Testimony of the Health Privacy Project, Georgetown University,
before the U.S. Senate Committee on Health, Education, Labor, and Pensions
hearing on
"Protecting Against Genetic Discrimination: The Limits of Existing Laws"
February 13, 2001

Mr. Chairman, Senator Gregg, and Members of the Committee, thank you for the opportunity to testify here today on behalf of the Health Privacy Project. I am Joanne L. Hustead, Senior Counsel for the Health Privacy Project and Assistant Research Professor at Georgetown University's Institute for Health Care Research and Policy. The Health Privacy Project is part of the Institute for Health Care Research and Policy.[1]

OVERVIEW OF THE HEALTH PRIVACY PROJECT

The Health Privacy Project's mission is to press for strong, workable privacy protections in the health care arena, with the goal of promoting increased access to care and improved quality of care. The Project conducts research and analysis on a wide range of health privacy issues. Recent Project publications include: *Best Principles for Health Privacy* (1999), which reflects the common ground achieved by a working group of diverse health care stakeholders; *The State of Health Privacy* (1999), the only comprehensive compilation of state health privacy statutes, which we are currently in the process of updating; *Privacy and Confidentiality in Health Research* (2001), commissioned by the National Bioethics Advisory Commission; *Report on the Privacy Policies and Practices of Health Web Sites* (2000), which found that the privacy policies and practices of 19 out of 21 sites were inadequate and misleading; and "Virtually Exposed: Privacy and E-Health" (2000), published in *Health Affairs*.

The Project also staffs the Consumer Coalition for Health Privacy, comprised of over 100 major disability rights, disease, labor, and consumer advocates as well as health care provider groups. The Coalition's Steering Committee includes AARP, American Nurses Association, Bazelon Center for Mental Health Law, National Association of People with AIDS, Genetic Alliance, National Multiple Sclerosis Society, and National Partnership for Women & Families.

The Project undertook two new initiatives in 2001. The first initiative seeks to protect the privacy of genetic information, as part of a larger effort to protect the privacy of all health information. The second initiative seeks to protect the privacy of health information, including genetic information, in the workplace. We are analyzing the legal framework that permits (and in some cases requires) employers to obtain health information about employees (and their dependents). The challenge is to accommodate the laudable goals

---

[1] Significant portions of the text in this testimony have been submitted to the American Journal of Law & Medicine for publication in Vol. 28, Nos. 2 & 3 (Summer/Fall 2002). The Health Privacy Project wishes to thank the American Society of Law, Medicine & Ethics and Boston University School of Law for permission to include portions of this article in this testimony.

of providing health insurance and other benefits and promoting worker safety and health, while at the same time respecting the intense desire of working people to keep their health information confidential.

SUMMARY OF TESTIMONY

Due to the Project's recognized expertise on the medical privacy regulation issued pursuant to the 1996 Health Insurance Portability and Accountability Act (HIPAA), this testimony focuses on that regulation, its application to genetic information, and the interplay between the regulation and legislation pending in this Congress.

The HIPAA privacy regulation will protect the privacy of genetic information, with one important caveat: it will only protect genetic information to the extent that it protects other health information. There are significant limits to what the HIPAA privacy regulation can and does accomplish. For example, the HIPAA privacy regulation does not generally prohibit the entities subject to the privacy regulation from collecting genetic information from individuals or from requiring people to provide genetic information or undergo genetic tests. The privacy regulation permits health plans and insurers to use protected health information, including genetic information, for a broad range of health care purposes, including medical underwriting. The HIPAA privacy regulation does not sufficiently regulate employers, who obtain vast amounts of medical information about employees (and their dependents). Thus, the enactment of additional legislation targeting the collection and use of genetic information could provide additional and significant privacy protections.

The two major pending genetic nondiscrimination bills, the Genetic Information Nondiscrimination in Health Insurance Act (S. 382), introduced by Senator Snowe, and the Genetic Nondiscrimination in Health Insurance and Employment Act (S. 318/H.R. 602), introduced by Senator Daschle and Representative Slaughter, take different approaches with respect to protecting the privacy of genetic information. Senator Snowe's bill (S. 382) would add some privacy protections in the health insurance context, primarily by putting limits on the collection of predictive genetic information and prohibiting the use of predictive genetic information for medical underwriting. Senator Daschle's bill would build upon HIPAA's privacy protections in more significant ways by:

- preventing group health plans and insurers from requesting or requiring individuals to provide protected genetic information (with more limited exceptions that S. 382);
- prohibiting the use of protected genetic information for medical underwriting;
- directly regulating employer acquisition, use, disclosure, and storage of protected genetic information; and
- creating a private right of action for people whose rights are violated, whether by group health plans, insurers, or employers.

THE HIPAA PRIVACY REGULATION

Medical information constitutes the most sensitive and personal information. Genetic information, which is a subset of medical information, is particularly sensitive because it reveals unique and immutable attributes, because those attributes are not just personal, but shared by family members as well, and because this information has the potential to give us (and others) a frightening (or reassuring) glimpse into the future. Faced with potential discrimination, loss of benefits, and stigma if their health information, including their genetic information, falls into the wrong hands, people are withdrawing from full participation in their own health care.

According to a national survey released by the California HealthCare Foundation in 1999, 15 percent of adults say they have done something out of the ordinary to keep medical information confidential. These privacy-protective behaviors include paying out-of-pocket despite having insurance coverage, doctor hopping to avoid a consolidated medical record, not seeking care to avoid disclosure to an employer, and giving incomplete or inaccurate information in a medical history.[2] A 1997 survey documenting people's fears about genetic discrimination showed that 63 percent of people would not take genetic tests if health insurers or employers could obtain the results, while 85 percent believed that employers should be prohibited from obtaining information about people's genetic conditions, risks, and predispositions.[3] A recent study involving genetic counselors documents that fear of discrimination is a significant factor affecting willingness to undergo testing and to seek reimbursement from health insurers.[4]

The medical privacy regulation was issued by the U.S. Department of Health and Human Services (HHS) in December 2000 in response to a mandate from Congress dating back to the 1996 HIPAA law. It is a milestone in federal law. It is the first – and only – federal law to protect the privacy of medical information in the hands of private health care providers and health plans. It constitutes a significant step toward restoring the public trust and confidence in our nation's health care system.

Despite intense pressure from some in the health care industry, the Bush Administration allowed this important regulation to go into effect in April 2001. The first implementation guidance document issued by HHS on July 6, 2001 addresses the many misstatements and exaggerations that some in the industry have been spreading about the privacy regulation for the last several months. On its face, the guidance is aimed at

---

[2] This survey is available at the California HealthCare Foundation's Web page: www.chcf.org.

[3] This and other surveys are summarized in a joint report, *Genetic Information and the Workplace,* issued on January 20, 1998 by the U.S. Departments of Labor, Health and Human Services, and Justice, and the U.S. Equal Employment Opportunity Commission.

[4] Hall, Mark A. and Stephen S. Rich, "Genetic Privacy Laws and Patients' Fear of Discrimination by Health Insurers: The View from Genetic Counselors," 28 Journal of Law, Medicine & Ethics 245-57 (2000).

calming industry fears, and it should lead to greater acceptance of the regulation and foster compliance with the regulation. The guidance also lays out a road map indicating what changes HHS is planning to make to the regulation. On the whole, the guidance is a welcome reaffirmation of the major provisions of the privacy regulation.

We acknowledge that the privacy regulation has significant shortcomings, but believe that, on the whole, it provides critically important privacy protections. One of the most notable shortcomings is the limited range of entities that must act to protect patient privacy.[5] It does not directly regulate all people or entities that have access to protected health information, such as employers (except possibly in their potential role as health care providers), pharmaceutical companies, workers' compensation insurers, and many researchers. Another significant shortcoming is the lack of a meaningful private right of action for people whose privacy rights are violated. These shortcomings reflect the limited authority given by Congress to HHS in HIPAA. Other shortcomings, in particular the regulation's approach to marketing, fundraising and law enforcement, reflect policy decisions made by HHS – policy decisions that we and many others have urged HHS to consider strengthening.

The HIPAA privacy regulation and genetic information

The HIPAA privacy regulation will protect the privacy of genetic information, with one important caveat: it will only protect genetic information to the extent that it protects other health information. Because there are limits to what the HIPAA privacy regulation can and does accomplish, the enactment of additional legislation targeting genetic information could provide additional and significant privacy protections.

Although the HIPAA privacy regulation singles out only one type of health information for special treatment -- psychotherapy notes -- genetic information will be protected by this regulation as long as it meets the definition of "protected health information." This term -- protected health information -- is defined broadly and includes information about the past, present, or future physical or mental health or condition of an individual, the provision of health care to an individual, or the past, present, or future payment for the provision of health care to an individual. HHS, in the preamble accompanying the final regulation, confirmed that "the definition of protected health information includes genetic information that otherwise meets the statutory definition." *See* 65 Fed. Reg. 82621.

---

[5] The following entities are required to comply with this new federal law:

- health care providers (doctors, hospitals, clinics, pharmacies, laboratories, *etc*.) that transmit claims-type information electronically in standard formats;
- health plans (broadly defined to include private insurers, employer-sponsored health plans, and HMOs, as well as a number of health programs sponsored by the federal and state governments); and
- health care clearinghouses (which act as claims processing intermediaries between health care providers and health plans).

Under this definition, information about genetic tests, services, or counseling will clearly be protected, as will information about an individual's family history – an important component of genetic information. Although the definition of protected health information does not explicitly refer to family history, HHS clarified in the introductory preamble to the regulation that medical information about a family member contained within an individual's medical record is information about the individual. *See* 65 Fed. Reg. 82493.

Health care providers that provide general medical services and that create or receive genetic information, as well as specialists that provide genetics services, perform genetic tests, or interpret genetic test results, will have to comply with the HIPAA privacy regulation if they otherwise meet the definition of a covered provider. The essential prerequisite for providers to be "covered" is that they transmit claims-type information electronically using HHS-prescribed standard formats.[6] This may mean that genetic information compiled, or genetic testing performed, in a research context will not be protected by the HIPAA regulation. Protection of genetic information in the research context will depend on whether the researcher is functioning as a health care "provider" and, if so, whether the researcher (or the institute that employs him or her) bills insurance companies for health care services.[7]

Falling within the scope of the HIPAA privacy regulation means that genetic information will be protected to the same extent as other health information. Once a health care provider obtains an individual's written consent, the provider can use and disclose that information for the provider's treatment, payment, and health care operations purposes (the latter is especially rather broadly defined). A health plan does not need to obtain the individual's consent before using and disclosing health information, including genetic information, for these purposes. As with other health information protected by this regulation, some uses and disclosures will require the opportunity for an opt-out in advance, some will require specific individual authorization, and other uses and disclosures can proceed without notice, authorization, or consent. One of the more controversial aspects of this regulation is that it will permit health care providers and plans to use and disclose protected health information for certain marketing and fundraising activities provided certain safeguards are met. The key is that within the confines of the HIPAA privacy regulation, genetic information is not treated differently than other types of protected health information.

It is important to note that the HIPAA regulation will **not** prevent covered health plans from requesting that individual plan members provide genetic information to the plan or from requiring applicants for insurance to provide genetic information or undergo genetic

---

[6] A new federal law (Pub. L. No. 107-105) eliminates, for the 6-month period between April 14, 2003 and October 16, 2003, any requirement that the electronic transmission conform to HHS-prescribed standard formats.

[7] Research involving genetic information will also be impacted by the regulation to the extent that researchers attempt to obtain protected health information from an entity that must comply with the regulation. Before covered entities can disclose patient identifiable information to researchers, certain requirements must be met.

tests as part of the insurance underwriting process. The regulation will, however, impact health plan or insurer requests that a covered health care provider disclose a patient's genetic information. How the privacy will impact those requests depends upon the context, specifically the purpose of the request. For example, an insurer seeking genetic information about an insurance applicant from a covered health care provider would need to provide the health care provider with an authorization signed by the applicant. Also, the regulation's "minimum necessary" standard should prevent a health plan from insisting that a covered health care provider disclose to it the results of a genetic test involving a plan member when the results of that test are not necessary for the health plan to reimburse the provider for conducting the test.

A noteworthy feature of the HIPAA privacy regulation is the way in which it will limit disclosures of protected health information, including genetic information, by group health plans and insurers to employers that sponsor group health plans. This is important because of the legitimate concern that many have about their employer having access to private medical information. The HIPAA regulation goes as far as it can to protect workers and their dependents from inappropriate disclosures *to* employers and from inappropriate uses *by* employers, but it cannot, given the fact that the employer has established the health plan, completely shut down the flow of information.

The HIPAA regulation permits group health plans and insurers to share protected health information with the employer/plan sponsor only in limited circumstances and only when certain requirements are met. The regulation does this by reconciling the employer/plan sponsor's legitimate need for access to some information with the need to ensure that protected health information is not used for employment-related purposes or purposes unrelated to the employer's management of the group health plan.

Of particular importance are the provisions that require the erection of firewalls to separate the group health plan functions of the employer/plan sponsor from the rest of the employer/plan sponsor. Under the regulation, only employees involved in health plan administration would have access to protected health information. Employees wearing multiple "hats" could legitimately use other employees' protected health information *to administer the group health plan*, but they could not use this information for any other purpose.

The HIPAA regulation may impact one other way that employers obtain protected health information about their employees. An employer that actually provides health care services to its employees, such as through an on-site medical clinic or employee assistance program, may, with respect to the provision of such care, be a health care provider that is required to comply with the HIPAA regulation. As with all other health care providers, the provider would have to engage in standard electronic HIPAA transactions in order to be a "covered" provider under the privacy regulation.[8] In general, providers will meet this electronic transmission prerequisite by engaging in electronic transactions with insurers, such as submitting claims for services to insurers. Since it is

---

[8] *See* footnote 6 regarding the temporary elimination of the standard format prerequisite.

hard to imagine an employer's on-site clinic engaging in such transactions, the health information created or received in these programs will generally not be protected by the privacy regulation.

PENDING GENETIC NONDISCRIMINATION BILLS AND PRIVACY

There are two major pending genetic nondiscrimination bills -- the Genetic Information Nondiscrimination in Health Insurance Act (S. 382), introduced by Senator Snowe, and the Genetic Nondiscrimination in Health Insurance and Employment Act, introduced by Senator Daschle (S. 318) and Representative Slaughter (H.R. 602).

Both bills build on the HIPAA privacy regulation and on another part of the HIPAA statute (the "nondiscrimination" provisions), which is separate from the part of the statute that led to issuance of the privacy regulation. The nondiscrimination provisions prevent health plans and insurers, in the group market, from refusing to enroll an individual due to that individual's (or a dependent's) genetic information. These provisions also prohibit charging one individual (or family) in a group more than others in the group on the basis of the individual's (or a dependent's) genetic information. This law also prohibits insurers in the individual insurance market from refusing to enroll, for any health-related reason, a subset of individuals who are leaving the group market and meet other prerequisites.[9] The genetic nondiscrimination bills discussed in this section of the testimony would build upon HIPAA by limiting health plan and insurer access to genetic information and further restricting the use of genetic information in medical underwriting.[10]

---

[9] HIPAA's nondiscrimination provisions leave many gaps. Even under HIPAA's nondiscrimination provisions, there are a number of ways that insurers can use genetic information. For example:

- Insurers in the mid- and large-size group market may refuse to cover an entire group because of the genetic information of one individual in the group. (Under HIPAA, employers with between 2 and 50 employees are considered to be the "small group market.")
- Insurers in the group market may charge an entire group (of any size) more than another group because of the genetic information of one individual in the group.
- Insurers may request, require, purchase or otherwise collect genetic information about an applicant's genetic information in the group and individual markets.
- Insurers in the individual market may deny coverage because of an applicant's genetic information unless the individual falls within the narrow category of individual market applicants that HIPAA protects (generally those leaving the group market who meet other prerequisites).
- Insurers in the individual market may treat a genetic predisposition as a preexisting medical condition (and refuse to provide coverage for expenses relating to it) unless the individual falls within the narrow category of individual market applicants that HIPAA protects.
- Insurers in the individual market can set premiums based on an applicant's genetic information.

[10] Neither bill reaches workers' compensation insurers, which also are not covered by the HIPAA privacy regulation, leaving workers' compensation insurers able, as a matter of federal law, to obtain, use, and disclose genetic information with impunity.

In several respects, however, these bills take different approaches to protecting the privacy of genetic information, beginning with some of the applicable definitions. Both bills include similar definitions of the terms "genetic information" and "genetic services." The key operational terms "predictive genetic information" (S. 382) and "protected genetic information" (S. 318) are defined differently (with the definition in S. 382 being more narrow), but both definitions would be encompassed by the term "health information" in the HIPAA privacy regulation.

The key features of these bills are outlined below.

The Genetic Information Nondiscrimination in Health Insurance Act (S. 382)

S. 382 directs group health plans and insurers to "establish and maintain appropriate administrative, technical, and physical safeguards to protect the confidentiality, security, accuracy, and integrity of predictive genetic information created, received, obtained, maintained, used, transmitted, or disposed of by such plan or issuer." It also requires group health plans and issuers to post or provide a notice to individuals of the plan or issuer's confidentiality practices. The bill further states that plans and issuers shall be deemed to be in compliance with these requirements if they are in compliance with the HIPAA privacy regulation (or the other regulations issued by HHS as part of HIPAA's administrative simplification title).

To the extent that this bill and the HIPAA privacy regulation reach the same covered entities, those covered entities would have to meet the same legal requirements (*i.e.*, the HIPAA privacy regulation). This bill, however, regulates more group health plans than are regulated by the HIPAA privacy regulation. The HIPAA privacy regulation applies to all group health plans **except** those that are self-administered **and** have fewer than 50 participants. Because S. 382 does not exclude this subset of group health plans, these plans would have to establish privacy safeguards and could, if they chose, meet this somewhat vague requirement by complying with the HIPAA privacy regulation, at least with respect to uses and disclosures of predictive genetic information.[11]

S. 382 permits group health plans and issuers to request that individuals provide predictive genetic information for diagnostic, treatment, or payment purposes, but otherwise prohibits plans and issuers from requesting or requiring individuals to provide predictive genetic information.

---

[11] In all likelihood, few group plans will fall into this category. According to congressional testimony submitted by the National Association of Health Underwriters, although it is not common, there are some employer groups in the mid-size range (50-300 participants) that self-administer their plans, but no mention is made of smaller groups where that is the case. *See* Testimony of Janet Stokes Trautwein before the U.S. House Committee on Education and the Workforce, Subcommittee on Employer-Employee Relations, Hearing on Hearing on Genetic Non-Discrimination: Implications for Employer Provided Health Care Plans (September 6, 2001).

S. 382 also prohibits the use of predictive genetic information in medical underwriting in the individual insurance market and in those aspects of the group market not addressed by the nondiscrimination provisions in HIPAA.

The Genetic Nondiscrimination in Health Insurance and Employment Act (S. 318)

S. 318 builds on HIPAA, the HIPAA privacy regulation, and the Americans with Disabilities Act (ADA) in several important ways. The most important new privacy protections in this bill are that it:

(1) prevents group health plans and issuers from requesting or requiring individuals to provide protected genetic information (with narrower and more tailored exceptions than S. 382);
(2) prohibits the use of protected genetic information for medical underwriting in the individual insurance market and in those aspects of the group market not addressed by the nondiscrimination provisions in HIPAA;
(3) directly regulates **employer** acquisition, use, disclosure, and storage of protected genetic information (primarily through Title II of the bill)[12]; and
(4) creates a private right of action for people whose rights are violated, whether by group health plans, insurers, or employers.

Title I (health insurance):
S. 318 does not include a general requirement that group health plans and issuers establish privacy safeguards. Instead, Title I contains targeted provisions limiting acquisition, use, and disclosure of protected genetic information.

Acquisition: This title of the bill prohibits acquisition of protected health information except in limited circumstances related to payment for health care services.

Use: This title prohibits the use of protected genetic information in medical underwriting in the individual market and in those aspects of the group market not addressed by the nondiscrimination provisions in HIPAA.

Disclosure: This title also limits certain disclosures by group health plans and issuers. Specifically, the bill prohibits group health plans and issuers from disclosing protected genetic information to:

- An entity that is a member of the same controlled group;
- Any other group health plan or issuer;
- The Medical Information Bureau (MIB) (or similar entity);
- The individual's employer or any plan sponsor; or
- Any other person the Secretary may specify.

---

[12] Title II of the bill also contains prohibitions that apply to employment agencies, labor organizations, and apprenticeship/training programs.

To the extent that this bill and the HIPAA privacy regulation reach the same covered entities, it is important to assess whether and how the above-listed disclosure prohibitions parallel or diverge from the HIPAA privacy regulation. (Like S. 382, this bill's privacy provisions would also apply to some group health plans that are not covered by the HIPAA privacy regulation -- self-administered plans with fewer than 50 participants -- though there are not likely to be many such plans.)

Controlled group/other group health plan or issuer. The HIPAA regulation does not contain general prohibitions on disclosures to affiliated companies or other group health plans/issuers. Rather than taking such an entity-based approach, the privacy regulation takes a functional approach. Thus, for example, a group health plan or issuer could disclose (without patient consent or authorization) protected health information (PHI) to an affiliated organization or to another group health plan or issuer if the disclosure was for the covered entity's treatment, payment, or health care operations purposes, though in some cases the regulation might require that the plan/issuer make such a disclosure pursuant to a contract with a "business associate." To the extent that this bill reflects concern about disclosures to entities that are not involved in core health care activities, the HIPAA regulation and S. 318 probably accomplish the same objective. To the extent that S. 318 would more uniformly prohibit disclosures to other affiliated companies (or all other plans/issuers), the approach in the bill and privacy regulation diverge.

Medical Information Bureau (MIB). The privacy regulation does not contain any explicit reference to the MIB. We believe the HIPAA privacy regulation does not permit group health plans and issuers to disclose PHI to the MIB without patient authorization because such disclosures do not fit within the definitions of treatment, payment, or health care operations. Insurers may attempt to argue that disclosures to MIB are permissible as part of underwriting. While plan/issuer requests for information **from** MIB as part of the plan's underwriting process would not be impacted by the privacy regulation, plan/issuer disclosures **to** MIB are different and would not be permitted without patient authorization. As a result, the explicit prohibition on disclosures to MIB in S. 318 parallels what the privacy regulation would accomplish.

Employers/plan sponsors. As discussed above, the HIPAA privacy regulation would permit group health plans and issuers to disclose PHI to an employer/plan sponsor in limited circumstances and only when certain requirements are met. In so doing, the regulation recognizes the employer/plan sponsor's legitimate need for access to some information to administer the group health plan that it sponsors. The blanket prohibition on disclosures to the employer/plan sponsor in S. 318 fails to recognize this legitimate and specific need.

Title II (employment):

The importance of directly regulating employer acquisition, use, and disclosure of protected genetic information should not be underestimated. This bill reaches the entire employer and covers all of the employer's activities. In contrast, the HIPAA privacy regulation reaches employers in their role as sponsors of group health plans, and reaches them only indirectly. As discussed above, employers are not likely to often come within the scope of the privacy regulation as health care providers. Yet, there are many ways in which employers obtain personal health information about employees (and their dependents). Other important avenues for collection of medical information are pre-employment or periodic medical exams permissible under the ADA, workers' compensation claims, medical examinations required or performed for occupational health and safety purposes, requests for paid or unpaid sick leave, and requests for family and medical leave.[13] Information obtained for these purposes and in these contexts will not be protected by the HIPAA privacy regulation. Thus, with respect to genetic information, S. 318 would provide significant additional privacy protections in the workplace.[14]

This title of the bill significantly limits employer acquisition of protected genetic information. It states that employers cannot request, require, collect, or purchase protected genetic information, with limited exceptions. In the House version of the bill, those exceptions relate to genetic monitoring consistent with federally established occupational health and safety standards and to genetics services offered by employers to employees with the employee's prior, knowing, voluntary written authorization. The Senate version of the bill includes an additional exception that permits employer acquisition of a limited amount of genetic information (specifically, information about the occurrence of a disease or disorder in family members) when such information is used exclusively to assess whether further medical evaluation is needed to diagnose a current disease or current medical condition or disorder **and** such disease, condition, or disorder could prevent the applicant (who has been given a conditional offer of employment) or the employee from performing the essential functions of the position.[15]

---

[13] Employer access to medical information generally, especially non-work-related medical information, as permitted in particular by the ADA, should be the subject of additional hearings by this Committee. For a recent comprehensive discussion and critique of the ADA's approach to medical examinations and inquiries, *see* Sharona Hoffman, *Preplacement Examinations and Job-Relatedness: How to Enhance Privacy and Diminish Discrimination in the Workplace*, 49 Kansas Law Review 517 (2001).

[14] The inadequacy of current law, in particular the Americans with Disabilities Act, to protect against employer use of genetic information to make hiring, placement, promotion, and discharge decisions is beyond the scope of this testimony. We note, however, that people with predictive genetic information will not likely fare too well in ADA challenges because of the trend of court decisions in recent years eroding the ADA's protections, especially the protections for people "regarded as" having a disability. For a comprehensive discussion of how the ADA's coverage has been significantly restricted, *see* Chai R. Feldblum, *Definition of Disability Under Federal Anti-Discrimination Law: What Happened? Why? And What Can We Do About It?*, 21 Berkeley Journal of Labor and Employment Law 91 (2000). For a thorough discussion of the ADA and genetic discrimination, *see* Paul Steven Miller, *Is There a Pink Slip in My Genes? Genetic Discrimination in the Workplace*, 3 J. Health Care Law & Policy 225-265 (2000).

[15] This section of the Senate bill also states that family history obtained for this purpose "will not be disclosed to persons other than medical personnel involved in or responsible for assessing whether further medical evaluation is needed to diagnose a current disease, or medical condition or disorder, except as otherwise permitted by this title." Section 203(a)(C)(III). If the purpose of this subsection is to limit access *within the employer organization* -- so that only medical personnel (as distinct from management, administrative, or supervisory personnel) are aware of the family history -- the language should be clarified to better protect privacy. The use of the word "disclosed" implies that there may be someone other than these medical personnel deciding whether to disclose it to the medical personnel. Stating that such

This title of the bill also prohibits employers from failing or refusing to hire or otherwise discriminating against an individual with respect to compensation, terms, conditions, or privileges of employment because of protected genetic information relating to the individual (or the individual's request for or receipt of genetic services). It further prohibits employers from limiting, segregating, or classifying employees in a way that would deprive or tend to deprive them of any employment opportunity or otherwise adversely affect their employment status because of protected genetic information (or the individual's request for or receipt of genetic services).

This title also contains a section on maintenance and disclosure of protected genetic information. It states that an employer must keep any protected genetic information that it does obtain as part of an employee's confidential medical file. The bill also states that employers cannot disclose protected genetic information except to the employee; an occupational or other health researcher (if research is conducted in accordance with part 46 of title 45 CFR); under compulsion of a federal court order; or to government officials investigating compliance with the law (if the information is relevant to such investigation).

The bill's privacy protections could be improved considerably by including provisions that explicitly give only licensed health care professionals who work with or for the employer access to protected genetic information in confidential medical files. When non-medical personnel ask to see actual employee medical files, they put occupational health professionals in a professional bind – disclose the requested information and violate patient/worker privacy, quite possibly in violation of the ADA, or risk being reprimanded, disciplined or fired. The bill already takes this approach in the genetic monitoring section where the bill states that employers, except for licensed health care professionals, only get aggregate (not individually identifiable) information.

In summary, S. 318 builds upon HIPAA, including the HIPAA privacy regulation, and upon the ADA by:

- Preventing group health plans and insurers from requesting or requiring individuals to provide protected genetic information (with limited exceptions);
- Directly regulating employer acquisition, use, disclosure, and storage of protected genetic information;
- Prohibiting the use of protected genetic information for medical underwriting in the individual insurance market and in those aspects of the group market not addressed by the nondiscrimination provisions in HIPAA;
- Providing patients with a meaningful private right of action when their rights are violated;
- Applying specific disclosure prohibitions to certain group health plans that are not reached by the privacy regulation; and

---

information "will not be available to, accessed by, or used by persons other than medical personnel" would be clearer and would better protect privacy.

- Confirming that group health and insurers cannot disclose protected genetic information to the Medical Information Bureau.

CONCLUSION

The U.S. Congress first took steps to prohibit certain uses of genetic information in the health insurance context with the enactment of HIPAA's nondiscrimination provisions. The recently issued HIPAA privacy regulation, a groundbreaking achievement set in motion by Congress in 1996, moves the ball forward. But HIPAA and the ADA do not, even together, constitute a comprehensive approach to protecting the privacy of genetic information. Bills pending in this Congress would build upon HIPAA, including the HIPAA privacy regulation, and upon the ADA to provide additional significant privacy protections for genetic information in the health insurance arena and in the employment sector.