Genetic Discrimination in the Workplace

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The surge in genetic research and technology, fueled in large part by the Human Genome Project, has resulted in the continuing expansion of the range of genetic tests and other genetic information available to physicians, insurance companies, employers, and the general public.[1] Genetic tests can provide presymptomatic medical information about an individual, including information about an individual's increased risk of future disease, disability, or early death. These tests can reveal information about an individual's carrier status, that is, the likelihood of parents passing on to their children a genetic condition, and about the health of the individual's family members. Although genetic information provides the promise of early detection and treatment of certain illnesses and disorders, it also poses risks. As a result of the increase in genetic testing and information, legal issues regarding employment discrimination on the basis of genetic information are emerging. These issues are important to all working Americans because genetic testing is becoming more prevalent. If employers are permitted to base personnel decisions on genetic information, people will be unfairly barred or removed from working for reasons that are unrelated to their ability to perform their jobs. In addition, people will be reluctant to take advantage of the growing array of genetic tests that can identify their vulnerability to specific diseases and possibly permit early treatment because of a fear that the information, or inferences drawn from the fact that an individual has sought to be tested, will be misused.

This article outlines the growing concerns about genetic discrimination in the workplace and suggests possible methods for addressing such discrimination. The first section outlines worker fears and the reality of genetic discrimination in employment; the next discusses the application of existing federal statutes, particularly the Americans with Disabilities Act (ADA), to genetic discrimination; the third discusses the very limited case law in this area; and the last provides an overview of current state laws enacted to protect workers from genetic discrimination, as well as of recently proposed federal legislation to address the current gaps in protection from genetic discrimination in the workplace.

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Workers' fears and the reality of genetic discrimination

Although little systematic data gauging the extent of actual genetic discrimination in the workplace are available, workers clearly fear that employers will use genetic information to lower their insurance and sick leave costs by weeding out individuals who have traits linked to inherited medical conditions. A 1997 national survey of 1,000 people conducted by the federally funded National Center for Genome Resources found that nearly two-thirds of respondents would not take a genetic test if employers and health insurers could see the results, and 85 percent felt that employers should be prohibited from obtaining information about an individual's genetic conditions and predispositions.[2] Similarly, a 1995 poll of the general public found that over 85 percent of survey respondents were very concerned or somewhat concerned about access to and use of genetic information by insurers and employers.[3] Researchers at Georgetown University conducted a survey of 332 individuals with one or more family members with a genetic disorder who were affiliated with genetic support groups.[4] The vast majority, 87 percent, said that they would not want their employers to know if they were tested and

found to be at high risk for a genetic disorder with serious complications.[5] Seventeen percent of respondents said that they have not revealed known genetic information to their employers for fear of losing their jobs or insurance coverage.[6]

Individuals' fears of workplace discrimination could keep them from being tested and learning whether they have genetic traits linked to breast cancer, cystic fibrosis (CF),[7] Huntington disease,[8] colon cancer, or other conditions, even though early detection and treatment could extend their lives. The Georgetown study (cited above) also revealed that, as a result of fears of discrimination, nearly one in ten persons surveyed chose not to undergo genetic tests.[9] The Clinton administration has noted findings that many women have refused to take advantage of genetic screening to determine the likelihood of breast cancer because they fear that the information might be made available to employers or insurers.[10] Individuals' refusals to get genetic tests because they fear genetic discrimination have negative consequences not just for those individuals, but also for scientific research in this area.[11] Some medical researchers have voiced concerns because individuals are refusing to participate in long-term medical studies to assess their risk of developing genetically linked diseases, such as various forms of cancer, because these individuals believe that involvement in such studies would be a red flag on their medical records that could subject them to genetic discrimination.[12]

Workers' fears of genetic discrimination are not baseless. Although no statistically representative studies measuring the extent of actual genetic discrimination have been conducted to date, and those studies that have been conducted rely in large part on individuals' perceptions of discrimination,[13] anecdotal evidence of genetic discrimination in employment has been compiled.[14] A 1996 study conducted by a team of medical researchers documented more than 200 cases of individuals with a genetic predisposition to certain diseases, but who were asymptomatic at the time, who reported a range of discriminatory actions, made on the basis of genetic information, by insurance companies, employers, and others.[15] A 1989 survey of 400 employers by Northwest Life Insurance found that, by the year 2000, 15 percent of employers plan to check the genetic status of prospective employees and their dependents before making job offers.[16] In the Georgetown study, 15 percent of respondents said that they or affected family members had been asked questions about genetic diseases or disabilities on job applications (although it is not clear how often this information was used subsequently to deny jobs to applicants).[17] Thirteen percent of respondents reported that they or another family member had been denied a job or terminated from a job because of a genetic condition in the family.[18] In a recent survey that attempted to assess the extent of discrimination against individuals with genetic abnormalities who were otherwise healthy, genetic services providers and primary care physicians who were surveyed reported knowing of 582 people who were refused employment or insurance based on a genetic predisposition.[19] Although the study's authors regarded this number as small in relation to the total number of patients seen by the surveyed professionals, they concluded that genetic discrimination does in fact exist.[20]

Protection against genetic discrimination under existing federal legislation

No current federal statute explicitly addresses genetic discrimination by employers. However, existing federal laws, which are designed to prohibit discrimination in employment based on certain disability characteristics that may be linked to genetic traits, provide protections against genetic discrimination. In particular, the ADA should be interpreted to prohibit discrimination in employment based on genetic characteristics.

The ADA and genetic discrimination

Title I of the ADA,[21] the federal law that protects individuals employed in the private sector from discrimination on the basis of disability, makes no explicit mention of genetic discrimination. However, the ADA does not explicitly identify any single medical condition for protection. Rather, the ADA contains broad language prohibiting discrimination against a qualified "individual with a disability" in hiring, promotion, discharge, compensation, and other terms and conditions of employment.[22] An individual with a disability is defined by the ADA as a person with one or more physical or mental impairments that substantially limits him/her in performing a major life activity; a person with a record of such an impairment; or a person who is regarded as having such an impairment.[23] The ADA requires that an employer make reasonable accommodations for qualified individuals with disabilities if such accommodations do not impose an undue hardship on the employer.[24] The ADA covers private employers with fifteen or more employees.[25]

It is clear that the ADA covers individuals who have a genetically related illness or disability once it becomes manifest and substantially limits a major life activity.[26] Moreover, little debate exists over the fact that the ADA covers individuals who have a prior record of a genetically related disability, for example, someone who has recovered from cancer.[27] And yet, courts have not yet determined whether the ADA should be understood to restrict discrimination on the basis of a diagnosed, but asymptomatic, genetic condition or trait.[28]

In 1995, the U.S. Equal Employment Opportunity Commission (EEOC) adopted the view that the ADA prohibits discrimination against workers based on their ge-

netic make-up. This view was contained in an EEOC policy guidance that clarifies the definition of *disability* under the ADA.[29] This policy guidance explicitly states that the third part of the definition of disability, the "regarded as" prong, covers individuals who are subjected to discrimination on the basis of genetic information relating to illness, disease, or other disorders—employers that discriminate against individuals on the basis of such information are regarding the individuals as having impairments that substantially limit a major life activity.[30] In the hypothetical example described in the EEOC guidance, an employer makes a conditional offer of employment and then learns that the candidate harbors a gene that increases her risk of colon cancer. Although the woman is healthy and may never get cancer, the job offer is withdrawn because of concerns about the possibility that she may contract the disease, which would impact on her future productivity and insurance costs. That woman, in the eyes of EEOC, would be covered under the antidiscrimination protections of the ADA.[31] A person who has a genetic predisposition to a disease, disorder, or disability is exactly the kind of person who Congress must have intended to be covered by the "regarded as" prong.

To be protected under the ADA, people who have an asymptomatic genetic trait must show not only that they were "regarded as disabled" by an employer, but also that the employer discriminated against them based on that perception.[32] Some have argued that the ADA may not cover individuals with genetic conditions that are not yet manifest, because to fall within the Act's definition, an employer who regards an employee as having an impairment that substantially limits a major life activity must regard that individual as *presently* disabled.[33] However, EEOC's Interpretive Guidance as well as several court decisions support the view that an employer's concerns for an employee's *future* productivity, health insurance costs, and attendance fall within the "regarded as" prong of the ADA.[34] For example, at least one court has held that an employer regarded an employee as disabled where the employer was concerned about the employee's future performance because of sickle cell disease.[35] Other courts have held that an employee has standing to sue under the "regarded as" prong of the ADA based on employer concerns about future health insurance costs.[36]

EEOC's position is clear that the ADA protects individuals with asymptomatic genetic conditions from discrimination in employment, and EEOC's Interpretive Guidance is used to interpret the law and can be used as persuasive authority. However, these policies do not have the force of law, as does a state or federal statute. EEOC's position regarding discrimination based on genetic information has yet to be tested in the courts, and not all observers agree that the ADA applies to people who may not presently have a disease such as breast cancer, CF, and certain types of colon cancer, but who have "unexpressed genetic conditions" that predispose them to those diseases.[37] Some observers argue that the ADA can be read to cover genetic carriers,[38] while others state that the ADA may not sufficiently protect all employees from genetic discrimination and that the advent of new genetic technologies requires new legislation regulating employer use of such technologies to close the coverage gaps.[39]

Although the ADA should be interpreted to prohibit employment discrimination based on genetic disorders, it does not prevent employers from using genetic testing in all circumstances.[40] The ADA generally prohibits preemployment medical examinations or inquiries designed to reveal information about disabilities,[41] although the ADA permits other types of inquiries related to an applicant's ability to perform the essential functions of the job, such as driving or lifting heavy objects.[42] Once a conditional offer of employment has been made, the ADA permits medical examinations as long as the examinations are given to all prospective employees and do not single out persons with disabilities.[43] Under the ADA, once the employment relationship is formed, an employer may not require further medical tests unless they are demonstrated to be "job-related and consistent with business necessity."[44] Employers are required to keep medical information confidential and to maintain such information separate from general personnel records.[45] Thus, under the ADA, employers are not prohibited from genetic testing of job candidates who have been given conditional offers of employment and may even test current employees if they can demonstrate that the testing is job-related and consistent with business necessity. Such employer access to genetic information may create opportunities for abuse.[46]

Title VII of the Civil Rights Act

Title VII of the Civil Rights Act of 1964[47] also may incidentally provide protection against some forms of genetic discrimination, because genetic discrimination may have a disparate impact based on race, color, religion, sex, or national origin.[48] For example, an employer may violate Title VII by engaging in discrimination based on a genetic trait that disproportionately impacts a particular protected group, such as sickle cell disease (individuals of African descent) or Tay-Sachs disease (Ashkenazi Jews).[49] Because genetic screening is a facially neutral policy, claims under Title VII would most likely be brought on a disparate impact theory.[50] Although some courts have implied that employment decisions based on genetic profiles associated with a particular protected class would violate Title VII, thus far, no successful lawsuits have been brought under this theory.[51] Also, many, if not most, genetically related diseases and disorders do not disproportionately affect one of Title VII's protected classes; thus, Title VII does not

provide comprehensive protection against genetic discrimination in employment.[52]

Genetic discrimination case law

To this point, virtually no case law exists regarding genetic discrimination in the workplace. However, one recent decision of the Ninth Circuit Court of Appeals provides an interesting example of how existing federal and state law can be used to challenge genetic and other medical testing by an employer. In *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*,[53] the plaintiffs sued the Lawrence Berkeley Laboratory, a research institution jointly operated by state and federal agencies, challenging the lab's practice of testing some employees for syphilis, pregnancy, and the sickle cell trait. The plaintiffs alleged that the genetic testing was conducted during routine mandatory medical exams without the employees' knowledge or consent, and that the conditions for which testing was performed bore no relationship to the clerical and administrative jobs the employees had been hired to perform. These practices were challenged under federal and state laws on the grounds that the practice constituted discrimination on the basis of sex, race, and disability as well as violated federal and state constitutional rights to privacy. In this case, the plaintiffs did not allege that the defendants took any subsequent employment-related action on the basis of their test results or that the results had been disclosed to third parties.

The appellate court reversed the district court's dismissal of these claims and allowed the case to go to trial on the following grounds: the court of appeals found sufficient evidence in the record to conclude that testing for syphilis, sickle cell trait, and pregnancy is not an appropriate part of an occupational medical examination, that the employer lacked any reasonable basis for performing these tests on clerical and administrative employees such as the plaintiffs, and that the performance of these tests, without explicit notice and informed consent, violates prevailing medical standards.[54] The court also found that the constitutional right to privacy clearly encompasses confidentiality of medical information, that unauthorized testing constitutes one of the most basic violations possible, and that, if such tests were unauthorized, the employer selectively unconstitutionally invaded the privacy of women (pregnancy tests) and blacks (tests for sickle cell trait).[55] The plaintiffs' Title VII claim also was permitted to go forward, based on their claim that different medical examinations were administered to African Americans (sickle cell trait) and women (pregnancy test), finding that such differential examinations constituted an "adverse effect" sufficient to support a Title VII claim.[56]

The Ninth Circuit upheld dismissal of the ADA claims on the following grounds: no job-related action was taken against the plaintiffs as a result of the testing; safeguards to protect the confidentiality of the medical information were not proven to be inadequate; and the scope of the exams did not violate the statute.[57] The court reasoned that the scope of the employer's genetic testing did not violate the ADA, because the Act does not restrict the scope of medical testing to job-related functions after an initial offer of employment has been extended.[58] What is not clear is why the Ninth Circuit, which recognized a Title VII claim because *different* medical examinations (consisting of additional genetic screening tests) were given to African Americans and women who had been given conditional offers of employment, did not find this procedure to violate the ADA's requirements that conditional post-offer medical tests must be given to all potential employees.

In another case, *Mayfield v. Dalton*,[59] two active duty U.S. Marines filed a class action suit opposing a requirement that they provide DNA samples to the armed forces. Rather than bringing suit under the ADA, the plaintiffs claimed that requiring them to provide DNA samples violated their right against unreasonable searches and seizures under the Fourth Amendment to the U.S. Constitution. The district court held that the DNA sampling did not constitute an unreasonable search and seizure because the DNA repository served the legitimate function of identifying the remains of soldiers killed in combat.[60] The Ninth Circuit did not address the constitutional issue on appeal, holding instead that the claim had become moot when the plaintiffs were discharged from the Marines.[61]

Genetic discrimination legislation

Some existing state and federal laws do explicitly prohibit genetic discrimination under certain circumstances, and yet these laws do not provide comprehensive coverage for workers. For example, although the ADA prohibits genetic testing of current employees unless it is job-related and consistent with business necessity, employers in most jurisdictions are not prohibited from requiring prospective employees to undergo genetic testing once a conditional offer of employment has been extended. Although a 1996 federal law, the Health Insurance Portability and Accountability Act (HIPAA),[62] prohibits group health plans from using genetic or other health-related information to deny or limit coverage, or to charge higher premiums, it does not address the larger problem of gathering or using genetic information in the workplace outside the health insurance context.[63]

State legislation

At least thirteen states have enacted laws providing additional protections against discrimination in the workplace on the basis of genetic information.[64] The form and coverage of these statutes varies considerably. The earliest state legislation addressing genetic discrimination in the work-

place prohibited employers from discriminating against individuals possessing particular genetic traits or disorders. For example, Florida prohibits entities from denying or refusing employment to any person or discharging any person from employment based on sickle cell trait.[65] A North Carolina statute has nearly identical prohibitions and also covers individuals with hemoglobin C trait.[66] Louisiana prohibits employers from refusing to hire, discharging, classifying, segregating, or discriminating with respect to the terms, conditions, and privileges of employment against individuals with sickle cell trait.[67] New Jersey prohibits employment discrimination based on sickle cell trait, hemoglobin C trait, thalassemia trait, Tay-Sachs trait, and CF trait.[68] New York prohibits discrimination based on sickle cell trait, Tay-Sachs trait, or ß-thalassemia trait.[69]

In the 1990s, a number of states passed more comprehensive statutes that either prohibit employers from requiring genetic testing as a condition of employment or prohibit the use of genetic information in employment decisions. Arizona, Iowa, New Hampshire, Oregon, Rhode Island, Texas, and Wisconsin prohibit employers and, in some cases, labor organizations, employment agencies, and licensing agencies, from discriminating against any individual in hiring or discharging or in the terms and conditions of employment based on the results of a genetic test.[70] Iowa, New Hampshire, Oregon, Rhode Island, Texas, and Wisconsin prohibit employers from soliciting, requiring, or administering a genetic test to individuals as a condition of employment or as part of the job application process.[71] Iowa, New Hampshire, and Wisconsin prohibit offering inducements such as employment, membership, licensure, pay, or benefits in return for taking a genetic test;[72] and Iowa, Rhode Island, and Wisconsin further prohibit discriminating with regard to hiring and to the terms and conditions of employment against people because they have obtained genetic tests on their own.[73] Some state statutes carve out exceptions to permit genetic testing, if the employee consents, for the purposes of investigating workers' compensation claims or determining and monitoring the worker's susceptibility to potentially toxic substances in the workplace.[74]

The coverage of these statutes is potentially anyone who is subjected to genetic testing by his/her employer. The statutory definition for "genetic testing" for Iowa is representative of the other state statutes:

> a test of a person's genes, gene products, or chromosomes, for abnormalities or deficiencies, including carrier status, that are linked to physical or mental disorders or impairments, or that indicate a susceptibility to illness, disease, impairment, or other disorders, whether physical or mental, or that demonstrate genetic or chromosomal damage due to environmental factors.[75]

Because coverage under most of these statutes revolves around who is or may be subject to genetic testing, coverage is both over- and underinclusive. Individuals who do not have any genetic abnormalities are protected from being subjected to testing while, at the same time, most of the statutes do not prohibit employers from genetic discrimination based on information obtained from sources other than testing.

New Jersey's law, the most comprehensive of state statutes regarding workplace genetic discrimination, avoids this problem by prohibiting employment discrimination based on categories including "genetic information," "atypical hereditary cellular or blood trait," or "because of the refusal to submit to a genetic test or make available the results of a genetic test to an employer."[76] Rather than focusing on results of genetic testing, "genetic information" is defined broadly to include "information about genes, gene products or inherited characteristics that may derive from an individual or family member."[77] New York and North Carolina also prohibit employment discrimination based on genetic information, regardless of the source from which such information is obtained.[78] Although most state statutes do not distinguish between genetic disorders that have become manifest and those that are as yet unexpressed, the New York and North Carolina statutes prohibiting discrimination by employers based on genetic characteristics or genetic predisposition define these terms generally as those identifiable chromosomal traits associated with an increased statistical risk of developing a disease or disorder that currently are asymptomatic of any disease or disorder.[79]

Beyond these laws specifically aimed at workplace discrimination, other states have enacted statutes that more generally limit genetic testing, require consent by the individual prior to testing, and require confidentiality with regard to results.[80] These general statutes place some limits on an employer's ability to require employees to take genetic tests or to get access to genetic test results of current or potential employees. For example, Florida regulates genetic testing and prohibits genetic testing except with the informed consent of the individual to be tested and provides that the results of such tests must not be disclosed without that individual's consent.[81]

To my knowledge, no cases have been reported, based on these state statutes, prohibiting genetic discrimination in the workplace.

Recent federal initiatives

Given the uncertainties and gaps in federal and state protections against genetic discrimination in employment decisions, comprehensive federal legislation to establish minimum protections may be needed to ensure that advances in genetic technology and research, while being used to address the health needs of Americans, are not used to deny

individuals employment opportunities and benefits. Recently, there have been proposals for federal legislation in this area.[82] Senator Tom Daschle (D. S.D.), and Representatives Joe Kennedy (D. Mass.) and Nita Lowey (D. N.Y.) have each introduced bills that would amend civil rights or labor laws to prohibit employment discrimination based on genetic information. Senator Daschle's bill (and the companion bill in the House of Representatives sponsored by Representative Lowey) prohibits employment discrimination, but permits employers to "collect" genetic information after making an offer of employment or if the information is job-related and consistent with business necessity, once consent has been obtained from the employee.[83] Representative Kennedy's bill would amend the Fair Labor Standards Act to prohibit the use of genetic information by employers unless they receive authorization from the employee.[84] In addition, Senator Pete Domenici (R. N.M.) and Representative Cliff Stearns (R. Fla.) have sponsored bills that include protection from genetic discrimination in the workplace within broader protections of genetic information.[85] Senator Domenici has proposed a far-ranging bill that defines genetic information broadly, gives individuals property rights over their DNA samples, prohibits disclosure of genetic information absent informed consent in most settings, and imposes strict limits on insurers' use of genetic information in their coverage decisions. Representative Stearns's bill also proposes to regulate genetic information broadly, but limits protection for genetic testing to certain instances and does not explicitly prohibit insurers from requiring people to disclose genetic information or from varying premiums on the basis of genetic information.

In January 1998, the Clinton administration called for legislation banning genetic discrimination in the workplace.[86] The guiding principles for the proposed legislation would generally prohibit employers (1) from requiring workers to take a genetic test or to provide genetic information as a condition of employment or benefits; (2) from using genetic information to discriminate against, limit, segregate, or classify workers; and (3) from disclosing genetic information. It would allow employers to monitor employees for the effects of a particular substance found in the workplace, exposure to which could cause genetic damage, but only with the employee's informed consent and assurance of confidentiality. Test results could be used only to identify and control adverse conditions in the workplace and to prevent risk of harm. Genetic information maintained under these circumstances also would have to be kept in medical files separate from personnel files.

Conclusion

Although advances in genetic research and technology portend tremendous benefits for humankind in medicine and science, adequate protections need to be in place to ensure that such technology will not be used for the wrong reasons. The use of genetic testing and/or genetic information to exclude qualified individuals from the workplace should be illegal. The ADA provides protection from workplace discrimination against individuals with disabilities and individuals who are regarded as disabled, including people with genetic predispositions. And yet, to date, no court has ruled on this issue. Moreover, genetic information is a very powerful tool that can be used by employers to preclude an otherwise qualified individual from getting or holding a job.

A job action based on a genetic predisposition is rooted in an employer's fears, myths, and stereotypes, rather than in an employee's ability to do the job, and therefore constitutes unlawful discrimination. As developing technology is increasingly able to reveal individuals' genetic predisposition for mental and physical disabilities and disorders, additional protections will be necessary to ensure that genetic information is not misused in the workplace. In the area of genetic technology, we are traveling down an unknown road. As new situations are posed by the rapid development of genetic technology, a flexible approach must be adopted to ensure that civil rights will continue to be protected. Courts will need to utilize the flexible structure of the ADA to apply its protections to those who are deprived of employment opportunities and regarded as disabled simply on the basis of genetic markers. In addition, state and federal legislation should be adopted to provide additional protections in this ever expanding area. In this way, one's genotype will not substitute for one's qualifications.

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References

1. The Human Genome Project (HGP) is a coordinated, international research effort, jointly managed by the U.S. Department of Energy and the National Institutes of Health, to analyze the structure of human DNA and to map and sequence the estimated 50,000 to 100,000 human genes. The HGP will improve technology for biomedical research and influence medicine, including reproductive planning, prenatal diagnosis and treatment, and preventive and therapeutic health treatment for a range of genetically related illnesses. Recognizing that the acquisition and use of genetic information has enormous individual and societal implications, analysis of the ethical, legal, and social implications of genetic knowledge has been an im-

portant component of the HGP research effort. For a discussion of the HGP, see, for example, National Human Genome Research Institute, *The Human Genome Project* (visited Oct. 27, 1998) < http://www.nhgri.nih.gov/HGP>; A. Patrinos and D.W. Drell, "Introducing the Human Genome Project: Its Relevance, Triumphs, and Challenges," *The Judges' Journal*, 36 (1997): 3, 5–10; and M.A. Rothstein, "Genetic Discrimination in Employment and the Americans with Disabilities Act," *Houston Law Review*, 29 (1992): at 24–25.

2. See S. Armour, "Workers Fear Genetic Discrimination," *USA Today*, Feb. 25, 1998, at 4B.

3. See Joint Report of Department of Labor, Department of Health and Human Services, Equal Employment Opportunity Commission, and Department of Justice, *Genetic Information and the Workplace*, at 2 (Jan. 20, 1998) (unpublished) (citing Harris Poll, no. 34 (1995)).

4. See E.V. Lapham, C. Kozma, and J.O. Weiss, "Genetic Discrimination: Perspectives of Consumers," *Science*, 274 (1996): at 621–24 (noting that survey findings are applicable only to the group studied because volunteers for this study were recruited through genetic support groups and did not constitute a statistically representative sample). The Health Insurance Association of America, which represents approximately 200 health insurers and managed care corporations, contends that fears of genetic discrimination are "overblown," because existing surveys of discrimination are usually self-selected, based on individual's perceptions of discrimination, and not statistically representative samples. See K.C. Swanson, "New Tests, New Concerns," *National Journal*, Jan. 4, 1996, at 29; and Health Insurance Association of America, *Genetic Testing: Media Kit* (visited Oct. 27, 1998) <http://www.hiaa.org/newsroom/genetic.html#1> (criticizing the study by E. Virginia Lapham, Chahira Kozma, and Joanne Weiss, *id.*, in particular).

5. See Lapham, Kozma, and Weiss, *id.*

6. See *id.*

7. Cystic fibrosis is an inherited multisystem disorder that is characterized by abnormal functioning of the endocrine gland and results in chronic progressive disease of the respiratory system for nearly all patients. See E. Braunwald et al., eds., *Harrison's Principles of Internal Medicine* (New York: McGraw-Hill, 11th ed., 1987): at 1085–86.

8. Huntington's disease is an untreatable, hereditary autosomal disorder that is characterized by involuntary movements and progressive dementia. See *id.* at 2014–15.

9. See Lapham, Kozma, and Weiss, *supra* note 4.

10. See Joint Report, *supra* note 3, at 2–3.

11. See K. Rothenberg et al., "Genetic Information in the Workplace: Legislative Approaches and Policy Changes," *Science*, 275 (1997): at 1755–57; Lapham, Kozma, and Weiss, *supra* note 4, at 621 (noting that fears of genetic discrimination may affect the number of individuals willing to participate in scientific research); and L. Gostin, "Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers," *American Journal of Law & Medicine*, XVII (1991): at 113 (noting that benefits of genetic data collection will not be achieved if fear of discrimination deters people from genetic diagnoses).

12. See G. Kolata, "Advent of Testing for Breast Cancer Genes Leads to Fears of Disclosure and Discrimination," *New York Times*, Feb. 4, 1997, at C1.

13. As Karen Rothenberg has noted, this lack of data is not surprising because there is an inherent problem in documenting actual genetic discrimination: because individuals must reveal that they have, or are at risk for, genetic abnormalities in order to register a discrimination complaint, many will not file a complaint because they have too much to lose by revealing this confidential information. See S.M. Kopinsky, "Genetic Discrimination is Less Widespread than Feared," *Health Care News Server* (Nov. 20, 1997) <http://www.healthcarenewsserver.com/stories/HCN1997112000021.shtml> (reporting Rothenberg's comments at an October 29, 1997 panel on Genetic Testing in the Marketplace).

14. See, for example, P.R. Billings et al., "Discrimination as a Consequence of Genetic Screening," *American Journal of Human Genetics*, 50 (1992): 476–82 (describing anecdotal evidence of discrimination against individuals based on "apparent or perceived" genetic abnormalities); Armour, *supra* note 2, at 4B (citing statements by that director of National Center for Genome Resources that people have lost jobs because of genetic discrimination).

15. See L.N. Geller et al., "Individual, Family, and Societal Dimensions of Genetic Discrimination: A Case Study Analysis," *Science & Engineering Ethics*, 2, no. 1 (1996): at 71–88.

16. See S. Page, "White House: Ban Gene Bias in Workplace," *USA Today*, Jan. 20, 1998, at A1.

17. See Lapham, Kozma, and Weiss, *supra* note 4.

18. See *id.*

19. See Kopinsky, *supra* note 13 (citing results of survey by Dorothy Wertz and colleagues at the Shriver Center for Mental Retardation, in Massachusetts).

20. See *id.*

21. Americans with Disabilities Act, 42 U.S.C. §§ 12111–12117 (1994).

22. See *id.* § 12112(a).

23. See *id.* § 12102(2).

24. See *id.* § 12112(b)(5).

25. See *id.* § 12111(5)(A).

26. See, for example, *Harris v. H & W Contracting Co.*, 102 F.3d 516 (11th Cir. 1997) (noting that an individual with Graves disease is covered by the Americans with Disabilities Act (ADA)); *Gilday v. Mecosta County*, No. 96-1571, 1997 U.S. App. LEXIS 33306 (6th Cir. Sept. 2, 1997) (noting that an individual with diabetes is covered by the ADA); and *Matczak v. Frankford Candy and Chocolate Co.*, 136 F.3d 933 (3rd Cir. 1997) (noting that an individual with epilepsy is covered by the ADA).

27. See R.S. Olick, "Genes in the Workplace: An Ethical and Legal Analysis of Genetic Discrimination Under the Employment Provisions of the Americans with Disabilities Act," Obermann Summer Seminar, 10 (1997) (unpublished) (on file with author); and M.S. Dichter and S.E. Sutor, "The New Genetic Age: Do Our Genes Make Us Disabled Individuals Under the Americans with Disabilities Act?," *Villanova Law Review*, 42 (1997): 613–33.

28. See Olick, *id.* at 10. The U.S. Supreme Court recently held in *Bragdon v. Abbott*, No. 97-156, 1998 WL 332958, at *5–*11 (U.S. June 25, 1998), that a person with asymptomatic human immunodeficiency virus (HIV) is an "individual with a disability" covered under the ADA. The Court reasoned that asymptomatic HIV is, in fact, a "physical impairment" that substantially limits the major life activity of reproduction. Because the Court found HIV to constitute a physical impairment in that it causes abnormalities in an infected person's hemic and lymphatic systems from the moment of infection, the reasoning of this case does extend to asymptomatic genetic conditions. An individual with a genetic predisposition is a person with a genetic marker for a particular trait, who may or may not develop the trait, disorder, or disease. Compare 1998 WL 332958, at *23 (Rehnquist, C.J., concurring in part and dissenting in part). For further analysis of *Bragdon v. Abbott*, see W.E. Parmet, "The Supreme Court Confronts HIV: Reflections on *Bragdon v.*

Abbott," *Journal of Law, Medicine & Ethics*, 26 (1998): 225–40.

29. See 2 *EEOC Compliance Manual (CCH)*, § 902 (Mar. 14, 1995).

30. See *id.*

31. See *id.*

32. *Id.* §§ 902–46.

33. See Dichter and Sutor, *supra* note 27, at 631.

34. See *id.* at 630–31; and *EEOC Compliance Manual*, *supra* note 29, at §§ 902–45.

35. The sickle cell trait originates through inheritance of an unstable hemoglobin variant (Hb S). The abnormality occurs almost exclusively in persons of color. About 8 percent of black Americans are heterozygous for Hb S. Although the genetic abnormality may give rise to congenital hemolytic anemia, Hb S carriers generally have minimal clinical problems. See Braunwald et al., *supra* note 7, at 1519. See also *Jones v. Inter-County Imaging Ctrs.*, 889 F. Supp. 741, 744 (S.D.N.Y. 1995) (holding that the plaintiff stated a valid claim under the ADA when he alleged that he was terminated by his employer because the employer believed that his sickle cell condition would adversely affect future work attendance).

36. See, for example, *Anderson v. Gus Mayer Boston Store*, 924 F. Supp. 763, 769 (E.D. Tex. 1996); 889 F. Supp. at 744; and *Sawinski v. Bill Currie Ford, Inc.*, 866 F. Supp. 1383, 1387 (M.D. Fla. 1994).

37. See, for example, Dichter and Sutor, *supra* note 27 (arguing that courts should refrain from interpreting the ADA to provide protection to individuals with genetic disorders that are currently asymptomatic).

38. See F.H. Miller and P.A. Huvos, "Genetic Blueprints, Employer Cost-Cutting, and the Americans with Disabilities Act," *Administrative Law Review*, 46 (1994): at 375–77).

39. See Gostin, *supra* note 11, at 109.

40. See Olick, *supra* note 27, at 14–16; and Rothenberg et al., *supra* note 11.

41. See 42 U.S.C. § 12112(d)(2)(A) (1994).

42. See *id.* § 12112(d)(2)(B).

43. See *id.* § 12112(d)(3)(A).

44. *Id.* § 12112(d)(4)(A).

45. See *id.* § 12112(d)(3)(B).

46. See Olick, *supra* note 27, at 14–16.

47. Civil Rights Act of 1964, 42 U.S.C. § 2000e (1994).

48. See Rothstein, *supra* note 1, at 32.

49. Tay-Sachs disease is a relatively common inborn error of metabolism with thousands of documented cases. The trait is associated with a deficiency of hexosaminidase A, a protein activator. The features are similar in all carriers, beginning in the third to sixth month of infancy with rapid neurological deterioration. Ashkenazi Jews are about 100 times more likely than other ethnic groups to carry the Tay-Sachs trait. See Braunwald et al., *supra* note 7, at 1667–68. See, for example, *Smith v. Olin Chemical Corp.*, 555 F.2d 1283, 1284–85 (5th Cir. 1977) (claiming that the plaintiff's dismissal was due to suspected sickle cell disease; alleging disparate impact race discrimination in violation of Title VII); and *Peoples v. City of Salina*, No. 88-42800-S, 1990 U.S. Dist. LEXIS 4070, at *1 (D. Kan. Mar. 20, 1990) (claiming dismissal based on employer's fears of sickle cell trait). One commentator has even suggested that discrimination in employment based on late-onset genetic conditions could constitute disparate impact age discrimination, in violation of the Age Discrimination in Employment Act, 29 U.S.C. §§ 621–634. See Rothstein, *supra* note 1, at 32 n.44.

50. See Gostin, *supra* note 11, at 138.

51. See *id.*; Rothstein, *supra* note 1, at 32; and K.A. Deyerle, "Genetic Discrimination in the Workplace: Employer Dream, Employee Nightmare—Legislative Regulation in the United States and the Federal Republic of Germany," *Comparative Labor Law Journal*, 18 (1997): at 568 (citing *Olin Chemical*, 553 F.2d 1283).

52. See Deyerle, *id.* at 567–68.

53. *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, 135 F.3d 1260 (9th Cir. 1998).

54. See *id.* at 1267–68.

55. See *id.* at 1269–71.

56. See *id.* at 1272–73.

57. See *id.* at 1273–74.

58. See *id.* at 1273. Under the ADA, an employer may condition an offer of employment based on the results of a medical examination if (1) the examination is given to all entering employees; (2) the results are kept confidential; and (3) the examination is not used to discriminate against individuals with disabilities, unless the results make the individual unqualified for the job. See 42 U.S.C. § 12112(c)(3) (1994).

59. *Mayfield v. Dalton*, 109 F.3d 1423 (9th Cir. 1997).

60. See *id.* at 1425.

61. See *id.*

62. Health Insurance Portability and Accountability Act, Pub. L. No. 104-191, 110 Stat. 1936 (1996).

63. For a discussion of the issue of gathering and use of medical information in general, see R.C. Turkington, "Medical Record Confidentiality: Law, Scientific Research, and Data Collection in the Information Age," *Journal of Law, Medicine & Ethics*, 25 (1997): at 122–26.

64. Arizona, Florida, Illinois, Iowa, Louisiana, New Hampshire, New Jersey, New York, North Carolina, Oregon, Rhode Island, Texas, and Wisconsin. See discussion below for specific statutes.

65. See Fla. Stat. Ann. § 448.075 (1998).

66. See N.C. Gen. Stat. § 95-28.1 (1997). The hemoglobin C trait (Hb C) is related to sickle cell disorders. Although the gene frequency for Hb C is only one-fourth that for Hb S, the prevalence of sickle cell–related symptoms and illness is far greater. The tendency of sickle cell red cells to sickle, compared with sickle cell traits, can be explained by two phenomena: increased intercellular hemoglobin concentration and significantly higher percentage Hb S. See Braunwald et al., *supra* note 7, at 1522–23.

67. See La. Rev. Stat. Ann. § 23:352 (West 1998).

68. See N.J. Stat. Ann. §§ 10:5-5(x), :5-12 (West 1998). The thalassemias are a diverse group of congenital disorders in which there is a defect in the synthesis of one (or more) of the subunits of hemoglobin. As a result of the decreased production of hemoglobin, the red blood cells are microcytic and hypochromic. Thalassemias can lead to a variety of conditions, from subtle abnormalities to life-threatening disease. The two types of thalassemias are classified as α-chain thalassemia and ß-chain thalassemia. Normal individuals inherit two α-chain genes from each parent. The great majority of cases of α-chain thalassemia result from deletion or impaired production of α-chain genes. See Braunwald et al., *supra* note 7, at 1525–26.

69. See N.Y. Civ. Rights Law §§ 48, 48-a (Consol. 1998). Normal individuals inherit only a *single* ß-chain gene from each parent. In persons who inherit the genetic ß-thalassemia trait, the ß-chains have normal structure but are produced at greatly reduces rates. The gene frequency for ß thalassemia approaches 0.1 in southern Italy and certain Mediterranean islands. Beta thalassemia is also encountered quite commonly in central Africa, Asia, and the south Pacific. See Braunwald et al., *supra* note 7, at 1525–27.

70. See Ariz. Rev. Stat. Ann. § 41-1463(B) (West 1998); Iowa Code Ann. § 729.6 (West 1997); N.H. Rev. Stat. Ann. § 141-H:3.I(b) (1997); Or. Rev. Stat. § 659.036(1) (1997); R.I. Gen. Laws § 28-6.7-1(a) (1997); Tex. Lab. Code Ann. §§ 21.401(2), .402(a)(1) (West 1998); and Wis. Stat. § 111.372 (1997).

71. See Iowa Code Ann. § 729.6.2.a; N.H. Stat. Ann. § 141-H:3.I(a); Or. Rev. Stat. § 659.227(1); R.I. Gen. Laws § 28-6.7-1(a)(1); Tex. Lab. Code Ann. § 21.402(a)(2); and Wis. Stat. § 111.372(1)(a).

72. See Iowa Code Ann. § 729.6.4; N.H. Stat. Ann. § 141-H:3.III; and Wis. Stat. § 111.372(3).

73. See Iowa Code Ann. § 729.6.2.b; R.I. Gen. Laws § 28-6.7-1(a)(2); and Wis. Stat. § 111.372(1)(b).

74. See Iowa Code Ann. § 729.6.7; N.H. Stat. Ann. § 141-H:3.IV; and Wis. Stat. § 111.372(4).

75. Iowa Code Ann. § 729.6.1.c.

76. N.J. Stat. Ann. § 10:5-12 (West 1998).

77. *Id.* § 10:5-5(oo).

78. N.Y. Exec. Law § 296 (Consol. 1998); and N.C. Gen. Stat. § 95-28.1A (1997).

79. See N.Y. Exec. Law § 292.21-b ("'Genetic predisposition' shall mean the presence of a variation in the composition of the genes of an individual or an individual's family member which is scientifically or medically identifiable and which is determined to be associated with an increased statistical risk of being expressed as either a physical or mental disease or disability in the individual or having offspring with a genetically influenced disease, *but which has not resulted in any symptoms of such disease or disorder.*" (emphasis added)); and N.C. Gen. Stat. § 95-28.1A(b) (similar).

80. For example, Florida regulates genetic testing and prohibits genetic testing except with the informed consent of the individual to be tested, and provides that the results of such tests may not be disclosed without the consent of the tested individual. See Fla. Stat. Ann. § 760.40(2)(a) (1998). See also 410 Ill. Comp. Stat. § 513/15-30 (West 1998) (Illinois statute regulating confidentiality and disclosure of genetic information); Tex. Lab. Code Ann. § 21.403 (West 1998) (prohibiting disclosure of genetic information unless specifically authorized by the individual); and Wis. Stat. § 942.07 (1997) (prohibiting employers, labor organizations, employment agencies, and licensing agencies from disclosing the results of an individual's genetic test without individual's written informed consent).

81. See Fla. Stat. Ann. § 760.40(2)(a). See also 410 Ill. Comp. Stat. § 513/15-30.

82. In addition to the bills discussed below, see also, H.R. 3299, 105th Cong. (1998) (establishing limits on use of genetic information in health insurance coverage and employment, introduced by Representative Linda Smith (R. Wash.)).

83. See Genetic Justice Act, S. 1045, 105th Cong. (1997); and Genetic Employment Protection Act of 1997, H.R. 2275, 105th Cong. (1997).

84. See Genetic Nondiscrimination in the Workplace Act, H.R. 2215, 105th Cong. (1997).

85. See Genetic Confidentiality and Nondiscrimination Act of 1997, S. 422, 105th Cong. (1997); and Genetic Privacy and Nondiscrimination Act of 1997, H.R. 2198, 105th Cong. (1997).

86. See Joint Report, *supra* note 3, at 8–9; and C. Harris, "Gore Pushes Bill to Outlaw Genetic Bias," *Federal Times*, Mar. 2, 1998, at 4.