

Editor's Notes

The Genetic Information Nondiscrimination Act—A Wake-Up Call: Great Intentions, but a Setback for Health Impact and Cost-Effectiveness of Workplace Health Promotion

The Genetic Information Nondiscrimination Act (GINA)¹ was signed into law on May 21, 2008. The act protects individuals from genetic information discrimination in health insurance and employment. Unfortunately, it is likely to have a negative effect on workplace health promotion programs. GINA Title I applies to health insurance and Title II applies to employment. Note: I am not commenting on GINA Title II because the rules had not yet been released when I wrote this column in mid-November 2009.

The purpose of this commentary is not to provide an in-depth review of the GINA provisions. Instead, the purpose is to use the GINA experience to illustrate that passing legislation is just the first step in integrating health promotion concepts into national policy. The second step is making sure the rules guiding implementation of the legislation are written in such a way that they achieve the intended purpose. The third step is to make sure agencies carry out the rules appropriately. If we want to integrate health promotion concepts into national health policy, we need to be involved in all three steps.

Purpose of GINA and Impact on Workplace Health Promotion

The intentions of the GINA legislation are laudable: to remove privacy concerns that might slow the integration of genetic testing and information into medical care, with the ultimate goal of protecting the privacy and enhancing the health of the individual patient. The language in the actual legislation seemed to be written appropriately to address this goal.² Unfortunately, the regulations³ written to guide implementation went beyond the intentions of the legislation and are likely to have a negative effect on workplace health promotion programs. This legislation was highly visible among genetic researchers and patient advocacy groups for

obvious reasons, but was not visible within the health promotion community because it had no apparent relevance. The final interim rules for GINA Title I were released on October 7, 2009, only 2 months before the regulations were scheduled to go into effect on December 7, 2009. This allowed very little time to review the implications and implement changes necessary to comply, let alone submit appeals to revise or delay the changes. Based on several independent legal reviews and feedback from federal officials, the following rules seem to apply to workplace health promotion programs:

1. Health risk assessments questionnaires (HRAs) offered by health insurance plans and self-insured employers are prohibited from including questions on family history if a financial incentive related to the health plan premiums is used to motivate employees to complete the questionnaire. It is not yet clear if financial incentives that are not related to the health plan may be used to motivate completion.
2. HRAs offered by health plans and self-insured employers are prohibited from including questions on family history if the information is used to determine eligibility for programs.

These rules are likely to impact health promotion programs in at least three ways.

1. If financial incentives are removed, participation rates in well-marketed employer-sponsored programs are likely to hover in the 20% to 30% range instead of the 70% to 90% range.^{4,5} If this happens, fewer people will be helped and medical costs will be moderated for a smaller portion of the workplace population.
2. If questions on family history are removed, accuracy of risk prediction will be reduced. This will make it more difficult to determine the optimal level of program intensity offered to each participant. This will in turn reduce program effectiveness or increase program costs.
3. If questions on family history are removed, feedback to participants will not be tailored as well to reflect this information and will be less effective in motivating participants to change health habits.

Implementation Dates and Appeal Process

The interim final rules for GINA Title I are scheduled to take effect on December 7, 2009. The public comment period is

Am J Health Promot 2009;24(3):iv-v
DOI: 10.4278/ajhp.24.3.iv
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scheduled to continue through January 5, 2010. Several health promotion providers and advocacy groups have articulated their concerns with the new rules and the short warning period, but genetic research groups and labor unions have already countered those appeals. Early indications are that the rules will be implemented as written, at least in the short term. Despite the short notice, HRA providers have already removed questions about family history from their questionnaires to comply with the new rules. Some employers are planning to offer two questionnaires, one with no family history questions that could be offered in conjunction with financial incentives, and one with family history questions that would be offered without incentives. Innovative providers will no doubt learn how to maximize program effectiveness and efficiency to comply with rules, but isn't it a little bit ridiculous that workplace health promotion programs need to jump through these hoops and increase costs to comply with legislation that should not apply to them?

Woulda, Coulda, Shoulda...Shall?

What could have been done to prevent this problem, and how should we act differently in the future?

1. Better monitoring of legislation. Our field has just begun to monitor legislation that will have a direct impact on our work; this is clearly not sufficient. We clearly need to do a better job of monitoring legislation that may have an indirect impact on our work. This will require a greater presence in Washington, D.C.
2. More proactive self-regulation. GINA legislation was developed to give physicians and other licensed medical professional *better* access to genetic information. What has happened to workplace health promotion programs that has made patient advocates concerned about family history information being provided to programs that use financial incentives? Have financial incentives gone too far? Has family history information been used improperly? Have confidentiality firewalls been pierced? Have program participants been hurt in any way? Do we need new covenants on professional ethics? Do we need new standards to govern providers, employers, insurance companies? Admittedly, it will be difficult for a field as small as ours to develop self-regulations that govern professionals from the many clinical and academic disciplines represented in our field and that also govern providers, employers, and insurance companies...especially when we have no single profession association or trade association that represents our field.
3. Better messaging. We may have a distorted sense of how we are perceived by people outside our field. Because of our devotion to helping people and because of the close relationships we form with people who have transformed their lives through our programs, it may be difficult for

us to understand that some individuals and groups do not admire our work, and may actually be suspicious of our work. We have very low visibility in the media and have done nothing to paint a positive picture. Think about it: the workplace programs that get the most publicity are those (or that ONE) that fire employees for smoking. Each of us can do a better job of making our work more visible in our own communities, and taking a stand against policies or programs that do not have personal health as their top priority. We also need to be actively involved at a personal level with union, patient advocacy, and other groups that may be concerned about these issues. This will help develop trust at a personal level. We also need to explore what must be done to enhance the image of our field at a national level.

4. Active involvement in the process of writing rules and regulations. Integrating health promotion concepts into national policy involves passing new legislation, writing regulations, and monitoring implementation of the regulations at the agency level. We need to be involved in all three steps. The good news is that Congress, regulating organizations, and government agencies welcome our input because they want to create sustainable solutions to improving the health of the nation and recognize that we can contribute valuable experience and perspective. This will require us to have a more active presence in Washington, D.C. Our first opportunity will be in the coming year, when all the health promotion provisions included in health care reform legislation move from the legislative to the rules stage.

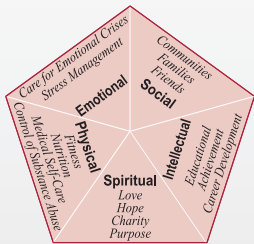
Michael O'Donnell

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(O'Donnell, *American Journal of Health Promotion*, 2009, 24,1,iv)

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