

THE NEED FOR AND REASONS WHY STATES SHOULD ADOPT THE UNIFORM PROTECTION OF GENETIC INFORMATION IN EMPLOYMENT ACT

The need for regulation of genetic information and the desirability of uniformity in the area was recognized at the federal level with the enactment of the Genetic Information Nondiscrimination Act (GINA) of 2008. 42 U.S.C. §§ 2000ff to 2000ff-11 (Supp. II 2008). However, much in the same way that states have supplemented federal employment nondiscrimination acts with their own fair employment acts, there is a role for states in the regulation of genetic information in the workplace. This role is explicitly contemplated by GINA; its employment provisions do not preempt state legislation that provides equal or greater protection to individuals. 42 U.S.C. § 2000ff-8(a)(1) (Supp. II 2008).

Approximately 37 states have statutes that regulate how employment entities collect, use, retain, or disclose employees' genetic information. State policy decisions to legislate in this area reflect the need to encourage beneficial uses of genetic information while protecting individuals' privacy and preventing misuse of that information. Scientific developments in the field of genetics bring with them the promise of a new era in understanding human biology and new approaches to medicine that offer individual treatments tailored to one's genetic characteristics. For these promises to become reality, however, individuals must be willing to take genetic tests. For that, they must have confidence that they can control the privacy of their genetic information and that it will not be used to harm them in the workplace for reasons that are not related to their ability to do the job.

Preemption of existing state statutes. GINA has created general uncertainty about the enforceability of state genetic statutes in the context of employment. Most of the state statutes have definitions of genetic information or genetic testing that are more limited than those in GINA. Many also have coverage that is less comprehensive than GINA. For example, many statutes prohibit discriminatory uses of genetic information, but do not restrict acquisition, retention, or disclosure of that information. Others are concerned primarily with privacy, but do not address discrimination. Some do not provide a private cause of action as an enforcement mechanism. As a result, GINA currently preempts most of the state statutes that protect genetic information in employment because they fail to provide protection equal to or greater than the federal statute.

Lack of uniformity among existing state statutes. To the extent that the state statutes remain enforceable in the wake of GINA, there is a lack of uniformity among the states. They have experimented with many different approaches to regulating genetic information in the employment setting. Some states have extended their disability or employment discrimination statutes to cover discrimination based on genetic information. Some have instead enacted specific statutes to regulate genetic testing or the use of genetic information. Yet others have statutes that focus on privacy of genetic test results. Some of the specific genetic statutes and privacy statutes are general provisions that apply to many types of entities; others are tailored for the employment setting. These different approaches have resulted in great variation in state regulation. Only a few states comprehensively cover acquisition, use, retention, *and* disclosure of genetic information by employers and other employment entities. There are also differences

in key definitions that result in significant variation in the scope of state regulation of genetic information. These inconsistent frameworks and requirements create burdens on employers that operate in more than one jurisdiction.

Highlights of the Uniform Act

The Uniform Act is designed to eliminate the preemption problems created by GINA for existing state statutes. It thus incorporates the key definitions and concepts of GINA. It also complements and supplements GINA with additional provisions that are more protective of employees, following the pattern of many state fair employment laws that supplement Title VII and other federal statutes. The Act comprehensively regulates acquisition, use, retention, and disclosure of genetic information in the employment setting.

The Uniform Act expands coverage beyond that of GINA in two principle ways. First, it closes a gap in GINA by extending coverage to entities that credential or license workers along with employers, unions, employment agencies, and training programs. Second, it includes employers with five or more employees, while giving states an option to extend coverage to smaller employers. This follows the pattern of state fair employment statutes, many of which cover smaller employers than Title VII.

The Act protects employees by requiring them to authorize employer acquisition of their genetic information and voluntary genetic testing as part of an employee wellness program or a genetic monitoring program. These authorization requirements are consistent with GINA, but more specific. The Act sets forth the desirable content for authorization forms to give employers guidance and the assurance that they are following the law. It also allows employees to submit genetic information voluntarily so that it can be used for their protection, for example, in support of a request for reassignment to avoid a workplace substance to which a worker has a genetic susceptibility.

The Act supplements GINA with specific provisions on genetic testing, which is treated in GINA as part of the general category of acquisition of genetic information. The Act allows an employer to offer genetic testing only as part of a voluntary employee wellness program or a genetic monitoring program. It recognizes the importance of genetic counseling for employees' decisions to have a genetic test and in interpreting the results. Unlike GINA, the Act thus requires genetic counseling before an employee or family member authorizes a genetic test and when a test predicts a disease or disorder unless the individual waives genetic counseling in writing. At the same time, the Act recognizes that genetic counseling is an emerging profession that is not regulated in many states and so it does not impose requirements on who may provide counseling. Therefore, unless there is state law to the contrary counseling may be provided by physicians, geneticists, and nurse practitioners in addition to trained genetic counselors. The Act also regulates genetic testing by setting standards that require reporting the results to the employee, destroying the employee's biological sample and expunging genetic information produced ancillary to the test.

In order to prevent employment discrimination based on genetic information, the Act follows GINA by prohibiting specific actions based on genetic information, such as failure to

hire, discharge, or discrimination in compensation or terms and conditions of employment. It also more comprehensively prohibits *any* adverse employment action against an employee based on the employee's genetic information.

The Act incorporates GINA's provisions that make genetic information confidential and limit disclosures of that information. It supplements GINA by allowing employees to direct disclosures to third parties and by giving employees a specific right to inspect and copy genetic information in the employer's possession and to submit corrected information.

The enforcement and remedies section establishes a state-law private cause of action for violations of the Act. It contains an option that allows a state to use its fair employment enforcement apparatus and an option to make exhaustion of administrative remedies optional prior to a private lawsuit. Unlike GINA, the Act does not prevent a state from enforcing the act or an employee from filing a cause of action on a theory of disparate impact. Remedies are not limited to those authorized for Title VII, and thus the federal caps on damages do not apply. Awards of attorney's fees generally follow federal law and are discretionary. They are authorized only for prevailing employees in order to cover the cost of enforcing the Act.

In sum, the Act provides for counseling, consent, and confidentiality and, through these mechanisms, gives employees control over their genetic information in the workplace. It allows states to use the enforcement mechanisms they have in place under their fair employment statutes. It eliminates preemption of state law under GINA and fosters uniformity among the states.