

TO: Drafting Committee, Uniform Protection of Genetic Information in Employment and Insurance Act
From: Reporter, Ellen E. Deason
RE: Summary of major decisions made at October 2009 Drafting Committee meeting and issues for consideration at March 2010 meeting.
Date: February 21, 2010

Article 2 Employment

At its meeting in October 2009, the Drafting Committee reviewed its first draft since the enactment of the federal Genetic Information Nondiscrimination Act (GINA). GINA does not preempt state statutes that provide “equal or greater protection to an individual.” Thus it contemplates parallel state laws in the same vein as those that supplement Title VII and other anti-discrimination laws in the field of employment. The Committee’s goal is to draft a state statute that parallels GINA and, when appropriate, supplements it with state-law provisions that are more protective of employees.

Unfortunately, although the employment provisions of GINA took effect in November 2009, the Equal Employment Opportunity Commission (EEOC) has not yet issued final implementing regulations. They are reportedly currently under review by the Office of Management and Budget. The current draft was prepared using the proposed regulations. If the final regulations make substantial changes from the proposal, further revisions to this article may be necessary to conform it to federal law.

The current draft of the employment article, which will be considered further by the Drafting Committee in March 2010, reflects the policy choices the Committee made in October. The Committee’s major decisions included the following:

Scope and key definitions:

- Change the wording of the definition of “genetic testing” to follow the exact language of GINA.
- Conform the definition of “genetic information” to the provisions in GINA .
- Allow states to exempt small employers from the coverage of the article by changing the definition of “employer” from employers with one or more employees to employers with five or more employees, while permitting states to set the limit at a smaller number of employees. Under this definition the act remains more protective than GINA, which covers employers with 15 or more employees. The more protective coverage of the act follows the pattern of many state employment discrimination statutes, which often expand their coverage beyond that of the federal statutes.
- Change the definition of “family member” to be more consistent with GINA.

- Retain a comprehensive definition of genetic counseling to supplement and strengthen GINA.

Acquisition of genetic information:

- Change the language of the section governing acquisition to be consistent with GINA and add exceptions from GINA that permit certain employer acquisitions of genetic information.
- Retain provisions supplementing GINA with requirements regarding genetic testing that define limited instances when it is permitted, require authorization and genetic counseling when it is voluntary, and protect the privacy of the test results and the individual's sample.
- Retain provisions that supplement GINA by allowing an employee to submit genetic information to the employer voluntarily.
- Retain provisions supplementing GINA to provide standards for genetic testing and employer access to genetic information in litigation that are more protective than the normal discovery standards for ordering a medical examination.

Employee authorizations:

- Eliminate broad requirements in prior drafts for detailed employee authorizations for most employer acquisition, use, retention, and disclosure of genetic information and the associated provisions on revocation of an authorization and retention of authorizations in order to be consistent with GINA and avoid increasing the paperwork burden on employers.
- In the context of a voluntary wellness program, voluntary genetic monitoring, and when an employee volunteers genetic information, supplement GINA by retaining detailed authorization requirements for voluntary employer-provided genetic testing and for employer acquisitions of genetic information.

Use of genetic information:

- Alter the approach of the prior drafts to match GINA by specifying improper employer actions.
- Retain a provision supplementing GINA that specifies acceptable employer uses for genetic information.

Retention and disclosure of genetic information:

- Eliminate authorization requirements for retention and disclosure of genetic information for consistency with GINA.
- Conform the provision on retaining genetic information to GINA through coordination with the retention provisions of the Americans with Disabilities Act.
- Reformulate the disclosure provisions to conform to the approach in GINA.
- Retain a provision supplementing GINA that establishes an employee right to access and correct genetic information.
- Retain a provision supplementing GINA that allows employees to request and authorize disclosures to a third party.

Remedies and limitation of actions:

- Retain a provision supplementing GINA with a private cause of action that does not require exhaustion of administrative remedies.
- Retain a two-year statute of limitations and include a tolling provision.

Miscellaneous:

- Add a section on medical information that is not genetic information for consistency with GINA.
- Move the definitions in Article 1 into Articles 2 and 3 for clarity.

At the March meeting, the Committee will need to prepare the employment article to be read at this summer's annual meeting. It will need to consider the reporter's implementation of the substantive decisions made last fall and review drafting choices, particularly when the reporter was guided only by a "sense of the committee."

The Committee needs to devote special attention to the remedies section, Section 211, which has been almost entirely redrafted based on the discussion at the fall drafting meeting.

In addition, I would like to flag the following items for your attention prior to the March meeting.

Section 210 is new. It derives from GINA's provision on confidentiality, § 206(c), 42 U.S.C. § 2000ff-5(c), and concerns the relationship of GINA's privacy protections to those contained in the regulations implementing the Health Insurance Portability and Accountability Act, which are commonly known as the HIPAA Privacy Rule. The language of the section follows that of the proposed EEOC regulation, 29 CFR § 1635.11(d). In addition to considering this section, the Committee should review 29 CFR § 1635.11 to decide if any other provisions on

construction of GINA should be carried over to the uniform act.

Section 205 on authorized use of genetic information does not have a corresponding section in GINA. It lists uses of genetic information that are permitted, based on provisions allowing acquisition of genetic information for certain purposes. Permission for those uses is arguably implicit in the acquisition provisions and there is a danger that Section 205 is under-inclusive. The Committee may want to consider eliminating this section for simplicity and consistency with GINA.

The prefatory note needs an extensive revision for the annual meeting draft. Suggestions on content will be welcome.

Article 3 Life Insurance, Disability-income Insurance, and Long-term-care Insurance

This article is unchanged from the prior draft except that the definitions that were previously located in Article 1 have been moved to the definition sections of Article 3. This was done at the Committee's suggestion to avoid the fragmentation of splitting the definitions. In addition, while some of these definitions share wording with those in Article 2, the reporter's notes sometimes differ for the insurance context.

At the drafting meeting in October 2009, the Committee decided to prioritize consideration of the employment article of the act. The insurance article will not be considered at the upcoming March 2010 meeting.