

**GENETIC DISCRIMINATION IN THE WORKPLACE:
THE ADA AND BEYOND**

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ABSTRACT

Recent medical breakthroughs in medicine, such as the Human Genome Project, allow scientists to identify changes in a person's genetic material or screen them for inherited traits or tendencies. Known as "markers," these predispositions toward certain diseases predict the development of future diseases. This knowledge not only has the potential for the development of medical treatment, it also has the potential to allow someone's genetic makeup to be known by other persons, who may make decisions affecting that person's future. This article examines the current status of genetic information in the employment arena. It discusses legislative actions and judicial rulings that address the questions being raised by the parties involved in this issue, focusing on the efficacy of Americans with Disabilities Act to protect employees' rights.

In a democratic society, public policy attempts to balance the needs and rights of multiple, often conflicting, interests. Such policy is developed sequentially. As technical knowledge is gained and individual and group circumstances become known, legislators, specialists in technical fields, special-interest groups, and the courts maneuver their way through issues. For example, changes in forensic sciences, such as fingerprinting, polygraph testing, and DNA testing, have resulted in changes in policy in the criminal justice system [1]. In a corresponding field, employee selection policy standards have evolved since the

passage of the Title VII of the Civil Rights Act of 1964 to balance the interests of employers and applicants.

The introduction of new scientific knowledge tends to create moral and ethical issues and raise previously unconsidered questions. One such recent scientific breakthrough is the Human Genome Project, which resulted in the sequencing of the human genome. The journal *Nature* reported, "The sequencing of the human genome has been likened to landing on the moon, splitting the atom, and even inventing the wheel" [2, p. 80]. This breakthrough has been heralded as having the potential to revolutionize the diagnosis and treatment of many diseases. However, this breakthrough also has the potential to allow an individual's genetic makeup to be known by other persons, who may make decisions affecting that person's future.

This article examines the current states of genetic information in the employment arena. It discusses legislative actions and judicial rulings that address the questions being raised by the parties involved in this arena. It focuses on the issue of the efficacy of Americans with Disabilities Act to protect employees' rights in this arena.

THE HUMAN GENOME PROJECT

The Human Genome Project (HGP) is a federally funded project coordinated by the National Institutes of Health and the Department of Energy. One of the major outcomes of the effort to assign genes to specific chromosomes is the discovery of the genes that are responsible for certain diseases. The ultimate goal of the HGP is to develop viable gene therapies for diseases [3]. In pursuit of that goal, the HGP is developing genetic tests to detect "disease-related genotypes, mutations, phenotypes, and karyotypes for clinical purposes" [4, p. 1]. These tests can monitor individuals for changes in their material or screen them for identification of inherited traits or tendencies [1]. Known as "markers," these predispositions toward certain diseases may predict the development of future diseases. Two of the most widely lauded are the genetic markers for Huntington's disease and breast cancer.

The potential use of a person's genetic information goes far beyond the clinical realm, however. As with most technological progress, the identification of genetic mutations within individuals is fraught with complications from moral and legal points of view. People who take genetic tests to determine their own potential medical risks may be exposing themselves and their family to discrimination in insurance and employment [3].

Employers' Reasons for Testing

Preemployment testing of job applicants is widely used and accepted in the United States. The use of employment testing, as long as it is job-related, has been

upheld in the courts since *Griggs v. Duke Power* in 1971 [5]. Employers have the right and the responsibility to select those job applicants with the greatest potential to perform well, as long as that selection is done within the limits established by public policy. Antidiscrimination laws are built on the premise that applicants should be selected on job-related knowledge, skills, abilities, and other characteristics (KSAOs), not on race, gender, ethnicity, religion, age, or disability [6].

Beyond selecting employees for their performance potential, employers also face other pressures. Employers are regularly asked to balance the safety and health of their workforce with performance issues. They are responsible for the damage caused to third parties by persons acting in their employ and can be found negligent if they do not discover background information that could have been known. Workers' compensation programs put qualifications on payments based on the characteristics and behaviors of the employee. Combining these pressures with the ever-increasing costs of health insurance coverage for employees, it is easy to see why employers want to know as much as they can about potential employees [7].

Even before the HGP, employers were gathering genetic information about potential and current employees. In 1991, the issue was whether employers should screen applicants/employees for genetic predispositions to develop diseases if exposed to certain worksite substances. For example, persons with a predisposition to sickle cell anemia are at increased risk if exposed to carbon monoxide or cyanide. Women capable of childbearing are at greater risk of complications during pregnancy from exposure to lead. The argument for genetic screening was that it would benefit employees, employers, and society as a whole, because workers could avoid worksite situations that would be more likely to make them ill, so they would be healthier and health-care costs (including workers' compensation) would be held down. Employees could make informed choices as to whether or not to take a job. Some even argued that employers who did not screen for high-risk employees could be held negligent for exposing these employees to risky substances because, under OSHA, employers have a duty to provide a safe workplace [8].

These arguments did not hold up, though. In one case, *Norman-Bloodsaw v. Lawrence Berkeley Laboratories*, the employer tested for sickle cell anemia, syphilis, and pregnancy without the consent of the employees [9]. The Ninth Circuit court ruled against the employer based on Title VII of the Civil Rights Act of 1964 and the Fourth Amendment, because only women and African-Americans were tested and they were not told of the tests [6].

The Americans with Disabilities Act

Many of the traits that could be tested for medically in 1990 were associated with membership in protected groups, such as sickle cell anemia and breast cancer.

As a consequence, the issues were settled under the U.S. Constitution and Title VII of the Civil Rights Act of 1964. The Americans with Disabilities Act (ADA) was passed by Congress in 1990 and phased into effect in 1992 and 1994. The ADA prohibits discrimination in employment on the basis of disability, which is defined as:

- a. a physical or mental impairment that substantially limits one or more major life activities;
- b. a record of such an impairment; or
- c. being regarded as having such an impairment [10, § 3(2)]

Employers cannot discriminate against a qualified individual with a disability who, with or without accommodation, can fulfill the essential functions of the job [10, § 101(8)].

The question that has not been determined is whether the ADA actually addresses genetic discrimination. The Equal Employment Opportunity Commission's (EEOC) compliance manual for the ADA states that discrimination based on genetic information is covered under the third prong ("regarded as") of the definition of disability, but there are several issues yet to be resolved. The courts do not abide by the EEOC's compliance manual and have so far interpreted the definition of disability very narrowly [11, 12]. Additionally, as stated above, using the "job-related" standard, after an offer has been made, the employer could test applicants for sensitivity to particular substances related to the essential functions of a job or for the potential of posing a threat. It is possible that a genetic marker may indicate predispositions to more than one medical disorder, some of which may not be job-related [6].

JUDICIAL RULINGS

Three cases have shed some light on the current status of genetic testing. As mentioned above, in the case of *Norman-Bloodsaw v. Lawrence Berkeley Laboratories* [9], the court ruled against unconsented-to testing for sickle cell anemia, syphilis, and pregnancy, based on Title VII of the Civil Rights Act of 1964 and the U.S. Constitution, but the ADA claim was dismissed [6].

In the case of *Echazabal v. Chevron*, Echazabal had hepatitis C, which is worsened by exposure to chemicals in the oil refinery industry [13]. He was asymptomatic, and his condition had not worsened while working for Chevron as a contractor. But when he applied to Chevron for employment, he was rejected because of his liver disease. The Ninth Circuit ruled in favor of Echazabal, but the Supreme Court remanded the case. The Supreme Court ruled 9-0 that Chevron did not have to hire him, because of the risk to his health. The Court said that by hiring employees whom they know will be injured by the job, employers would be complicit in injury to their employees [14]. Thus, under this ruling, the "danger" aspect of the ADA could be interpreted to mean "danger to self," not just

“danger to others.” The Court said that Chevron could apply the “danger to self” issue to an individual without being paternalistic because this was made in an individualized risk assessment as opposed to a group [15].

The first explicitly workplace “genetic discrimination” case was settled in 2002 [16]. Burlington Northern Santa Fe (BNSF) Railway tested employees who had complained of carpal tunnel syndrome (CTS) without their consent for a genetic marker believed to be predictive of CTS. In at least one case an employee was threatened with termination for refusing to submit to a blood test. Despite the fact that BNSF admitted no wrongdoing, it agreed to a mediated settlement resulting in payments of \$2.2 million dollars divided among 34 employees. The EEOC claims to have won based on the “regarded as” prong of the ADA [17]. Because BNSF was mediated, the courts did not have a say. The issue in the settlement appears to be largely that the tests were done without consent [6].

The Current State

Based on the court cases to date, no conclusion can be drawn concerning employees’ versus employers’ rights in the realm of genetic discrimination. There are at least three areas that must be ironed out in the legislatures and the courts. These have to do with privacy, the reliability and validity of the tests, and the state/federal statutes addressing these issues.

The acquisition and use of personal medical information by an employer highlights the privacy issue. What neither *Norman-Bloodsaw* nor *BNSF* settled was how much testing an employee must agree to. Once employers have the blood needed to run the tests for the job-related conditions, what is to keep them from gathering a little extra information? Once the extra data is collected, what is to keep them from looking at it? Even if they don’t intentionally discriminate, how can they “un-know” what they’ve seen?

Other issues that have not been addressed yet are the job-relatedness issue and the reliability/validity issue of genetic tests. An employee-selection theory based on the *Uniform Guidelines on Employee Selection Procedures* serves as a guideline to employers and to courts in establishing the reliability and validity of selection devices [18]. To date, these have not been applied to genetic tests in employment. For example, ADA does not define what standard of care a medical test has to meet to be job-related. Furthermore, how reliable and valid a predictor is a genetic test? To date, genetic screening has to do with “predictive genetics,” which is different from expressed genes. In layman’s words, genetic markers do not indicate with any level of certainty that an individual *will* get sick, only that there is a greater chance of that person getting sick. Such tests cannot, obviously, take into account environmental conditions or lifestyle choices by the person that might aggravate or mitigate the onset of the condition [6].

Another public policy issue is whether, even if we can predict, should we? It is widely known that pregnant employees will cost employers money by asking

for leave and using more health-care resources. However, as a society, the United States has decided that the Pregnancy Discrimination Act and the Family and Medical Leave Act should protect employees who want to have a family [6]. Genetic testing stigmatizes currently healthy people (and often their descendants) as defective [8]. In fact, the EEOC's position is that genetically predisposed individuals should be classified as "impaired" under the ADA, thus qualifying them for coverage. Do we as a society really want to label everyone with a genetic marker as "impaired"? Or, if genetic tests were to be mandated, would employees "lose their freedom not to know" [3, p. 450]. Alternatively, the fear of being labeled may lead people to not take advantage of screenings that are available.

BEYOND THE AMERICANS WITH DISABILITIES ACT

As stated above, to date it is unclear whether the ADA is sufficient to protect employees from genetic discrimination. Despite the EEOC's position that genetic discrimination is covered under the "regarded as" prong, some argue that the ADA is insufficient protection for genetic discrimination. How can a person be "regarded as" disabled when that person is not currently ill? In *Sutton v. United Airlines, Inc.*, the Supreme Court ruled that persons whose disability can be corrected (e.g., eyesight with eyeglasses) are not covered by the ADA [19]. Using the analysis from *Sutton* as a basis, it would seem that an employee could not be "regarded as" disabled based on genetic predispositions because no current major life activity is substantially limited [11, 20].

Additionally, according to Cooper, the ADA's privacy provision is not sufficient to prevent inquiries. Violations of privacy are not self-enforcing; employees must prove actual damages occurred from the breach of confidentiality [20]. So an employee must actually suffer damage from misuse of personal medical information before his/her privacy is covered by the ADA [20]. This leads again to the issues of "unknowing."

Attempts to clarify the issues not addressed by the ADA have resulted in a myriad of state laws. At least half of the states have laws that either prohibit genetic testing for insurance and employment decisions or protect against genetic discriminations [21]. (See Von Bergen, Evers, & Soper [1] for a discussion of specific state laws.) Generally state laws fall into three types [7]:

1. Based on sickle cell research, most states passed laws in the 1970s prohibiting discrimination in employment based on genetic characteristics. For example, North Carolina passed legislation in 1975 prohibiting employers from discriminating against any person possessing the traits for sickle cell anemia [22].

2. Some states prohibit employers from requiring applicants or employees to undergo genetic testing. For example, in 1991, Wisconsin's legislature made it unlawful for employers, labor unions, employment agencies, and licensing agencies to use genetic testing for employment decisions [23].
3. Some states ban discrimination based on genetic test results, genetic information (such as from questionnaires), or the refusal to take a genetic test. For example, New Jersey's 1996 legislation prohibits employment discrimination based on use of any genetic information and prohibits retaliation by employers for refusal to take tests or reveal results of such tests [24].

But the issue is, of course, whether a patchwork of state legislations is sufficient to protect employees. For example, Minnesota's law requires that all medical tests be strictly limited to job-related performance ability. Some argue that BNSF's program of testing would not have violated this law [7]. Those who propose federal legislation to assure equality of treatment have some models to use in crafting such legislation, including the Health Insurance Portability and Accountability (HIPAA) and Executive Order 13145.

HIPAA applies to employer-based group health insurance plans. Among other provisions concerning preexisting conditions, HIPAA states that presymptomatic diagnosis does not qualify as a preexisting condition. Further, HIPAA prohibits insurers from denying or limiting coverage or charging higher premiums based on genetic information [21]. The legislation does not, however, ban employers or insurers from gaining access to genetic information [1].

In 2000, President Clinton issued Executive Order 13145, which prohibits discrimination in federal employment based on "protected genetic information" in the executive branch in making employment decisions [25, 26]. Employers also are prohibited from collecting and disclosing such information. "Protected genetic information" means information about the results of an individual's or family member's genetic tests and information about the occurrence of disease or medical condition or disorder in family members of the individual (i.e., family medical history) [25].

There are two limited exceptions to the prohibition on genetic testing, both of which are not to be used as the basis for employment decision. Employees can be monitored for the effects of toxic substances in the workplace under limited circumstances, and departmental or agency health offices may collect "protected genetic information" about employees who use the genetic or health-care services offered by the health office. Family medical histories can be collected only if needed to make disability-related inquiries of post-offer employees and employees to determine whether further medical evaluation is needed to diagnose a current disease that could prevent the performance of the essential functions of the job.

Legislation that parallels the Executive Order and HIPAA for employees in the private sector has been introduced several times into the U.S. Senate in the

last few years. The latest is the Genetic Information Nondiscrimination Act of 2002 (GIHNA) [27]. Introduced into the Senate, this legislation provides enforcement, limits on damages, and defense against disparate impact claims consistent with ADA and Title VII of the Civil Rights Act of 1964. The legislation treats genetic information in the same manner as other forms of employment discrimination (protected groups) and covers employers, unions, employment agencies, and training programs. It prohibits the use of genetic information in employment decisions. Employers are prohibited from intentionally requesting, requiring, or purchasing genetic information about employees or family members except for legitimate reasons, such as monitoring effects of toxic substances, to comply with federal state or local law, or with the employee's consent.

Some argue that all this concern about employment testing is unfounded, because the sheer costs of testing and the low probabilities of finding particular markers make it not cost-justified. In some cases, discrimination is cost-justified, but as yet genetic testing is not cost-justified [12]. But as the cost of testing goes down and the cost of health care goes up, the incentive for testing increases. For example, the director of the HGP predicts that by 2010 a test for a multitude of genetic markers will be available for about \$100 [6]. Without legislation expressly forbidding genetic discrimination in employment, there may be great incentive for employers to discriminate in selection. And, because of HIPAA's restrictions on discrimination in health-care coverage based on genetic conditions, it becomes imperative for employers not to hire people with genetic predispositions [28].

Even if federal legislation were to limit genetic discrimination, the questions will not be settled. After all, decades after the passage of the Civil Rights Act of 1964 the courts are still interpreting its implementation. As with cases of sex discrimination, the issues of job-relatedness in genetic discrimination will be narrowly defined and slowly carved out, case by case. What makes this even more interesting, however, is that progress in the medical community will be continuing while we in the public policy, law, and human resources sector strive to keep up.

As progress continues, the issues remain the same. Even as legal constraints are imposed, organizations must go beyond the letter of the law if they are to act ethically in this arena. Murry, Wimbush, and Dalton present an ethical framework based on the medical model of preventive ethics for organizations to use in establishing genetic screening policies [29]. They posit that any genetic screening policy should be based on five ethical principles: voluntary consent to testing; privacy of information; justice according to society's standards; equity of access to information and resources; and quality systems for oversight [29]. Organizations that design their genetic screening programs with these ethical standards in mind should be able to withstand changes in legal and judicial evolutions, knowing that their policies are in line with internationally accepted ethical standards.

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