

Genetic discrimination in the workplace

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Recent advances in genetic research and technology fueled by the Human Genome Project bring a promise of improved health through revolutionary new treatments for illness and disease. Unfortunately, coupled with the great potential of this revolution is the possibility for abuses invited by gathering genetic information. As genetic testing becomes a more frequently used tool, the legal issues regarding employment discrimination on the basis of genetic information are beginning to emerge. If employers are permitted to consider genetic information in making personnel decisions, employees may be unfairly barred or removed from employment for reasons wholly unrelated to their ability to perform their jobs. Moreover, a fear of workplace genetic discrimination may result in a reluctance to take advantage of the growing array of genetic tests that can identify vulnerability to specific diseases. While all agree that advances in genetic research and technology portend tremendous benefits for humankind, it is important that people are aware of their civil rights in this area.

The US Equal Employment Opportunity Commission (EEOC) is the federal agency that enforces federal employment discrimination laws, including the Americans with Disabilities Act (ADA), which prohibits discrimination on the basis of disability. Most states, and many cities and local governments, also have agencies that enforce state and local antidiscrimination laws. The ADA makes no explicit mention of genetic discrimination. Indeed, rather than identify any specific disability or medical condition, the ADA contains broad language that prohibits discrimination in hiring, promotion, discharge, compensation, and other terms and conditions of employment against a “qualified individual with a disability.”

There is little question that the ADA covers individuals with a genetically related illness or disability once it becomes manifest, as long as it substantially impairs a major life activity. The ADA likewise protects individuals with a prior record of a genetically related disability, such as someone who has recovered from cancer. The more challenging question is whether the ADA prohibits discrimination on the basis of a diagnosed, but asymptomatic, genetic condition that does not substantially limit a major life activity. No court has yet ruled on the issue of whether the ADA prohibits discrimination based upon genetic information in the workplace, so the issue is still undecided.

However, it is the opinion of the EEOC that the ADA does prohibit genetic discrimination. The EEOC found that Congress, in enacting the ADA, was mindful that the reactions to a perceived impairment may be just as disabling as an actual

impairment. Accordingly, Congress specifically included individuals “regarded as” disabled in the definition of those covered by the ADA. Congress sought to address and combat the traditional myths, fears, and stereotypes about disabilities. Discrimination in the workplace based on genetic information is exactly the kind of behavior Congress intended to prohibit when it passed the ADA. Given this rationale, the EEOC issued policy guidance on the definition of disability concluding that the ADA prohibits discrimination against workers based on their genetic makeup. EEOC policy guidances can be found on its website at www.eeoc.gov.

Recently, the US Supreme Court decided a case that may have an impact on the issue of genetic discrimination. In *Bragdon v. Abbott*, the majority ruled that a person with asymptomatic human immunodeficiency virus (HIV) is an “individual with a disability” under the ADA. Finding that HIV infection is a “physical impairment” that substantially limits the major life activity of reproduction—even in the absence of any manifest visible symptoms of the illness—the Court recognized that a disability may be based solely upon the cellular and molecular changes in the body. The reasoning behind the *Bragdon* decision suggests that individuals with asymptomatic genetic disorders and genetic predisposition are protected by the ADA, both when their condition is viewed as an actual and a perceived impairment. However, in a foreboding dissent, Chief Justice Rehnquist wrote, “Respondent’s argument, taken to its logical extreme, would render every individual with a genetic marker for some debilitating disease ‘disabled’ here and now because of some future effects.” Justice Rehnquist’s comments raise the specter that he might reject the ADA’s protection of individuals with asymptomatic genetic conditions. Furthermore, three later Supreme Court decisions significantly narrowed the scope of the ADA and, in so doing, may have limited the ADA’s coverage of genetic predisposition discrimination.

On February 8, 2000, President Clinton signed the first Executive Order of the 21st century prohibiting the federal government from using genetic information in hiring, promotion, discharge, and all other employment decisions. Since the prohibition is contained in an executive order, it applies only to applicants, employees, and former employees of the federal government. It is important to note, however, that bipartisan legislation designed to extend the protection of genetic information in the President’s Executive Order to the private sector has been introduced in Congress. Finally, 25 states have enacted laws against employment discrimination on the basis of genetic information.

The EEOC is interested in learning about and combating discrimination on the basis of genetic information. Individuals

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who believe that they have faced, or are facing, discrimination on this basis should contact their local EEOC office. Local EEOC offices can be identified by consulting the Commission's website at www.eeoc.gov or the federal government listings in the telephone directory, or by calling a toll-free information number at 800-669-4000 or 800-669-6820 (TDD). **Be**

aware that strict time frames control the filing of charges of employment discrimination. Private sector employees may have as little as 180 days from the date of the alleged discriminatory act to initiate a claim. Federal government employees must contact an EEO counselor at their agency within 45 days of the act of alleged discrimination.

Erratum

The table of contents of the November/December 2000 issue of *Genetics in Medicine* contains an error. The heading that reads "Reviews: Society for Inborn Errors of Metabolism, Presented at ACMG" should have read "Reviews: Society for Inherited Metabolic Diseases, Presented at ACMG."