



GENETICS BRIEF

BRIEFING PAPERS ON IMPORTANT GENETICS ISSUES OF THE DAY

JUNE 2002

ISSUE NO. VI

Genetics and Employment

*By Alissa Johnson and Cheye Calvo
National Conference of State Legislatures*

Genetic discovery has real implications for the workplace. While employers and employees tend to agree that genetic information has few appropriate uses at work, employers have economic incentives to exclude from the workforce individuals who are at a higher risk of absenteeism, reduced productivity, higher turnover, increased rates of occupational illness or—most significantly—increased medical claims. To address this concern, most states have enacted genetic workplace protections to prevent misuse of genetic information.

Federal Action

Genetic workplace protections are grounded on existing fair employment practices, primarily Title VII of the Civil Rights Act of 1964, which prohibits discrimination based on race, religion, sex and national origin. Especially important to genetics laws are disability protections—such as the Americans with Disabilities Act of 1990 (ADA)—that restrict medical examinations and inquiries in the workplace and forbid employment discrimination based on disabilities that have no influence on job performance. The Equal Employment Opportunity Commission (EEOC) in 1995 interpreted the ADA to protect a person's genetic predisposition to disease, but recent court actions suggest that the Supreme Court may favor a more narrow reading of the law.

State Action

States addressed genetics and employment prior to the federal government with the first law to forbid genetic discrimination in employment enacted by the Wisconsin Legislature in 1991. Today laws in 30 states restrict the use of genetic information in the workplace. Eight states considered genetics and employment legislation in 2002—Utah and Virginia enacted new measures and Rhode Island revised its existing law. As of June 2002, legislation to enact a new genetic discrimination law in Hawaii was awaiting the governor's action.

Twenty-eight of the 30 state genetic employment laws have “exceptional” genetic protections, which establish higher legal protections for genetic information than other health data. Illinois and Michigan take an inclusive approach to genetics and employment issues and treat genetic information the same as any other form of medical information. These states incorporate standards for the use of genetic information into current workplace disability protections. In addition, California and Minnesota, which have genetic-specific protections, also expanded their disability laws in recent years to curb the use of medical information by employers more than any other states.

Components of State Protections

Access to Genetic Information. Violations of privacy in the workplace can be discrete and difficult to identify, particularly in the case of genetic information. As a result, many states have taken steps to limit employer access to genetic information initially to prevent the likelihood that discrimination could occur. Policymakers first dealt with this issue with the enactment of ADA and disability protections in some form in every state. Today in 48 states, these laws include restrictions on medical examinations and inquiries in the workplace and set basic confidentiality standards for employees' medical information. Although these protections extend to genetic information, they regulate—but do not forbid—employer access to medical

**Health Resources
and Services Administration**
*Genetic Services Branch
5600 Fishers Lane, Room 18A-19
Rockville, MD 20857
Phone (301) 443-1080
Fax (301) 443-8604*

**National Conference
of State Legislatures**
*Genetic Technologies Project
1560 Broadway, Suite 700
Denver, CO 80202
Phone 303-830-2200
Fax (303) 863-8003*

**Association of State
and Territorial Health Officials**
*Genetics Program
1275 K Street, NW, Suite 800
Washington, DC 20005
Phone (202) 371-9090
Fax (202) 371-9797*

information, including genetic information. In fact, they allow genetic tests and inquiries by employers in limited circumstances.

Acquisition of Genetic Information. Eighteen states have enacted laws that place greater limits on the ability of employers to request genetic information, and 10 of those states forbid employers from obtaining genetic information. Many of these laws have exceptions, however. Exceptions typically are limited to narrowly defined “job-related” situations, such as tests to measure an individual’s ability to perform essential job functions, to promote workplace safety or to investigate a workers’ compensation claim.

Use of Genetic Information. State genetics and employment laws often identify appropriate use of genetic information by employers. Some observers—in fear of great potential for employer misuse—want absolute bans on the use of genetic information. This approach would treat genetic predispositions in the same way as Title VII criteria. Others—in hope of valuable future benefits—prefer restrictions during some stages of employment only, such as prior to an offer of employment, similar to disability protections. A wide range of alternatives exists between the two extremes. Although all of the 30 states with genetics and employment laws expressly prohibit genetic discrimination in employment, the laws include different exceptions where employers can potentially use genetic information in the workplace, particularly when it might be considered job-related. Factors to determine appropriate use may include the relevance of genetic information to job qualifications, health and safety issues and employer liability.

Definitions of Genetic Information. The definition of genetic information under the law establishes the scope of protections. The inclusion or omission of terms in the definition of genetic information erects the boundary between “protected” versus “unprotected” genetic information. Relevant terms include predictive genetic information, genetic test results, information about genetic testing—such as a bill noting the receipt of genetic services, family history, inherited characteristics, and symptomatic or presymptomatic genetic conditions.

Enforcement

Enforcement of employment protections presents special challenges under any circumstances. With regard to genetic protections, the principal question is whether they should be enforced in the same way as other prohibited employment criteria or whether genetic protections warrant special measures. Enforcement measures may involve methods for the filing of claims and investigation, due process and appropriate remedies in the event of wrongdoing. States have enacted a mixture of administrative, civil and—to a much lesser extent—criminal processes to give teeth to genetic discrimination laws. Most states require that employees submit claims of unlawful employment practices with a state agency or the EEOC.

Selected References

National Conference of State Legislatures, Blue Ribbon Panel on Human Genetic Technologies, *Genetics Policy Report: Employment Issues* (Denver: NCSL, 2001).

National Conference of State Legislatures, Genetic Technologies Project.
<http://www.ncsl.org/programs/health/genetics.htm>

Contacts for More Information

Alissa Johnson
NCSL-Denver
(303) 830-2200, ext. 274
Alissa.Johnson@ncsl.org

Amy Klein
ASTHO
(202) 371-9090, ext 1616
aklein@astho.org