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# The ACA, Wellness **Programs, and People** with Disabilities By Heidi Siegfried, Esq. **Director of Health Policy** The author gratefully acknowledges the support of United Hospital Fund, which provided a grant for preparation of this paper. CIDNY would like to thank all the individuals with disabilities and many of the organizations that represent them for sharing their experiences and commenting on the ideas





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#### INTRODUCTION

The Affordable Care Act (ACA) made a number of changes to permissible Financial Incentives in Wellness programs. This is significant for people with serious illnesses and disabilities because these provisions allow a link between an employee's ability to achieve employer defined health targets (for example, Body Mass Index, cholesterol, blood glucose, or blood pressure levels) and the amount he or she pays for health care.

Why is this important? People who are at the highest risk for poor health status due to factors other than "lifestyle" should not be punished for things they cannot control. For example, people with Lupus who are prescribed steroids and use walkers may have weight gain as a side effect of the steroids and may not be able to participate in a particular exercise program. Weight gain is also side effect of many anti-depressants. An older woman taking a drug for Osteoporosis may have the commonly reported side effect of high blood pressure, when she has had low blood pressure for her entire life. In fact, many of the health standards may be more difficult for an older person, people of certain races and ethnicities, or people with disabilities to meet. These people will be at highest risk for higher premiums or cost sharing based solely on their health status. For this reason, wellness programs should be voluntary, accessible, and not unduly coercive.

At the end of this paper, we will have recommendations developed by members of New Yorkers for Accessible Health Coverage (NYFAHC) and other advocates who have been studying the ACA and its implementation.

#### WHAT ARE WELLNESS PROGRAMS?

Wellness programs promote health and well-being through activities such as healthy eating, exercise programs, educational seminars, tobacco cessation programs and health screenings that are designed to help employees eat better, lose weight, and improve their overall physical health. Programs for smoking cessation, weight management, stress management, physical fitness, nutrition, heart disease prevention, healthy lifestyle support, and diabetes prevention are all considered wellness programs.

How Wellness Programs Affect People with Serious Illnesses and Disabilities

#### Alba's story – A Successful Wellness Program

Alba S. is a person with a primary diagnosis of spinal cord injury and severe osteoporosis. She had chronic diseases and diabetes in her family and was worried about her weight. She was prescribed the painkiller Lyrica for fibromyalgia and noticed after 6 months that she was gaining weight and was still gaining weight after a year. According to Pfizer's labeling information Lyrica treatment may cause weight gain and controlled clinical trials did show a gain of 7% or more over baseline weight in 9% of Lyrica-treated patients as compared to 2% of placebo- treated patients. She was able to stabilize her weight, but not able to lose weight. She says it was like "carrying 2 bags of rice on my body" and she was having a hard time lifting. She was referred to several nutritionists, but was not able to use her coverage for a weight loss



program. She finally found Changing Lifestyles for Better Health, a privately funded program offered by Fair Haven Community Health Center that included diabetes prevention. It was a 12 week program with a weekly nutrition class offered in English and Spanish that taught how to count calories, grams of fat, and cook healthy foods. It

also included an exercise class and physical activity. Because she is had not been cleared by her doctors to do certain things like bend down or lift weights she modified the exercises. She feels safe because a nurse is present. She says "I take my time. I don't lay down because it would be difficult for me to get up. I thank God for the instructor....they don't make me feel embarrassed." The program also includes an organic garden. She says, "They are so human based, we are the ones who plant melons and cucumbers, and take away the little dry leaves... the vegetables are so

I am building up friendships and I feel good.

good." In 3 months she had lost 21.5 pounds. For Alba the true motivation for her participation in the program was her concern about her weight, but also the welcoming nature of the program and most of all, the reward of losing the weight and feeling better. "I am building up friendships and I feel good," she says.

#### I. Financial Incentives in Wellness Programs

The Affordable Care Act endorses the use of financial incentives for wellness program participation by beneficiaries of group health plans. Such incentives were first permitted under HIPAA in 2006, but the ACA increased the rewards or penalties available to wellness program participants in the group insurance markets from 20 percent to 30 percent of the cost of employee-only coverage (employer and employee share) in 2014 and authorized the Secretaries of HHS, Labor, and Treasury to further increase them in 2017 to 50 percent of the cost of coverage.<sup>1</sup>

#### II. Changes to Federal and State Law Made By the ACA

#### A. Federal Law

The ACA codifies regulatory changes that were made to the non-discrimination provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) to permit wellness programs that had previously been deemed discriminatory, provided that certain consumer protections are in place.

HIPPA amended the Internal Revenue Code, the Employee Retirement Income Security Act and the Public Health Service Act to provide for, among other things, improved portability and continuity of health coverage. It prohibits discrimination in health coverage based on health status factors, medical condition (including both physical and mental illnesses), claims experience, receipt of health care, medical history, genetic information, evidence of insurability (including domestic violence), and disability. At first this meant that rewards and penalties in wellness programs were simply not permitted.

In 2006, the Departments of Treasury, Labor, and Health and Human Services made an exception to this prohibition on discrimination in new amended rules for wellness programs. The exception allows rewards based on an individual satisfying a health standard such as a certain cholesterol level, body mass index, blood pressure, or glucose level; or requiring employees not meeting those levels to take additional steps to obtain the reward if the program meets the following five requirements to protect consumers:

- 1. The total of reward or penalty could not exceed 20 percent of the cost of employee-only coverage.
- 2. The program must be reasonably designed in that:
  - It must have a reasonable chance of improving the health of or preventing disease in participating individuals,
  - It must not be overly burdensome,
  - It must not be a subterfuge for discriminating based on a health factor, and
  - It must not be highly suspect in the method chosen to promote health or prevent disease.
- 3. People must be given an opportunity to qualify for the program at least once a year.



- **4.** The reward must be made available to all similarly situated individuals and must allow for a reasonable alternative standard or a waiver for anyone for whom it is:
  - Unreasonably difficult to satisfy the standard due to a medical condition, or
  - Medically inadvisable to attempt to satisfy the standard.
- **5.** The plan must disclose in all plan materials the availability of a reasonable alternative standard or the possibility of a waiver.

The regulations also made clear that a wellness program that is participatory and has a reward or penalty that is not dependent on satisfying a standard related to a health factor, does not violate the non-discrimination provisions of HIPPA as long as it is made available to all similarly situated individuals. Examples would be reimbursement of a fitness center membership, a reward for participation in a diagnostic testing program that is not dependent on the outcome, or a reward for participating in a health education seminar.

The Affordable Care Act codified the exception to the prohibition on discrimination in the 2006 rules with respect to group health plans, increased the allowable amount of the reward or penalty for health contingent wellness programs to 30 percent of the total cost of employee-only coverage, and gave the Secretary of HHS authority to increase the amount of the reward to 50 percent.

#### B. New Federal Regulations

Final regulations published June 3, 2013 adopt the increase to 30 percent in the maximum permissible reward or penalty allowable under a health contingent wellness program.<sup>2</sup>

The regulations further clarify how the five, now statutory, requirements for an exception to the general prohibition on discrimination based on a health factor apply to different types of health-contingent wellness programs. They divide health-contingent wellness programs into activity-only wellness programs and outcome -based wellness programs.

Activity-only programs provide a reward for completing an activity such as a walking, diet, or exercise program. A person might be unable to participate in an activity-based program due to health factors such as severe asthma, pregnancy, or a recent surgery. A reasonable alternative standard for getting the reward needs to be provided in these programs for people who have a medical condition that makes it difficult for them to satisfy the condition for the reward or for which it is medically inadvisable to attempt to satisfy the condition in order to ensure that the reward is uniformly available.

Outcome-based wellness programs provide a reward to people who meet a standard for a condition like a cholesterol, blood pressure, BMI, or glucose level. A reasonable alternative standard for getting the reward needs to be provided in these programs to ensure that the programs is reasonably designed and is not a subterfuge for underwriting or discrimination.

The regulations offer language which strengthens the determination of whether an alternative standard is reasonable. The regulations require all factors and circumstances to be taken into account, including but not limited to, paying any membership or participation fees or other costs of such things as educational or diet programs and requiring the plan, rather than the individual, to make the program available or to assist the employee in finding an alternative educational rogram. The final regulations also required an alternative standard to have a reasonable time commitment and suggested that requiring nightly attendance at a one hour class would not be reasonable.

New regulations also require an alternative standard to accommodate medical appropriateness according to the recommendations of the person's personal physician.

The final regulations require notice of the availability of a reasonable alternative standard or waiver to qualify for the reward and a statement that the recommendations of a personal physician will be accommodated in all plan materials describing the terms of an activity-only or outcome-based wellness program or disclosure that a person did not satisfy an out-come based standard. They also improve the sample language that is required to be included in plan materials



describing other means of qualifying for the reward or avoiding the penalty. The language does not, however, make clear that there is also the possibility of a waiver.

The Departments anticipate issuing future sub-regulatory guidance to provide additional clarity and potentially proposing, modifications to this rule as necessary.

#### C. New York Law

New York law currently bans insurance discrimination in the individual and small group markets. It requires pure community rating in the individual market. Community rating is methodology in which the premium for all people covered by a policy is the same based on the experience of the entire pool of risks without regard to an individual's age, sex, health status, or occupation.<sup>3</sup> It does not permit an exception for wellness programs or tobacco use. A wellness program may use rewards and incentives for participation provided that, where the contract is required to be community rated, the rewards and incentives shall not include a discounted premium rate or a rebate or refund of the premium.<sup>4</sup> A reward or incentive that involves a discounted premium rate or a rebate or refund of a premium must be based on an actuarial demonstration that the wellness program can reasonably be expected to result in the overall good health and well being of the group.<sup>5</sup>

Federalism Statements in both the 2006 Nondiscrimination and Wellness Programs in Health Coverage Final Rules and in the new Final rules indicate that states may continue to apply state law requirements except to the extent that such requirements prevent the application, portability, access, and renewability requirements of the HIPAA, which include HIPAA's nondiscrimination requirements provisions. State insurance laws that are more stringent than the federal requirements are unlikely to "prevent the application of" the HIPAA nondiscrimination provisions, and therefore are not preempted. Accordingly States have significant latitude to impose requirements on health insurance issuers that are more restrictive than the federal law.<sup>6</sup> New York State Exchange officials have indicated that they will not be asking any questions about tobacco use in their Health Benefit Exchange enrollment portal because there will be no premium variation based on tobacco use in policies sold there.

#### D. Decisions on Wellness Benefits Made by New York's Health Benefit Exchange

The Affordable Care Act requires a minimum set of core benefits called Essential Health Benefits to be in the private plans being sold in the Health Benefit Exchanges, in all new individual and small group plans sold outside the Exchanges, and in new Medicaid coverage. Preventive and wellness services are one of the ten Essential Health Benefits identified by the ACA.

Each state had to choose or default to a 'benchmark' plan on which to model their Essential Health Benefits. New York selected the benefits of the State's largest small group plan, Oxford EPO, as the benchmark plan. The wellness benefit in New York's Essential Health Benefits is Gym Membership Reimbursement of up to \$200 for the subscriber and \$100 for the subscriber's spouse every six months if the member or spouse is an active member of the facility and completes 50 visits in a six month period. Draft Model Contract Language for Standard Qualified Health Plans (QHP) to be sold in the Exchange permits the Standard Plan to offer this for an exercise facility that maintains equipment and programs that promote cardiovascular wellness and not for membership in tennis clubs, country clubs, weight loss clinics or spas.

Reimbursement is limited to actual work-out visits and will not be provided for equipment, clothing, vitamins or other services that might be offered. The member must submit a facility bill showing the membership fee paid and a reimbursement form with documentation of visits from the facility and the Plan may require a facility representative to sign and date it. Insurers may substitute benefits in the preventive, wellness, and chronic disease management categories.

Insurers may offer up to 3 non-standard products in the Exchange to allow for innovation. Non-Standard Qualified Health Plans sold in the Exchange may offer health or fitness center memberships in different amounts than the standard QHP, health risk assessment tools, on-line wellness activities, self-management of chronic diseases, designated smoking cessation programs, weight management programs, stress management programs, worker injury prevention program or fitness incentive programs.



Rewards can include full or partial cost of participation in the program or health or fitness center. Monetary rewards in the form of cash, gift cards, or gift certificates can also be included, so long as the recipient is encouraged to use the reward for a product or service that promotes good health, such as healthy cook books, over the counter vitamins, or exercise equipment; and waiver or reduction of co-payments, coinsurance, or deductibles. Rewards must also follow federal and state law so that a community-rated contract policy may not include a discounted premium rate or a rebate or refund of a premium as a reward. "Experience rated" plans offering this sort of reward would have to be based on an actuarial demonstration that it would result in overall good health and well being of the group.

#### III. Policy Arguments Made During the Course of the Debate

During the health care reform debate, patient and consumer advocacy organizations, including New Yorkers for Accessible Health Coverage (NYFAHC) and Center for Independence of the Disabled, NY (CIDNY) raised a number of concerns about the Senate proposals to expand on the existing regulatory authority, particularly the proposal to increase the amount of the reward or penalty for satisfying a health standard. We supported the House bill that contained the small business grant program. We joined with national organizations such as the American Cancer Society, the American Heart Association and the American Diabetes Association, all of which have mission statements that seek to prevent and cure disease and "build healthier lives" in our efforts to raise concerns. Patient and consumer groups raise concerns about affordability, lack of evidence, and privacy.

#### A. Affordability

Premium Surcharges or Discounts. Patient and Consumer groups strongly objected to the increase in premium variation to 30 percent, and potentially 50 percent, making coverage unaffordable for low-income people who need it the most to help them address risk factors for chronic disease and other health issues.

Affordability Determination for Premium Subsidy Eligiblity. Patient and consumer groups, including NYFAHC, met with the Treasury Department which invited comment on future rulemaking to determine how wellness incentives should be factored into an employee's premium for the purpose of determining affordability of their employer sponsored coverage. If employer coverage is not affordable, an employee may go to the Exchange in order to get premium subsidies that help make coverage affordable.

Under the ACA, employer-sponsored coverage is only considered affordable if the premium contribution required by the employee is no more than 9.5 percent of household income. We recommended, in situations where an offer of employer coverage includes a premium-based wellness incentive, that the larger premium assessed on employees who do not meet the wellness incentive requirement should always be used by the Exchange when determining whether an offer of affordable coverage is affordable. We argued that using the larger premium was critical for preventing premium-based wellness programs from being used as a subterfuge for discrimination in which employers offer affordable coverage to healthier workers that meet wellness requirements and send their less healthy workers to the Exchange for coverage. Such a practice would not only be a subterfuge for discrimination, it could threaten the affordability and sustainability of Exchange coverage, as disproportionately less health individuals would seek Exchange coverage.

On May 3, 2013 The Treasury Department published a notice of proposed rule making in the Federal Register regarding Minimum Value of Employer Sponsored Plans. They proposed to determine affordability of an employer sponsored plan without regard to reduced cost-sharing available under a wellness program. However, for wellness programs designed to prevent or reduce tobacco use, they decided to assume that every eligible individual could satisfy the terms of the program. In their view this is consistent with the Affordable Care Act's permission to charge higher premiums based on tobacco use.<sup>7</sup>

#### B Lack of Evidence

Patient and consumer groups pointed out that there was no peer reviewed research evidence documenting that this increase in the level of premium incentives would encourage employees to live healthier lives and, as a result, reduce



health care costs, but that there is evidence showing that patients are far less able to manage chronic conditions such as hypertension or diabetes when their deductibles or co-payments are too high.

#### C. Privacy Issues.

Patient and consumer groups questioned whether personal medical information obtained through health risk assessments or screenings offered by non-medical companies would be protected. They also raised concerns about higher premiums for people who fail to provide information for lengthy or invasive health risk assessments.<sup>8</sup>

The American Cancer Society, American Heart Association and American Diabetes Association continued to lobby against language allowing the variation of premium rates based on satisfying a standard that is related to a health status factor, saying that this language on its face seems to violate the health reform's promise to end discrimination based on health status.<sup>9</sup>

#### IV. Protections for People with Serious Illnesses and Disabilities That Were Inserted Into the Law

As mentioned above, the ACA adopted the 2006 final HIPAA regulations with modifications, into law. The intent of these regulations is to assure that wellness programs are reasonably designed and that people for whom it is unreasonably difficult to satisfy a standard due to a medical condition, or for whom it is medically inadvisable to attempt to satisfy the standard, are allowed a reasonable alternative standard or a waiver of the requirements for a reward.

Final regulations add a few additional protections for defining what a reasonable alternative standard is. They do not allow the plan to shift the burden of finding the reasonable alternative onto the individual. They do not permit the reasonable alternative to result in additional fees or costs to the individual. They require the time commitment for the wellness program to be reasonable. Finally they require a reasonable alternative to accommodate the recommendations of the individual's physician with regard to medical appropriateness.

#### V. Models for Wellness Programs Appropriate to People with Serious Illnesses and Disabilities

People with serious illnesses and disabilities are more likely to have the risk factors targeted by wellness programs, such as obesity, hypertension, and high cholesterol. Co-morbidity (i.e., medical conditions existing simultaneously that could be caused by or otherwise related to another medical condition) are quite common. For example, more than half (53%) of adults with arthritis have high blood pressure, 47% are inactive, 47% have high cholesterol, 36 % are obese, and 19% are smokers.<sup>10</sup> In 2011, New Yorkers with disabilities were more likely to be obese (34.9%) than their counterparts without disabilities (21.2%). They were also more likely to smoke (24.3%) than their counterparts without disabilities (15.7%).<sup>11</sup>

The causes of obesity, hypertension, and high cholesterol are many and may be within or outside of a person's control. For instance, genetic predisposition is an important factor in many conditions. Some risk factors might be a side effect of a medication. Penalizing individuals for risk factors beyond their control is not warranted and consumer protections should be strengthened. At the same time, the disparities in health risk factors experienced by people with serious illness and disabilities point to the need for wellness programs that are voluntary, accessible, and non-coercive. Some of the most effective programs that help improve health risk factors are those that reduce barriers or provide the supports needed for individuals to change their health behaviors. Voluntary health promotion activities, "motivated by the desire to increase well being and actualize human potential" were recommended by the U.S. Surgeon General's Call to Action to Improve the Health and Wellness of Persons' with Disabilities.<sup>12</sup> These encompass a number of self-initiated health behaviors such as physical activity, stress management, healthy eating, and cultivation of supportive interpersonal relationships.

A review of 246 studies of health promotion wellness interventions for persons with chronic and disabling conditions concluded that health promotion/wellness interventions for persons with chronic and disabling conditions can have positive health impacts. These studies included people with heart disease, diabetes, arthritis, multiple sclerosis, COPD, asthma, emphysema, HIV, cancer, spinal cord injury, spina bifida, stroke, renal failure, lupus, and sickle cell anemia and a variety of



health promotion behaviors such as exercise (53%), psychological well-being and stress management (14%). and nutrition (4%) or some combination of these health behaviors.<sup>13</sup>

While many people with disabilities would like to participate in wellness programs, not all wellness programs provide accommodations so that they can participate. For example, the American Association on Health and Disability has noted that the CDC has recommended increased walking as a primary mode for increasing physical activity among Americans, but this might not be the best approach for 40 million Americans who have a physical disability and/or chronic health condition such as spinal cord injury, multiple sclerosis, cerebral palsy, limb loss, Parkinson's, knee, hip, or back pain, extreme obesity, or pulmonary disease. They recommend greater access to local fitness centers and recreation facilities and the use of alternative strategies to increase physical activity such as warm water pool exercise, adaptive exercise classes like yoga and tai chi, and exercise machines for people with these conditions. The National Center on Health, Physical Activity, and Disability (www.nchpad.org) has many suggestions for physical activity programs for people with varying levels of disability and functional limitations.

The Chronic Disease Self Management Program model is another well studied model that includes several health behavior topics. The model was developed by the Division of Family and Community Medicine in the School of Medicine at Stanford University and received a five-year research grant from the federal Agency for Health Care Research and Policy and the State of California Tobacco-Related Diseases office. It includes workshops developed with consumer input which cover:

1) techniques to deal with problems such as frustration, fatigue, pain and isolation; 2) appropriate exercise for maintaining and improving strength, flexibility, and endurance; 3) appropriate use of medications; 4) communicating effectively with family, friends, and health professionals; 5) nutrition; 6) decision making; and; 7) how to evaluate new treatments.

Over 1,000 people with heart disease, lung disease, stroke or arthritis participated in a randomized, controlled test of the program, and were followed for up to three years. Subjects who took the program, when compared to those who did not, demonstrated significant improvements in exercise, cognitive symptom management, communication with physicians, self-reported general health, health distress, fatigue, disability, and social/role activities limitations. They also spent fewer days in the hospital, and there was also a trend toward fewer outpatient visits and hospitalizations. These data yield a cost to savings ratio of approximately 1:4. Many of these results persist for as long as three years. YFAHC member, S.L.E. Lupus Foundation, offered this program at their site through the Institute for Family Health as a six week program, 2 ½ hours per week, for 10-18 people. They report that their clients really enjoyed this program.

The 2010 U.S. Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities focuses on goals that go beyond the behaviors of the person with a disability to address the barriers they experience. Goal one of the program is that people nationwide understand that persons with disabilities can lead long, healthy, productive lives. The Surgeon General believes that challenging the misconceptions about people with disabilities and the elevation of the importance of their health and wellness in the public consciousness are steps that can begin to help improve the health status of persons with disabilities. Goal two is that health care providers have the knowledge and tools to screen, diagnose and treat the whole person with a disability with dignity. Goal three is that people with disabilities can promote their own good health by developing and maintaining healthy lifestyles, but the focus continues to be on providers who do not discuss health risk factors with people with disabilities. Goal four is providing accessible health care and support services that promote independence for people with disabilities. These goals address the healthy behaviors that an individual with a disability can adopt, but also address the need for an environment that can support these behaviors.

#### IX. What People with Serious Illnesses and Disabilities Think

During the summer and early fall of 2012, NYFAHC conducted seven listening sessions around the state for over 80 consumers and people who serve them discussing some of the options for the New York State Health Benefit Exchange. Sixty people completed surveys developed by Health Care for All New York (HCFANY) to get the views of consumers on some of the decisions that need to be made. NYFAHC added a question to the survey asking people if they had encountered wellness programs that offer premium reductions or other incentives for such things as participating in physical



ativities, weight loss, successfully quitting smoking, or achieving a particular outcome. We also asked if they thought it would be difficult to participate in such programs.

Most people, both those that had encountered wellness programs and those that had not, thought that it would not be difficult to participate in wellness programs and liked the concept. One person said that he found that his private insurer did not inform customers of its programs very well.

Some people said they would like more coverage for gyms, yoga, and alternative therapies and treatments for wellness. One person thought it would be a good idea to have plans offer discounts for health programs and gyms because it would lower costs in the long run as people get healthier.

Some people had taken advantage of diabetes prevention programs working with nutritionists, or hiring a health coach through their insurance.

Some people had also encountered programs that offered financial incentives for participation and felt that it offered additional motivation to achieve fitness goals. It should be noted that the comments we received did not relate to health-contingent programs.

"I like these wellness programs. I work hard at staying healthy despite some major physical challenges."

Other people worried whether or not they would be able to participate in wellness programs due to body pain, energy level and other physical limitations,—"it depends." One person said it would depend on the time of year, "cold weather makes it more difficult for me to participate in anything."

Respondents thought that programs would not be accessible plus the providers would not be trained in working with people with disabilities. One person said that none of the plans provide for transportation to any of the services for people who don't drive and don't have access to public transportation for some reason. Another person thought it would be extremely difficult to participate, "I work full time—have an hour commute each way and have a toddler at home—and I have lupus. This seems discriminatory against busy people."

Another person saw the down side of plans that attract people with their wellness and fitness plans, but then lack a comprehensive provider network. "I saw a friend join T\_\_\_\_\_\_for their wellness and fitness programs and watched her scramble for decent, adequate medical care when she got sick. All her doctors opted out of T\_\_\_\_\_\_. Therefore, I would not trust any health insurer who wants to expand into the wellness/fitness area."

X. NYFAHC members concerns about whether current legal protections adequately protect consumers and ensure meaningful access to appropriate programs for people with serious illnesses and disabilities.

NYFAHC members examined the proposed rules and some of the examples offered by them at a monthly Roundtable.

#### **Time, Travel, and Costs Count**

NYFAHC members believe that the new language requiring all factors and circumstances to be taken into account in determining whether an alternative standard for a reward must go further. In addition to not allowing additional financial costs of participation to be imposed on the individual, we believe that costs of participation in terms of a person's time, travel distance, and travel costs should be taken into consideration. People with disabilities, in particular, have more difficulty traveling given the inaccessibility of public transportation. All factors and circumstances should also consider the accessibility of the alternative. The final rule has added the consideration of a person's time, but not these additional factors and circumstances. We believe that these additional clarifications could help prevent wellness programs that provide little or no support to help enrollees improve health.



#### **Privacy Must Be Assured**

FAHC members are very concerned about privacy and the possibility of discriminatory action by the employer. If employers are given the option to request verification of a medical condition as part of a reasonable alternative standard, it would be important to make clear to the physician and the employee that they are not required to disclose any details related to the particular medical condition. It should be sufficient for the personal physician to simply verify, as stated in the statute, that a health status factor makes it unreasonably difficult or medically inadvisable for the individual to satisfy or attempt to satisfy the otherwise applicable standard without providing any details about the specific medical conditions. The physician verification process should comply with the HIPPA privacy and security requirements.

#### **Physicians Should Prevail**

NYFAHC members appreciate the requirement that the recommendations of a person's personal physician be accommodated in determining the reasonableness of an alternative standard, but our experience with prior authorization and step therapies leads us to advocate for the "physician prevails" standard in this context. Under no circumstances should a person be required to participate in an activity that his or her personal physician does not approve of in order to gain a reward or avoid a penalty related to health coverage.

#### **Protections Against Discrimination**

NYFAHC members are very concerned about the possibility of discrimination against employees beyond the 30 percent premium variation based on whether they were participating in a wellness program. They suggest developing a method for preventing the employer from having the knowledge of which individuals are receiving a discount based on wellness to avoid employment discrimination. Those employees who are receiving a discount based on an alternative standard should not be identifiable by the employer.

#### **RECOMMENDATIONS:**

New York should not permit deviation from its community rating in the individual and small group markets for the purpose of wellness incentives.

While wellness programs can have positive effects for those who voluntarily participate in them, without community rating they can continue to be a subterfuge for discrimination for people who are unable to to participate due to a health status related factor. Consumer protections added by HIPAA in 2006 and by the more recent final regulations are difficult to navigate and may result in making coverage unaffordable to those who need it most.

#### Wellness programs should be evidence-based to be considered "reasonably designed".

The preamble to the regulations repeats the language of the 2006 regulations stating that "reasonably designed" was intended to be an easy standard to satisfy. There does not need to be a scientific record that the method promotes wellness to satisfy this standard. It is intended to allow experimentation in diverse ways of promoting wellness. The 2006 regulations gave as an example that the plan or issuer could satisfy this standard by providing rewards to individuals who participated in a course of aromatherapy. Such capricious programs without a strong evidence-base to support their efficacy demonstrate why we need a clear definition of reasonable design that is based on evidence. While the recent Final Regulations do not require programs to be accredited or based on any particular evidence-based clinical standards so as to continue to provide plans and issuers flexibility and encourage innovation, they do encourage practices such as those found in the CDC's Guide to Community Preventive Services as a best practice.

The Health Enhancement Research Organization in collaboration with Mercer and drawing on a database of 800 employers is now releasing a Best Practices Scorecard to help employers and others identify and learn about employee health



#### management best practices.17

The grant programs for small businesses to offer employees access to wellness programs provide that they be comprehensive and the Secretary of Health and Human Services is supposed to develop criteria for this program based on evidence-based research and best practices. Section 4303 of the ACA requires that the Centers for Disease Control Director give technical assistance to employers to expand utilization of evidence-based prevention and wellness programs. Other sections of the ACA require wellness program evaluation. There is no reason why, especially in a situation in which a person might incur a financial penalty, reasonably designed programs should not be required to be evidence-based. It is particularly important that there be evidence that the size of the reward or penalty is one that motivates change.

#### Wellness programs should not be "overly burdensome."

"Overly burdensome" remains undefined under the proposed rule. We believe that all factors and circumstances should be taken into account in determining whether all wellness programs, both participatory and health contingent programs, are overly burdensome, not just those that are alternative standards. Again we believe that all factors and circumstances should include accessibility, additional financial costs of participation; the costs of participation in terms of a person's time; and travel distance, time, and costs.

### Notice, due process, an appeals process and consumer assistance should be available to all employees who cannot meet a program's required health standard resulting in a reward or penalty.

Procedures for getting an alternative standard will be difficult to navigate, particularly for people with disabilities. The suggested notice in the proposed regulations is good but the possibility of waiver should be in the notice in addition to the availability of an alternative standard.

Employees should be able to adjust their program or ask for an alternative standard for medical reasons (e.g., pregnancy, cancer diagnosis, and acute injury) at any time during the course of a year and remain eligible for the reward. Employers should be required to provide a timely response to requests for an alternative standard or reasonable alternative means of qualifying for a reward, and the employee should not be penalized in any way during the interim period.

The recommendations of a person's personal physician should prevail in designing an alternative standard. An adverse benefit determination based on whether a participant or beneficiary is entitled to a reasonable alternative standard under a wellness program is considered to involve medical judgment and therefore is subject to external review. Due process protections in the form of an appeals process should be made available to any employee who has not met a health standard, regardless of whether they have sought an alternative standard.

To optimize confidentiality, employers should use an independent adjudicator that specializes in these sorts of appeals. Consumer assistance to help people negotiate an alternative standard should be made available.

## Wellness programs should comply with the Americans with Disabilities Act, the Age Discrimination in Employment Act, the Genetic Information Non-Discrimination Act, and Title VII of the Civil Rights Act of 1964 and Section 1557 of the Affordable Care Act.

While wellness programs must not be a subterfuge for discrimination based on a health factor, this is a phrase that remains undefined. Wellness programs should be required to comply with non-discrimination laws to ensure that they are not a subterfuge for discrimination based on health status factors. The 2006 final regulations note that compliance with non-discrimination regulations by plan provision or practice with respect to benefits including cost-sharing mechanisms made available under a wellness program does not affect whether the provision or practice is permitted under the American's with Disabilities Act or other state or federal laws.<sup>18</sup>

A Joint Consensus Statement produced by the Health Enhancement Research Organization, American College of Occupational and Environmental Medicine, American Cancer Society, Cancer Action Network, American Diabetes Association



and American Heart Association advocates that employees should not be required to disclose a disability protected by the Americans with Disabilities Act and that any medical information obtained as part of a wellness program should be kept confidential. It should be kept apart from personnel files. HIPPA prohibits employers from using protected health information for employment-related reasons such as firing or promotion. In addition, the results of biometric screenings or reasons for obtaining an alternative standard should not be shared with the employer. Employers should receive aggregate, de-identified reports that stratify the population, classify risk, and allow interventions to be targeted toward groups of unidentified employees. Stratification, categorization, or grouping should not be done when there are not enough individuals in a group for each employee to remain anonymous.<sup>19</sup>

#### The ACA, relying on other federal anti-discrimination statutes, provides that,

"an individual shall not, on the ground prohibited under title VI of the Civil Rights Act of 1964 . . . , title IX of the Education Amendments of 1972 . . . , the Age Discrimination Act of 1975 . . . , or section 504 of the Rehabilitation Act of 1973 . . . be excluded from participation in, be denied the benefits of, or be subjected to discrimination under, any health program or activity, any part of which is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance."

Wellness Programs should comply with all state and federal laws that apply with respect to privacy, disclosure, and confidentiality of information provided to the programs. They should comply with HIPPA Privacy and Security Rules and any applicable ADA requirements for disclosure and confidentiality of medical information.

The Office of Civil Rights in the Department of Health and Human Services has the responsibility of enforcing these laws as well as section 1557 of the ACA, which is self-executing. They have received 300 cases under section 1557 already and are investigating 200 in their 10 regional offices. They have indicated that people who feel that workplace wellness programs violate Section 1557 can file a complaint with their regional Office of Civil Rights.

<sup>&</sup>lt;sup>1</sup> Affordable Care Act § 1201, Public Health Service Act § 2705, 42 U.S.C. 300gg-4 (j) (3) (A)

<sup>&</sup>lt;sup>2</sup>Incentives for Nondiscriminatory Wellness Programs in Group Health Plans; Final Rules [Federal Register: June 3, 2013 (Volume 78, Number 106, Pages 33158 – 33192.

<sup>&</sup>lt;sup>3</sup>New York State Insurance Law § 4317

<sup>&</sup>lt;sup>4</sup>NYS Insurance Law New York State Insurance Law § 3239 (c) (1)

<sup>&</sup>lt;sup>5</sup>New York State Insurance Law § 3239 (c) (4)

<sup>&</sup>lt;sup>6</sup>Nondiscrimination and Wellness Programs in Health coverage in the Group Market; Final Rules [Federal Register: December 13, 2006 (Volume 71, Number 23, Page 75023 -750240];

<sup>&</sup>lt;sup>7</sup>Incentives for Nondiscriminatory Wellness Programs in Group Plans; Proposed Rules [Federal Register: November 26, 2012 (/ Volume 77, Number 227, Pages 70630 -706310]

<sup>&</sup>lt;sup>8</sup>Minimum Value of the Eligible Employer-Sponsored Plans and Othe Rules Regarding the Health Insurance Premium Tax Credit; Proposed Rules [Federal Register: May 3, 2013 (Volume 78, Number 86, Pages 25909 – 25916.

<sup>&</sup>lt;sup>9</sup>October 5, 2009 letter to Members of Congress signed by 59 patient advocacy and consumer groups. Available?

<sup>&</sup>lt;sup>10</sup>Pecquet, Julian, Patient Advocates View Senate Bill's Wellness Incentives as Discriminatory, Inside Health Policy News (11/23/09).

<sup>&</sup>lt;sup>11</sup>http://www.cdc.gov/arthritis/data\_statistics/comorbidities.htm

<sup>&</sup>lt;sup>12</sup>Houtenville, Andrew J. and Ruiz, Tony. 2011. Annual Disability Statistics Compendium: 2011. Durham, NH: University of New Hampshire, Institute on Disability sourced from 2011 Behavioral Risk Factor Surveillance Survey.

<sup>&</sup>lt;sup>13</sup>U.S. Department of Health and Human Services, Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities. Washington D.C. U.S. Department of Health and Human Services, Office of the Surgeon General, 2005.

<sup>14</sup>A. Stuifbergen, M. Morris, Jae Hak Jung, D. Pierini, S. Morgan, Benefits of wellness interventions for persons with chronic and disabling conditions: A review of the evidence, Disability and Health Journal, Volume 3, Issue 3 (July 2010.

<sup>&</sup>lt;sup>15</sup>Carlin, Roberta, Response to Request for information in Federal Register Announcement (Vol. 78, No. 62) from the Department of Health and Human Services, Center for Disease Control and Prevention, Docket No. CDC2013-0003- Walking as a Way for Americans to Get the Recommended Amount of Physical Activity for Health, April 30, 2013.

<sup>&</sup>lt;sup>16</sup>http://patienteducation.stanford.edu/programs/cdsmp.html

<sup>&</sup>lt;sup>17</sup>A. Stuifbergen, M. Morris, Jae Hak Jung, D. Pierini, S. Morgan, Benefits of wellness interventions for persons with chronic and disabling conditions: A review of the evidence, Disability and Health Journal, Volume 3, Issue 3 (July 2010.

<sup>&</sup>lt;sup>18</sup>HERO Employee Health management Best Practice Scorecard, Annual Report 2012.

<sup>&</sup>lt;sup>19</sup>Nondiscrimination and Wellness Programs in Health coverage in the Group Market; Final Rules [Federal Register: December 13,2006 (Volume 71, Number 23, Page 75039).