arise from the necessity of diagnosing an abnormality without disrupting any of the small number of cells that have formed. Id.
12. See infra notes 15-33 and accompanying text.
13. See infra notes 34-41 and accompanying text.
14. See infra notes 42-62 and accompanying text.
15. See generally Office of Technology Assessment, U.S. Congress, Technologies for Detecting Heritable Mutations in Human Beings (1986) [hereinafter Detecting Heritable Mutations] (providing a broad overview of presently available diagnostic techniques); Caskey, Disease Diagnosis by Recombinant DNA Methods, 236 Sci. 1223 (1987) (discussing prenatal diagnosis of both sickle-cell anemia and AAT deficiency made possible by RFLP association with the disease alleles, and discussing in situ hybridization of tissues or cultured cells which made diagnosis of acute and chronic herpes infection possible).
16. See Detecting Heritable Mutations, supra note 15, at 3; see also Caskey, supra note 15, at 1228.
17. A "false positive" occurs when the test claims that an individual has a given condition when in fact he or she does not.
18. A "false negative" occurs when the test claims that an individual does not have a given condition when in fact he or she does.
possibility of a mistaken diagnosis raises questions regarding the distribution of the risks and benefits of an imperfect testing procedure. Nevertheless, this Article assumes, for the purposes of this discussion, that the tests are flawless, since it is important to look at the ethical issues arising from the success of genetic testing. These ethical considerations point to deeper problems that cannot be resolved merely by improving the technology.

There are three types of individuals to whom the technology of genetic testing could be applied: (1) individuals who have a genetic disease; (2) individuals who, although they do not have an inheritable disease, are carriers of such a disease, and (3) individuals who have a genetic disposition or “susceptibility” to a specific disease.

A good example of the first type of individual is one suffering from Huntington’s disease, an autosomal dominant disorder in which the person undergoes fatal neurological deterioration. This disease is usually not apparent until the individual is more than thirty-five years of age. Although there is at present no cure for Huntington’s disease, early detection could be an important element in any treatment program. Furthermore, even if there is no available cure, some people may want to know whether they have the disease in order to plan their lives accordingly and prepare themselves, their family, their friends, and others for the eventual onset of the symptoms.

19. See Genetic Screening, supra note 2, at 75-86 (discussing the cost-benefit analysis used within an ethical framework to determine which groups are at sufficiently high risk to warrant testing). The Report recommends that screening be separately determined for different sub-populations since the benefits and harms from false positives and false negatives will vary with the incident of disease within a group. Id. For example, physicians commonly suggest amniocentesis only to women age thirty-five or older, because such women have an increased risk of bearing a child with a chromosomal defect, while counseling women younger than age thirty-five that amniocentesis is unavailable or inappropriate. Id. at 75-81.

20. Although being a carrier is different from having the disease, this difference has not always been duly noted, as the history of sickle-cell anemia legislation unfortunately reveals. See P. Reilly, Genetics, Law, and Social Policy 65-67 (1977).


23. See Huntington’s Disease: Some Prefer Not to Know, Med. World News, April 5, 1974, at 743 (hereinafter Huntington’s Disease) (discussing a National Institute of Neurological Diseases and Stroke survey in which 23% of the respondents at high risk for Huntington’s disease indicated that they might not be willing to submit to a safe screening test
Examples of the second type of individual who could benefit from genetic screening are those who are carriers of sickle-cell anemia or Tay-Sachs disease. If an individual is heterozygous, i.e. only one of the two alleles of the relevant gene is defective, then that individual will not have the disease. The individual will, however, be a carrier, and the defective gene will be passed on to his or her offspring. If both parents are carriers, then there is a significant probability that some of their offspring will inherit a pair of defective alleles, resulting in the disease. Consequently, an individual may want to know whether he or she is a carrier of a genetic disease since that knowledge might affect reproductive decision-making. Such information could thus plainly form an important part of prenatal counseling.

Individuals with a genetic susceptibility to a specific disease constitute the third group to whom genetic testing could be applied. The interests in the genetic testing of those who are predisposed to specific diseases are considerable, because, according to some researchers, the detectable susceptibilities are not limited to rare afflictions but also include more common diseases such as certain forms of cancer. However, in contrast to the other two applications of genetic screening, it is unclear what it means to detect a genetic susceptibility to a particular disease.

Individuals with a genetic susceptibility will not necessarily manifest, or even be likely to manifest, the particular disease.

if one were to be developed).

25. See supra note 2 (defining sickle-cell anemia).

26. Tay-Sachs disease is a metabolic disorder that usually results in death during early childhood. It is found chiefly among children of Jewish descent. See DETECTING HERITABLE MUTATIONS, supra note 15, at xii; see also GENETIC SCREENING, supra note 2, at 13, 18-20 (discussing the development of a genetic test for Tay-Sachs).

27. This occurs either because the defective allele, and therefore the disease, is recessive, as in the case of Tay-Sachs, or because the product of the other allele is sufficient for the health of the individual, as in the case of sickle-cell anemia. See GENETIC SCREENING, supra note 2, at 105-15 (providing a brief explanation of patterns of inheritance). Every gene has two copies; one is inherited from the mother and one from the father. These two genes are called alleles and occupy identical sites on a chromosome. Id. at 105, 110-11. When the two alleles are identical and defective, the individual is homozygous and will manifest the defect or disease. Id. at 111. When the two alleles are different, alternate forms of the same gene, the individual is heterozygous. Id.; see also HUMAN GENE THERAPY, supra note 1, at 13-17 (providing a general explanation of the inheritance of diseases).

28. GENETIC SCREENING, supra note 2, at 111-12.

29. Id. When both parents are carriers, each child they produce together has a 25% chance of inheriting the disease itself, a 50% chance of being a carrier, and a 25% chance of not having the abnormal gene at all. Id. at 111.

Rather, their condition is such that if they were in certain environments, or maintained certain lifestyles, then they would, or would be likely to, manifest that disease. For example, a genetic susceptibility to lung cancer might mean that the individual's genetic makeup is such that if he smokes or is in smoke-filled environments for an extended period, then he will be likely to develop lung cancer.

This formulation of genetic susceptibility, without further elaboration, is problematic. If the formulation is not confined within definite parameters, the classification of genetic susceptibility will be rendered useless. Almost any genetic makeup could fit the pattern of revealing a genetic susceptibility to any disease. If there is some environment or lifestyle in which an individual could contract a particular disease, then he would fit within this definition of genetic susceptibility. For example, people who are heterozygous for the sickle-cell trait have some immunity to malaria. Therefore, one could say that the genetic makeup of people who do not have the sickle-cell gene is such that if they were in certain environments (so-called "malaria-infested" environments), then they would be likely to develop malaria. However, it cannot be seriously maintained that people who are not carriers of sickle-cell anemia have a genetic susceptibility to malaria.

An alternative method of analyzing this definitional problem is by noting that "susceptibility" is fundamentally comparative, formulated in terms that person A is more susceptible than person B. The positive claim that someone has a susceptibility to a particular disease merely means that he is more susceptible to that disease than some specified standard. What is this standard or baseline?

A simple response would be to characterize this standard in terms of the "normal" genetic makeup — if an individual has a higher probability of contracting a specific disease in a given environment than someone with a normal genetic makeup, then that individual has a genetic susceptibility to that disease. The difficulty with this simple response is in articulating what "normal" means. "Normal" is not a scientific term. Modern evolutionary biology does not recognize anything that would count as the "normal genetic makeup" for a species.

32. See E. Mayr, Evolution and the Diversity of Life 26, 28 (1975) (contrasting typological/essentialist thinking, in which "the type (eidos) is real and the variation an illusion," and population thinking, in which "the type (average) is an abstraction and only the variation is real."); see also Sober, Evolution, Population Thinking, and Essentialism, 47
Setting the baseline for susceptibility requires a decision which will reflect the significance of attributing to an individual a "genetic susceptibility" to a disease. If an individual contracts a disease for which he or she does not have a susceptibility, there is a presumption that the disease is due to an "unhealthy" environment. If, however, an individual contracts a disease for which he does have a susceptibility, then there is a presumption that the disease is due in part to his genetic makeup.\textsuperscript{33} Since these presumptions can significantly affect public policy regarding the prevention and control of the disease, setting the baseline for genetic susceptibility will have important ethical and social implications.

While there is little chance that individuals who are not carriers of sickle-cell anemia will be classified as genetically susceptible to malaria, the prospects of developing tests for what might be called "genetic susceptibilities to cancer" require a clear definition of the term. If some individuals are to be classified as members of a high-risk group, the classification must be precise in order to avoid unnecessary fears. Unfortunately, there has been little effort in this direction.

\section*{II. Issues of Access}

Who should have access to the information derived from genetic screening? A good first answer acknowledges the value of confidentiality — only the person being tested, and anyone else he or she explicitly authorizes, should have access to this information. There are problems, however, with this simple answer.

One might wonder whether the individual being tested should

\textsuperscript{PHIL. SCI. 350 (1980) (critiquing Mayr's reasons for rejection of essentialist theory). As Sober has stated, "No phenotypic characteristic can be postulated as a species essence . . . . Similar considerations show that no genotypic characteristic can be postulated as a species essence . . . ." Id. at 379-80.}

\textsuperscript{33. This same point can be made in terms of causation. Every disease is the result of environmental and genetic factors. To claim that some diseases are not the result of environmental factors would be to make the unverifiable claim that such diseases will always be untreatable, since treatment consists of a certain kind of environmental intervention. To claim that some diseases are not the result of genetic factors would be to make the absurd claim that such diseases do not depend upon biology. Nevertheless, we do usually draw distinctions between environmental and genetic factors, calling some "the cause" and others "the background conditions." This distinction is not dictated as much by the facts as by features of the context of the inquiry, the interests being pursued, or some other contextual consideration. For a general discussion of this point, see H.L.A. HART & A. HONORÉ, CAUSATION IN THE LAW 10-12, 31-38 (1978). The problem of defining genetic susceptibility can thus be seen as the problem of drawing the distinction between the cause and the background conditions of a disease. Put this way, the issues regarding responsibility may perhaps become a bit clearer.}
be informed if the test reveals that he or she has a condition that is untreatable. Since such knowledge could be psychologically devastating, some may consider this knowledge undesirable. Huntington's disease is a case in point. A significant number of people would apparently rather not know they are afflicted by the disease.\textsuperscript{34} Be that as it may, this situation is not significantly different from many others where the diagnostic techniques are far more advanced than the available treatment regimens. Given the importance our society attaches to individual autonomy, this sort of paternalism — denying people access to their own test results — would not appear to be morally acceptable.\textsuperscript{35}

A more difficult problem arises from the recognition that other people could arguably have a legitimate interest in, if not a right to, that information. If the information indicates that some of the patient's relatives might have a genetic disease, they could assert that their legitimate health concerns entitle them to the test results. Furthermore, the patient's relatives could claim that this genetic information is important to their reproductive decision-making. For example, a sibling might decide not to have children if the tests revealed a serious genetic disease. Additionally, the state might claim a right to know in the interests of public health. Finally, employers and other parties could claim that the genetic information is essential to informed business decisions, such as the consideration of whether the hiring or promotion of an individual is economically justifiable given his or her genetic makeup.

If the individual does not want or has not authorized these parties access to his or her genetic information, then a conflict arises between the rights of the individual being tested, e.g. the right to privacy, and the value of maximizing the welfare of the other parties involved, e.g. the health concerns of relatives. The difficult question of access therefore concerns the resolution of this conflict. Strictly speaking, this conflict need not be explicit and could be avoided in the case of genetic testing by making the availability of such tests contingent on counseling. Not only would mandatory counseling explain the significance of what the tests might reveal, but it could also be used to secure the patient's agreement that others may have a legitimate interest in the information and can therefore be granted

\textsuperscript{34} See Huntington's Disease, supra note 24, at 741.

\textsuperscript{35} For a good discussion of paternalism, see Gert & Culver, Paternalistic Behavior, 6 \textit{PHIL. & PUB. AFF.} 45 (1976).
access to the test results. Indeed, since there is no moral right to genetic testing, such tests could be made contingent on the patient agreeing to specified limitations on his claim of confidentiality. Nevertheless, there is still the problem of how society determines which parties have interests sufficient to warrant the conditioning of genetic testing on a grant of access to them.

These issues of access can be illustrated through the use of various hypotheticals. In the first type of case, where the prevention of serious harm to others from a treatable disease is the distinctive concern, some would argue that the individual’s confidentiality can (perhaps even must) be breached. Surely, it is difficult to sustain one individual’s right of privacy against the clear benefit of preventing serious harm to identifiable persons. The situation is, of course, not so clear when the harm is less than “serious.” In any event, insofar as one accepts the proposition that confidentiality can be overridden in the interest of preventing harm to third parties, a requirement that genetic testing be contingent on the acknowledgement of those interests is justifiable.

The second type of case, where informed reproductive decision-making of the patient’s relatives is at issue, seems to be quite different, since no actual person’s health is at stake. Furthermore, if a couple is sufficiently concerned about the possibility of having children with birth defects, they should undergo genetic testing themselves. The patient’s genetic information is not a unique source of the information that would be relevant to his relatives’ reproductive decisions.

Nevertheless, the considerations underlying the first case, that is, preventing harm to relatives from treatable conditions, apply here as well. There is no relevant moral distinction between preventing harm to actual identifiable persons and preventing harm to future

36. Genetic testing conditioned on the patient’s agreement to receive counseling and on his or her consent to access by relatives who may be affected by the results is in fact the recommendation of the President’s Commission. See Genetic Screening, supra note 2, at 43-44. Since required counseling might discourage some people from being tested, the Commission acknowledges that such a requirement must be balanced against the severity of the disease in question. Id.

37. The distinction between a treatable disease and an untreatable disease is not precise, since such a determination turns not only on whether treatment is technically feasible, but also on matters of cost, availability, convenience, and acceptability of treatment.

38. See, e.g., S. Bok, Lying: Moral Choice in Public and Private Life 147-64 (1978) (discussing the competing values when professionals maintain confidentiality in the face of probable harm to others).
persons. Just as the individual’s genetic information is not a unique source of information relevant to reproductive decisions, it is similarly not a unique source of information relevant to the health concerns of the individual’s relatives. The individual’s relatives can always have themselves tested as well. The driving consideration is not uniqueness but urgency — if no other source of the information is likely to be forthcoming in time, then the information provided by the patient’s test results is unique for all practical purposes. Thus, if genetic testing is not widely performed, or if people generally see no reason to submit to genetic testing, the information is unique within the domain of reasonable expectations.

The situation is different, on the other hand, if the condition is untreatable, since a relative’s use of the genetic test results in informing his or her reproductive decision cannot prevent a harm. It may prevent a birth, but one would have to establish that the child’s life would be a life not worth living in order to argue that preventing the birth amounts to preventing a harm.

The third case, where a putative state claim of access to an individual’s genetic information is asserted in the interest of public health, rests on an analogy to contagious diseases. If a medical test reveals a serious contagious disease, then the interest in confidentiality should be rejected if breaking confidentiality is necessary to check the spread of the disease. The prevention of harm to third parties implicates those considerations which underlie the first case, only writ large. To be sure, the diseases that genetic testing would reveal are not “contagious” in the usual sense, but they can nonetheless be transmitted to later generations. They are “vertically contagious” rather than “horizontally contagious.”

There are, however, important differences. While measures such as quarantine can typically check the spread of harmful germs, only the most draconian measures to control reproduction could check the spread of harmful genes. Moreover, one of the standard calculations in population genetics is to show how slowly the frequency of a gene in a population will change. For example, if symptomatic individua-
als of a recessive trait do not reproduce, it would still take over fifty generations, approximately 1500 years, for the gene frequency to go down from two percent to one percent. If these are the time scales involved, then managing the quality or diversity of the genes in the population cannot be said to constitute a serious public health concern.

In any event, the crucial question is not whether the state should have access to the information, but what it can do on the basis of that information. The same holds true for the fourth type of case, which involves the distinctive concerns of employers. In both the government and employer access cases, the legitimacy of obtaining access to an individual's genetic information depends largely upon the legitimacy of the actions that will be based on that information. Few question the right of individuals to base their own health care or reproductive decisions on another individual's genetic information; rather, the issue is solely whether such people should be given access to such information. In the case of the state or employers, on the other hand, the situation is reversed. Questions regarding the propriety of actions based on genetic information determine the issue of access — if the actions based on genetic information are justified, then access to that information would also appear to be justified. The issue becomes one of actions rather than access. Consequently, further assessment of the third and fourth types of cases should be discussed in the context of issues of actions.

III. ISSUES OF ACTIONS

Clearly, the results of genetic screening can have an impact beyond the care and treatment of the individual tested. As previously indicated, genetic information can affect family planning and employment practices. Each of these areas raises several important ethical and public policy questions apart from those arising from genetic testing.

When a genetic test reveals that an individual has an inheritable disorder, he or she may, on the basis of this information, alter reproductive plans. As with issues of access, the discussion turns on whether the disease is treatable. If the disease is treatable, the individual may arrange for the appropriate pre- and post-natal care. In fact, some may argue that the individual has a moral or legal duty to

41. See id.
42. See supra note 37 and accompanying text.
arrange for such care. From this proposition, it would seem to be only a small step to argue that such tests should be mandatory. Such an argument might proceed by drawing a comparison with phenylketonuria (PKU) testing of neonates.

PKU is an autosomal recessive disease which can lead to mental retardation and other abnormalities in children. Early diagnosis and treatment, consisting merely of a change in the infant's diet, can successfully prevent all the clinical manifestations of the disease. Most states routinely test for PKU without seeking the permission of the mother. While this testing may therefore be considered mandatory, it does not violate anyone's informed consent. The mother's authority to consent on behalf of her child is not absolute, but rather is based on the assumption that she is the best judge and representative of the child's interests. If she refuses to consent to PKU testing, her authority to consent on behalf of the child is thereby undermined since she is not acting in the best interests of the child. Consequently, there is no need to seek her permission. In other words, the moral justification for this “mandatory testing” is that the child's health interests are so clearly served that it is reasonable to assume that when the infant becomes a competent adult, he or she will be glad to have been tested. A reasonable person would consent to PKU testing, and an infant plainly has no beliefs, plans, or projects that could be at odds with this standard.

While PKU testing might serve as a model for compulsory genetic testing, its utility as a model is limited. If the testing must be performed prenatally, then the mother's consent will become an issue, although the significance of this issue is not clear. Of course, the severity of the illness threatening the fetus and the intrusiveness of the procedure on the woman will be factors in determining whether


44. See generally P. Reilly, supra note 20, at 43-61 (discussing PKU screening laws); GENETIC SCREENING, supra note 2, at 12-15 (discussing the 1962 Massachusetts voluntary PKU screening program pilot test and subsequent adoption of similar legislation by 43 states).

45. GENETIC SCREENING, supra note 2, at 12.

46. Id. at 12-13.

47. See COMM. FOR THE STUDY OF INBORN ERRORS OF METABOLISM, NAT'L ACADEMY OF SCIENCES, GENETIC SCREENING: PROGRAMS, PRINCIPLES AND RESEARCH 56-59 (1975) (summarizing state statutes requiring PKU screening).

consent is required. In large part, however, the resolution of this matter will depend upon how our culture refines its understanding of parental responsibility in light of new technology.49

In the case of prenatal testing for a disease which is not treatable, the couple is faced with more difficult decisions. They might choose simply to forego reproduction, or, alternatively, decide that the woman should undergo selective abortions. For example, if one member of the couple has Huntington’s disease, then there is a twenty-five percent probability that any child they conceive will have the disease.50 Rather than choosing to forego reproduction, the couple could have the appropriate tests taken to determine whether their embryo has the disease and choose to abort the pregnancy if the tests are positive. This would enable individuals who have or are carriers of an inheritable disease to have healthy children.51

A couple’s decision to forego reproduction can be a difficult one, but few would claim that such a decision is morally objectionable. Some might argue, on the other hand, that it is morally irresponsible to give birth to children knowing that they will be handicapped.52 Such a position would require a showing that the child’s handicap would be so severe that its life would not be worth living. The appeal to general utilitarian concerns such as societal costs does not seem strong enough to support what would otherwise be viewed as an extremely paternalistic and meddlesome moral view which denies the level of privacy appropriate to family planning.

A decision to undergo selective abortions also raises several ethi-

49. At least two genetic technologies have made available to the parent the knowledge of whether the child will be born free of defects. See Shaw, supra note 43, at 76-78. Chorionic villi biopsy enables prenatal diagnosis of chromosomal and biochemical defects by obtaining fetal cells from the chorionic villi between the eighth and tenth weeks. Id. at 76 (citing Kolata, First Trimester Prenatal Diagnosis, 221 Sci. 1030 (1983)). Restriction fragment length polymorphisms are used to map the entire human genome. Id. at 77-78 (citing Botstein, White, Skolnick & Davis, Construction of a Genetic Linkage Map in Man Using Restriction Fragment Length Polymorphisms, 32 AM. J. HuM. GENETICS 314 (1980)). Since these tests provide the parent with vital information about the future of the child at a very early stage in the pregnancy, society may have to reconsider parental responsibility to the fetus.

50. See supra note 29 and accompanying text.

51. There are, of course, other options. Most notably, alternative methods of reproduction such as surrogate parenting and artificial insemination enable a couple to have healthy children. In order to appropriately focus on the issues raised by genetic screening, these options will not be discussed.

52. Such an argument assumes that the parents are fully prepared to care for a handicapped child. If they are not prepared, then one could plausibly argue that the decision to reproduce is the moral equivalent of child abuse.
cal issues apart from the issues raised by genetic testing.\textsuperscript{53} As genetic testing grows more sophisticated, the number of detectable fetal conditions will become larger, thus increasing the number of circumstances that could lead to a decision to abort a pregnancy. The result may be that some couples will abort a pregnancy not only when an untreatable disease is detected, but also when a merely undesired condition, such as the “wrong” gender or eye color, is detected. If aborting a fetus because it has Down’s Syndrome\textsuperscript{54} is morally acceptable and aborting a fetus because of its gender is morally unacceptable, where is society to place conditions such as dwarfism, myopia, or susceptibility to heart disease? Where is the line to be drawn?

The answer to this question will largely depend on societal views of the moral justification for abortion. Insofar as a woman’s moral right to an abortion is believed to derive from her right to bodily autonomy, considerations regarding her reasons for wanting an abortion should play no role. Her right would not be one of autonomy if it depended upon her reasons and motivations. Under an autonomy justification for abortion, there is no line to be drawn.

If, on the other hand, society does not accept this autonomy justification, there will be a need to draw a line, and our conception of parental responsibility will determine where the line will be drawn. Simply drawing the line around untreatable diseases will not work. Not only is the distinction between treatable and untreatable diseases vague, it also embodies value judgments regarding treatment and cost priorities.\textsuperscript{55} It is unlikely that these could be rationally balanced without first presuming a conception of parental responsibility.

Finally, it is necessary to examine actions based on the results of testing for genetic susceptibilities. Conceptual problems and value claims in any statement of genetic susceptibility have previously been noted.\textsuperscript{56} A claim that an individual has a “genetic susceptibility” to a disease suggests that it is that person’s genetic makeup, rather than his or her environment, which is responsible for the individual being at risk. Such a characterization goes beyond the mere

\textsuperscript{53} See generally Feinberg, Abortion, in Matters of Life and Death 183 (T. Regan ed. 1980) (discussing the ethical issues in the decision to undergo selective abortions).
\textsuperscript{54} Down’s Syndrome is a congenital chromosomal abnormality in which the individual is born with an extra twenty-first chromosome. Holmes, Congenital Malformations, in 1 Cecil Textbook of Medicine, \textit{supra} note 23, at 144, 145. The extra chromosome comes from the mother 75\% of the time. \textit{Id}.
\textsuperscript{55} See \textit{supra} note 37 and accompanying text.
\textsuperscript{56} See \textit{supra} notes 30-33 and accompanying text.
biological facts and implicates cultural norms and conventions.

The difficulties inherent in a characterization of genetic susceptibility must be considered when examining an employer's use of genetic information. The basic question with regard to such a use is whether an employer may rightfully base hiring and promotion decisions on genetic information, or whether this practice would constitute unfair discrimination.

The discussion should begin by distinguishing between two kinds of anti-discrimination arguments — feature-based arguments and category-based arguments. According to a feature-based argument, there are certain general human features or traits such as race or religion that are morally irrelevant. Unfair discrimination consists in hiring or promotion decisions based on such features. Hiring practices should, for example, be "color blind." According to a category-based argument, there are certain classes of people that society believes need special protection, typically because society acknowledges past injustices to that class of individuals. Unfair discrimination under a category-based argument consists not in an appeal to irrelevant features, but rather in an appeal to any factor which yields the same result as discriminating against a protected class of people. Thus, discriminating against carriers of sickle-cell anemia would be unfair discrimination since that action would have largely the same effect as discriminating against blacks.57

Discrimination against individuals who have a genetic susceptibility to a disease does not clearly fall under either of these schemes. At present, ascriptions of genetic susceptibility are just too vague and indeterminate. Depending upon the disease and the standard selected, the class of individuals with a particular genetic susceptibility could be identical to an antecedently identified protected class, and discrimination against them would thus be unfair. However, this need not be the case. Without an explicit and adequate definition, anyone can be classified as genetically susceptible to disease.58 Moreover, the feature of genetic susceptibility is not obviously an irrelevant factor in the safe performance of a job.

Some people have denied the difficulties inherent in classifying

57. See Genetic Screening, supra note 2, at 20 (discussing the high percentage of sickle-cell carriers in the black population). Another way the feature-based and category-based arguments differ is in their position on affirmative action. A feature-based approach would see little justice in a affirmative action policy, whereas a category-based approach could easily construe such policies as part of the definition of protection.

58. See supra note 31 and accompanying text.
an individual as genetically susceptible to a disease, arguing that an individual with a genetic susceptibility should be regarded as a handicapped individual and therefore protected by the Rehabilitation Act of 1973.\(^5\) This position is not well reasoned, apparently resting on the claim that such individuals, while not presently impaired, \textit{may become impaired}.\(^6\) Since anyone who rides in an automobile may become involved in an accident and thus \textit{may become impaired}, automobile riders would be regarded as handicapped under this theory and accorded the same anti-discrimination protection. This result is plainly contrary to the goal of the Rehabilitation Act, since such a broad scope would jeopardize the special protection provided to those ordinarily thought of as handicapped. The truly handicapped would form only a small minority of this new classification.

Nevertheless, there is something morally objectionable about basing employment decisions on genetic information. Consider an employer with an extremely unsafe workplace, and a group of individuals with a genetic immunity to the significant hazard of the employer's workplace. The employer, learning of these individuals, decides not to render his workplace safe. Instead, the employer screens all employee applicants so that only those with the "right" genetic makeup are exposed to the hazards.

The morally objectionable aspect of this behavior is the employer's refusal to acknowledge the responsibility to maintain a safe workplace. Rather, the employer finds fault with the applicants—they have, in effect, a genetic susceptibility to that hazard. The central ethical concern regarding the use of genetic testing information by employers is therefore the issue of responsibility for workplace safety. Should a safe workplace be achieved by modifying the workplace itself or by screening, and therefore modifying, the workforce? There is no general answer to this question, since each case will depend upon the particular hazard involved, the workplace modifications that are technologically feasible, and the allocation of the re-

\(^{59}\) See, e.g., Rothstein, \textit{Employee Selection Based on Susceptibility to Occupational Illness}, 81 Mich. L. Rev. 1379, 1443 (1983) (discussing E.E. Black Ltd. v. Marshall, 497 F. Supp. 1088 (D. Haw. 1980), which held that a carpenter's apprentice who suffered from a "lower back anomaly" fell within the scope of the Rehabilitation Act); see 29 U.S.C. §§ 701-796 (1982 & Supp. IV 1986). Based on the reasoning employed by the \textit{Marshall} court, Professor Rothstein concluded that "to come within the purview of the Act an individual must have been rejected for a position for which he or she was qualified because of an impairment or perceived impairment that constitutes, for the individual, a substantial handicap to employment." Rothstein, \textit{supra}, at 1443.

\(^{60}\) See Rothstein, \textit{supra} note 59, at 1442.
sponsibility for workplace safety. 61

The cultural and value components inherent in claims of genetic susceptibility are again implicated here. 62 Information about individual genetic susceptibilities is not "out there," waiting to be discovered, with the ethical question being whether this information should be used. Rather, it is only after the specific questions about workplace safety and responsibility are settled that it is possible to determine whether an employee's contraction of a disease may be appropriately called a result of his or her "genetic susceptibility."

CONCLUSION

New technologies not only enhance our abilities but they also increase our responsibilities. These responsibilities extend not only to our actions but also to the concepts that inform our goals. The technology of genetic testing aptly illustrates this effect. This emerging technology forces society to define more precisely the concept of genetic susceptibility and the limits of confidentiality, as well as to confront the question of which actions may fairly be taken on the basis of this knowledge. While this Article has not surveyed all of the relevant issues, 63 some of the most salient ones have been pointed out. It should be noted, however, that in the analysis of these issues, it is essential to avoid compartmentalization. Some of these issues are subsumed within the more general issues arising from medical testing. Others are more properly seen as issues uniquely arising from a technology that has generated a substantial amount of public anxiety on its own. In any case, the time has come for society to examine and confront these issues. Otherwise, we will find ourselves in a "brave new world." 64

61. For an informed discussion of this subject, see N. DANIELS, JUST HEALTH CARE 140-79 (1985).
62. See supra notes 30-33 and accompanying text.
63. Two subjects not covered by this Article are the impact of genetic testing on insurance and on adoption. See Boutchee, Genetic Counseling and Medical Malpractice: Recognizing a Cause of Action for Wrongful Life, 8 T. MARSHALL L.J. 154 (1982) (discussing implications of genetic screening for medical malpractice and insurance); Clark, New Wine in Old Skins: Using Paternity-Suit Settlements to Facilitate Surrogate Motherhood, 25 J. FAM. L. 483 (1986) (discussing the role of genetic screening in surrogacy and adoption).
64. See A. HUXLEY, BRAVE NEW WORLD (1956).