

Putting the Genetic Information Nondiscrimination Act in context

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In this issue, the article by Lowstuter et al. (page 691) is especially important in light of the recently enacted federal law prohibiting genetic discrimination in health insurance and employment. The subject of genetic discrimination has beguiled clinical and research geneticists, genetic counselors, and patients for many years, but the new law is unlikely to resolve the uncertainty surrounding the lawful uses of genetic information.

On May 21, 2008, President Bush signed into law the Genetic Information Nondiscrimination Act (GINA). Because the issue of genetic discrimination had been considered for 13 years in Congress, and even longer in genetics circles, many of the advocates who worked on this legislation expressed an understandable sense of relief and exhilaration. Now that the ink has dried on the President's signature, and before GINA takes effect, it is appropriate to consider what GINA does and—perhaps more importantly—what it does not do.

The legislative landscape in 2008 is vastly different from 1995, when Representative Louise Slaughter first introduced her bill to prohibit genetic discrimination. In 1996, Congress enacted the Health Insurance Portability and Accountability Act (HIPAA). An important but little known provision in HIPAA prohibits employer-sponsored group health plans (the source of most private health coverage) from charging individuals within health plans different rates or varying their eligibility for coverage based on their health status, including their “genetic information.” In 2000, President Clinton issued Executive Order 13145 to prohibit discrimination in federal employment based on genetic information.

During the 1990s, almost every state enacted one or more laws to prohibit genetic discrimination. By the time GINA was enacted in 2008, 47 states had laws banning genetic discrimination in health insurance and 35 states had laws proscribing genetic discrimination in employment. State health insurance laws prohibit the use of predictive genetic information in medical underwriting for individual health insurance. (Federal law preempts state regulation of employer-sponsored group health plans.) State employment laws prohibit employers from requiring genetic testing as a condition of employment or using genetic information in personnel decisions.

With such widespread legislative action on genetic discrimination, one might assume that there have been numerous incidents of individuals being denied jobs and health insurance because of their genetic risk of illness. In fact, several studies have concluded that this is not the case. As genetic information becomes more common in health records, however, there could be an increased risk of discrimination.

The primary impetus for legislation at the state and federal levels is that many at-risk individuals who might benefit from undergoing genetic testing decline to do so because they are worried about the economic consequences of their genetic information. Indeed, the “findings” section of GINA specifically states that federal legislation “is necessary to fully protect the public from discrimination and allay their concerns about the potential for discrimination, thereby allowing individuals to take advantage of genetic testing, technologies, research, and new therapies.”

The health insurance provisions of GINA apply to both individual and group health insurance. GINA prohibits health insurers from using genetic information to discriminate in rates or coverage. The employment provisions of GINA prohibit employers from requesting, requiring, or purchasing genetic information; requiring an individual to take a genetic test as a condition of employment; or discriminating on the basis of genetic information. Genetic information is defined as “information about an individual's genetic tests, the genetic tests of family members, or the occurrence of a disease in family members of the individual.”

GINA helps prevent some genetic discrimination in ways that are tangible (e.g., enabling genetically at-risk individuals to obtain individual health insurance) and symbolic (i.e., it establishes a national policy against genetic discrimination). Nevertheless, GINA is seriously deficient for at least the following three reasons. First, GINA does not apply to life insurance, disability insurance, long-term care insurance, or other uses of genetic information. It is not clear whether a federal law prohibiting discrimination in only health insurance and employment will be enough to allay the concerns of individuals about other possible consequences of genetic testing.

Second, GINA applies only to individuals who are asymptomatic. It does not prohibit adverse action based on “genetic information about a manifested disease, disorder, or pathologic condition.” In the context of individual health insurance, GINA prohibits discrimination against an individual who is at a genetically increased risk of, for example, breast or colon cancer. If the individual later developed cancer, however, GINA would not apply. State insurance law would then govern

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the insurance company's options. In the overwhelming number of states, health insurers may lawfully refuse to renew an individual health insurance policy or increase premiums substantially to reflect the individual's new health status.

The essence of genetic discrimination in health insurance has nothing to do with genetics, it involves health policy. The best way to resolve the problem would be to enact laws based on the principle that individuals who are sick or more likely to get sick (from whatever cause) are entitled to access to health coverage without regard to their current health status or risk. Such a policy is a fundamental element of Medicare, Medicaid, and other government-sponsored programs, but it is not embodied in laws regulating the private health insurance market.

Third, the employment discrimination provisions of GINA prohibit employers from requesting or requiring genetic information as a condition of employment. Yet, under the Americans with Disabilities Act, employers may lawfully require individuals to release all of their health records after a conditional offer of employment. At the present time, there is no feasible way for custodians of health records to separate genetic information from "other" health information in either paper or electronic files. Thus, it is common for custodians of health records to release all of an individual's health records to a prospective employer, even if they receive a limited request. Substantial funding for research and development is necessary to

create computer software for new electronic health record systems that can release only essential, job-related health information.

When presented with these three concerns, supporters of GINA typically have one of two reactions. Either they are surprised by GINA's limitations or they concede that GINA's protections are limited, but assert that GINA is the best legislation that could be enacted at this time. Such a response may be an accurate assessment of the political realities in 2008. Yet, it is indisputable that GINA provides inadequate protections for individuals at genetically increased risk of illness, and it is indefensible to continue permitting discrimination against already-affected individuals.

A final, overarching concern is that GINA may do more harm than good. Misinformed individuals might erroneously rely on the supposed protections of GINA, undergo genetic testing, and then suffer from discrimination beyond the scope of GINA's protections. Furthermore, as a matter of political strategy—and at the risk of mixing metaphors—is GINA "a foot in the door" of meaningful protection that will be improved over time or is GINA the genetic community's "one bite of the apple" that will actually delay the enactment of effective legislation? Time will tell, but now is not the time for irrational exuberance or undue celebration, regardless of the difficulty in obtaining GINA's passage.