

## Genetic Discrimination and the Law

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### Summary

The use of genetic tests can lead to genetic discrimination, discrimination based solely on the nature of an individual's genotype. Instances of the discriminatory uses of genetic tests by employers and insurance companies have already been reported. The recently enacted Americans with Disabilities Act of 1990 (ADA), together with other federal and state laws, can be used to combat some forms of this discrimination. In this article we define and characterize genetic discrimination, discuss the applicability of the various relevant federal and state laws, including the ADA, in the areas of employment and insurance discrimination, explore the limitations of these laws, and, finally, suggest some means of overcoming these limitations.

### Introduction

The remarkable advances in genetics during the past few years have already led to dramatic improvements in the diagnosis and understanding of a significant number of human diseases. RFLP techniques have been used to map numerous genetic diseases to specific locations in the genome and thus can be used to determine the likelihood that an individual carries an altered gene responsible for some disease. Other techniques, such as assays using mutation-specific DNA probes and DNA sequencing, allow direct detection of an altered gene. These techniques have already been applied to many diseases, including cystic fibrosis, Duchenne muscular dystrophy, and Huntington disease (Childs et al. 1988; Antonarakis 1989). Similar advances have been made in human biochemical genetics (Scriver et al. 1989).

As has been the case with many other new technologies, the implementation of genetic technology raises a number of social problems. These problems arise because many of the tests enable clinicians to diagnose a disease even though there are no overt symptoms or

to establish the carrier status of an individual. As the number of different genetic polymorphisms that can be detected both pre- and postnatally increases, the social problems associated with genetic testing will become increasingly important. An abbreviated list of such issues includes the disclosure of the test results to relatives and unrelated third parties, the use of genetic tests in adoption and alternative reproductive procedures, and the use of genetic tests in making decisions concerning abortion (Rowley 1984; Holtzman 1989; Nelkin and Tancredi 1989).

In this paper we focus on another social problem created by genetic technology which is becoming increasingly important but which has not as yet been extensively reviewed in the medical literature: genetic discrimination. The practice of genetic discrimination has the potential of creating a new group of disadvantaged people who will need the same protections now accorded those suffering from race and sex discrimination.

We begin the body of the paper by defining genetic discrimination, distinguishing it from discrimination based on disability, and characterizing its various manifestations. The major portion of the paper is devoted to a discussion of existing legislation, both state and federal, which could be used to prevent and combat genetic discrimination. Of greatest importance is the recently enacted Americans with Disabilities Act of 1990 (ADA), which we believe will have a great impact in combating discrimination. It is important

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that clinicians and allied health professionals involved in genetic testing become aware of the problems of genetic discrimination and of the most important laws that provide some measure of protection against such discrimination. However, all the statutes discussed in this paper have their limitations. After describing these limitations, we conclude with some suggestions of additional legal and social measures for overcoming these limitations.

### Genetic Discrimination

Genetic discrimination can be defined as discrimination against an individual or against members of that individual's family solely because of real or perceived differences from the "normal" genome in the genetic constitution of that individual. We have placed "normal" in quotation marks because it is impossible to give a characterization of what constitutes a normal genome. Although severely deleterious mutations are readily classifiable as abnormal genes, many not-so-deleterious mutations and an even greater number of benign polymorphisms are present in all individuals. This definition of genetic discrimination was developed by ourselves and our colleagues for use in our preliminary study of incidents of genetic discrimination (Billings et al. 1992).

We distinguish genetic discrimination from discrimination based on disabilities caused by altered genes by excluding from the former category discrimination against an individual who at the time of the discriminatory act is affected by the genetic disease. Thus, the denial of employment to an asymptomatic person who has the genotype for hemochromatosis constitutes genetic discrimination, whereas the denial of employment to a person with the same genotype suffering from liver disease caused by that genotype does not. As another example, the denial of insurance coverage to an individual whose (noninherited) cancer had been long cured would not constitute genetic discrimination, while the denial of insurance to that individual's relatives because of the (erroneous) belief that that type of cancer is heritable would be genetic discrimination.

People at risk for genetic discrimination are (1) those individuals who are asymptomatic but carry a gene(s) that increases the probability that they will develop some disease, (2) individuals who are heterozygotes (carriers) for some recessive or X-linked genetic condition but who are and will remain asymptomatic, (3) individuals who have one or more genetic

polymorphisms that are not known to cause any medical condition, and (4) immediate relatives of individuals with known or presumed genetic conditions.

Individuals in the first category include (a) individuals with conditions that can be treated before symptoms become manifest or whose symptoms can be effectively controlled so that the disease is not disabling (e.g., phenylketonuria and hemochromatosis), (b) individuals who in the future will be affected by untreatable and fatal conditions (e.g., Huntington disease), (c) individuals whose conditions, when they appear, vary in their degree of severity or in the effectiveness of treatment (e.g., neurofibromatosis type 1 and Charcot-Marie-Tooth disease), (d) individuals whose genes do not ineluctably lead to disease but do increase the probability of becoming affected by the disease (e.g., putative genes for diabetes, various forms of cancer and heart disease), and (e) individuals whose genotypes make them susceptible to adverse effects from exposure to various environmental agents that would have minimal or no effect on persons with a normal genotype (e.g., malignant hyperthermia and pseudocholinesterase deficiency). It should be emphasized that at present there is convincing evidence for the existence of only a very few of the types of predisposing genes described in (e). Glucose-6-phosphate dehydrogenase deficiency is probably the most publicized genetic condition that may predispose a person to the effects of an environmental toxin. However, the extent to which mutations at this gene locus pose problems in the workplace is still largely unclear (Office of Technology Assessment 1990).

Individuals in the second category are male and female carriers for the autosomal recessive diseases and women who are carriers for X-linked conditions. Among the most common of these diseases in the United States are cystic fibrosis and sickle cell disease (autosomal diseases) and Duchenne muscular dystrophy (X-linked).

Examples of the third category are individuals with benign genetic polymorphisms such as many of the blood group polymorphisms and the pseudodeficiency alleles common to many lysosomal enzymes.

Individuals in these categories might encounter genetic discrimination in the course of dealing with any social institution that provides a benefit or a service. However, because those individuals who are potential victims of genetic discrimination are asymptomatic or presymptomatic and thus not readily identified, genetic discrimination is most likely to occur in two areas: employment and insurance. Both employers

and insurance companies may have access to detailed medical records of their employees or customers, and both may believe that the information in these records is relevant to the efficient and profitable conduct of their businesses. If they do not have access to such records, they may want to order their own genetic tests.

Employment discrimination includes unfavorable treatment in hiring, promotion, assignment of duties, discharge, compensation, and other terms, conditions, and privileges of employment. A well-known instance of discrimination on the basis of a genetic condition occurred in the United States Air Force, which, at one time, prohibited carriers of sickle-cell disease from becoming pilots (Uzych 1986). The blood of a person affected with sickle-cell disease has a reduced ability to transport oxygen. Despite a lack of evidence, the Air Force argued that carriers, each of whom have only one copy of the sickling gene, would encounter difficulties at high altitudes because of the reduced oxygen level in the plane. At present, most clinicians believe that heterozygosity for sickle-cell disease is not associated with any adverse effects. Although a number of abnormalities have been reported in heterozygotes, most of these are anecdotal and the association may be coincidental (Weatherall et al. 1989) except possibly for abnormalities arising in certain physiologically stressful environments (Kark et al. 1987).

At least two types of employment discrimination are foreseeable. First, an employer might not hire someone who is likely to develop a genetic disease (or a common multifactorially determined disease like diabetes) and who, as a result, would be frequently absent from work, be less productive than other workers, or might require more health care. Second, an employer might not hire or permit an individual to work in an area where there would be exposure to some toxic chemical if that individual were known to have a heightened susceptibility to the toxic effects of that chemical. While the first type of discrimination is motivated by pure economic self-interest, the second type serves a public health purpose as well. At present, few instances of genetic conditions that would place individuals in the second category have been documented. However, because of economic incentives, it seems inevitable that, as more is learned about the genetic influence on disease, there will be a dramatic increase in workplace genetic screening and that widespread discrimination will result from its use (Rothstein 1990).

Insurance companies might discriminate by denying life, health, or disability insurance to people on the basis of their genotypes because these individuals or members of their families may have a higher incidence of claims. Consider the case of a young woman one of whose parents was affected by Huntington disease. Because there is a 50% probability that she will also develop the disease, an insurance company might refuse to underwrite a life insurance policy unless she agreed to be tested for the disease and was found not to have the Huntington disease gene. As another example, consider a married couple who plan to have children. If both spouses were determined to be carriers of cystic fibrosis, an insurance company might refuse to underwrite a family health insurance plan that would cover their children because any child of theirs would have a 25% probability of having cystic fibrosis. The company might agree to sell them a health insurance policy if they agreed to prenatal testing and to terminate any pregnancy in which the fetus was found to be affected with cystic fibrosis. The questions of whether entitlement to life insurance and to health insurance should be treated differently and whether genetic discrimination in either type of insurance is legally justifiable will be discussed in a later section of this paper.

Genetic discrimination in employment and in insurance are closely coupled. Most larger employers offer their employees health insurance at either no cost or reduced cost. The employer either purchases a group policy from an insurance company or is self-insured. Since the employer either pays insurance premiums which are based on experience ratings (a history of the frequency and amount of the claims) or pays the actual medical expenses of the employees, the cost of this benefit to the employer depends on the incidence of disease among the employees and their dependents. In attempting to reduce the incidence of disease among employees and simultaneously to increase profitability, the employer might require, as a condition of employment, genetic tests that could result in genetic discrimination.

The examples given above are primarily hypothetical and were chosen for illustrative purposes. Recently, however, a preliminary survey of individuals labeled with genetic conditions that was designed to gain information about the variety and significance of genetic discrimination uncovered several instances of genetic discrimination which vividly illustrate the need for legislative and/or other remedies (Billings et al. 1992; M. Natowicz, unpublished data).

Individuals with Charcot-Marie-Tooth disease were denied life insurance, automobile insurance, or employment even though the disease is not fatal and those individuals had extremely mild forms. An unaffected heterozygote for Gaucher disease was denied a government job because of that genetic diagnosis. A man with hemochromatosis was denied health insurance even though the disease was completely controlled and the man had no health problems. These denials were based solely on the existence of particular genes. They were not based on the life expectancy, driving record, ability to perform the job, or health of the individuals involved (Billings et al. 1992).

### Legal Protections against Genetic Discrimination

Within the past 20 years, the federal government and all 50 states have enacted laws prohibiting discrimination on the basis of handicap in employment and certain other areas. These laws offer limited but very real protection against genetic discrimination. In this section we will discuss the major federal laws, the Rehabilitation Act of 1973 and the ADA, as well as the additional protection that some state laws offer. Because many of the important concepts and definitions contained in the ADA and state laws derive from the Rehabilitation Act, much of the discussion will focus on the Rehabilitation Act.

#### Federal Laws

1. *The Rehabilitation Act of 1973.*—The federal Rehabilitation Act was the first major legislation that addressed the problem of discrimination on the basis of handicap. Section 501 of the act (29 U.S.C. § 791) prohibits employment discrimination on the basis of handicap by federal agencies. Section 503 (29 U.S.C. § 793) prohibits such discrimination by employers having contracts of \$2,500 or more with the federal government. Section 504 (29 U.S.C. § 794), the broadest and farthest-reaching section of the act, prohibits discrimination of all types against “qualified handicapped persons” by any program or activity which receives federal financial assistance. Section 504 applies to schools and colleges whose students receive federally guaranteed student loans, hospitals and health care providers receiving Medicare and Medicaid reimbursements, public transportation authorities, state and local governmental agencies that receive or disburse federal funds, and public housing authorities (*Grove City College v. Bell*; *U.S. v. Baylor Univ. Med. Center*; *Henning v. Village of Mayfair Village*;

*Disabled in Action of Penn. v. Sykes*; *Cason v. Rochester Housing Authority*). Section 504 also applies to federal agencies themselves, except when they act as employers (29 U.S.C. § 794(a)). Although this paper deals only with discrimination in employment and insurance, it should be noted that section 504 also prohibits discrimination in such areas as education, public housing, and eligibility for government benefits and services.

The definition of “individual with handicaps” in the Rehabilitation Act and in regulations adopted by various federal agencies with responsibility for its enforcement has served as the model for legislation in many states and for the ADA. An individual with handicaps under the act is any person who either (1) has a physical or mental impairment which substantially limits one or more major life activities, (2) has a record of such an impairment, or (3) is regarded as having such an impairment (29 U.S.C. § 796(8)(B)).

The Supreme Court has stated that in extending the act’s coverage to people who were regarded as being handicapped and, as a result, were limited in a major life activity such as employment, “Congress acknowledged that society’s accumulated myths and fears about disability and disease are as handicapping as are the physical limitations that flow from actual impairment” (*School Board of Nassau County v. Arline*). The Rehabilitation Act has been held to apply to individuals regarded as being handicapped by purely latent conditions, such as an asymptomatic congenital back anomaly which a prospective employer believed to pose a heightened risk of injury (*E. E. Black, Ltd. v. Marshall*) and asymptomatic HIV infection (*Ray v. School Dist. of DeSoto County*; *Doe v. Centinela Hospital*). Although the authors know of no cases involving genetic discrimination that have yet been decided under the Rehabilitation Act, we believe that there is no legal justification for treating such discrimination differently from discrimination on the basis of other latent conditions. A person with asymptomatic HIV infection or a back anomaly detectable only by X-ray is indistinguishable, from the point of view of risk of future illness or injury, from a person who carries a gene which increases the probability of developing a disease later in life.

Not all handicapped people are protected under the Rehabilitation Act and the ADA, only “qualified” handicapped people. In the context of employment, a qualified handicapped person is one who is capable of performing the essential functions of a particular job or who would be capable of performing the essential

functions of the job with reasonable accommodation (28 C.F.R. 41.32, 45 C.F.R. 84.3(k), 41 C.F.R. 60-741.2; sec. 101(8), 42 U.S.C. § 12111(8)). Failure to provide a reasonable accommodation constitutes unlawful discrimination unless the employer can show that providing such accommodation would cause undue hardship (28 C.F.R. 41.53, 45 C.F.R. 84.12(a); sec. 102(b)(5), 42 U.S.C. § 12112(b)(5)). Reasonable accommodations include modified or flexible work schedules to enable an employee to keep medical appointments, transfer of certain job functions to co-workers, provision of auxiliary aids such as a part-time reader for a blind employee, and removal of architectural barriers for a mobility-impaired employee (29 C.F.R. 1630.2(o); 41 C.F.R. 1613.704(b); 45 C.F.R. 84.12 (b)).

A reasonable accommodation could also include transferring an employee with a heightened susceptibility to the toxic effects of a chemical substance as a result of a genetic condition to another area of the workplace. However, such an accommodation poses its own problems. It is based on the assumption that the genetic condition and its effects are well documented and that the tests are reliable, which may not be the case. Moreover, many of the chemicals in question may be toxic to all workers, albeit only at larger concentrations. It has been argued that the screening and transferring of workers should not substitute for minimizing the levels of all potentially dangerous workplace substances (Daniels et al. 1990).

Many cases decided under the Rehabilitation Act have involved discrimination by employers based not on the employee's present condition but on the employer's fear that at some time in the future the employee's real or perceived disability may affect his or her ability to perform the job adequately or safely. Courts have ruled that the employer in such cases must prove through expert testimony the existence of a reasonable probability of substantial risk that the employer's fear is justified (*Bentivegna v. U.S. Dept. of Labor*; *Mantolite v. Bolger*; *School Board of Nassau County v. Arline*). The risk must be imminent, not speculative or remote in time. Even if the employer meets this burden, the employer must still show that no reasonable accommodation exists that would eliminate the risk.

Based on our understanding of the present state of the law, we believe that most if not all kinds of genetic discrimination in employment are prohibited. In order to prevail in this type of discrimination case an employer would have to prove (1) that the employee's genotype actually predisposed him or her to a partic-

ular disease, (2) that the risk of developing the disease was significant and imminent, and (3) that the employee would be incapable of performing the job even with reasonable accommodation if he or she developed the disease.

The one kind of genetic discrimination that is likely to be upheld is discrimination on the basis of a genotype associated with an increased susceptibility to the effects of workplace toxins. The employer would still have to demonstrate the probability and significance of the risk and the unavailability of a reasonable accommodation, but such a demonstration might not be unduly difficult.

It is important to note that this line of argument cannot be used to restrict women of childbearing age from working in certain environments because of risk of fetal injury. In a recently decided case, the Supreme Court ruled that such a practice constituted discrimination on the basis of sex because it was based on childbearing capacity rather than on fertility (*Int'l Union, UAW v. Johnson Controls, Inc.*). In addition, the Court noted that while sex discrimination is permissible if the sex of an employee is a "bona fide occupational qualification" (BFOQ), protecting a fetus cannot be considered a BFOQ.

A concern about future costs of employment, such as higher medical or worker's compensation insurance premiums, may not be used by employers to exclude people with disabilities from the workplace (*Chrysler Outboard Corp. v. Dept. of Ind. Labor and Human Rel.*; *Sterling Transit v. Fair Employment Practice Comm'n*; *Ackerman v. Western Electric Co.*). Thus, an employer could not lawfully use an individual's genetic predisposition to disease as grounds for denying or terminating employment based on the fear of future health care costs. It has been suggested (Gostin 1991) that additional protection for current employees from genetic discrimination based purely on cost factors may be provided by the Employee Retirement Income Security Act of 1974 (ERISA; 29 U.S.C. § 1001-1461 (1988)).

Of particular importance from the standpoint of genetic discrimination is the law's prohibition of pre-employment inquiry about health or disability (28 C.F.R. 41.55; 45 C.F.R. 84.14(a)). An employer may condition employment upon a medical examination but only after the employer has made a job offer to the prospective employee and only if all prospective employees are required to undergo medical examination. The employer may refuse employment on the basis of the medical examination only if it reveals that

the individual is unable to perform the essential functions of the job despite reasonable accommodation (45 C.F.R. 84.14(c)). Thus, refusing employment on the basis of the results of genetic testing would be prohibited in most cases; the clearest exception would be testing for a condition known to increase sensitivity to a workplace toxin.

The major drawback to the use of the Rehabilitation Act to combat genetic discrimination in the employment area is its limitation to certain employers having a nexus to the federal government. This defect is cured by the ADA.

2. *The Americans with Disabilities Act of 1990.*—The ADA, signed into law on July 26, 1990, is the most sweeping civil rights legislation ever enacted on behalf of disabled people. It prohibits discrimination on the basis of disability and mandates equal access to private employment, public services including public transportation, public accommodations, and telecommunications for people with hearing and speech impairments.

The purpose of the act is “(1) to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities; (2) to provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities; (3) to ensure that the Federal Government plays a central role in enforcing the standards established in this Act on behalf of individuals with disabilities; and (4) to invoke the sweep of congressional authority . . . in order to address the major areas of discrimination faced day-to-day by people with disabilities” (sec. 2(b), 42 U.S.C. §12101 (b)).

By July 26, 1994, the ADA will cover all employers with 15 or more employees (except for the federal government and tax-exempt private clubs). For the first 2 years beginning on July 26, 1992, the act will cover only employers with 25 or more employees. The definition of an “individual with disability” in the ADA parallels the definition of an individual with handicaps in the Rehabilitation Act, and the legislative history of the ADA makes it clear that the definitions are to be construed in the same way. The discussion in the legislative history states that the definition covers “individuals with stigmatic conditions that are viewed as physical impairments but do not in fact result in a substantial limitation of a major life activity” (S. Rep. No. 101–116, 101st Cong. 1st Sess. 21, 24 (1989)). The conclusions above regarding the applicability of the Rehabilitation Act to genetic discrimination are equally applicable to the ADA.

The issue of genetic discrimination was raised in the congressional debates that preceded passage of the ADA. Representatives Owens, Edwards, and Waxman stated, as one reason for supporting the ADA, its importance in protecting people who are identified through new genetic tests as being carriers of a disease-associated gene (136 Cong. Rec. H 4623, H 4624–4625, H 4627 (July 12, 1990)). Representative Waxman noted that a genetic condition would fall within the ADA’s definition of a disability, “being regarded as having an impairment which substantially limits a major life activity” (136 Cong. Rec. H 4627 (July 12, 1990)).

Although the regulations recently promulgated under Title I of the ADA dealing with employment do not mention genetic discrimination, the appendix to the regulations states that the definition of “physical or mental impairment” does not include “characteristic predisposition to illness or disease” (29 C.F.R. 1630 App.; 56 Fed. Reg. 35741 (July 26, 1991)). We believe that this definition does *not* exclude genetic discrimination from the scope of the ADA and present our argument in the Appendix to this paper. However, even if our interpretation of the appendix to the regulations is not that intended by its authors, we note that, in general, regulations and comments produced by executive agencies to interpret laws enacted by legislatures cannot lawfully change the substance of the laws they interpret. To the extent that the language in the appendix excludes from coverage people Congress intended to protect in enacting the ADA (including people with genetic predispositions to disease) it is invalid and should be capable of successful challenge in a legal action to enforce the ADA.

The ADA limits inquiries about health or medical conditions in several ways. It prohibits all preemployment inquiries and medical examinations except examinations conducted after a job offer has been made (sec. 102(c)(3), 42 U.S.C. § 12112(c)(3)). The ADA regulations provide that a medical examination conducted after a conditional offer of employment has been made does not have to be “job related and consistent with business necessity.” The examination may include all types of tests, including genetic tests. However, the results of these tests may not be used to exclude an individual from the job unless the exclusion is shown to be job related, consistent with business necessity, and not amenable to reasonable accommodation (29 C.F.R. 1630.14(b)(3)).

The ADA further requires that inquiries about disability made after hiring and medical examinations

performed at any time during employment must be “shown to be job-related and consistent with business necessity” (sec. 102(c)(4), 42 U.S.C. § 12112(c)(4)). Presumably, an employer who could demonstrate that a physical examination or test to determine the presence or absence of a condition that would significantly increase the employee’s risk of injury or harm could test for that condition without being guilty of discrimination. Thus, genetic tests for a condition that would demonstrably increase the hazards of a particular kind of work would be allowed, subject to the requirements discussed above under the Rehabilitation Act regarding the significance and immediacy of the risk, the necessity of corroboration by expert opinion, and the duty of reasonable accommodation. The duty of reasonable accommodation under the ADA expressly includes the duty to transfer an employee to a vacant position for which the employee is qualified (42 U.S.C. § 12111(9)(B)). Thus, an employee who tested positive for a genotype that posed a known hazard to continued employment at a particular site would have the right to transfer to another available position with the employer.

A major weakness of the ADA is one that it inherits from antidiscrimination law generally: the burden of proving discrimination (proving both that a disability exists and that it was used in the employer’s decision) rests with the applicant or employee. Nevertheless, the extensive legislative history of the ADA and its explicitly broadly remedial purpose may assist in persuading courts and agencies charged with enforcing it to adopt a less restrictive view of its provisions.

Perhaps the most important weakness of the ADA is the exception it provides for insurance companies. Section 501(c) of the act states that none of its sections are to “be construed to prohibit or restrict—(1) an insurer, hospital or medical service company, health maintenance organization, or any agent, or entity that administers benefit plans, or similar organizations from underwriting risks, classifying risks, or administering such risks that are based on or not inconsistent with State law; or (2) a person or organization covered by this Act from establishing, sponsoring, observing or administering the terms of a bona fide benefit plan that are based on underwriting risks, classifying risks, or administering such risks that are based on or not inconsistent with State law; or (3) a person or organization covered by this Act from establishing, sponsoring, observing or administering the terms of a bona fide benefit plan that is not subject to State laws that regulate insurance.” The section ends with the state-

ment that these provisions “shall not be used as a subterfuge to evade the purposes of title I [employment] and III [public accommodations].”

Thus, an insurer is free to discriminate on the basis of demonstrable risk as long as no state law prohibits such discrimination and, furthermore, an employer or other entity covered by the ADA may provide discriminatory insurance coverage to its employees, clients or others without violating the provisions of the ADA. What an employer may not do is use the discriminatory practices of insurance companies as a pretext for refusing to hire, firing, or taking other adverse action against an applicant or employee.

The interrelationship between the employment and insurance provisions is complicated by the fact that the ADA also prohibits an employer from “participating in a contractual or other arrangement or relationship that has the effect of subjecting a . . . qualified applicant or employee with a disability to discrimination.” Among the relationships covered are those with “an organization providing fringe benefits to an employee” (sec. 102(b)(2), 42 U.S.C. § 12112 (b)(2)).

The legislative history of the ADA attempts to address the inherent contradiction between these sections without notable success. It states that “employers may not deny *health* insurance coverage *completely* to an individual based on the person’s diagnosis or disability” (emphasis added) (S. Rep. No. 101-116, 101st Cong., 1st Sess. 29 (1989)). It goes on to say that an employer may offer insurance which limits coverage for certain procedures, treatments, or conditions, for example, exclusion of preexisting conditions, as long as the employer provides insurance for non-disability-related conditions such as a broken leg. Although “all people with disabilities must have equal access to the health insurance coverage that is provided by the employer to all employees,” there is no requirement that the insurance provided be of any real use to the disabled employee. Furthermore, since the legislative history refers only to health insurance, it is not clear whether Congress intended to allow disabled employees to be denied other kinds of insurance such as life and disability insurance provided by employers.

Since the ADA relegates the area of insurance discrimination to state law, we will next discuss the efficacy of state law in prohibiting genetic discrimination both in employment and in insurance.

#### State Laws

All states have laws prohibiting unfair discrimination by life insurers, and 41 states prohibit unfair dis-

crimination by health insurers (Miller 1989). However, these laws typically define unfair discrimination as discrimination which is not justified by actual risk and provide little protection for a person whose longevity or future health may demonstrably be affected by a presently asymptomatic genetic condition. In general, existing state law provides minimal protection against genetic discrimination in the insurance field, although recent notable exceptions exist.

All states have laws which prohibit employment discrimination on the basis of handicap, and the definition of handicap in many of these states is broad enough to encompass presymptomatic as well as asymptomatic genetic conditions. Some states adopt the model of the Rehabilitation Act (California, Colorado, Hawaii, Iowa, Louisiana, Massachusetts, Minnesota, Missouri, New Mexico, North Carolina, Oklahoma, Oregon, Pennsylvania, Rhode Island, Utah, Vermont, Virginia, and West Virginia) and thus extend protection to individuals who are "regarded" as being impaired, whether or not they have a disability (Cone 1989). Those state laws provide equivalent protection against discrimination on the basis of a latent condition, such as an asymptomatic or presymptomatic genetic condition, to the protections afforded by the Rehabilitation Act and the ADA discussed above. State laws typically reach smaller employers than do the ADA, with its 15-employee limit, and the Rehabilitation Act, which is limited to recipients of federal financial assistance, federal contractors, and the federal government. For example, Massachusetts law covers almost all employers with more than five employees (Mass. Gen. L. ch. 151B, § 1). Some state courts and agencies have given state antidiscrimination laws a more liberal reading than have federal courts interpreting equivalent federal laws. For all of these reasons, state laws generally provide a useful supplement to the employment provisions of the ADA and Rehabilitation Act.

In addition to the laws common to all or most states, a small but growing number of states have laws that specifically restrict the use of genetic information by employers or insurers. Maryland, for example, prohibits life, health, and disability insurers from considering genetic conditions without actuarial justification (Md. Ann. Code art. 48A, § 223). Other states, for example, North Carolina and New Jersey, prohibit discrimination by insurers or employers on the basis of heterozygosity for specific disorders such as sickle-cell disease, Tay-Sachs, hemoglobin C, or cystic fibrosis (N.C. Gen. Stat. §§ 58-195.5; 95-28.1; N.J.

Stat. Ann. §§ 10:5-5, 10:5-12). California provides broader protection by banning discrimination on the basis of heterozygosity for any genetic disorder (Cal. Ins. Code § 10143(a)).

Recently, both houses of the California legislature passed a bill (A.B. 1888) that significantly restricts the use of genetic tests. The bill provides that information obtained from genetic tests cannot be used (1) in making decisions concerning employment, (2) by insurance companies in making decisions about eligibility for group life and disability insurance, and (3) by insurance companies in making decisions about eligibility for health insurance for the next eight years. Although this bill was vetoed by the governor, it has attracted widespread interest and similar proposals for legislation will most likely be considered by other states.

## Conclusions

Genetic discrimination exists now and will become more prevalent over time. Given the remarkable progress of genetic technology over the past 20 years and the potential of projects such as the Human Genome Initiative to expand our knowledge of the genetic basis of many diseases and disabilities, it is probable that genetic testing for a variety of conditions will become more common in the near future. Clinicians and allied health professionals involved in genetic testing must become aware of the possibility of genetic discrimination resulting from the use of such tests. They should also become aware of currently existing legal protections against discrimination and of their limitations.

We believe that genetic discrimination in employment is already covered adequately by the ADA, the Rehabilitation Act, and similar state laws. The strengths of these laws lie in two areas. First, they provide a broad definition of a disability. This definition includes both actual disabilities and conditions that are merely perceived as being disabilities. Second, the laws cover all terms, conditions, and privileges of employment, subject to the limitations regarding insurance.

A number of authors have pointed out limitations in the ADA provisions concerning genetic discrimination and have suggested that it be amended to remedy these deficiencies. For example, the Joint Working Group on the Ethical, Legal, and Social Implications in Human Genome Research (ELSI) is concerned that genetic discrimination is not mentioned explicitly in the ADA and argue that the ADA does not "expressly



state that unaffected heterozygote carriers of recessive disorders and X-linked disorders are covered when the basis for their exclusion is the fear that the individual is at risk of parenting a child who will have the condition" (ELSI 1991). The ELSI committee was also concerned that since medical tests given after a conditional offer of employment need not be job related such tests, including genetic tests, could result in the withdrawal of an offer of employment. Challenging the withdrawal often presents problems, since a prospective employee might find it difficult to learn what tests were performed and the results of those tests. Other authors point out that the ADA is silent about discrimination based on future disability, that is, the presence of a genotype in an individual that will most probably result in a disabling condition at some future time (Office of Technology Assessment 1990; Rothstein 1990; Gostin 1991).

It is our belief that these forms of discrimination, as well as related forms mentioned by other commentators, are indeed covered by the ADA, because in these cases the prospective employee is *regarded* as having some form of disability, although the disability in question does not prevent the prospective employee from performing the essential functions of the job at the time of hiring. We do agree with all these authors that, because the ADA does not explicitly prohibit these forms of discrimination, courts might find them permissible under the ADA. Nevertheless, because the legislative history indicates widespread support for a liberal interpretation of the ADA encompassing a wide variety of forms of genetic discrimination, we believe that it is premature to advocate immediate amendment of the ADA.

Although genetic tests cannot legally be used by employers to discriminate against most prospective or current employees, their use is not proscribed totally. In addition, any use of genetic (or any other medical) tests by employers and insurance companies raises serious issues involving privacy and the confidentiality of the test results. Clearly, there is a strong link between the issues of confidentiality and genetic discrimination, since discrimination on the basis of the genotype of an individual is a *de facto* violation of privacy. Issues involving confidentiality are becoming increasingly important as medical records are put into computer data bases which are accessible to a large number of individuals and companies (Andrews 1987; Norton 1989; Cunningham 1990; DeGorgey 1990; Andrews 1991; Andrews and Jaeger 1991). Because employers and insurers will claim a right to know the results of

any genetic tests, it will not be easy to restrict their availability and use. It seems clear that new legislation will be needed to resolve conflicts between the right of privacy and the right to know.

Despite our optimism about the scope of the ADA, it is important to bear in mind that it does not eliminate the root causes of discrimination, genetic or otherwise. No law can eliminate entirely the causes of the evils it seeks to prevent or punish. The large number of cases litigated successfully under the various federal and state antidiscrimination laws (and the far larger number of discrimination cases that are never challenged legally) indicates that, while laws may punish some individuals who discriminate and may discourage others from discriminating by making the practice costly or otherwise unattractive, laws alone cannot eliminate discrimination.

As discussed above, the ADA does not forbid discrimination by insurance companies. Access to health care is as essential as food and housing. Consequently, we believe that health insurance should be viewed as an entitlement without preconditions and that denying health insurance on the basis of genotype or any other predisposing condition of an individual is wrong. In terms of the analysis given by Stone, we take the position that the benefits of insurance should be distributed according to need rather than according to the dollar amount of insurance premiums paid (Stone 1990). To help accomplish this end with regard to genetic discrimination, state laws could be amended to prohibit genetic testing as a precondition for health insurance. The California bill discussed above, which amends that state's civil rights laws, is a major step in the regulation of genetic testing.

With regard to other kinds of insurance, such as life and disability insurance, the argument supporting the allowance of genetic testing as a precondition for obtaining insurance is thought by some to be stronger for two reasons. First, adverse selection, if it exists at all, would presumably have a much greater effect on life insurance than it would on health insurance. Adverse selection occurs when people who know that they are at increased risk for particular illnesses or early death purchase larger amounts of insurance coverage than do those people who are at average or below average risk.

Second, it has been argued that life and disability insurance should not be considered necessities, since they are usually not the exclusive means of providing financial security for most people or their dependents. Consequently, it could be argued that insurance com-

panies should be allowed greater freedom in setting preconditions for obtaining these types of insurance. However, given the unequal access to education and well-paying jobs in our society, the failure of public welfare programs to provide an acceptable standard of living, and the high cost of living, especially of medical care, even these types of insurance may be regarded as necessities.

Several avenues exist for overcoming the problems caused by genetic discrimination. First, insurance companies, employers, and the governmental agencies that regulate them should be made more aware of the existence of discriminatory practices and the effects of these practices. The education of consumers regarding their rights under the law is similarly important. Second, legislative remedies such as the ADA should be enforced and strengthened. Despite the pessimism of some regarding the efficacy of the ADA in protecting against genetic discrimination, we believe that the ADA will provide substantial protection in the area of employment, although not in insurance. We have stressed the strengths of the ADA in this paper in order to encourage people who have experienced discrimination or whose patients have experienced discrimination to make full use of and attempt to broaden the scope of the ADA.

Nevertheless, the law is not a panacea. We believe that the only real solution to the problems posed by genetic testing and the more general problem of unequal access to health care and other resources in our society is to create alternatives to private insurance as the primary means of health care coverage. This will involve developing a system of universal health care and adequate subsidies for those who cannot support themselves because of economic status, age, or disability.

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### Appendix

#### Interpretation of the Regulations Concerning the ADA

There is no explanation of what is meant by the phrase "characteristic predisposition to illness or disease"

found in the appendix to the regulations. However, it appears immediately following a discussion of the distinction between conditions that are impairments and "physical, psychological, environmental, cultural and economic characteristics" that are not impairments. The examples given in the register of these latter characteristics, "eye color, hair color, left-handedness, or height, weight or muscle tone that are within 'normal' range and *are not the result of a physiological disorder*" (emphasis added). These examples suggest that the predispositions which are not covered by the ADA are predispositions to such illnesses and diseases as the common cold which are not the result of a "physiological disorder." Elsewhere in the appendix, the authors indicate that such conditions as controlled high blood pressure or HIV infection are covered disabilities if an employer uses these conditions as a reason to exclude an individual from employment (29 C.F.R. 1630 App.; 56 Fed. reg. 35741-35742 (July 26, 1991)), even though these conditions could be considered predispositions to illness or disease.

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