


2010

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Repository Citation

Kim, Pauline, "Regulating the Use of Genetic Information: Perspective from the U.S. Experience" (2010). *Scholarship@WashULaw*. 441.
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Regulating the Use of Genetic Information: Perspectives from the U.S. Experience

[forthcoming 31 COMP. LAB. L. & POL'Y J. --- (2010)]

Pauline T. Kim*

In their article, *Practices and Attitudes of Australian Employers in Relation to the Use of Genetic Information*,¹ Margaret Otlowski, Mark Stranger, Sandra Taylor, Kristine Barlow-Stewart and Susan Treloar set out to document the policies, practices, and attitudes of Australian employers regarding the use of genetic information. This empirical investigation is motivated by a deeper concern—determining whether discrimination in employment on the basis of genetic characteristics is a problem that calls for legal regulation. The same question and the empirical uncertainties surrounding it have been the focus of policy debates in the United States as well. Recently, the U.S. Congress responded to these concerns by passing the Genetic Information Nondiscrimination Act of 2008 (GINA)² which, among other things, prohibits employment discrimination on the basis of genetic information and restricts employers' access to their employees' genetic information.³ Although it is too early to evaluate the effectiveness of GINA's employment provisions,⁴ an examination of the history and language of the statute offers some insights concerning the possibilities and challenges involved in regulating the use of genetic information in the workplace. This examination suggests that relying solely on an anti-discrimination framework is likely to be inadequate; the key to preventing misuse of genetic information by employers will be creating robust privacy protections.⁵ Fully restricting the flow of genetic information, however, poses a number of challenges for regulators.

The study by Otlowski et al. undertook a survey of Australian businesses regarding their use of employees' genetic information. The survey focused on Australia's largest employers, as well as its fast-growing small and medium businesses.⁶ The authors explained that they intended to focus on the organizations "most likely to use genetic information in their screening and monitoring of employees,"⁷ rather than trying to obtain a random or stratified sample of all employers, given that genetic technologies are relatively new and do not appear to be in

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¹ Margaret Otlowski et al., *Practices and Attitudes of Australian Employers in Relation to the Use of Genetic Information: Report on a National Study*, 31 COMP. LAB. L & POL'Y J. --- (2010).

² Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (codified as amended in scattered sections of 26, 29, 42 U.S.C.).

³ Title I of GINA prohibits insurance companies from discriminating against individuals based on their genetic information. However, this aspect of GINA is not discussed here.

⁴ The employment provisions of GINA became effective on November 21, 2009, eighteen months after its enactment. Pub. L. No. 110-233, § 213, 122 Stat. 881, 920.

⁵ See Pauline T. Kim, *Genetic Discrimination, Genetic Privacy: Rethinking Employee Protections for a Brave New World*, 96 NW. U.L. REV. 1497, 1532-37 (2002).

⁶ Otlowski, *supra* note 1, at [21].

⁷ *Id.*

widespread use.⁸ Their survey asked about current employer policies and practices regarding employee genetic information, pre-employment health screening practices, and health monitoring practices, as well as the employers' attitudes towards the use of genetic testing in the future for screening or monitoring employee health.⁹

The authors concluded that currently there is “no evidence of *systematic* use of genetic testing or other genetic information by Australian employers for screening or monitoring purposes.”¹⁰ In fact, they found no evidence that employers were using genetic tests at all, despite the fact that the survey targeted the employers mostly likely to do so.¹¹ Moreover, they found that only a relatively low percentage of respondents (around six percent or less) were using genetic information revealed through family medical history to screen or monitor employee health.¹² These findings were corroborated by surveys of both occupational physicians and consumers in Australia, leading the authors to conclude that “Australian employers do not appear to be utilizing genetic information in any systematic or widespread manner for screening or monitoring their employees.”¹³

Examining the legal landscape, Otlowski et al. note that employer use of genetic testing and information is not regulated in Australia, except perhaps to the extent that legislation prohibiting disability discrimination might be applied to employer use of genetic information. Disability discrimination is sometimes defined as “less favourable treatment in similar circumstances on grounds of present, past, future or imputed disability,”¹⁴ and this broad definition likely encompasses discrimination based on genetic traits that may indicate a predisposition to certain diseases. Nevertheless, as a result of gaps in the legislation and barriers to enforcement by aggrieved individuals, employees have not invoked legal protection against employer use of genetic information in Australia.¹⁵ Because many believe that the use of genetic testing is likely to expand in the future, there have been calls to strengthen legal protections against employer use of genetic information.¹⁶

Prior to the passage of GINA, the situation in the U.S. was roughly similar to what Otlowski et al. describe in Australia. Although there have been a couple of high profile cases alleging employers' improper use of genetic information,¹⁷ the available evidence suggests that the vast

⁸ *Id.* at [21-22].

⁹ *Id.* at [22-23].

¹⁰ *Id.* at [42].

¹¹ *Id.*

¹² *Id.* at [29, 42].

¹³ *Id.* at [43].

¹⁴ *Id.* at [17].

¹⁵ *Id.* at [19].

¹⁶ *Id.* at [17].

¹⁷ Two federal cases are repeatedly cited as examples of genetic discrimination in employment. IN one, the plaintiffs alleged that their employer had conducted a number of medical tests, including a genetic test for sickle cell trait, on samples of their blood without their knowledge or consent. *See Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260 (9th Cir. 1998). In the other, the EEOC brought suit alleging that Burlington Northern Santa Fe Railway Co. was requiring genetic testing of employees to see if they had a predisposition to carpet tunnel syndrome. *See Tamar Lewin, Commission Sues Railroad to End Genetic Testing in Work Injury Cases*, N.Y. TIMES, Feb. 10, 2001, at A7. The EEOC eventually reached a settlement with Burlington Northern in which it agreed to pay \$2.2 million to workers who had been subjected to the genetic tests. *See Lisa Girion, Railroad Settles Suit over*

majority of employers do not currently engage in genetic testing or use genetic information to make personnel decisions.¹⁸ Determining the extent of genetic testing by employers is difficult for the same reasons discussed by Otlowski et al. As they point out, identifying a representative sample of all employers would be prohibitively expensive,¹⁹ and relying on employers' self-reports of their practices risks producing biased data.²⁰ Thus, the survey data available for U.S. employers must also be interpreted with caution. Trying to make comparisons across countries is even more hazardous. Nevertheless, treating the empirical evidence somewhat impressionistically, it appears that while medical testing and screening may be somewhat more common in the U.S. than Australia—likely because many U.S. employers provide health insurance for their employees—genetic testing and screening still appear to be relatively unusual, even among the largest U.S. companies.²¹ Other evidence from the U.S. is consistent with this conclusion. A number of stories of genetic discrimination by employers have been collected,²² but these have generally not been independently verified. And despite the existence of thirty-four state statutes restricting genetic testing or prohibiting employers from relying on genetic information,²³ no reported cases have been brought under any of these statutes, even though some have been in effect for decades.²⁴ Thus, while there have undoubtedly been instances of employers misusing genetic information, it does not appear that genetic testing or screening of employees is common in the American workplace.²⁵

Despite the lack of evidence of systematic and widespread abuse of genetic information by employers, Congress nevertheless responded to the concerns about misuse of genetic information by passing GINA, which aims to eliminate the use of genetic information in decision-making by employers. Much like the situation in Australia, it appeared quite uncertain whether any existing federal laws prohibited employers from using information about an individual's genetic traits, apart from any present disability those traits might have caused. Title VII of the Civil Rights Act of 1964,²⁶ which prohibits discrimination on the basis of race, color, sex, national origin, and religion, may protect against genetic testing or screening if an employer imposes such a

Genetic Testing in Workplace, L.A. TIMES, May 9, 2002, at C3; T. Shawn Taylor, *Railroad Settles Genetic-Test Suit*, CHI. TRIB., May 9, 2002, at A3.

¹⁸ Jessica L. Roberts, *Preempting Discrimination: Lessons from the Genetic Information Nondiscrimination Act*, 63 VAND. L. REV. 439, 468 (2010).

¹⁹ Otlowski, *supra* note 1, at [20].

²⁰ *Id.* at [40].

²¹ See U.S. CONGRESS, OFFICE OF TECHNOLOGICAL ASSESSMENT, GENETIC MONITORING AND SCREENING IN THE WORKPLACE (1990), available at <http://www.princeton.edu/~ota/disk2/1990/9020/9020.PDF>; see also AMERICAN MANAGEMENT ASSOCIATION, AMA 2004 WORKPLACE TESTING SURVEY: MEDICAL TESTING (2004), available at http://www.amanet.org/research/pdfs/Medical_testing_04.pdf.

²² Roberts, *supra* note 18, at 466-67 (citing Secretary's Advisory Committee on Genetics, Health, & Society, U.S. Department of Health & Human Services Public Perspectives on Genetic Discrimination: Secretary's Advisory Committee on Genetics, Health, & Society 21 (2004), available at http://oba.od.nih.gov/oba/sacghs/reports/Public_Perspectives_GenDiscrim.pdf).

²³ Conference of State Legislatures, Employment information, available at <http://www.ncsl.org/programs/health/genetics/ndiscrim.htm> (last visited June 4, 2010). In addition to the thirty-four state statutes, the U.S. Congress has passed a genetic information employment nondiscrimination law covering DC.

²⁴ The first state laws banning employment discrimination based upon genetic information (but limited to discrimination based upon the sickle cell trait) were enacted in the 1970s. Mark A. Rothstein, *Is GINA Worth the Wait?*, 36 J.L. MED. & ETHICS 174, 175 (2008).

²⁵ See *supra* note 18.

²⁶ 42 U.S.C. §§ 2000e to 2000e-17 (2006).

requirement only on members of a certain group—for example, screening only African-Americans for sickle cell disease—but not if all its employees are subject to the same practices.²⁷ And while the Americans with Disabilities Act²⁸ clearly protects against discrimination based on current or past disability that has a genetic origin, the Equal Employment Opportunity Commission (EEOC) and the courts have disagreed about whether it protects an individual who carries a disease-linked genetic trait but who does not yet have a legally-defined disability.²⁹ Largely because of these gaps and uncertainties, advocates continued to push for federal legislation specifically aimed at genetic discrimination.

When the U.S. Senate passed GINA in April 2008, Senator Edward Kennedy heralded it as “the first civil-rights bill of the new century.”³⁰ And, at first glance, it 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. In fact, GINA’s operative language precisely tracks the language of Title VII: it is unlawful for an employer “to fail or refuse to hire, or to discharge, any employee, or otherwise to discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment of the employee, because of genetic information with respect to the employee.”³¹ GINA also makes it unlawful for an employer “to limit, segregate, or classify the employees of the employer in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect the status of the employee as an employee, because of genetic information with respect to the employee.”³² In addition, the procedures for enforcing GINA follow those established under Title VII, vesting responsibility for interpreting the statute, and for investigating and resolving charges of discrimination in the EEOC.³³

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 U.S., and the effects of racial discrimination and inequality were starkly apparent. On virtually every measure of social and economic well-being—income, educational opportunities, employment, access to adequate housing, infant mortality, etc—African-Americans were doing worse than white Americans.³⁴ By contrast, there have been only a handful of documented cases of genetic discrimination. Genetic discrimination is not an on-going and widespread social practice that has produced a visible underclass. In fact, individuals with genetic predispositions to disease do not even constitute an identifiable social group. It has been estimated that every individual carries at least a handful of genetic

²⁷ *Norman-Bloodsaw*, 135 F.3d at 1272.

²⁸ 42 U.S.C. §§ 12101-213(2006).

²⁹ See Kim, *supra* note 5, at 1514. See also William J. McDevitt, *I Dream of GINA: Understanding the Employment Provisions of the Genetic Information Nondiscrimination Act of 2008*, 54 VILL. L. REV. 91, 102-05 (2009).

³⁰ Press Release, Kennedy, Enzi, Snowe Celebrate Passage of Genetic Information Nondiscrimination Act (April 24, 2008), available at <http://help.senate.gov/newsroom/press/release/?id=313bfde8-f967-46b4-aa9d-11bc73728813>.

³¹ 42 U.S.C. § 2000ff-1(a)(1).

³² 42 U.S.C. § 2000ff-1(a)(2).

³³ 42 U.S.C. § 2000ff-6(a)(1).

³⁴ 36. REPORT OF THE NATIONAL ADVISORY COMMISSION ON CIVIL DISORDERS (U.S. Government Printing Office, 1968). For notable excerpts from the report, see *Report of the National Advisory Commission on Civil Disorders: Summary of Report*, available at <http://www.eisenhowerfoundation.org/docs/kenner.pdf> (last visited June 4, 2010).

characteristics that render them vulnerable to some (albeit differing) diseases,³⁵ making it difficult to determine who is or is not in the “protected class.” Moreover, unlike race or sex, the traits that would be the basis for discrimination are not readily detected through casual observation, and systematic discrimination cannot occur unless information about genetic characteristics becomes widely available.³⁶

Thus, unlike traditional civil rights legislation, the purpose of GINA is not to counteract systemic disadvantage and existing inequalities. Instead, it aims to prevent *prospectively* the emergence of genetic discrimination and to do so specifically in order to promote the use of genetic technologies.³⁷ This purpose is clearly visible in the bill’s first congressional finding:

Deciphering the sequence of the human genome and other advances in genetics open major new opportunities for medical progress. New knowledge about the genetic basis of illness will allow for earlier detection of illnesses . . . and may allow for the development of better therapies that are more effective against disease or have fewer side effects than current treatments.³⁸

Given the promise of these new technologies, Congress passed GINA not only to prevent discrimination but also to “reliev[e] the fear of discrimination” and “allay [the public’s] concerns about the potential for discrimination, thereby allowing individuals to take advantage of genetic testing, technologies, research and new therapies.”³⁹ GINA, then, is more about addressing the perception or fear of genetic discrimination than reversing any present reality of such discrimination.

Such a goal may be a worthy one, particularly if it facilitates research and encourages greater use of beneficial genetic therapies. However, the anti-discrimination provisions of GINA alone will be ineffectual in preventing genetic discrimination by employers.⁴⁰ Experience with Title VII has shown that enforcing an anti-discrimination mandate can be difficult. Once overt discriminatory policies had been eliminated, employers were unlikely to admit when their personnel decisions had been influenced by race or sex, creating challenging problems of proof.⁴¹ And unconscious stereotypes or cognitive biases may operate, even though an employer honestly believes that its decisions were not influenced by race or sex.⁴² As a result, much of the

³⁵ See Louise McIntosh Slaughter, *Genetic Testing and Discrimination: How Private is Your Information?*, 17 STAN. L. & POL’Y REV. 67, 69 (2006) (“No human being has a perfect set of genes. In fact, every one of us is estimated to be genetically predisposed to between five and fifty serious disorders. Every person is therefore a potential victim of genetic discrimination.”); Hank Greely & Francis S. Collins, *Genetic Information Gains Federal Bias Protection* (2008), available at http://www.insurancenewsnet.com/article.aspx?a=top_lh&neID=200806013000.1_a58c0036a6ee057a (“Since each of us has dozens of genetic variations that may put us at risk for disease, we all would have had a reason to be concerned about the possible misuse of genetic information.”).

³⁶ See Kim, *supra* note 5, at 1521.

³⁷ Roberts, *supra* note 18, at 441. See Perry W. Payne, Jr., *Genetic Information Nondiscrimination Act of 2008: The Federal Answer for Genetic Discrimination*, 5 J. HEALTH & BIOMEDICAL L. 33, 38-40 (2009).

³⁸ Pub. L. No. 110-233, § 2, 122 Stat. 881, 881-82.

³⁹ Pub. L. No. 110-233, § 2, 122 Stat. 881, 882-83.

⁴⁰ See Kim, *supra* note 5, at 1515-32.

⁴¹ *Id.* at 1515.

⁴² *Id.* at 1527.

litigation under Title VII has struggled over questions of proof—whether and to what extent race or sex influenced a particular employment decision; and how much influence is enough to constitute actionable discrimination.

These same difficulties are likely to reoccur under GINA. Aggrieved employees will need to prove that the adverse personnel actions they suffered were motivated by their latent genetic traits in the face of employer denials. However, genetic discrimination differs in a crucial way from more traditional forms of discrimination. Race and sex are salient characteristics—attributes of an individual that are usually easily observable and difficult to conceal. Employers’ personnel decisions are sometimes influenced by these characteristics, whether consciously or unconsciously, precisely because they are so salient and often activate stereotypes about different social groups. By contrast, as noted above, individuals with genetic predisposition to disease are not currently an identifiable social group. Not only are genetic traits not socially salient, they are not even readily ascertainable about an individual. 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 employment decision may be quite challenging. On the other hand, if genetic information is unavailable, 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 employers from requesting, requiring, or purchasing such information with respect to an employee or a family member of the employee.⁴³ These restrictions, however, are subject to a number of exceptions.⁴⁴ For example, acquisition of genetic information is not unlawful if an employer offers a wellness program that includes genetic services, so long as the employee voluntarily participates and any individually identifiable information is not disclosed to the employer.⁴⁵ Similarly, no violation occurs if the employer acquires genetic information when requesting medical information in order to comply with federal or state family and medical leave laws,⁴⁶ or when the employer undertakes genetic monitoring to determine the effects of exposure to toxic substances in the workplace, as long as such monitoring complies with certain requirements.⁴⁷

The most expansive exceptions exempt an employer from liability when it “inadvertently requests or requires family medical history of the employee or family member of the employee,”⁴⁸ 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.”⁴⁹ The former exception, known as the “water-cooler” exception, is intended to protect the employer who learns genetic information—for example, of a genetically-based disease suffered by an

⁴³ 42 U.S.C. § 2000ff-1(b).

⁴⁴ 42 U.S.C. §§ 2000ff-1(b)(1) – 2000ff-1-(b)(6).

⁴⁵ 42 U.S.C. § 2000ff-1(b)(2).

⁴⁶ 42 U.S.C. § 2000ff-1(b)(3).

⁴⁷ 42 U.S.C. § 2000ff-1(b)(5).

⁴⁸ 42 U.S.C. § 2000ff-1(b)(1).

⁴⁹ 42 U.S.C. § 2000ff-1(b)(4).

employee's family member—through casual conversation. The latter exception reflects the pervasiveness of genetic information in a myriad of information sources.

These exceptions highlight the difficulty in completely restricting the flow of genetic information. Preventing employers from acquiring *any* genetic information about their employees will be impossible for at least two reasons. First, genetic information is pervasive. It cannot easily be segregated or isolated from other types of information. For example, medical records typically contain both genetic and non-genetic information, and the two types of information may not be easily distinguished as a conceptual matter. Professor Mark Rothstein has argued that the statute is “based on a scientifically dubious dichotomy between genetic and non-genetic information, tests, and disorders . . . [V]irtually all human disease has both genetic and environmental components.”⁵⁰ GINA defines a “genetic test” as “an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes”⁵¹ but excludes from this definition “an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes,”⁵² even though the latter types of tests may indirectly provide information about “genotypes, mutations, or chromosomal changes.” Thus, even if all “genetic information” is stripped from medical records before it is seen by an employer, other “non-genetic” tests—as defined by the statute—may nonetheless indirectly provide employers with genetic information about their employees.

Family medical information is another type of genetic information⁵³ that is not easily contained. Many diseases are now known to have a genetic basis, and employers may unwittingly learn genetic information about their employees simply by hearing about a family member's health condition, or reading an obituary. Because a great deal of personal information, including family medical history, may be publicly available through print media or the internet, it is virtually impossible to prevent employers from accessing this type of information about their employees and it seems unfair to hold them liable when they learn this type of information even though they had not intent to do so. Thus, GINA makes exceptions for information acquired “inadvertently” or from “publicly available” documents.⁵⁴

The second reason employers cannot be entirely prevented from acquiring genetic information is that other social policies will sometimes require that employers have access to this information. Employers have a legitimate interest in performing genetic monitoring when such testing can help to detect the effects of workplace exposure to toxins. Similarly, in order to comply with family and medical leave laws, as well as to accommodate employee disabilities, an employer may need to verify the medical condition of an employee or family member, a process which may reveal genetic information. Finally, many employers have introduced “wellness programs” in recent years to promote healthy lifestyles and encourage preventive care. To the extent that these programs attempt to tailor the advice they provide based on individual risk

⁵⁰ Mark A. Rothstein, *GINA, the ADA, and Genetic Discrimination in Employment*, 36 J.L. MED. & ETHICS 837, 839 (2008).

⁵¹ 42 U.S.C. § 2000ff(7)(A).

⁵² 42 U.S.C. § 2000ff(7)(B).

⁵³ The statute defines “genetic information” as “information about—(i) [an] individual's genetic tests, (ii) the genetic tests of family members of such individual, and (iii) the manifestation of a disease or disorder in family members of such individual.” 42 U.S.C. § 2000ff(4)(A).

⁵⁴ See *supra* notes 48-49.

factors, they are also likely to rely on employees' family medical histories, which will include genetic information. GINA allows wellness programs to acquire this information, but the employee must participate voluntarily and the employer must now have access to any individualized information. Thus, GINA attempts to balance other social policies against employees' interest in privacy by allowing employers to acquire genetic information under certain specified conditions.⁵⁵

Importantly, when an employer acquires genetic information under any of the exceptions, it must maintain the confidentiality of the information⁵⁶ and may not rely upon it to make employment decisions.⁵⁷ However, once genetic information is known by an employer, preventing it from influencing personnel decisions and proving when it has influenced these decisions may be nearly impossible. Thus, the many exceptions to the prohibition on employers acquiring genetic information will likely make it more difficult to meet GINA's goal of "fully protect[ing] the public from discrimination and allay[ing] their concerns about the potential for discrimination."⁵⁸

The U.S. experience with GINA and other laws like Title VII suggests that anti-discrimination mandates and privacy rights will interact in complex ways in the effort to regulate employer use of genetic information. Because of the difficulty of proving employer motivation, simply prohibiting discrimination alone is unlikely to be effective in preventing discrimination on the basis of genetic characteristics. In an ideal world, genetic information would simply not be available to employers when making hiring, promotion or other personnel decisions, making discrimination on that basis impossible. Robust privacy protections are therefore key to preventing genetic discrimination. However, accomplishing this is not easy, as genetic information is difficult to segregate from medical and other types of information to which employers legitimately have access, and because allowing employers to learn some types of genetic information may be necessary to achieve other socially valued purposes. Thus, policy-makers cannot rely solely on either restricting genetic information, or prohibiting use of that information. Rather, preventing improper employer use of genetic information will require careful attention to privacy rights *and* anti-discrimination norms and a careful balancing of both.

⁵⁵ See *supra* notes 45-47.

⁵⁶ 42 U.S.C. § 2000ff-5(a).

⁵⁷ 42 U.S.C. § 2000ff-1(a).

⁵⁸ Pub. L. No. 110-233, § 2, 122 Stat. 881, 882-83.