TO: Drafting Committee, Uniform Protection of Genetic Information in Employment and Insurance Act
From: Reporter, Ellen E. Deason
RE: Policy Issues in Reformulating the Employment Article as a State Version of the Federal Genetic Information Nondiscrimination Act (GINA)
Date: October 5, 2009

In May 2008, the federal Genetic Information Nondiscrimination Act (GINA) was signed into law. It contains titles on Health Insurance and Employment. After consultation with the Committee on Scope and Program and the Executive Committee of the Uniform Law Commission, the Drafting Committee was asked to redraft its article on employment as a state provision that will parallel and supplement GINA.

GINA creates limitations in federal law on access and use of genetic information by employment entities, but it does not preempt state statutes that provide "equal or greater protection to an individual." Thus GINA contemplates parallel state laws in the same vein as state laws that supplement Title VII and other anti-discrimination laws in the field of employment.

Your reporter has taken the following steps in redrafting the employment provisions of the ULC act:
1) identified the major differences between the employment article of the ULC annual meeting draft of 2008 and GINA;
2) analyzed the proposed EEOC regulations under GINA and the comments filed on the proposals for further perspective on issues related to GINA; and
3) examined the relationship between Title VII and selected state antidiscrimination employment laws for examples to help guide the Committee as it considers how to structure a supplementary state law.

The guiding principle in constructing the current draft has been how to best present the Drafting Committee with policy choices based on the comparison between GINA and the decisions the Committee has made for prior drafts. In considering these policy choices, the Committee will need to weigh the desirability of consistency with GINA against the desirability of including provisions that are more protective for employees.

Many of the provisions of the prior draft Uniform Act were already generally consistent with GINA's provisions. For example, both statutes had similar definitions of genetic testing and genetic information and both had provisions on acquisition, use, retention and disclosure. The new draft adds provisions from GINA and frequently adopts GINA's language (with some necessary adaptations). These changes are discussed in the Reporter's Notes.

In addition, because GINA contemplates that state statutes may be more protective, the new draft also presents the Drafting Committee with policy choices when the approach the Committee took in the prior ULC draft diverges from that of GINA. To do this, I often retained provisions from the prior draft, either in combination with provisions from GINA or as an alternative. When presenting alternatives, I adopted a new convention and placed the alternative policy

formulations taken from GINA in double brackets. These contrasting alternatives are discussed in the reporter's notes. They are also highlighted below as the major policy and drafting choices for the Drafting Committee to consider at this fall's meeting.

A. Coverage of employment entities

1. Size. In the private sector, GINA covers only employers with at least 15 employers. The 2008 Annual Meeting draft Uniform Act covered all employers without regard to size (i.e., with one or more employees). The decision on threshold size of employer involves balancing the burden placed on small employers with the desirable extent of coverage by the act. It is an area in which state EEO acts have often diverged from Title VII and the ADA by mandating coverage of employers with a smaller number of employees. The following chart shows the distribution of the threshold number of employees for coverage under state EEO statutes. It was prepared with information kindly provided by NFIB based on research done in May 2008, which I partially updated in August 2009.

Thresholds for Applicability of State EEO Laws

Number of Employees	Number of States with this threshold
1 (law applies to public employers only)	2
1	16
2	1
3	1
4	6
5	2
6	6
8	2
9	1
12	1
15	13

2. Types of employment entities. GINA and Title VII cover employers, employment agencies, labor organizations, and training and apprenticeship programs offered by an employer, labor organization, or joint labor-management committee. In contrast, the 2008 Annual Meeting

ULC draft covers employers, employment agencies, labor organizations, and credentialing authorities, which it grouped together for ease of drafting under the term "employment entity." The current draft adds provisions for training programs for consistency with GINA.

The policy question for the Drafting Committee is whether or not to expand the scope of the draft beyond that of GINA by continuing to cover credentialing authorities. Credentialing authorities serve as gatekeepers to certain types of employment by providing credentials that are required either under state law or by an employer. They are defined in the act as governmental or private entities that provide licenses, registrations, or credentials or certify competence that is necessary for an individual to qualify for employment or to participate in an occupation or profession. Examples include state bar and medical examination boards, which control entry to the practice of law and medicine, and state departments of motor vehicles, which issue commercial drivers licenses necessary for some employment. The Committee's rationale for covering these entities was that acquisition or use of genetic information by a credentialing authority could have the same effects on employees and applicants for employment as acquisition or use by an employer. Many credentialing authorities, however, are not traditionally considered as employment organizations.

B. Genetic Testing

1. Definition of genetic test. The current draft adopts the definition of genetic test that GINA uses in its employment section. In the 2008 Annual Meeting draft, the definition also included the concept of intent. It required that the test be given with the intent to detect a genotype, mutation, or chromosomal change. This requirement had been included to help assure insurance company representatives that the test would not be misused and the former definition, with the intent requirement, is retained in the insurance article.

2. Provision prohibiting genetic testing (with exceptions). GINA has no explicit provisions on genetic testing provided by employers. It does, however, generally prohibit testing indirectly by making it unlawful (subject to exceptions) for an employer to request, require, or purchase genetic information, which is defined to include information about an individual's genetic tests. In contrast, the 2008 Annual Meeting ULC draft explicitly prohibits employment entities from offering or requiring genetic testing, with limited exceptions for genetic screening, monitoring, and preventive health programs. It protects individuals through requirements for employee authorization, payment by the employer, reporting requirements, genetic counseling, and destruction of the employee's biological sample.

The current draft follows GINA by eliminating the separate section on genetic testing. It does, however, include protective provisions from the prior ULC draft that relate to testing — authorization requirements, reporting test results to the employee, providing genetic counseling, and destruction of the employee's biological sample. The Drafting Committee needs to decide if it wishes to supplement GINA's protections with these provisions.

C. Genetic Counseling

1. Definition of genetic counseling. Both GINA and the 2008 Annual Meeting draft include genetic counseling as part of the definition of genetic services and protect information about an employee's use of genetic services as part of genetic information. GINA defines genetic counseling parenthetically within its definition of genetic services as "including obtaining, interpreting, or assessing genetic information." In contrast, the 2008 Annual Meeting draft, and the current draft, contain a comprehensive definition of genetic counseling. This more comprehensive definition seems justified if the Drafting Committee retains the requirement that employers provide counseling in association with genetic tests, as discussed below.

2. Requirement for genetic counseling. GINA does not include a provision requiring an employer to provide genetic counseling. The current draft, drawing on the prior ULC draft, requires an employer to provide genetic counseling about the risks and benefits of a genetic test before an employee makes a decision to have a genetic test under either a health program offered by the employer or a genetic monitoring program (when the employee is not required to participate by state or federal law). It also requires genetic counseling about a positive test result. As indicated in the definition of genetic counseling, the purpose of the counseling at that point is to communicate and interpret the test results and to provide support, informational resources, and referrals as appropriate to help an individual adapt to the medical, psychological, and familial implications of having or being at risk of having a genetic condition. The Committee needs to decide whether or not to keep these genetic counseling requirements.

D. Acquisition of genetic information

Both GINA and the 2008 Annual Meeting ULC draft make it unlawful for employers to request or require an employee to provide genetic information, including family medical history. GINA's provision, which is used in the current draft, does not allow an employer to "request, require, or purchase genetic information" of an employee. This is narrower than the prior ULC draft, which also prohibited indirect employer inquires and did not allow an employment entity to "knowingly obtain" genetic information.

1. New exceptions. The current draft includes a number of new exceptions that are drawn from GINA for consistency. These are highlighted here because some of them may make the current draft less protective of employees than the prior ULC draft.

a. Inadvertent acquisition. An employer is not to be held liable for an unlawful employment practice if its request or requirement for family medical history is "inadvertent." Congress included this provision to address the "water cooler problem" – when an employer unwittingly receives information through casual conversation or by overhearing conversations. While GINA's exception is expressly limited to requests for family medical history, the proposed regulations expand it to include any genetic information on the theory that it should not matter whether the employee is discussing a genetic test or a relative's disease. The proposed EEOC regulations include examples of circumstances in which the acquisition of genetic information would be deemed inadvertent. These include overhearing conversations, receiving information that is not solicited, genetic information submitted in response to a request for medical information, and information submitted by an employee seeking an accommodation or leave.

b. Family Medical Leave Act. This exception is limited to requests for family medical history. An employee seeking leave to care for an ill relative is asked about the relative's illness on FLMA certification forms.

c. Purchased documents. GINA has an exception when employers purchase commercially available materials that may contain family medical history. The proposed EEOC regulations expand the scope of this provision to include any genetic information. GINA explicitly includes newspapers, magazines, periodicals, and books as "excused" media and excludes medical databases and court records. The proposed EEOC regulations expands the list of excused media to include the internet, television, and movies.

d. DNA analysis for law enforcement. This GINA exception allows a limited subset of employers – those that perform genetic testing for identification for law enforcement purposes or to identify human remains – to collect DNA samples from employees in order to check for contamination of samples with the employees' DNA. DNA identification uses a small portion of the genome which is not thought to have any medical or predictive significance.

2. Employee Health or Genetic Services. Both GINA and the prior ULC draft include an exception designed to allow employers to offer genetic services as part of a workplace "wellness" program. Both require employee authorization for this service. The ULC annual meeting draft contemplates that while the employer might provide testing, it could not receive any resulting genetic information unless the employee voluntarily submitted it to the employer. In contrast, GINA allows the employer to receive genetic information in an aggregate form and a health care professional involved in providing the services for the employer to receive individualized genetic information. The current draft combines acquisition provisions from both the prior ULC draft and from GINA. It permits an employer to offer genetic testing and adopts GINA's provision permitting access for a health care professional involved in providing the services for the employer, but it differs from GINA in that it does not permit the employer to acquire the resulting information, even in aggregate form. The Committee needs to decide if it is appropriate to retain this extra protection for employees.

As discussed above in the section on genetic testing, the current draft also includes provisions from the former ULC draft that require protections to accompany genetic testing. The Committee needs to decide if it wants to include provisions on counseling, authorization for testing, reporting test results, and destroying the employee's sample.

3. Genetic Monitoring Program. Both GINA and the prior ULC draft include exceptions for employer acquisition of genetic information obtained in conjunction with a genetic monitoring program. Both GINA and the prior ULC draft limited employer access to aggregate genetic data that does not individually identify employees. This provision is retained with an additional exception taken from GINA that allows access to individual genetic information for employees administering the monitoring.

The prior ULC draft permitted genetic testing for monitoring only with the authorization

of the employee. This draft follows GINA by also permitting testing, without employee authorization, when monitoring is required by federal or state law. When monitoring is conducted by employee consent, however, the draft expands GINA's protections by including the provision from the prior ULC draft for genetic counseling prior to the employee's authorization.

And as in the case of employer-provided genetic services, the current draft also includes provisions from the former ULC draft that require protections to accompany genetic testing. The Committee needs to decide if it wants to include provisions on counseling, reporting test results, and destroying the employee's sample in the monitoring subsection.

4. Exceptions from the prior ULC draft. The current draft retains some additional provisions designed to protect the employee that do not appear in GINA. It permits an employee to provide genetic information voluntarily so that an employee may grant employer access for the employee's benefit. It also sets forth a strict standard for employer acquisition to genetic information in litigation. The Committee will need to decide if it wishes to retain these measures as a supplement to GINA.

The current draft drops one of the prior ULC draft exceptions. It allowed an employment entity to supply testing for genetic susceptibility to workplace substances. Unless the employee volunteered the test results, however, the employment entity was not authorized to obtain them. The Committee should consider whether this exception could be regarded as providing more protection for employees and whether or not it would like to include it as a supplement to GINA.

E. Use of genetic information

GINA lists specific employment practices that are prohibited if they are based on genetic information. In contrast, the 2008 Annual Meeting ULC draft prohibits "adverse employment actions" based on genetic information. The Drafting Committee regarded "adverse employment actions" as a term of art in employment law that does not need to be defined in this act. The Drafting Committee decided not to list adverse employment actions in the black letter law because of the risk that something would be left off the list and the list would be treated as limiting. The Committee needs to decide which approach to employ. In addition, the Committee needs to decide whether or not to retain a section from the prior ULC draft that specifies uses that employers are permitted to make of genetic information.

F. Privacy provisions on retention, disclosure, and employee access and authorization

Both GINA and the draft Uniform Act make employees' genetic information confidential and require that it be segregated from employee personnel records. Both contain a general prohibition on disclosures. The primary differences in privacy provisions between GINA and the prior draft stem from the centrality of the employee authorizations for acquisition, use, retention, and disclosure in the prior ULC draft. There is not equivalent provision on authorization in GINA. In addition, GINA includes exceptions for disclosure beyond those of the prior draft. It also attempts to coordinate how employers treat confidential records under GINA with how they are required to treat them under the Americans with Disability Act.

1. Emphasis on employee authorization for retention and disclosure of genetic information. Employee authorization for retention and disclosure of genetic information, coupled with an ability to revoke that authorization, was a cornerstone of the privacy protections in the prior draft. The Drafting Committee needs to consider if this requirement is feasible given the many ways in which employers may acquire genetic information without employee consent under GINA, and the extent to which genetic information is likely to be mixed with other medical information.

a. Retention. Under the prior draft, if an employment entity obtains any genetic information, it needs the employee's authorization to retain the information. This was consistent with the prior draft's provisions on acquisition of information, which do not include the range of acquisition possibilities that are included in GINA and which contemplate that genetic information the employer receives would be authorized by the employee. GINA's provision on retention operates if an employer "possesses" genetic information. It does not require an employee to authorize retention of the information. This is consistent with the avenues by which an employer might inadvertently obtain genetic information, as recognized in GINA.

b. Disclosure. GINA contains provisions authorizing disclosure of genetic information without a provision for employee authorization. Employers may make these disclosures to health researchers, to comply with court orders, to government officials investigating compliance with GINA, under the FLMA, and to report life-threatening disease to public health authorities. Notice to the employee is required for disclosures made under court order and to public health authorities. These provisions are included in the current draft for the Committee's consideration.

2. Employee's right to access and correct genetic information in employer's files. The prior ULC draft gave employees a right to inspect and correct genetic information held by the employer and provided a procedure. This provides stronger protection than GINA; it permits employers to disclose an employee's genetic information to the employee, but does not give employees a right to this information. This is another policy choice where the Committee needs to decide if it wishes to provide stronger protections than GINA.

G. Remedies and enforcement

For private employees, GINA adopts the enforcement and remedy structure of Title VII of the Civil Rights Act of 1964. Title VII requires an employee to first file a discrimination charge with a state or local agency (if state law covers the offense) or alternatively, if there is no state coverage for the claim, with the EEOC. The employee has 180 days from the violation to file with the EEOC and the time period is extended to 300 days if the charge is also covered by state or local law. If the EEOC decides to dismiss a charge or the parties do not reach a settlement, the agency issues a right to sue letter to the complainant. Or, after 180 days, the complaining employee may request this notice. An individual may file suit within 90 days of receiving the "right to sue letter" from the EEOC. Possible remedies include injunctive relief, back pay and other equitable relief, and, for intentional discrimination, compensatory and punitive damages up to a cap based on the size of the employer. GINA differs from Title VII, however, in that it

excludes claims for disparate impact, subject to study by a Commission.

Under the prior ULC draft, an aggrieved individual may take advantage of state administrative avenues, but is not required to exhaust them before filing suit. The statute of limitations is two years. The remedy provisions of the current draft remain identical to the prior draft to enable the Committee to make decisions on the extent to which the draft will supplement GINA.

Relationship of State EEO law to federal law in general. Remedies and procedures for complaints are areas in which the state EEO statutes often differ from federal law and vary greatly among themselves. In deciding whether to provide enforcement or remedy provisions that are more protective of employees than those in GINA, the Committee may find the following information on state EEO laws useful.

1. Authorization for court action. Many states, but not all, authorize a private suit under certain circumstances after an aggrieved person files a complaint or charge with the state EEO administrative agency. In some states, a plaintiff may file a court action if the agency has failed to conciliate or take final action on a charge within 180 days, or even shorter time periods, after the charge was filed. (E.g., Mass. (90 days), Minnesota (45 days), Missouri (180 days), RI (120 days)) Other states follow procedures similar to those under federal law, in which a plaintiff may file suit only after the agency issues a "right to sue letter." (E.g. California, Iowa).

In 17 states (as of 2005), private EEO causes of action may be brought without first filing a charge with an administrative agency. (Alaska, Arkansas, District of Columbia, Idaho, Kentucky, Louisiana, Maine, Minnesota, New Jersey, New York, North Dakota, Ohio, Oregon, Tennessee, Vermont, Virginia, Washington)

2. Statutes of limitations. In states in which a plaintiff may file a suit in state court (other than for review of an agency determination), statutes of limitations range from 6 months (Colorado) to six years (Ohio). For example, Michigan, New York, and Washington grant a plaintiff three years; New Jersey grants two years; Oregon grants one year.

In many states, the time limit for filing a charge with the state administrative agency is the same as the federal EEOC limit of 180 days. However, there is variation and some states set administrative filing requirements that are more generous than Title VII. The table below indicates the number of states with each filing requirement (as of 2005):

Time Limitation for filing administrative claim	Number of States
90 days	2
180 days/6 months	31
300 days	4

365 days/1 year	9

3. Remedies. Prior to the availability of compensatory and punitive damages under federal law pursuant to the Civil Rights Act of 1991, many states provided for these damages either as agency remedies, court remedies, or both. Compensatory damages have typically been defined to include coverage for emotional distress, mental anguish, pain, suffering, humiliation, and the like. When punitive damages are available, the plaintiff usually must show that the defendant acted with malicious or intentional disregard for statutory rights. Attorney's fees and costs are generally available under state acts.

Several states also make civil penalties available to remedy unlawful discriminatory practices. These penalties range from small (< $1000) to significant amounts (up to $50,000 or $100,000 per violation). Some states also authorize criminal penalties, although typically only for willful violations of agency orders.