New Federal Initiatives Project

EEOC Proposes Regulations on Title II of the Genetic Information Nondiscrimination Act of 2008

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EEOC Proposes Regulations on Title II of the Genetic Information Nondiscrimination Act of 2008

On March 2, 2009, the Equal Employment Opportunity Commission ("EEOC") promulgated a proposed rule[2] that would implement Title II of the Genetic Information Nondiscrimination Act of 2008 ("GINA").[3] GINA, which was signed into law by President Bush on May 21, 2008, prohibits discrimination in health benefits (Title I) and employment (Title II) on the basis of genetic information. More than twelve years in the making, the statute is designed to encourage individuals to take advantage of new advances in the field of genetics and genetic testing without fear of adverse health coverage or employment-related consequences. Congress was concerned that in the absence of such protections, individuals would be reluctant to get genetic testing or participate in genetic research studies, which would in turn hamper scientific research, thwarting the development of new drugs and treatments for genetic disorders.[4] Furthermore, it worried that the concentration of many genetic conditions and disorders (or markers thereof) within particular racial and ethnic groups and genders might make members of those groups more susceptible to stigmatization or discrimination as a result of that genetic information.[5] GINA marks the first legislative expansion of the EEOC's jurisdiction in almost twenty years, since the enactment of the Americans With Disabilities Act in 1990.[6]

Title II of GINA, which governs the employment context, places broad restrictions on the acquisition, use and disclosure of genetic information by covered employers and requires such employers to keep confidential any genetic information they do possess. The EEOC's proposed regulations implementing Title II closely track the statute's terms and are generally consistent with the terms and definitions the agency has employed to enforce other discrimination laws, including Title VII of the Civil Rights Act of 1964 and the Americans with Disabilities Act. For example, GINA defines "employee" as it is defined in Sections 701(b) of Title VII, along with a number of other statutes defining various state, legislative and executive branch employees. The regulations do the same, specifically including applicants for employment within the definition of "employee" pursuant to the express language of the statute.[7] The regulations also define "employee" to include "former employee[s]" based on Supreme Court precedent placing such individuals within the ambit of Title VII's nondiscrimination protections.[8] Similarly, GINA defines "employer" as it is defined in Section 701(f) of Title VII (i.e. a person engaged in an industry affecting commerce who has 15 or more employees), as well as to employment agencies, joint labor-management committees and labor organizations. The proposed regulations include a concise explanation of employers covered under the statute, rather than simply providing citations to other laws.

The proposed regulations also elaborate and provide guidance on six terms unique to GINA that are uncommon in other employment discrimination statutes, including "family member," "family medical history," "genetic monitoring," "genetic services" and "manifestation" of a genetic condition or disease. The agency specifically requests comments on these definitions because they are outside the scope of EEOC's typical proficiency. The proposed rule also lays out what is and is not included within the definition of "genetic test," clarifying that routine tests for drug or alcohol abuse or tests for the presences of viruses not composed of human DNA, RNA, chromosomes, proteins or metabolites are not covered under the Act. The EEOC requests comments on whether other types of tests should be included or excluded from the definition of "genetic test."

Under Title II of GINA, an employer may not discriminate against an individual in hiring, firing, compensation or the terms and conditions of employment based on genetic information, nor may it engage in activities that limit, segregate or classify an employee in a way that deprives or tends to deprive an individual of employment opportunities based on such information.[9] Similarly, employment agencies may not refuse to refer individuals for employment and labor unions may not exclude, expel or otherwise discriminate against members based on genetic information.[10] Although the statute does not expressly prohibit an employer from causing other covered entities like employment agencies or unions, to

discriminate or improperly obtain genetic information, the EEOC notes in its comments to the proposed regulations that it will apply Title VII case law to define "employer" to include employer's agents consistent with common law agency principles. GINA also adopts Title VII's anti-retaliation provisions. The EEOC's comments on the proposed regulations indicate that the agency will interpret those provisions consistent with its standard for determining what constitutes retaliatory conduct under Title VII.[11]

Unlike Title VII, GINA expressly precludes a cause of action for disparate impact at this time[12] and the proposed regulations reiterate the same.[13] However, the statute does call for the creation of a Congressionally-selected commission in six years, to be housed within the EEOC, to study developments in genetic science to assess whether a disparate impact theory cause of action is warranted.

Mirroring Title I (which applies to health insurers), Title II prohibits employers and other covered entities from requesting, requiring or purchasing genetic information about an applicant or employee absent one of six exceptions provided for under GINA that attempt to account for the practical nature of the employer-employee relationship.[14] The prohibitions will not apply where: (1) an applicant or employee inadvertently or voluntarily discloses his or a family member's genetic information (the "water-cooler exemption");[15] (2) an employer acquires information pursuant to an employer-provided wellness program, but only if the employee knowingly and voluntarily signs a written consent and where individually identifiable information remains undisclosed;[16] (3) an employer requests family medical history to comply with the provisions of federal, state or local family and medical leave laws such as FMLA; (4) the genetic information is obtained through broadly-accessible, commercially and publicly available resources (such as books, magazines, the internet, television, etc.[17]); (5) the covered entity acquires the information for use in monitoring the effects of toxic substances in the workplace, but only where written notice has been provided to the employee, the employee has voluntarily submitted to a test or the test is required by law, the employee gets the results of the test, the employer does not receive personally-identifiable information about individual employees, and the monitoring complies with genetic monitoring regulations; and (6) the employer is conducting DNA analysis for human remains identification or law enforcement purposes. In its comments to the proposed regulations, EEOC seeks public comment on how this exception would impact law enforcement.

Title II and the draft implementing regulations also guard the privacy of genetic information by requiring any such information in the employer's care be kept separately from general personnel files as a "confidential medical record" as defined by the Americans with Disabilities Act.[18] The statute permits disclosure of such information in limited circumstances:[19] (1) to the individual to whom it relates if such person requests the disclosure in writing; (2) to an occupational health researcher pursuant to federal regulations; (3) to comply with the letter of a court order so long as the entity has informed the individual about the order and what information it disclosed; (4) to government officials investigating compliance with GINA; (5) to offer proof of an employee's compliance with a federal, state or local family and medical leave law; or (6) to a health agency investigating contagious disease that presents an imminent hazard of death or serious illness.[20]

Title II and its accompanying draft regulations utilize the same enforcement mechanisms and remedies for violations of GINA as Title VII, including the requirement that an aggrieved employee first file with the EEOC before filing with a court.[21] Finally, the regulations advise covered entities that GINA renders unlawful certain inquiries that the ADA had permitted, such as the ability of employers to collect medical information, including genetic information, from post-offer applicants for employment.

Title II becomes effective on November 21, 2009. Pursuant to the statute, the EEOC has is required to issue final regulations implementing Title II by May 21, 2009—within one year of the statute's enactment.[22] On February 25, 2009, the agency held a public meeting to discuss its notice of

proposed rulemaking.[23] Public comments on the proposed regulations may be submitted electronically or in writing and are due by May 1, 2009.

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[1] Dominique Ludvigson is Counsel & Special Assistant at the U.S. Commission on Civil Rights. These comments do not necessarily represent the views of the Commission or of individual Commissioners.
[2] Regulations Under the Genetic Information Nondiscrimination Act of 2008, 74 Fed. Reg. 9056 (proposed Mar. 2, 2009) (to be codified at 29 C.F.R. § 1635) *available at* http://edocket.access.gpo.gov/2009/pdf/E9-4221.pdf.
[3] P.L. 110-233, 122 Stat. 881 (codified at 42 U.S.C. §§ 2000ff *et. seq.*) *available at http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=110_cong_public_laws&docid=f:publ233.110.pdf*(last visited March 26, 2009). For a thorough summary of GINA's provisions, *see* NANCY LEE JONES AND AMANDA K. SARATA, CRS REPORT FOR CONGRESS, THE GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008 (GINA) (JULY 9, 2008).
[4] *See* P.L. 110-233 § 2(5).
[5] *See* P.L. 110-233 § 2(3).
[6] *See* Comments of Acting Chairman Ishimaru, EEOC Meeting Transcript, Feb. 25, 2009, *available at* http://www.eeoc.gov/abouteeoc/meetings/2-25-09/transcript.html (hereinafter EEOC Meeting Transcript).
[7] 42 U.S.C. 2000ff(2)(A)(5).
[8] *See Robinson v. Shell Oil Co.*, 519 U.S. 337, 346 (1997).
[9] 42 U.S.C. §§ 2000ff-1(a), (b).
[10] 42 U.S.C. § 2000ff-2(a) and § 2000ff-3(a), respectively.
[11] The Supreme Court announced the Title VII standard for retaliation in *Burlington Northern & Santa Fe Ry. v. White*, 548 U.S. 53 (2006). In that case, the Court held that employees are protected from retaliatory conduct that, whether related to employment or not, a reasonable person would find "materially adverse," meaning action that "well might have 'dissuaded a reasonable worker from making or supporting a charge of discrimination.'" *Burlington*, 548 U.S. at 57-58 (internal citations omitted).
[12] 42 U.S.C. § 2000ff-7(a).
[13] Proposed 29 C.F.R. § 1635.5(b).
[14] The exemptions are laid out in 42 U.S.C. § 2000ff-4(b).
[15] The regulations point out that this exemption would apply even in certain circumstances where the voluntary disclosure was made at the employer's prompting, for example, where an employer makes a reasonable (i.e. not overly-broad) request for medical information (other than genetic information) to support an employee's request for an ADA accommodation. The EEOC advises covered entities to take proactive steps to ensure that any such requests are narrowly tailored to avoid the inadvertent acquisition of genetic information. *See* 74 Fed. Reg. 39 at 9062.
[16] Though not stated in the proposed regulation, a covered entity may violate GINA if "the small number of its wellness-program participants, alone or in conjunction with other factors, makes an individual's genetic information readily identifiable" even though the entity has collected the information in the aggregate. 74 Fed. Reg. 39 at 9062.
[17] The statute provides a list of media sources that may make an individual's genetic information publicly available; the EEOC has added electronic media (movies, TV, internet) to its regulations and seeks further input on whether other types of sources should be added to the list.
[18] *See* 42 U.S.C. § 2000ff-5(a) and draft 29 C.F.R. § 1635.9.
[19] *See* 42 U.S.C. § 2000ff-5(b) and draft 29 C.F.R. § 1635.9(b).
[20] Even in this circumstance, the covered entity may only disclose information regarding a *manifested* disease in the employee or a family member, not one for which genetic markers are present alone.
[21] *See* 42 U.S.C. § 2000ff- 6 and proposed 29 C.F.R. § 1635.10.
[22] GINA § 211, 42 U.S.C. § 2000ff-10. Under GINA, the Departments of Labor, Health and Human Services and Treasury are responsible for issuing regulations implementing Title I of the Act. To ensure consistency throughout Title I and II, these agencies are sharing information regarding comments to their proposed rules and any requests for information with one another.
[23] EEOC Meeting Transcript, *supra* note 5.