When Public Health and Genetic Privacy Collide: Positive and Normative Theories Explaining How ACA's Expansion of Corporate Wellness Programs Conflicts with GINA's Privacy Rules

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Introduction

The passing of the Patient Protection and Affordable Care Act (ACA)¹ is a triumph for the field of public health. Its inclusion of many provisions intended to prevent illness and promote health endorses the core belief of public health as expressed by Dr. Georges Benjamin, the long-time executive director of the American Public Health Association, in a *Washington Post* opinion piece praising ACA for "provid[ing] care as far upstream as possible... [in order to] reduce costs by identifying problems early and then managing them to reduce or eliminate the need for more costly care in the future."² In this article, I consider the conflict between ACA's adoption of public health goals seeing population health and societal interests in protecting individuals from discrimination based on their health. The article focuses on one aspect of ACA which seeks to lower the costs to employers who provide health insurance for their employees by making it easier for them to offer their employees substantial incentives for participating in and meeting the goals of employer-sponsored Wellness Programs.³

This conflict is illustrated by the fact that while ACA changes a number of provisions intended to protect individuals against discrimination in order to allow employers to tie the cost of health insurance to participation in Wellness Programs, it does not change the recently enacted rules by the Equal Employment Opportunity Commission (EEOC), which interpret the Genetic Information Non-Discrimination Act (GINA) as prohibiting the use of family history in Wellness Programs.⁴ This conflict provides a particularly apt example because it allows looking at ACA provisions, which encourage corporations to provide incentives for their employees to participate in Wellness Programs, and anti-genetic discrimination provisions in GINA, which limit the ability of employers to use family history as a method of risk assessment in these same programs.⁵ This article analyzes the conflict by providing positive legal theories, descriptions and explanations, of how these statutory changes will actually work and the consequences likely to occur from their adoption, and then discusses the conflict

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between the normative principles of lowering costs by adopting public health principles of collective prevention and of protecting individuals from discrimination based on their genetic makeup.

This article concludes with the prediction that ACA's goal to decrease health costs, and therefore increase access to health care, by emphasizing prevention will inevitably find itself in stark conflict with the goal of protecting individuals from paying more for health insurance based on their health status. While the laws discussed in this article currently prohibit this kind of discrimination, as health care costs continue to rise and as science becomes better able to predict risk of future illness, there will be pressure on employees at least to mitigate risks that make them more expensive to insure. Since there is very little existing case law directly addressing risk assessment in Wellness Programs and since many of ACA's provisions are yet to be implemented, this article can only raise these issues as potential risks of taking a public health approach to lowering the cost of health insurance.

Just as Sherlock Holmes noted the significance of the "dog which did not bark,"⁶ this article emphasizes the significance of ACA's failure to change GINA's provisions limiting employers' use of family history in Wellness Programs. It is important because it restricts employers' use of Wellness Programs to save money at the same time ACA amends three other statutes expanding employers' ability to do so. This conflict represents an inherent and ongoing dispute between the normative, public health-based goal of privileging the good of the population in contrast to anti-discrimination laws which are designed to protect the rights of specific individuals.⁷

ACA's Emphasis on Prevention

Before this article can analyze the inherent conflict between ACA's choice to seek cost savings by focusing on the health of the public as a whole, and the protection of individuals against discrimination based on health status or genetics, it is important to lay the groundwork demonstrating ACA's emphasis on public solutions to the problem of rising health care costs. It is this balance of public good versus protection of individual autonomy that is one of the core struggles of public health law today.⁸ As Professor Elizabeth Weeks writes, "In the traditional public health view, states avoid interfering with individual rights unless necessary to protect the community. However, the 'new' public health takes a broader view, addressing seemingly individual health habits or conditions, such as obesity, smoking, domestic violence, firearms, and socioeconomic disparities."⁹ While ACA and GINA

are federal statutes, they exemplify the same conflict between collective and individual rights.

This article addresses the conflict between promoting the public and the individual's health by pointing out a substantial and highly visible conflict: the legislative decision to protect information about an individual's family health history at the possible cost of reducing the effectiveness of Wellness Programs designed to individualize risk-reduction strategies for participating employees.

Writing in the *New England Journal of Medicine*, Secretary of Health and Human Services Kathleen Sebelius and her co-author Dr. Harold Koh, Assistant Secretary for Health, decry the poor state of the nation's health noting that "[t]oo many people in our country are not reaching their full potential for health because of preventable conditions. Moreover, Americans receive only about half of the preventive services that are recommended."¹⁰ In light of these conditions, they enthuse that "[t]he 2010 Affordable Care Act responds to this need with a vibrant emphasis on disease prevention."¹¹ The authors describe the Act as "[m]oving prevention toward the mainstream of health" and go on to detail 10 sections of ACA which they believe, "[w]ill reinvigorate public health on behalf of individuals, worksites, communities, and the nation at large ...and will usher in a revitalized era for prevention at every level of society."¹² They sum up by declaring that "[t]he Act breaks new ground [in order to] prevent disease and promote health and wellness..." and conclude that:

[W]e believe the law reaffirms the principle that 'the health of the individual is almost inseparable from the health of the larger community. And the health of each community and territory determines the overall health status of the Nation.' Moving prevention toward the mainstream of health may well be one of the most lasting legacies of this landmark legislation.¹³

Many different provisions of ACA promote preventive care such as mandating that insurance companies cover regular examinations, appropriate screening tests, and free vaccinations.¹⁴ For the purposes of this article, however, the relevant parts of ACA are those which specifically promote Wellness Programs. Secretary Sebelius and Dr. Koh cite section 4303, [E]mployer Based Wellness Plans,¹⁵ which they describe as "[p]romot[ing] wellness in the workplace, providing new health promotion opportunities for employers and employees."¹⁶ These provisions authorize funds for grants for small businesses to provide

comprehensive workplace wellness programs and amend laws which limit the incentives employers can provide for participation.¹⁷ Recognizing ACA as a force for public health and wellness is not limited to government officials. An article summarizing the impact of ACA on public entities' benefit programs began with the sentence: "The overwhelming emphasis on wellness and health promotion in the recently passed health care reform legislation — the Patient Protection and Affordable Care Act, or PPACA — demonstrates a concerted effort to change the behaviors of stakeholders in the health care system from reactive to preventive."¹⁸ Defending the kind of health care reform implemented by ACA as cost effective, David C. Clark, Otto Eckstein Professor of Applied Economics at Harvard University, identified its prevention provisions as one of its keys for success, stating that the emphasis on prevention should result in "[f]ewer and less expensive acute episodes. We devote far too little attention to prevention, and when acute episodes occur, they are more expensive than need be."¹⁹ ACA promotes prevention by supporting a wide variety of programs that focus on the public health model of identifying and minimizing risk.

ACA's Support of Wellness Programs

A. What Is Wellness?

In a world where AIDS,²⁰ polio,²¹ and malaria²² remain endemic and 884 million people in the developing world lack access to clean water,²³ the Wellness Programs described in this article are a luxury in that they enhance the lives of a population with access to the highest standards of living in the United States. A working definition of wellness can be found in the World Health Organization's declaration that "[h]ealth is more than the absence of illness. It is the active state of physical, emotional, mental and social wellbeing."²⁴ Much of the interest in wellness as a method of saving costs in future health care stems from a 2002 National Institutes of Health Report from the U.S. Preventive Services Task Force (USPSTF), which advocated routine weight screening for all adults in order to lower the risks of heart disease, diabetes, and stroke.²⁵ Whether or not wellness promotion through risk assessment, let alone Wellness Programs, saves money by improving health is a topic of great debate.²⁶ Part of the answer, certainly, is that some preventive interventions are more likely to save money than others. On the other hand, screening for diseases could well increase costs because treatment

was started sooner.²⁷ As one commentator noted in *Health Affairs*, "[I]f one focuses on interventions that preserve health (for example, immunizations and lifestyle interventions) rather than those that are intended to interrupt the progression of disease (for example, screening for disease), a set of efficacious preventive interventions that reduce the net cost of health care can be identified."²⁸

Wellness Programs have become increasingly popular based on findings widely accepted by U.S. employers that they save money in health costs and, as an added bonus, raise productivity.

B. What Are Wellness Programs?

Wellness Programs are organized efforts by employers who provide health insurance to their employees to reduce costs, both from illness and absenteeism, by encouraging employees to adopt healthier lifestyles and, more specifically, to address behaviors or inherited characteristics which put them at greater risk for illness than the general population. These programs typically target behaviors like quitting smoking, losing weight, and lowering blood pressure and cholesterol.²⁹

Many different variations exist of the basic concept of a Wellness Program, but the one dividing point is between voluntary ones and mandatory ones.³⁰ Voluntary programs work by encouraging employees to adopt healthier lifestyles.³¹ They range from distributing literature about living a healthier life, subsidizing the cost of gym membership or programs to help quit smoking, to elaborate in-house recreation centers staffed by company employees devoted to counseling their fellow employees about living a healthier life.³² Mandatory programs require participation and may also require employees to achieve health-related goals, like losing weight, in order to get any incentive such as a reduction in the price they have to pay for health insurance. This article's focus is on mandatory programs that require meeting health goals since they are the ones subject to the most legal oversight.

C. Why Do Employers Have Wellness Programs?

Many employers believe that healthy employees are more productive and offer programs to "create a culture of health." Discussing her company's cafeterias that serve healthy food and their 19,000 square-foot recreation facility for employees, Barbara Schaefer,

senior vice president of human resources at Union Pacific Railroad Corporation, says that “[t]here are three main things that affect employee health: whether or not they exercise, eat right and smoke.” She further states that “[f]ocusing on those three things over the last 20 or so years has become such a mantra for us that I think anyone at the company could tell you that we’re always worrying about them.”³³ Wellness Programs have become increasingly popular based on findings widely accepted by U.S. employers that they save money in health costs and, as an added bonus, raise productivity.³⁴ In 2008, the Robert Wood Johnson Foundation funded a study of workplace Wellness Programs and found that “[t]he majority of [the worksites] (64.6%) employed at least 1 full- or part-time staff person who was directly responsible for health promotion and worksite wellness.”³⁵ They also found that approximately 26% of worksites reported using incentives to increase employee participation. Incentives involving gifts and discounts were mentioned most often, followed by cash incentives.³⁶

What has caused employers to spend money on developing Wellness Programs, however, is not so much general concern for the welfare of their employ-

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ees as the need to save money in the face of rising health care costs. A December 2010 article in the *Harvard Business Review* reports that “[e]very dollar invested in [Wellness Programs] yielded \$6 in health care savings.”³⁷ Exhorting business leaders to adopt these programs, the authors point out that “[w]ith tax incentives and grants available under recent federal health care legislation, U.S. companies can use wellness programs to chip away at their enormous health care costs, which are only rising with an aging workforce.”³⁸

By encouraging Corporate Wellness Programs, ACA advances its general goal of promoting public health by intervening to prevent illness in populations rather than waiting to treat individuals who become ill. The EEOC, in its most recent budget request to Congress, described its own goals and objectives for their own, agency-wide Wellness Program.³⁹

D. What Criticisms Have Been Made about Wellness Programs?

The criticisms of Wellness Programs take three major forms: those concerned about issues of social justice, those concerned about economics, and those concerned about their efficacy.

I. SOCIAL JUSTICE CONCERNS: ARE WELLNESS PROGRAMS DISCRIMINATORY?

Describing the incentives offered for participation in Wellness Programs as “lifestyle discrimination,” Michelle Mello, a public health and law scholar at Harvard University, has taken the lead in highlighting the social justice concerns raised by programs that reward a level of self-care which is not equally accessible to all employees.⁴⁰ Her criticisms have been taken up by an impressive array of disability rights scholars in both law and public policy.

A. DO WELLNESS PROGRAMS DISCRIMINATE AGAINST THOSE LIVING WITH CHRONIC ILLNESS?

One core criticism of Wellness Programs is that they target a population that is not currently protected by law but who are still often perceived as expensive to insure: the chronically ill who lack a disabling condition sufficient to qualify them for protection or accommodations under the ADA.⁴¹ As Professor Elizabeth Pendo explains, the “significant and growing population” of “working-age adults with a major chronic condition” is a “[c]hallenge for employers” because “[m]any of the cost-control methods used by employer-based plans simply

shift rather than lower health care costs.”⁴² Considering the issue, policy expert Sara Rosenbaum notes that “[w]hether wellness policies ultimately serve to discriminate against persons in poor health by penalizing them for their failure to aggressively take charge of their health remains to be seen.”⁴³ She suggests that this is possible in the case of “widespread use of wellness programs in an era of shrinking coverage” giving as an example a diabetic whose employer does not cover the service of a podiatrist but penalizes employees for failing to engage in self-care.⁴⁴

B. DO WELLNESS PROGRAMS DISCRIMINATE BASED ON CLASS, SEX, AGE, AND GENDER?

Beyond discrimination regarding health status are concerns about discrimination based on more traditional, if not Constitutionally protected, categories of class, sex, and race. Already, a considerable body of literature identifies Wellness Programs as discriminatory against women and under-represented minori-

ties.⁴⁵ It also can be an extra burden on employees who must work more than one job and, therefore, do not have time to exercise or participate in wellness activities. It is difficult to avoid class bias when describing the difference between employees who already put a priority on health and fitness and employees who do not. Many articles directed at employers imply class bias. In an article intended to advise human resources managers, Todd Underwood, a management consultant in health care, writes, “[W]e haven’t quite found out how to motivate people who have tried and failed or those who have multiple conditions and don’t think anything can help; who think they are too busy; or who simply would rather go home and have a pizza, six pack and watch TV.”⁴⁶ Another concern is that women often have significant care obligations for children or elderly parents or both, which means they do not have time to exercise.⁴⁷ In 2008, the U.S. Department of Labor reported that 71.3% of women with children were in the labor force.⁴⁸ Another factor which could reduce the ability to participate is the need to work more than one job. Even if these programs are not intended to target specific under-represented minorities, in fact, this is exactly the population most likely to have more than one job. Forty-three percent of working families with at least one minority parent were low income, nearly twice the proportion of white working families (22%).⁴⁹

C. DO WELLNESS PROGRAMS DISCRIMINATE AGAINST PEOPLE PERCEIVED AS OBESE?

Another related concern is discrimination against those whose weight is perceived as being outside social norms. Much of this discrimination is based on perceptions about how people look. One of the often-made criticisms of programs that intend to improve health by lowering weight is that such programs reinforce existing perceptions that people who do not fit within contemporary society’s range of acceptable weight are unhealthy, poor workers, and undisciplined.⁵⁰ In light of that stigma, Wellness Programs, which provide rewards based on weight loss, are viewed by some commentators with suspicion. For one thing, “association between obesity and health outcomes may vary by ethnic group...”, thus making weight bias a proxy for race or ethnic bias.⁵¹ Also, as the influential National Institutes of Health Report from the U.S. Preventive Services Task Force acknowledges, very little evidence demonstrates that losing weight improves health.⁵² Justifying its call for universal weight screening, the Task Force noted that “[o]besity and overweight are associated with an increased risk for coronary heart disease (CHD), hypertension, and stroke; type 2 diabetes; several types of cancer, including those of the

colon, kidney, gallbladder, breast, and endometrium; sleep apnea; gall bladder disease; and certain musculoskeletal disorders, such as knee osteoarthritis.”⁵³ But it does not provide data describing the effectiveness of losing weight in reversing any of these risks. Interestingly, the next line in the overview justifying the war on obesity was that “obesity is associated with decreased quality of life, including diminished mobility and social stigmatization.”⁵⁴

In the first sentence of an article titled, “*Mandatory Wellness Programs: A Plan to Reduce Health Care Costs or a Subterfuge to Discriminate Against Overweight Employees?*”, Jennifer Dianne Thomas writes that “[i]n many ways, social conditioning in American society silently encourages a palpable level of disdain for overweight individuals.”⁵⁵ Obesity is perceived as an epidemic in the United States. She points to research showing that weight discrimination is so pervasive in the workplace that in one study, 50.8% employees themselves believe that “companies should be allowed to charge higher premiums to overweight employees,” and 28.3% agreed that “companies should be allowed to reject job candidates who are overweight.”⁵⁶ Employers believe that people they perceive as obese use far more health care resources than do non-obese ones. One of many examples of this found in literature aimed at employers is the following:

Obesity’s co-epidemic, type 2 diabetes, has increased six-fold in the last 5 decades. An estimated 14% of persons over the age of 20 have diagnosed diabetes, undiagnosed diabetes, or impaired fasting glucose. It’s also estimated that 22% of overweight adults, age 45-74 have pre-diabetes and could benefit significantly from lifestyle interventions.⁵⁷

One common belief is that obesity is synonymous with diabetes.

Fact #584: The per capita annual health care costs for people with diabetes rose from \$10,071 in 1997 to \$13,243 in 2002, an increase of more than 30%. These costs are 5 times greater than the cost for a person without diabetes.⁵⁸

A large part of the difficulty in resolving the legal status of those perceived as being obese is a lack of consensus about the causes of obesity. As the CDC explains in discussing the growing rate of obesity, “although changes in the genetic makeup of populations occur too slowly to be responsible for this rapid rise in obesity, genes do play a role in the development of obesity. Most likely, genes regulate how our bodies capture, store, and

release energy from food. The origin of these genes, however, might not be recent.”⁵⁹

Obesity is a frequent target of Wellness Programs. The National Summit on Legal Preparedness for Obesity Prevention and Control has developed a range of legal options; a research team advised “[l]everag[ing] tax incentives to attract companies with demonstrated success in promoting workplace wellness, as well as to motivate existing organizations to develop robust obesity prevention offerings.”⁶⁰

2. ECONOMIC CONCERNS: DO WELLNESS PROGRAMS ACTUALLY REDUCE HEALTH CARE COSTS?

Another concern about Wellness Programs is that they may save employers money by shifting costs to the public. ACA, as currently structured, is built on the foundation of the existing system of employer provided health insurance.⁶¹ It is not, at any time in the near future, intended to replace the coverage of people who are already receiving insurance from their employers.⁶² A large influx of people who had previously received insurance at work but who now find it prohibitively expensive because of their failure to participate in, or satisfy the requirements of, the Wellness Program would be a substantial financial burden on the newly created exchanges.⁶³ Professors Amy Monahan and Daniel Schwarcz have conducted empirical research, which causes them to be concerned that “there is a substantial prospect that ACA will lead some, and perhaps many, employers to implement a targeted dumping strategy designed to induce low-risk employees to retain [employer-sponsored insurance] but incentivize high-risk employees to voluntarily opt out...and instead purchase insurance” in whatever emerges as a state financed public option.⁶⁴ While they discuss many aspects of ACA, they identify Wellness Programs as a particularly troubling way for employers to avoid paying for the health insurance of employees most likely to be sick. They anticipate that this cost shifting could occur whether or not employee premiums were tied directly to achieving health goals. They write that “these types of programs may be disproportionately utilized by employees who are relatively low risk and thus help facilitate indirect risk classification. For instance, gym memberships are likely to be utilized more by relatively healthy employees. As a result, a wellness program that offers premium discounts for gym usage may disproportionately appeal to low-risk employees.”⁶⁵

They note further that although “ACA does explicitly attempt to limit this risk, prohibiting the usage of wellness programs tied to health factors when they are a subterfuge for discriminating based on a health status factor...this provision is unlikely to be effective,

as it seems almost impossible to apply in practice.”⁶⁶ They explain that this is because “[t]he core problem is that in order to incentivize healthy living, a wellness program must provide benefits only to those who are, in fact, healthier. Thus, while there is certainly a risk of liability under ACA to an employer that seeks to implement a wellness program based on health related status, this risk ultimately seems limited.”⁶⁷ If Wellness Programs drive away employees less interested in meeting health guidelines and they do not get other jobs which provide health insurance, then they may resort to relying on the government-sponsored exchanges created by ACA.⁶⁸

3. DO WELLNESS PROGRAMS ACTUALLY IMPROVE PARTICIPANTS’ HEALTH?

A final concern expressed about Wellness Programs is that there is insufficient proof of their efficacy to outweigh their possible economic and social costs. Pointing out how little data there is on what makes a Wellness Program effective as a cost-saving measure, Michelle Mello notes several areas which suggest problems.⁶⁹ One overall question is “[h]ow large an incentive is needed to gain widespread participation in wellness programs” and does the amount vary among employees?⁷⁰ Even under the amendments to HIPAA and the ADA made by ACA, employers could not offer different incentives to different employees without triggering the anti-discrimination laws discussed later in this article.⁷¹ She also questions effectiveness of a program based on incentives writing that, “[a] strand of economic theory — and some empirical evidence — suggests that negative incentives have a more powerful effect on behavior than positive ones.”⁷²

The data from the program profiled in the *Harvard Business Review* article claiming a one to six return on investment is a good example of the problem.⁷³ It draws this conclusion from one study which tracks 185 workers and spouses without heart problems for six months. After cardiac rehabilitation, 57% of the subjects “were converted to low-risk status” and “medical claim costs had declined by \$1,421 per participant” while “a control group showed no such improvement.”⁷⁴

A closer look at this study illustrates why actual improvements in health are hard to measure by studying Wellness Programs and may also be difficult to achieve. First, those in the study were well enough to participate in a vigorous exercising program. Second, lowering risk factors for heart disease is not the same as lowering incidence of heart disease. Finally, there is no way of knowing how long the lowered risk factors continued beyond the six month follow-up period or, of course, whether or not the subjects eventually contracted heart disease. This is because the subjects were

not at high risk and would not be expected to actually experience for heart disease for many years.

On the other hand, public health scholars continue to publish work, which supports the cost savings of prevention programs. A March 2011 article in the *American Journal of Public Health* described the findings of a study that, its authors claim, demonstrates that workplace prevention programs, in which people are covered by private insurance, pay off later when the same individuals become eligible for Medicare.⁷⁵ They explain that “[b]ecause the prevalence

ACA encourages but does not require anyone to create or enroll in a Wellness Program. In strong statutory language, it states that “[n]otwithstanding any other provision of this part, any recommendations, data, or assessments carried out under this part shall not be used to mandate requirements for workplace wellness programs.”⁸⁰ Because private health insurance in the United States is provided primarily through employers, many of ACA’s reforms directly intersect with statutory schemes intended to protect employee benefits, which are regulated by ERISA.⁸¹ In order to expand

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of chronic disease rises with age, the implications of failing to address modifiable risks at younger ages are higher costs for private insurers and Medicaid for the working-age population in the short run and greater Medicare costs to treat related advanced disease in the longer run.”⁷⁶ This supports the categorical statement by the American College for Environmental Medicine’s Guidance Statement that “[t]he workforce is the engine that drives the economy and supports the financial underpinnings of the health care system. The working-age population is, therefore, the key to assuring the future availability of health care in the U.S.” and that “well designed, integrated and supported health promotion programs in industry can reduce health care costs, at least over a short term.”⁷⁷

E. How Has ACA Promoted the Development of Wellness Programs?

There are two main ways in which ACA has promoted the development of Wellness Programs. The first is by providing grant funding for employers to create programs, and the second is by changing laws that restricted the incentives employers could offer employees for participation and for actual success in changing health measures.⁷⁸ ACA will increase the amount employers can discount by 30% the cost of health insurance for those participating in and meeting health-related goals. Employers can now offer employees a 20% discount in the price the employee pays for health insurance, and ACA makes provision for a 50% discount at the discretion of the Secretary of Health and Human Services.⁷⁹

employers’ ability to develop programs that they believe will reduce their costs, ACA directly changes federal laws, which limit employers’ ability to provide substantial incentives to employees based on their successful participation in Wellness Programs.

Employers were quick to recognize the assistance being provided to them by ACA. Employee benefit specialists, both those who worked inside companies and those who provide consulting services, were tracking ACA’s support of Wellness Programs well before its passage. Once passed, they were quick to pass on the news that “[t]he White House has publicly backed the expanded use of wellness programs.”⁸² Employee benefits experts believe that many companies will take advantage of this encouragement by adding new Wellness Programs or expanding existing ones.⁸³ A spokesman for Paychex, Inc., a \$2 billion dollar company with 100 branch offices around the country that provides human resource services to companies, predicted that “[w]ith [the increased costs imposed on them by] health reform, there is some desperation among employers that is driving them to look at positive solutions as to what works for wellness, such as examining their work culture.”⁸⁴

A briefing by an employee benefits consulting firm explained the situation on its website, stating:

We have discussed the merits of a corporate wellness program in great lengths with our clients. While a few have implemented programs that have achieved some positive results, many employers have simply kicked the tires and

passed on a program. [ACA] may change your philosophy regarding wellness programs.⁸⁵

For the purpose of understanding the effect ACA has had on expanding employers' ability to link health insurance premiums to participation in programs that use health factors to measure success, it is important, first, to consider the amendments it makes to HIPAA and the ADA and then compare this with its failure to make any amendments to GINA.⁸⁶ Taken together, these regulations establish the parameters within which employers can develop Wellness Programs. ACA amends HIPAA and the ADA, and as a procedural matter to implement these changes, ERISA, but not GINA, to make it easier for employers to increase participation.

1. ACA PROVIDES FINANCIAL ASSISTANCE TO EMPLOYERS TO CREATE OR MODIFY WELLNESS PROGRAMS

The first way that ACA affects Wellness Programs is by providing funds to create more of them. As currently drafted, the law provides \$200 million in federal grant money to be awarded to small businesses that do not already have a Wellness Program in place. Describing a program to provide grants to small businesses to offer Wellness Programs to their employees, the statute instructs the Secretary of Health and Human Services to "develop program criteria for comprehensive workplace wellness programs under this section that are based on and consistent with evidence-based research and best practices, including research and practices as provided in the Guide to Community Preventive Services, the Guide to Clinical Preventive Services, and the National Registry for Effective Programs."⁸⁷ It then goes on to describe what components should be part of such a program:

- (A) Health awareness initiatives (including health education, preventive screenings, and health risk assessments).
- (B) Efforts to maximize employee engagement (including mechanisms to encourage employee participation).
- (C) Initiatives to change unhealthy behaviors and lifestyle choices (including counseling, seminars, online programs, and self-help materials).
- (D) Supportive environment efforts (including workplace policies to encourage healthy lifestyles, healthy eating, increased physical activity, and improved mental health).⁸⁸

2. ACA MAKES SPECIFIC AMENDMENTS TO STATUTES ALREADY REGULATING WELLNESS PROGRAMS

The second way ACA supports Wellness Programs is by changing laws that currently limit an employer's ability to tie the costs employees pay for health insurance to participation in the program, or achievement of specific health goals. Outlined below is a brief overview of how these specific changes promote Congress' normative goal of increasing employers' ability to make use of Wellness Programs to reduce the cost of providing their employees with health insurance by raising the discount they can offer employees for participating in these programs and meeting specific health-related goals. Since these provisions are all new and some have not yet taken effect, the agencies involved in their enforcement make ongoing efforts to provide advisory information even as they are drafting new implementing rules. Anyone seeking a contemporaneous, or real-time, understanding of how these provisions will affect a specific aspect of an individual program is best advised to consult the websites of the Departments of Health and Human Services, Labor, and the Treasury, which have together prepared jointly explanatory information, advisory opinions, and draft rules.⁸⁹ I provide this overview as a basis to contrast the absence of any changes to existing provisions of GINA, which limit an employer's use of genetic information in Wellness Programs.

Employer-sponsored Wellness Programs are regulated by an overlapping patchwork of both federal and state law. Employers do not have to offer any kind of health insurance, let alone a Wellness Program, but if they do, it has to be available to everyone. As a recent Department of Labor bulletin explains, before ACA, "A wellness program subject to the HIPAA nondiscrimination regulations must be available to all similarly situated individuals, provide a reasonable alternative standard, and the reward must be limited to no more than 20 percent of the total cost of coverage."⁹⁰ The DOL now expects this amount to increase to 30% by 2014.⁹¹ Employers cannot discriminate in their offering of health insurance based on an employee's health status or disability except to the extent specifically allowed by the federal law.⁹²

When an employer creates a Wellness Program that appears to discriminate by closely linking an employee's access to health insurance with his or her individual health status, it raises red flags with an array of federal agencies, all of which have overlapping authority in the workplace. ACA makes specific changes to several statutes, including most notably the Health Insurance Portability and Accountability Act (HIPAA)⁹³ and the ADA,⁹⁴ which reduce individual employees' protection against discrimination in return for greater cost

savings from Wellness Programs for employers. It also makes changes to ERISA that are necessary to implement the increase in the allowable incentive.⁹⁵

One of the things that makes legal analysis of Wellness Programs difficult is, as discussed above, that there are so many different kinds.⁹⁶ Some are subject to legal restrictions regarding the information they can ask for, and some are not. This is because the EEOC recognizes that an employer may have legitimate, job-related interests for inquiring about an employee's health. Two major categories of these inquiries exist. One is where an employee has voluntarily come forward, and another is when the employer initiates the questions and where the disclosure may be followed by some negative consequence for the employee. For the purposes of this article, I consider only the ones that are legally problematic because they fall into the category the EEOC has identified as "mandatory." As discussed below, this means more than an explicit requirement that employees participate but also includes incentives.⁹⁷

The legal restrictions intended to prevent discrimination against employees enrolled in Wellness Programs only apply when there is an exchange of information related to health between employer and employee. Services, which are offered as a benefit but which involve no exchange of information, like an Employee Assistance Plan (EAP), which offers help to employees or their family members, are not regulated in the same way so long as employers meet appropriate confidentiality standards.⁹⁸ The guidance provided by the EEOC for employers structuring their own Wellness Programs explains that "many employers contract with EAP counselors so that employees can voluntarily and confidentially seek professional counseling for personal or work-related problems without having to be concerned that their employment status will be affected because they sought help."⁹⁹ Answering the question whether it was permissible for a counselor associated with an EAP to "ask employees about their medical condition(s)," the guidance advises that the counselor "may...if s/he: (1) does not act for or on behalf of the employer; (2) is obligated to shield any information the employee reveals from decision makers; and, (3) has no power to affect employment decisions."¹⁰⁰

Three major statutory schemes regulate employers' ability to penalize employees for failing to participate in Wellness Programs, which uses health markers as measures of success. They are (1) HIPAA, which requires that if an employer offers health insurance, it must make it equally available to all similarly situated employees; (2) the Americans with Disabilities Act as Amended (ADAA), which prevents discrimina-

tion based on physical or mental disability; and (3) ERISA, which provides oversight regulations on all benefits offered by employers who meet its requirements of offering a "qualified plan."¹⁰¹ The Genetic Information Non-Discrimination Act (GINA), which is described later, also affects employers' ability to discount the cost of health insurance based on participation in a Wellness Program when the measures of success are affected by a genetic condition.¹⁰² In other words, if the goal is a 10% reduction in cholesterol and the individual employee has a recognized genetic condition which makes this impossible, she would be exempt in the same way the ADA would protect against meeting a requirement made impossible, or much more difficult, by a disabling condition. However, it has an additional impact on Wellness Programs, which has not been changed by ACA in that it prevents employers from asking for family history, or collecting any other kind of genetic information, for the purpose of participating in risk assessment activities. This later prohibition applies whether or not the Wellness Program as a whole sets standards based on "health factors." As a result, the GINA prohibitions are more extensive because they limit the tools employers can use to reduce risk in any Wellness Program.

A. ACA AMENDS HIPAA TO ALLOW EMPLOYERS TO PROVIDE GREATER INCENTIVES FOR EMPLOYEES TO PARTICIPATE

All employers who offer health benefits that qualify for regulation under ERISA¹⁰³ must comply with HIPAA's non-discrimination provisions.¹⁰⁴ Although HIPAA is most commonly associated with privacy rules, it plays an important role in assuring that employer-provided health insurance is portable by requiring equal access to all similarly situated employees regardless of their health status or that of their dependents.¹⁰⁵ It is this portability protection in HIPAA that makes it possible to change jobs without being penalized for having a pre-existing condition.¹⁰⁶ As policy expert Sara Rosenbaum explains it, "HIPAA's central purpose was to eliminate health status considerations from eligibility for coverage or from the cost of coverage in the group market."¹⁰⁷ While HIPAA does not require employers to offer health insurance, should they do so, it does require that employers make it equally available to all employees regardless of their health status.

When applied to Wellness Programs, this principle of non-discrimination and equal access means that all employees of equal job status must have equal access to the program regardless of health status either before starting employment or at any time while covered by the employer.¹⁰⁸ Put directly, Wellness Programs can-

not be made available, nor can they be restricted, based on the health status of an individual employee.

If taken literally, this provision of HIPAA would prohibit any discounting of health insurance based on health status either before or during employment. However, as Professor Rosenbaum notes, this is not true.¹⁰⁹ She writes that employer-sponsored Wellness Programs are permissible because “although HIPAA bars discrimination, the law does not prohibit an employer or insurer from offering premium discounts or modified cost sharing in exchange for participation in a bona fide wellness program.”¹¹⁰

As the EEOC explains, by allowing employers, before ACA, to provide employees a 20% discount for meeting goals based on health standards, it recognized the need to:

[o]ffer plans maximum flexibility while avoiding the effect of denying coverage or creating an excessive financial penalty for individuals who cannot satisfy the initial standard based on a health factor.¹¹¹

Although ACA has increased the amount of the allowable discount from 20% to 30%, and possibly 50%, it has not changed the five conditions set out in the 2006 rules that employers must satisfy if “a condition for obtaining a reward is based on an individual satisfying a standard related to a health factor.”¹¹² In addition to encouraging the creation of new programs through direct grant funding, ACA changes the provisions in HIPAA’s privacy rule which limits employers’ ability to provide incentives for employees achieving goals in either a voluntary or mandatory Wellness Program.¹¹³ The relevant portion of HIPAA is not its privacy rules, but rather, its provisions for non-discrimination.¹¹⁴ As the regulations explain,

Under the 2001 interim rules and these regulations, a plan or issuer is not required to provide coverage for any particular benefit to any group of similarly situated individuals. However, benefits provided must be uniformly available to all similarly situated individuals.¹¹⁵

The primary effect of HIPAA on Wellness Programs has been to limit employers’ ability to discount the cost of health insurance based on employees’ meeting targets based on health factors such as a lowered blood pressure or body mass index.¹¹⁶ The changes ACA makes to HIPAA, the ADA, and ERISA give employers with existing programs, as well as those who want to start new ones, a greater ability to tie what their employees pay for health care to compliance with specific

wellness targets.¹¹⁷ ACA expands the ability of private employers to lower an individual employee’s cost for health insurance as much as 30% and grants the Secretary of Health and Human Services the discretion to increase that discount to 50% at her discretion. Until now the maximum was 20%.¹¹⁸

B. ACA AMENDS THE ADA

The other major regulatory provision structuring Wellness Programs is the Americans with Disabilities Act. The ADA provides that employers “shall not require a medical examination and shall not make inquiries of an employee as to whether such employee is an individual with a disability or as to the nature and severity of the disability, unless such examination or inquiry is shown to be job-related and consistent with business necessity.”¹¹⁹ The provisions of the ADA are enforced by the EEOC. In a July 2007 guidance memo on Disability-Related Inquiries and Medical Examinations of Employees explaining the nature of ADA protections for employees, the EEOC made two primary points.¹²⁰ The first is that the ADA protects all employees, not just those with statutorily recognized disabilities. The second is that it provides protection at all stages of employment. Participation in a Wellness Program falls into the category of inquiries made during employment.

As Wellness Programs become more common in U.S. workplaces, the EEOC has provided more explicit guidance about how to avoid illegal discrimination. In a series of memorandums providing enforcement guidance, the EEOC has addressed directly how it will interpret the ADA in the context of an employee Wellness Program. It has identified the potential for discrimination based on disability because “[t]hese programs often include blood pressure screening, cholesterol testing, glaucoma testing, and cancer detection screening. Employees may be asked disability-related questions and may be given medical examinations pursuant to such voluntary wellness programs.”¹²¹ It therefore gave the following advice, in question and answer format:

22. May an employer make disability-related inquiries or conduct medical examinations that are part of its voluntary wellness program?

Yes. The ADA allows employers to conduct voluntary medical examinations and activities, including voluntary medical histories, which are part of an employee health program without having to show that they are job-related and consistent with business necessity, as long as any medical records acquired as part of the wellness

program are kept confidential and separate from personnel records.¹²²

According to the EEOC, “[a] wellness program is ‘voluntary’ as long as an employer neither requires participation nor penalizes employees who do not participate.”¹²³ As an example of an acceptable program, the guidance notes that “[i]f a program simply promotes a healthier lifestyle but does not ask any disability-related questions or require medical examinations (e.g., a smoking cessation program that is available to anyone who smokes and only asks participants to disclose how much they smoke), it is not subject to the ADA’s requirements concerning disability-related inquiries and medical examinations.”¹²⁴

health information. In 2010, the county decided to increase participation in the screening by charging “any employee who did not complete the questionnaire and undergo the screening...\$20.00...on each bi-weekly paycheck.”¹³¹ The court rejected the employees’ claims that this penalty violated the ADA and held instead that “the wellness program falls under the safe harbor provision [which allows employers to conduct risk assessment] because it is designed to develop and administer present and future benefits plans using accepted principles of risk assessment.”¹³² The court noted that “[t]he County uses this information to classify various risks and decide what type of benefits plans will be needed in the future in light of these risks.”¹³³ It went on to address specifically

Readers well versed in the current state of genetic science may question the significance of preventing the use of family history as a method of promoting wellness. Science is still very far from its goal of reliably predicting the likelihood of any one individual’s risk for specific illnesses from the direct study of genes, let alone from a recounting of family history. Moreover, as scientists build on the discoveries of the human genome project, they are discovering that with very few exceptions, there is no one-to-one correlation between a specific gene, or even a cluster of genes or genotypes, with a specific illness.

Seff v. Broward County, one of the only reported cases involving Wellness Programs, concerns the applicability of the health risk assessment under the ADA.¹²⁵ The case was filed in April of 2010, based on events which occurred before GINA became effective and, therefore, only interprets the ADA.¹²⁶ In *Seff*, the Federal District Court for the Southern District of Florida granted Broward County’s motion for summary judgment dismissing a claim made by employees that the county’s Wellness Program violated the ADA because it required employees to supply medical information that would divulge their current state of health.¹²⁷ As the court described it, “In October 2009 Broward County adopted a wellness program [with] two components: a Health Risk Assessment questionnaire and a biometric screening.”¹²⁸ The Health Risk Assessment consisted of a “[q]uestionnaire [which] was confidential and conducted online.”¹²⁹ The second element of the screening was “a finger stick blood test to measure glucose and cholesterol levels. The screening may also be done through an at-home kit.”¹³⁰ Broward County hired an independent company to analyze the information and received back only aggregated results. It never saw any individual’s

the issue that the screening was part of the Wellness Program, writing that the program “is an initiative designed to mitigate risks. It is based on the theory that encouraging employees to get involved in their own healthcare leads to a more healthy population that costs less to insure.”¹³⁴ With the caveat that an opinion by a federal district court binds only those within its jurisdiction, the court’s careful analysis of when employers could collect otherwise prohibited information for the purpose of general risk assessment will certainly be cited in future cases concerning genetic information in the form of family history or otherwise.

What Conflict Now Exists between the Positive and Normative Goals of ACA and GINA in the Context of Wellness Programs?

GINA was enacted to replace a patchwork of state laws with uniform protection against discrimination in health insurance or employment, “on the basis of genetic information, 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.”¹³⁵ Congress’ intent was to

make explicit to employers and insurers that discrimination based on genetic information was as impermissible as discrimination based on disability. GINA does this by tracking the ADA's preemptive prohibitions against collecting information which could later lead to discrimination.¹³⁶ GINA represents a societal interest in preventing discrimination as the science of genetics evolves. It was enacted without any particular evidence of genetic discrimination in either employment or insurance.¹³⁷

GINA limits how employers can use their employee's genetic information.¹³⁸ GINA is primarily an anti-discrimination statute but one that encompasses the workplace, the private market for insurance, and the tax laws. One of the challenges in analyzing a Wellness Program for compliance with GINA is that, as of the writing of this article, there have been no reported cases invoking its protection against disclosure of family history.¹³⁹ Although not brought under GINA, a recent case addresses directly the legality of using family medical history as part of a Wellness Program and concludes that it is permissible so long as the information does not affect the amount paid for health insurance by any individual employee.¹⁴⁰

Employers have been on notice since 2009 that the EEOC final rules implementing GINA prohibit employers from requesting their employees' genetic information, including family history, as a condition for participation in Corporate Wellness Programs that discount the price of employer-provided health insurance.¹⁴¹

A. What Role Does Family Health History Play in Wellness Programs?

Readers well versed in the current state of genetic science may question the significance of preventing the use of family history as a method of promoting wellness. Science is still very far from its goal of reliably predicting the likelihood of any one individual's risk for specific illnesses from the direct study of genes, let alone from a recounting of family history.¹⁴² Moreover, as scientists build on the discoveries of the human genome project, they are discovering, that with very few exceptions, there is no one-to-one correlation between a specific gene, or even a cluster of genes or genotypes, with a specific illness.¹⁴³ Recent work mapping haplotypes is intended to better understand and identify patterns which may predict future risk, but is still in its early stages.¹⁴⁴ Moreover, it now seems that genetic activity is affected by the environment in which a person lives. As one commentator explains, this is because "[o]nly when disease-related genotypes are simultaneously present at many different loci, and

when certain environmental exposures occur, do common diseases develop in the vast majority of individuals who will get the disease."¹⁴⁵

GINA, however, is intended to provide protection, not just against discrimination about what is known today, but also in the future.¹⁴⁶ Professor Mark Rothstein, one the leading legal experts in the law of genetics, writes that the intent of GINA was to make "at-risk individuals...more willing to undergo potentially beneficial genetic testing" as these tests became more available.¹⁴⁷ Quoting from the congressional findings associated with GINA, he writes that even in the absence of evidence that employees were currently subject to discrimination based on genetics, Congress felt that "federal legislation...[was] 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, new technologies, and new therapies."¹⁴⁸

Whether acquired as a family health history or through direct genetic testing, today's conventional wisdom suggests this information is helpful in assessing, and therefore taking steps to prevent, future ill health. Explaining the theory, the Genetics and Public Policy Center writes that "[g]enetic information helps you know and understand health conditions that run in your family, as well as your risk for developing certain health conditions or having a child with certain conditions. This information can help you make healthy lifestyle choices and important life and medical decisions. It also helps your doctor in providing you the best care possible."¹⁴⁹

There are differences of opinion in the scientific and medical community about the ability of family history to predict future illness. The CDC's Public Health Genomics project identifies "family health history" as an important tool that "provides information [which] may help health care providers determine which tests and screenings are recommended to help family members know their health risk."¹⁵⁰ Assembling family health history is an important component to most programs. Mark Head, chief solutions officer of Vivarae, explained the significance of the ban "estimat[ing] that upward of 75% to 85% of employers include family medical history questions in their health risk assessment tools, or use such histories to link an employee's participation in these types of risk assessments to wellness rewards or penalties" and opined that it would "hamstring companies' ability to collect more extensive information to help design wellness programs."¹⁵¹

Family history as a method of risk assessment is a key component in most Wellness Programs, and these limits will directly limit the effectiveness of many cur-

rent plans. It is, however, only one component of a health risk assessment (HRA). An article advocating adoption of these programs in the *Harvard Business Review* explains that “[m]any organizations use on-line HRAs to guide investment in wellness. An HRA combines a lifestyle survey and biometric tests such as blood pressure, cholesterol, glucose, and body mass index.”¹⁵² The “lifestyle” and “biometric” responses are then used “to calculate health-risk status, or ‘real age.’”¹⁵³

Moreover, although reliance on family health history to assess risk has become routine, in fact there is no consensus that is particularly effective in promoting any one individual's health. Speaking to a reporter from the *New York Times*, Dr. Clyde Yancy, president of the American Heart Association, said, “No data points suggest that knowing family history per se affects the success of a wellness program.” Nevertheless, it continues to play an important role in programs that purport to improve future health through risk awareness. The Surgeon General's Office and the CDC believe that knowing one's family health history is an important step in managing your own care.¹⁵⁴

Addressing human resources officers, a company offering its consulting services summarized the magnitude of the changes employers would have to make in their Wellness Programs writing that “[j]ust when you thought you had the right formula for success in boosting participation with incentives, the feds may now tie your hands.”¹⁵⁵ It went on to explain that “GINA prohibits group health plans and insurers from collecting [information and]...asking questions about family medical history...for underwriting purposes or prior to or in connection with enrollment.”¹⁵⁶ Acknowledging that there are many different ways in which employers are currently seeking to reduce costs by promoting employee health, it advises, “[I]f you currently give rewards for employees who complete a [health risk assessment form] or participate in a wellness program, you could be in violation unless you make some changes.”¹⁵⁷

B. State Law Regulation of Wellness Programs

Although beyond the scope of this article, state law plays an important role in Wellness Programs since employment, like health care, is an area regulated by both the state and federal government.¹⁵⁸ ACA does not change any state laws, but its efforts to promote Wellness Programs could be hampered by existing state laws which provide independent employees independent protection against discrimination and unjust dismissal.¹⁵⁹ While no state can offer less protection than that in the relevant federal statutes, they are free to provide more, and many do. Moreover, states are

free to make their own laws limiting or bolstering an employer's ability to fire an employee without cause. This can have a substantial effect on the success of a program intended to change behavior that occurs outside the workplace. The best example of this is the Massachusetts Supreme Court's upholding of Scott's Miracle Grow's decision to fire an employee for being a smoker even though he had never smoked at work.¹⁶⁰

There are also significant differences among the states regarding the extent to which they provide protection under their own disability anti-discrimination laws. For example, some states provide more extensive protection for those who are perceived as overweight, if not actually obese, than does the ADA. Moreover, there are significant differences in protection for activity that takes place outside of the work place. In some states, like Massachusetts, it is legal for an employer to fire an employee for unhealthy behavior he engages in outside of the workplace. In a Comment devoted to analyzing the *Miracle Grow* decision, Jennifer Pierrotti criticizes the ability of employers to penalize employees for smoking outside of work. She writes that “[t]he last time morality so brutally twisted the law and public policy was during Prohibition.”¹⁶¹ She also directly raises the concern that a ban on smokers, rather than smoking, will disproportionately affect under-represented minorities such as African-Americans, American Indians, and Native Alaskans who are more likely to be smokers.¹⁶²

HOW DO THE EEOC'S FINAL RULES APPLY GINA TO WELLNESS PROGRAMS?

The EEOC has issued its final rules implementing GINA's limits on how employers can use their employees' genetic discrimination.¹⁶³ The final rules issued by the EEOC in November of 2010, which are not in relevant part different from those proposed in the 2009 draft rules, specifically prohibit employers from offering their employees any inducement to provide genetic information, including family history, as part of a Corporate Wellness Program. Explaining the rule in the form of advice to small businesses, the EEOC writes that “[t]he final rule says that while employers may offer certain kinds of financial inducements to encourage participation in health or genetic services under certain circumstances, they may not offer an inducement for individuals to provide genetic information.”¹⁶⁴ Even more specifically, the EEOC advises that while employers are allowed:

[T]o offer financial inducements for participation in disease management programs or other programs that encourage healthy lifestyles, such as programs that provide coaching to employees

attempting to meet particular health goals (e.g., achieving a certain weight, cholesterol level, or blood pressure).... to avoid a violation of Title II of GINA...employers who offer such programs and inducements to individuals based on their voluntarily provided genetic information must also offer the programs and inducements to individuals with current health conditions, and/or to individuals whose lifestyle choices put them at risk of acquiring a condition.¹⁶⁵

In other words, no inducements or services can be provided based on either actual genetic testing or family history. This affects employers in two ways. First, it directly prevents them from discriminating against someone based on any genetic condition which affects the wellness markers the company is using to base health insurance rates. For example, should science discover and accept an "obesity gene," the individual who has it might be exempt from meeting generalized weight targets.

One of the many law firms that summarized what these changes would mean to their clients' Wellness Programs explained that under the new rules:

GINA will not prohibit a health care provider who is treating an individual from requesting that the patient undergo genetic testing. The rules permit a plan to obtain genetic test results and use them to make claims payment determinations when it is necessary to do so to determine whether the treatment provided to the patient was medically advisable. Plans can request, but not require, genetic testing in certain very limited circumstances involving research, so long as the results are not used for underwriting, and then only with written notice to the individual that participation is voluntary and will not affect eligibility for benefits, premiums or contributions.¹⁶⁶

The second way this will affect employers is indirect but is likely to be much more pervasive. GINA defines "family history" as identifiable genetic information and specifically forbids employers from requiring employees to reveal their family history as part of a Wellness Program that either provides incentives for meeting wellness targets or penalties for not doing so. Disclosing family health history, however, is at the core of most Wellness Programs because it is the starting point of assessing what particular risks an individual employee faces.

C. How Do the Goals of GINA Conflict with the Goals of ACA?

No scholar or business advocate has complained that the current restrictions on the use of family history cancel out the benefits of ACA's modifications to HIPAA and the ADA, which increase the percentage by which employers can discount the cost of the insurance they provide employers based on meeting health-related goals by participating in a Wellness Program. However, as the knowledge about the ability of genetic, and epigenetic, information to predict which employees will incur greater health costs, the balance between providing genetic privacy and controlling the cost of health care will continue to be an issue.¹⁶⁷ Although the ability to make specific predictions is limited, scientists expect they will continue to find proof that knowing a person's genetic makeup can help predict her future susceptibility to specific illnesses. As the CDC explains, "Genomics plays a role in nine of the ten leading causes of death in the United States, most notably cancer and heart disease. These diseases are partly the result of how genes interact with environmental and behavioral risk factors, such as diet and physical activity. Also, a large fraction of children's hospitalizations are due to diseases that have genetic components."¹⁶⁸ The issue is not whether or not genetics play a role in future health, it is to what extent individuals can be held responsible for paying more for employer-sponsored health care based on their inherent risk of future illness.

It is the nature of the rapid, and often unexpected, discoveries coming from genetic research that we cannot know exactly how GINA's privacy protections will hamper future efforts by either private companies or public payors to reduce health care costs. One emerging possibility is that just as the ADA protects employees with a disability that limits or prohibits their participation in a Wellness Program or their meeting of a goal such as lowering their cholesterol, GINA will protect individuals with an inability to participate because of a genetic condition. In that sense, it can be used by employees as a shield protecting them from demands that they are physically unable to meet. Should advances in treatment of genetic conditions keep pace with advances in identifying them, we will have to consider whether employees have a duty to mitigate the effects of a genetic condition. As disabilities law scholar Professor Sharona Hoffman describes, the problem in the context of the newly amended ADA is that "[t]here may be plaintiffs who could ameliorate their conditions through mitigating measures such as medication, surgeries, or assistive devices but choose not to do so or cannot afford the cost of such interventions."¹⁶⁹ While it is likely that the first test cases will be

in the area of disabilities, the resulting principles will also apply to genetics. As a public policy matter, we will need to ask whether it is just to spend money on health care for an employee who chooses not to pursue an intervention that would mitigate this risk. As the science of genetics evolves, there will most likely be further examples of how our current conceptions of “wellness” are likely to conflict with scientific discoveries regarding the links between genetics and physiological functions such as losing weight or even quitting smoking. As a result, the projected savings from increased spending on wellness will not be realized, thus making health care, if anything, more expensive than it is already.

Conclusion

By passing ACA, Congress has given employers a substantial incentive to develop Wellness Programs, which seek to lower health care costs by reducing illness. They have done so in the face of objections that these programs may discriminate on the basis of class, race, and gender as well as skepticism about their ability to reduce health care costs beyond the time of any individual's employment. Yet at the same time, by not revisiting recently enacted rules intended to protect genetic privacy, which may hamper the effectiveness of Wellness Programs, Congress has deliberately not sacrificed its commitment to protecting individuals from genetic discrimination even when the result is higher health care costs for the population. This article has described how ACA encourages employers to adopt Wellness Programs and how the genetic privacy regulations may impede the effectiveness of these same programs. Although both ACA and GINA are new statutory schemes so far lacking any definitive legal interpretation, this article hopes to be a resource for those who must develop and evaluate Wellness Programs in advance of any further guidance from the courts.

This article has presented positive theories explaining these changes and how they are likely to work. Equally importantly, however, this article presents the conflict between the goals of saving money on health care by adopting public health, population-based interventions and of protecting individuals from genetic discrimination. This clash of normative goals is likely to be a persistent feature of ongoing efforts to control health care costs by adopting public health-inspired, population-based illness prevention measures. At some point, the cost of making health care accessible to those who need it may make it impossible to ignore factors, such as genetic predispositions to illness, which make one person more expensive to care for than another. The present limited ability of medi-

cal science to accurately predict, let alone prevent, any significant percent of the population's future sickness sustains Congress' ability to take measures to control health care costs while at the same time maintaining a commitment to preventing genetic discrimination. Should the situation change and the ability to predict illness improve, society will have to make a choice. This choice is inherent in all decisions to pursue public health principles over the interests of any particular individual and, through the passage of ACA, will be important to monitor in the years to come.

Acknowledgements

Thank you to Dana K. Braland (class of 2013) at Drake Law School and Amanda McKinzie (class of 2013) at Texas Tech University School of Law for their excellent research assistance and Kristi A. Longtin at Drake Law School for her extraordinary secretarial assistance.

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 120. *EEOC Enforcement Guidance on Disability-Related Inquiries and Medical Examinations of Employees Under the Americans with Disabilities Act (ADA)*, *available at* <http://www.eeoc.gov/policy/docs/guidance-inquiries.html#N_12_> (last visited July 1, 2011). Accompanying the memo is a state of acknowledgement that the ADA was amended in 2008 and that the Office of Legal Counsel would be reviewing all previously issued Guidance material. However, it is unlikely that these changes will change the prohibitions on when employers can ask about disabilities or who they can ask. As the EEOC explains, the changes primarily concern “the definition of the term ‘disability’ by rejecting the holdings in several Supreme Court decisions and portions of EEOC’s ADA regulations. The effect of these changes is to make it easier for an individual seeking protection under the ADA to establish that he or she has a disability within the meaning of the ADA,” *available at* <http://www.eeoc.gov/laws/statutes/adaaa_notice.cfm> (last visited July 1, 2011).
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 123. *Id.* (citing See H.R. Rep. No. 101-485, pt. 2, at 75 (1990) (“As long as the programs are voluntary and the medical records are maintained in a confidential manner and not used for the purpose of limiting health insurance eligibility or preventing occupational advancement, these activities would fall within the purview of accepted activities.”).
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