



# THE GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008: *Observations and Implications*

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On May 21 last, President George W. Bush signed into law the Genetic Information Nondiscrimination Act of 2008 (GINA). Congress passed GINA with a bipartisan consensus unprecedented in living memory: unanimous in the Senate and 414-1 in the House. In his signing message, President Bush said: "I want to thank the members of Congress who've joined us as I sign the Genetic Information Nondiscrimination Act, a piece of legislation which prohibits health insurers and employers from discriminating on the basis of genetic information. In other words, it protects our citizens from having genetic information misused, and this bill does so without undermining the basic premise of the insurance industry".<sup>1</sup>

I'm not sure what President Bush meant by the "basic premise of the insurance industry." However, if pressed to define the "basic premise" to which he refers, I would suggest that it is the long established policy of the medical insurance industry to avoid coverage of persons with any semblance of increased risk, (particularly if not in conjunction with a large group contract), and to base individual premiums on perceived risk. If this were not the case, Congress would not have resorted to GINA to prevent insurer access to personal genetic data and thereby to prevent consequent denial of health insurance or to assess prohibitively high premiums. The latter is specifically proscribed by GINA.

Actually, concern for the consequences of personal genetic information falling into the hands of medical insurers is not new. In 1993, the National Institute of Health-Department of Energy (NIH-DOE) Working Group on Ethical, Legal and Social Implications of Human Genome Research, issued the "Genetic Information and Health Insurance Report of the Task Force on Genetic Information and Insurance."<sup>2</sup>

This 1993 report emphasized that "One of the ironies in the current health care coverage crisis is that developing more accurate biomedical information could make things worse rather than better. In the current American

health care system, information about an individual's risk of disease plays a crucial role for many people in determining access to health care coverage. This link between the likelihood of needing health care and the ability to obtain coverage, unfortunately, may cause those with the greatest need to have the most difficulty finding affordable health insurance. Recent advances in human genetics are transforming medicine by making increasing amounts of information about risk available."

The first of the 1993 Task Force Recommendations, and perhaps the most important and far reaching, is that "Information about past, present, or future health status, including genetic information, should not be used to deny health care coverage or service to anyone." The key element in the recommendation is that it draws an analogy between genetic information and medical history, and makes the point that neither should be an impediment to health insurance in terms of eligibility or cost.

This principle, I believe, is of paramount importance if we are to achieve our goal of making equitable and affordable health care coverage available to all of us. It is reiterated several times in the Task Force Report from somewhat different vantage points, presumably for emphasis, as follows: "The U.S. health care system should ensure universal access to and participation by all in a program of basic health care services that encompasses a continuum of services for individuals and families, *for the healthy to the seriously ill; The cost of health care coverage borne by individuals and families for the program of basic health services should not be affected by information, including genetic information, about an individual's past, present or future health status; Participation in and access to the program of basic health services should not be conditioned on disclosure by individuals and families of information, including genetic information, about past, present or future health status.*" (Italics mine)

Further, the 1993 Task Force Report clarified its use of the term "program of basic health care services" as follows:

*“We use the phrase ‘program of basic health services’ to describe the array of services that would be available to all after implementation of major health policy reforms, such as those being considered by the President’s Health Policy Task Force. We explicitly reject all connotations of ‘basic’ as minimal, stingy, or limited to such services as immunization and well-child care. A program of ‘basic’ health services could encompass a broad range of care for those most in need.”*  
(Italics theirs)

The significance of GINA 2008 is that it prevents access by medical insurers to personal genetic information. As alluded to above, this is a principle that the 1993 Task Force, although clearly aware of, could only hope for and advocate, but GINA 2008 made it the law of the land. GINA also allayed the fears of many who could benefit from genetic testing, but were reluctant to undergo it because of the potential negative impact on their insurability.

The 1993 Task Force also enunciated a principle which may in time become as important as GINA: “Information

about past, present, or future health status, including genetic information, should not be used to deny health care coverage or service to anyone.” Could this become a new frontier, analogous to what GINA has done to protect the confidentiality of genetic information? This concept already applies in large groups, such as in companies where risk is spread among a spectrum of ages and in a population well enough to work. If, somehow, family and health history could be protected by legislation just as GINA protects genetic information, more affordable health insurance and health care would become available to hundreds and even thousands who are now being denied much needed care.

Implementation of this approach would probably require the creation of large insurance pools open to individuals, not just groups. In essence this is an extension of community-rating, hardly a new idea in health insurance. This concept is not a panacea. Neither is GINA. But like GINA it is a serious response that deals forthrightly with a specific problem. That approach is all too rare in health care.

REFERENCES

1. Office of the Press Secretary, May 21, 2008: President Bush Signs H.R. 493, the Genetic Information Nondiscrimination Act of 2008 [www.whitehouse.gov/news/releases/2008/05/20080521-7.html](http://www.whitehouse.gov/news/releases/2008/05/20080521-7.html).
2. National Human Genome Research Institute - National Institutes of Health: Health Insurance in the Age of Genetics [www.genome.gov/10000879](http://www.genome.gov/10000879).



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