Privacy Protections Key to Preventing Genetic Discrimination

When the Genetic Information Nondiscrimination Act (GINA) was signed into law last year, the late Senator Edward Kennedy heralded it as “the first civil rights bill of the new century.” Its substantive provisions, which become effective this year, aim to eliminate discrimination based on genetic information by health insurers and employers.

At first glance, GINA seems like a typical anti-discrimination law. It adds a new category of forbidden discrimination, and its employment provisions are modeled on Title VII of the Civil Rights Act of 1964, which forbids race and sex discrimination. On closer examination, however, GINA is a strange sort of anti-discrimination law. Title VII was enacted as part of the Civil Rights Act of 1964 in response to the civil rights movement and widespread racial unrest. At the time, schools, workplaces, and public accommodations remained segregated in many parts of the country, and the effects of racial discrimination and inequality were starkly apparent. By contrast, there have been only a handful of documented cases of genetic discrimination. Additionally, no visible underclass, set apart by genetic risk of disease, has yet emerged in this society.

Thus, unlike traditional civil rights legislation, the purpose of GINA is not to counteract systemic disadvantage and existing inequalities. Instead, it aims to prevent the emergence of genetic discrimination and to do so specifically in order to promote the use of genetic technologies. Given the promise of genetic science, Congress passed GINA to “allow … individuals to take advantage of genetic testing, technologies, research, and new therapies.” Its stated purpose was not only to prevent discrimination, but also to “reliev[e] the fear of discrimination” and “allay concerns about the potential for discrimination.”

Such a goal may be a worthy one; however, the anti-discrimination provisions of GINA alone would be inadequate to achieve it. Experience with Title VII has shown that proving discrimination can be difficult. An employer is unlikely to admit when its personnel decisions have been influenced by race or sex. And unconscious stereotypes or cognitive biases may operate, even though the employer honestly believes that its decisions were not influenced by race or sex. As a result, much of the litigation under Title VII has struggled over questions of proof—whether and to what extent race or sex influenced a particular employment decision.

These same difficulties of proving discrimination are likely to reoccur under GINA. However, genetic discrimination differs in a crucial way. Race and sex are salient characteristics—attributes of an individual that are usually easily observable and difficult to conceal. By contrast, information about individual genetic traits is not readily apparent. For example, a carrier of the gene that causes increased risk of breast cancer cannot be identified through casual observation. And therefore, insurers and employers can only discriminate against that individual if they have access to the relevant genetic tests.

Thus, the key to preventing discrimination based on genetic traits lies in protecting the privacy of genetic information. If genetic information is available, it may be difficult for decision-makers to ignore, and yet proving that genetic information has influenced an insurance or employment decision may be quite difficult. On the other hand, if genetic information is unavailable, insurers and employers simply cannot discriminate on the basis of latent genetic traits.

Congress recognized this reality, and therefore, GINA also seeks to protect the privacy of genetic information by restricting insurers and employers from requesting, requiring, or purchasing such information. These restrictions, however, are subject to a number of exceptions. For example, in the employment context, it is not a violation if an employer learns of genetic information when requesting medical information in order to comply with federal or state family and medical leave laws; or when it “inadvertently requests or requires family medical history of the employee”; or where the information is acquired from “documents that are commercially and publicly available (including newspapers, magazines, periodicals, and books, but not including medical databases or court records) that include family medical history.”

The number of exceptions and their vagueness reflect the difficulty of protecting all genetic information about an individual, given how pervasive genetic information is in our society. Medical records typically contain both genetic and nongenetic information, and knowledge about the illness of a person’s parent may reveal genetic information about that individual. Whether GINA has the effect that Congress desired—“relieving the fear of discrimination”—will depend less upon its anti-discrimination provision than upon how successful its privacy provisions are in protecting against the disclosure of individual genetic information.

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