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Genetic Information and the Workplace - Full Report

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Comments

Joint Agency Report

GENETIC INFORMATION AND THE WORKPLACE - Full Report

Recent advances in genetic research have made it possible to identify the genetic basis for human diseases, opening the door to individualized prevention strategies and early detection and treatment. These advances hold much promise for improving health. However, genetic information can also be used unfairly to discriminate against or stigmatize individuals on the job. For example, people may be denied jobs or benefits because they possess particular genetic traits--even if that trait has no bearing on their ability to do the job. In addition, since some genetic traits are found more frequently in specific racial or ethnic groups, such discrimination could disproportionately affect these groups. This report demonstrates why American workers deserve federal legislation to protect them from genetic discrimination in the workplace.

The Promise of Genetic Information

Unprecedented progress in identifying and understanding the 50,000 to 100,000 or so genes that make up the human genome provides an opportunity for scientists to develop strategies to prevent or reduce the effects of genetic disease. Scientists have shown that straightforward inherited errors in our genes are responsible for an estimated 3,000 to 4,000 diseases, including Huntington's disease, cystic fibrosis, neurofibromatosis, and Duchenne muscular dystrophy. More complex inheritance of multiple genetic errors also can increase an individual's risk of developing common disorders such as cancer, heart disease, and diabetes. Genetic technologies, such as simple DNA tests, increasingly are becoming available to identify people who might have an increased likelihood of developing a disorder. The majority of diseases Americans encounter, however, do not result solely from genetic predisposition but from the interaction of genes with environmental factors, including occupation, diet, and lifestyle. Consequently, genetic tests alone cannot predict with certainty whether a person with a particular genetic error will in fact develop a disease.

With tools from the Human Genome Project, a new gene discovery is reported nearly every week. For example, scientists recently reported the discovery of a genetic alteration that, in early studies, appears to double a person's risk of colon cancer. The genetic alteration, which can be identified with a \$200 blood test, is most prevalent among Jews of Eastern European descent. Once identified, people who carry this mutation can use regular colon examinations to detect cancer growth early when it is most easily treated.

Where effective means of early detection and treatment have been established, knowledge of genetic alterations can help a person prevent or reduce the likelihood of illness, and in some instances actually reduce health care costs. For example, genetic testing for hemochromatosis,⁽¹⁾ glaucoma, and some cancers can alert the individual to begin preventive measures before the disease causes harm.

Genetic Information and Discrimination

There are several ways to gather genetic information. It can be deduced from a family's medical history or during a physical examination. Routine laboratory tests that measure the body's output of specific substances might also suggest the genetic make-up of the individual. But the most direct approach to obtaining genetic information is through analysis of DNA, the material that makes up genes. Such genetic tests identify specific DNA features in people who have already developed a disease, in healthy people who *may* be at risk of developing a genetic disorder later in life, or in people who are at risk of having a child with an inherited disorder. Thus, genetic information includes information about genes, gene products, and inherited characteristics that may derive from individuals or their family members.

While genetic technology increases the ability to detect and prevent health disorders, it can also be misused to discriminate against or stigmatize individuals. A 1996 survey of individuals at risk of developing a genetic condition and parents of children with specific genetic conditions identified more than 200 cases of genetic discrimination among the 917 people who responded. The cases involved discrimination by insurance companies, employers, and

other organizations that use genetic information.⁽²⁾ Another recent survey of genetic counselors, primary care physicians, and patients, identified 550 people who had been denied employment or insurance based on their genetic predisposition to an illness.⁽³⁾ In addition, because an individual's genetic information has implications for his or her family members and future generations, misuse of genetic information could have intergenerational effects that are far broader than any individual incident of misuse.

Many Americans are reluctant to take advantage of new breakthroughs in genetic testing for fear that the results will not be used to improve their health but rather to deny them jobs or health insurance.

- A 1995 Harris poll of the general public found that over 85 percent of those surveyed indicated they were very concerned or somewhat concerned that insurers or employers might have access to and use genetic information.⁽⁴⁾
- Sixty-three percent of the participants in a 1997 national telephone survey⁽⁵⁾ of more than 1000 people reported that they would not take genetic tests for diseases if health insurers or employers could get access to the results. Eighty-five percent felt that employers should be prohibited from obtaining information about an individual's genetic conditions, risks, and predispositions.
- Researchers conducting a multi-year Pennsylvania study designed to understand how to keep women with breast cancer gene mutations healthy reported that nearly one-third of the high-risk women invited to participate in the study refused because they feared discrimination or a loss of privacy.⁽⁶⁾
- Another study of 332 people who belonged to support groups for families with genetic disorders found that fear of genetic discrimination resulted in 17 percent of the participants not revealing genetic information to employers.⁽⁷⁾

In addition, people have hidden genetic information about themselves due to fear of the effects of disclosure. For example, an 18-year-old man, at risk for inheriting Huntington's disease from one of his parents, who wished to enlist in the Marines to serve in the Persian Gulf War, believed that knowledge of his risk status would disqualify him from service, even though it was unlikely that he would become symptomatic during his tour of duty. He therefore answered "no" to questions regarding hereditary disorders on his application and did not include Huntington's disease in his family medical history.⁽⁸⁾ Another individual whose parent died of Huntington's disease also chose to hide the truth from his employer. Fearing adverse consequences at work if this cause of death was known, the individual arranged for the diagnosis of asphyxiation to be reported as the cause of death to avoid mention of the disease in an obituary.⁽⁹⁾ Fear of genetic discrimination and the consequences of this fear have been reported in both the scientific literature and the popular press.

Genetic Information in the Workplace

Two types of genetic testing can occur in the workplace: genetic screening and genetic monitoring. Genetic screening examines the genetic makeup of employees or job applicants for specific inherited characteristics. It may be used to detect general heritable conditions that are not associated with workplace exposures in employees or applicants. For example, employers used genetic screening in the early 1970s to identify African Americans who carried a gene mutation for sickle cell anemia. Those carrying the gene mutation were denied jobs—even though many of them were healthy and would never develop the disease. In these cases, genetic screening to identify the sickle cell trait often occurred without the consent of the individuals.

Genetic screening can also be used to detect the presence of genetically determined traits that render an employee susceptible, or "hypersusceptible," to a certain disease if exposed to specific environmental factors or substances that may be present in the workplace. In theory, genetic screening for occupationally relevant traits has the potential to be used to assign employees who are genetically susceptible to certain occupational diseases away from harmful exposure. However, no consensus currently exists regarding the validity of the scientific evidence or the usefulness of the genetic tests reported to predict an individual's susceptibility to exposure.

Genetic monitoring, a second type of testing, ascertains whether an individual's genetic material has changed over

time due to workplace exposure to hazardous substances. Evidence of genetic changes in a population of workers could be used to target work areas for increased safety and health precautions and to indicate a need to lower exposure levels for a group exposed to a previously unknown hazard. The ultimate goal of genetic monitoring is to prevent or reduce the risk of disease caused by genetic damage.

Although genetic changes such as chromosomal damage have been associated with exposure to radiation and some chemical mutagens or carcinogens, little is known about which changes are predictive of subsequent disease risk. Much more research is required to establish the relationship, if any, between those changes and subsequent disease risk for affected populations and individuals. For this reason, use of genetic monitoring results to make employment decisions is rarely justifiable.

In addition, some employers may seek to use genetic tests to discriminate against workers—even those who have not yet or who may never show signs of disease—because the employers fear the cost consequences. Based on genetic information, employers may try to avoid hiring workers who they believe are likely to take sick leave, resign, or retire early for health reasons (creating extra costs in recruiting and training new staff), file for workers' compensation, or use health care benefits excessively. A 1989 survey of large businesses, private utilities, and labor unions found that 5 percent of the 330 organizations responding conducted genetic screening or monitoring of its workers.⁽¹⁰⁾ Another 1989 survey of 400 firms, conducted by Northwestern National Life Insurance, found that 15 percent of the companies planned, by the year 2000, to check the genetic status of prospective employees and their dependents before making employment offers.⁽¹¹⁾ Thus, there is evidence that genetic information continues to be used to discriminate against qualified workers. The economic incentive to discriminate based on genetic information is likely to increase as genetic research advances and the costs of genetic testing decrease.

Real People—Real Discrimination

Genetic predisposition or conditions can lead to workplace discrimination, even in cases where workers are healthy and unlikely to develop disease or where the genetic condition has no effect on the ability to perform work. As a result, real people are denied employment opportunities.

- One individual was screened and learned he was a carrier of a single mutation for Gaucher's disease.⁽¹²⁾ His carrier status indicates that he might pass this mutation to his children, but not that he would develop Gaucher's disease himself. He revealed this information when applying for a job and was denied the job because of his genetic mutation, even though it had no bearing on his present or future ability to perform a job.⁽¹³⁾
- A 53-year-old man at a job interview with an insurance company revealed that he had hemochromatosis but was asymptomatic. During the second interview, he was told that the company was interested in hiring him but would not be able to offer him health insurance because of his genetic condition. He agreed to this arrangement. During his third interview, the company representative told him that they would like to hire him, but were unable to do so because of his genetic condition.⁽¹⁴⁾
- An employee's parent developed Huntington's disease—indicating that the employee had a 50 percent chance of inheriting the mutated gene that would cause her to develop the disease. She decided to be tested. A genetic counselor advised her to secure life and health insurance before testing, because a positive test result would not only mean that she would get the disease but would probably prevent her from obtaining insurance as well. A co-worker who overheard her making arrangements to be tested reported the employee's conversations to their boss. Initially, the boss seemed empathetic and offered to help. When the employee eventually shared the news that her test results indicated that she did carry the mutated gene, she was fired from her job. In the 8-month period prior to her termination, she had received three promotions and outstanding performance reviews. Frightened by their sister's experience, none of her siblings are willing to undergo genetic testing for fear of losing health insurance or jobs. Consequently, they must live with the uncertainty of not knowing whether they have inherited the genetic trait that leads to Huntington's disease.⁽¹⁵⁾

Efforts to Restrict Use of Genetic Information in the Workplace

There is no scientific evidence to substantiate a relationship between unexpressed genetic factors and an individual's ability to perform his or her job. Thus, most expert groups recommend prohibiting or severely restricting the use of genetic testing and access to genetic information in the workplace. The American Medical Association's (AMA) Council on Ethical and Judicial Affairs concludes that it is inappropriate to exclude workers with genetic risks for disease from the workplace because of that risk.⁽¹⁶⁾ In the future, however, the AMA Council acknowledges there may be an appropriate but limited role for genetic testing in certain situations to protect workers who have a genetic susceptibility to occupational illness when health risks can be accurately predicted by the test.

The National Action Plan on Breast Cancer (NAPBC) and the National Institutes of Health—Department of Energy Working Group on Ethical, Legal and Social Implications of Human Genome Research also has drafted recommendations for state and federal policy makers to protect against genetic discrimination in the workplace. Generally, the recommendations limit the collection, disclosure, and use of genetic information and support strong enforcement of these limitations through governmental agencies or private right of action. Exceptions are made for possible situations in the future that may arise if testing is shown to be scientifically valid to predict occupational risk and situations where an individual is unable to meet the performance requirements of a job.⁽¹⁷⁾

Existing Protections are Limited

There are no federal laws that directly and comprehensively protect against abuses in the gathering or use of genetic information in the workplace. A few protections exist incidentally under federal laws enacted to address other types of workplace discrimination. The incidental federal protections against workplace discrimination based on genetic information that do exist are narrow in scope and, in large measure, not well established. They are not sufficient to provide Americans with adequate protection against genetic discrimination in the workplace. States continue to enact legislation in response to growing concern over the specter of genetic discrimination in the workplace. Existing state laws, however, differ in coverage, protections afforded, and enforcement schemes. Federal leadership is necessary to ensure that all workers are protected against discrimination based on genetic information.

Federal Laws

The only federal law that directly addresses the issue of genetic discrimination is the 1996 Health Insurance Portability and Accountability Act (HIPAA). HIPAA prohibits group health plans from using any health status-related factor, including genetic information, as a basis for denying or limiting eligibility for coverage or for charging an individual more for coverage. In addition, the Administration has worked closely with Congress on legislation that would prevent an insurance company or HMO from disclosing genetic information or charging an entire plan or group more for health insurance on the basis of genetic information. These efforts, however, do not address the larger problems of the gathering or use of genetic information in the workplace outside of the health insurance context.

The most likely current source of protection against genetic discrimination in the workplace is provided by laws prohibiting discrimination based on disability. Title I of the Americans with Disabilities Act (ADA), enforced by the Equal Employment Opportunity Commission (EEOC), and similar disability-based anti-discrimination laws, such as the Rehabilitation Act of 1973, do not explicitly address genetic information, but they provide some protections against disability-related genetic discrimination in the workplace. Under the ADA, individuals with symptomatic genetic disabilities have the same protections against discrimination as individuals with other disabilities. However, as we make new advances in genetics, this protection will not be sufficient. More and more people will be vulnerable to genetic discrimination based on unexpressed genetic conditions that do not fall within the clear disability-based discrimination prohibitions of the ADA.

Protection against discrimination based on genetic information for those who do not currently have a symptomatic

genetic disability is not well established. Individuals who do not currently have a symptomatic genetic disorder and, therefore, may not be protected against discrimination as a currently disabled person include unaffected carriers of a disease who may never get the disease themselves, individuals with late-onset genetic disorders who may be identified through genetic testing as being at high risk of developing the disease, and others who are identified through family history as being at high risk of developing the disease.

The EEOC has tried to provide ADA protection to individuals who do not have symptomatic genetic disabilities but who may be subject to discrimination based on genetic information. In 1995 the EEOC issued enforcement guidance advising that an employer who takes adverse action against an individual on the basis of genetic information relating to illness, disease, or other disorders regards that individual as having a disability within the meaning of the ADA.⁽¹⁸⁾ The ADA prohibits discrimination against a person who is regarded as having a disability. The guidance, however, is limited in scope and legal effect. It is policy guidance that does not have the same legally binding effect on a court as a statute or regulation and has not been tested in court. Moreover, many cases based on the argument that an employer has discriminated against workers by regarding them as disabled have not been well-received by the courts.⁽¹⁹⁾

In addition, the ADA does not protect workers from requirements or requests to provide genetic information to their employers. Under the ADA, an employer generally may not make medical inquiries about a job applicant prior to extending a conditional offer of employment. However, once a conditional offer of employment has been extended, but before the individual begins work, the employer may obtain extensive medical information about the applicant, including genetic information. During this period an employer could, for example, obtain and store genetic samples of job applicants, require genetic screening as a condition of employment, or purchase genetic information about applicants from a genetic information data bank. In addition, once the applicant is hired the employer may request medical information that is job related and consistent with business necessity.

It is difficult to ensure that medical information is not used to discriminate. Detecting discrimination based on genetic information, which indicates a risk rather than a manifestation of disease, is particularly difficult. As a result, genetic information could be used to deny workers employment or opportunities regardless of their ability to do the job. This concern is especially significant because of the rapid advances in genetic research. For instance, genetic information obtained today may, in the future, be found to indicate a risk factor that could be the basis for discrimination. Moreover, this information also could be used to predict the health risks of an individual's family members--creating the potential that genetic information could be used to discriminate against future generations of workers.

Another federal law that may incidentally provide protection against some forms of genetic discrimination is Title VII of the Civil Rights Act of 1964. An argument could be made that genetic discrimination based on racially or ethnically linked genetic disorders constitutes unlawful race or ethnicity discrimination. Protection under Title VII, however, is only available where an employer engages in discrimination against a particular racial or ethnic group based on a genetic trait that is substantially related to a race or ethnic group. Since a strong nexus between race or national origin has been established for only a few diseases, Title VII will not be an effective tool for combating most forms of genetic discrimination. Thus, it is clear that current anti-discrimination laws would not adequately address the issue of genetic-based discrimination in employment.

State Laws

A number of states have addressed the issue of genetic discrimination in employment through state legislation. As of October 1997, 14 states had enacted laws to provide protections against various forms of genetic discrimination in the workplace. There are wide variations among these state laws.

Some of the first state laws enacted to address this issue prohibited discrimination against individuals with specific genetic traits or disorders, such as the sickle-cell trait (Florida and Louisiana) or the hemoglobin trait (North Carolina). Later laws cover broader categories of genetic traits and disorders. For example, a 1981 New Jersey statute (later broadened) prohibits discrimination in employment based on an "atypical hereditary cellular or blood trait," and a New York law prohibits employers from denying equal employment opportunities based on "unique genetic disorders."

Other state laws regulate both the use of genetic testing in employment decisions and the disclosure of genetic test results. These state laws generally prohibit employers from requiring workers and applicants to undergo genetic testing as a condition of employment.

For example, Oregon state law prohibits employers from using genetic information to distinguish between or discriminate against applicants and employees and prohibits employers from subjecting applicants and employees to genetic testing. A recently enacted Texas law prohibits employers, labor organizations, licensing agencies, and employment agencies from discriminating against any individual on the basis of the results of a genetic test or because of the individual's refusal to submit to genetic testing.

Some states permit genetic testing when it is requested by the worker or applicant for the purpose of investigating a worker's compensation claim or determining the workers' susceptibility to potentially toxic chemicals in the workplace. These statutes often require the worker to provide informed written consent for such testing and contain specific restrictions governing disclosure and prevent the employer from taking adverse action against the employee.

Given the substantial gaps in state and federal protections against employment discrimination based on genetic information, comprehensive federal legislation is needed to ensure that advances in genetic technology and research are used to address the health needs of the nation—and not to deny individuals employment opportunities and benefits. Federal legislation would establish minimum protections that could be supplemented by state laws.

The need for federal protection has been recognized by Congress with the introduction of numerous bills with bipartisan support. Three stand-alone bills have been introduced that amend existing civil rights or labor laws to protect workers against employment discrimination based on genetic information (S. 1045, Sen. Daschle; H.R. 2275, Rep. Lowey; H.R. 2215, Rep. Kennedy). Two additional bills have been introduced that include worker protections against discrimination based on genetic information, as part of broader proposals addressing the use of genetic information (S. 422, Sen. Domenici; H.R. 2198, Rep. Stearns).

Guiding Principles for Federal Action

Federal legislation is needed to ensure that knowledge gained from genetic research is fully utilized to improve the health of Americans and not to discriminate against workers. This legislation should provide a floor or minimum level of protection and allow existing state laws to provide greater protection. Workers should not be forced to avoid tests that can help prevent disease because of fear of discrimination. At the same time, we must preserve the ability of scientists to continue the research, including studies of occupational health and safety, that is so vital to expanding our knowledge of genetics and health.

The Administration proposes that Congress pass a law to ensure that discoveries made possible by the Human Genome Project are used to improve health and not to discriminate against workers or their families. Legislation generally should include the following basic protections against misuse of genetic information in the workplace.

- Employers should not require or request that employees or potential employees take a genetic test or provide genetic information as a condition of employment or benefits.
- Employers should not use genetic information to discriminate against, limit, segregate, or classify employees in a way that would deprive them of employment opportunities.
- Employers should not obtain or disclose genetic information about employees or potential employees under most circumstances.

Genetic testing and the use of genetic information by employers should be permitted in the following situations to ensure workplace safety and health and to preserve research opportunities. However, in all cases where genetic information about employees is obtained, the information should be maintained in medical files that are kept separate from personnel files, treated as confidential medical records, and protected by applicable state and federal laws.

- An employer should be permitted to monitor employees for the effects of a particular substance found in the workplace to which continued exposure could cause genetic damage under certain circumstances. Informed consent and assurance of confidentiality should be required. In addition, employers may only use the results to identify and control adverse conditions in the workplace and to take action necessary to prevent significant risk of substantial harm to the employee or others.⁽²⁰⁾
- The statutory authority of a federal agency or contractor to promulgate regulations, enforce workplace safety and health laws, or conduct occupational or other health research should not be limited.
- An employer should be able to disclose genetic information for research and other purposes with the written, informed consent of the individual.

These recommendations should apply to public and private-sector employers, unions, and labor–management groups that conduct joint apprenticeship and other training programs. Employment agencies and licensing agencies that issue licenses, certificates, and other credentials required to engage in various professions and occupations also should be covered.

Individuals who believe they have been subjected to workplace discrimination based on genetic information should be able to file a charge with the Equal Employment Opportunity Commission, Department of Labor, or other appropriate federal agency for investigation and resolution. The designated agency should be authorized to bring lawsuits in the federal courts to resolve those issues that would not settle amicably. The courts should have the authority to halt the violations and order relief, such as hiring, promotion, back pay, and compensatory and punitive damages, to the individual. Alternatively, an individual should be able to elect to bring a private lawsuit in federal or state court to obtain the same type of relief plus reasonable costs and attorney’s fees. In order to enforce these protections, the designated enforcement agency must be given sufficient additional resources to investigate and prosecute allegations of discrimination.

Endnotes

1. Hemochromatosis (H.H.) is an iron storage disorder that affects about 1 in 300 individuals of Northern European descent. The major symptoms of H.H.—liver cirrhosis, heart deterioration, and other organ failures—are caused by the accumulation of excess iron and do not occur until mid-life. Left untreated, the disease causes early death. Treatment by simple blood donation to remove excess iron allows people with H.H. to live a normal lifespan.
2. Lisa Geller, et al., “Individual, Family and Societal Dimensions of Genetic Discrimination: A Case Study Analysis,” *Science and Engineering Ethics*, Volume 2-1, 71-88 (1996).
3. J.C. Fletcher and D.C. Wertz, *Refusal of Employment or Insurance*, abstract for presentation made at the Annual Meeting of the American Society of Human Genetics, Baltimore, November 1, 1997.
4. Harris Poll, 1995 #34.
5. National Center for Genome Resources unpublished survey, 1997.
6. Gina Kolata, “Advent of Testing for Breast Cancer Genes Leads to Fears of Disclosure and Discrimination,” *The New York Times*, January 4, 1997.
7. E. Virginia Lapham, Chahira Kozma, Joan O. Weiss, “Genetic Discrimination: Perspectives of Consumers,” *Science*, Volume 274, 621-624 (1996).
8. Geller, et al.
9. Id.
10. U.S. Congress, Office of Technology Assessment, “Genetic Monitoring and Screening in the Workplace,” OTA-BA-455 (1990).

11. Gostin, "Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests By Employers and Insurers," *American Journal of Law, Medicine, and Ethics*; Volume 17- 1,2 (1991).
12. Gaucher's disease is an inherited metabolic disorder in which harmful quantities of a fatty substance called glucocerebroside accumulate in the spleen, liver, lungs, bone marrow, and, in rare cases, the brain. Carriers are unaffected, but the child of two carriers has a one in four chance of being affected. Highly effective enzyme replacement therapy (that reduces liver and spleen size and other abnormalities and successfully reverses other manifestations of the disorder) is available for patients with the most common form of the disease.
13. Paul R. Billings, et. al., "Discrimination as a Consequence of Genetic Testing," *American Journal of Human Genetics*, 50:476-482, 1992.
14. Lisa Geller, et. al., "Individual, Family and Societal Dimensions of Genetic Discrimination: A Case Study Analysis," *Science and Engineering Ethics*, Volume 2-1, 71-88 (1996)
15. *60 Minutes*, "Genetic Discrimination" segment, April 21, 1996.
16. Council on Ethical and Judicial Affairs, American Medical Association, "Use of Genetic Testing by Employers," *Journal of the American Medical Association*-1830 (1991).
17. Karen Rothenberg, et al. "Genetic Information and the Workplace: Legislative Approaches and Policy Challenges," *Science*, 1755-1757 (1997).
18. Equal Employment Opportunity Commission, Compliance Manual, vol. 2, Section 902, Order 915.002,902-45 (1995).
19. See *Farmland Foods*, 58 F.3d 382 (8th Cir. 1995); *Dutcher v. Ingalls Shipbuilding*, 53 F.3d 723 (5th Cir. 1995); *Hites v. Patriot Homes*, 904 F.Supp. 880 (N.D. Ind 1995).
20. See 29 CFR 1630.2(r). Under the Americans with Disabilities Act, the term "[d]irect threat" means "a significant risk of substantial harm to the health or safety of the individual or others that cannot be eliminated or reduced by reasonable accommodation."