

Ms. Bernadette B. Wilson, Acting Executive Officer
Executive Secretariat
U.S. Equal Employment Opportunity Commission
131 M St., NE
Washington, DC 20507

June 19, 2015

RE: RIN 3046-AB01, Amendments to Regulations under the Americans with Disabilities Act

The undersigned organizations representing individuals with eating disorders, eating disorders researchers, clinicians, treatment professionals, treatment centers, nutrition professionals, obesity experts and advocates ask that the U.S. Equal Employment Opportunity Commission (EEOC) reevaluate the April 20, 2015 proposed rule to amend the Americans with Disabilities Act (ADA) regulations.

The eating disorders community alone consists of more than 30 million people¹, an estimated 10% of which will die from complications due to these conditions making eating disorders the highest mortality rate mental health disorder².

Many of the common practices used in employer wellness programs can trigger eating disorders and dangerous disordered eating behaviors among people at all levels of health. Weight loss discussions, invasive health history inquiries, measurements, diet talk and Biggest Loser style competitions are the prime tools used in the vast majority of these programs as the intent for these programs is to promote weight loss.³ As it is commonly understood, people with eating disorders, a mental health concern, come in all body sizes and cannot be distinguished from any other individual, making blanket wellness programs that focus on BMI harmful on a systemic, programmatic scale.

Because these programs encourage people, including those with eating disorders, to engage in behaviors that directly harm their health and wellness, people with eating disorders should not be 'incentivized' to participate, or 'penalized' for non-compliance, in employer designed programs that contradict the standard of care for treatment and recovery. In order to support these individuals, and the health of others at risk, we believe it incumbent upon the EEOC to require wellness programs using health history screenings and biometric exams to be both evidence-based as well as directly related to the performance of the job in question. We believe it to be discriminatory to require personal health histories that are tangential to the job requirements of the employee in question, and beyond that, we believe that any such inquiry must meet the minimum standard of having proved its design and implementation to be effective in supporting or enhancing overall health.

¹ <http://www.eatingdisorderscoalition.org/documents/FactsAboutEatingDisorders2014.pdf>

² American Journal of Psychiatry, Vol. 152 (7), July 1995, p. 1073-1074, Sullivan, Patrick F.

³ <https://s3.amazonaws.com/public-inspection.federalregister.gov/2015-08827.pdf>

These requirements would go far in eliminating the types of activities that currently reinforce negative health outcomes for people with disordered food relationships and for those with eating disorders.

Well designed program are those that can demonstrate credible, long-term evidence of efficacy in promoting health or preventing disease.

According to the Americans with Disabilities Act (ADA), wellness programs that include medical screenings and inquiries must be “voluntary”⁴. Therefore, financial penalties and other inducements must not be allowed to play a role in whether an individual participates lest an undue hardship is created which can lead directly to discrimination among that population.⁵ It is the strongly held view of the undersigned that the proposed rules are antithetical to the principal protections of the ADA because financial penalties and rewards for compliance are used as tools to reinforce programs which show little to no long-term efficacy as reported in the Rand Corporation Final Report and other studies.^{6,7}

Because the Affordable Care Act (ACA) allows these penalties, individuals - particularly those in low paying jobs - are coerced into participating due to the financial harm that can be inflicted upon them for non-compliance. For those with an eating disorder, that can be a choice between a living wage and living.

To clarify, the ACA permits penalties of up to 30% of the value of an employee’s health premium, and that of their dependents in certain wellness program models, however, the ACA does not supersede the ADA.

The ADA was designed to protect employees under just these circumstances; times when individuals can be potentially harmed or coerced to engage in deleterious behaviors simply to ensure full compensation for a job performed. In addition, the ADA is clear that wellness program medical inquiries and exams must be voluntary. Voluntary means “without pressure.” The proposed rule, deferring to the ACA, strips away those important protections and we think it is critical for them to remain in full force.

As a matter of practice, contractors administer health screenings without the knowledge required to identify and support people with eating disorders. Further, employer wellness programs frequently countermand sound medical advice at the risk of the employee’s health.

The framework of most wellness programs is designed to encourage employees to diet in order to reach specific BMI goals, a measure that has been established as a faulty gauge of overall health, and may cause a significant increase in stress. This stress can exacerbate a preexisting eating disorder jeopardizing the employee’s chance of recovery, which ultimately affects

⁴ 42 U.S.C. § 12112(d)(4)(B)

⁵ <http://www.law360.com/articles/642901/eec-wellness-program-proposal-troubling-law-prof-says>

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http://www.rand.org/content/dam/rand/pubs/research_reports/RR200/RR254/RAND_RR254.pdf

⁷ http://www.benefitspro.com/2015/05/07/how-wellness-is-measuring-up?eNL=554d133e150ba03b1eb219ce&utm_source=BenefitsWeekendPro&utm_medium=eNL&utm_campaign=BenefitsPro_eNLs&LID=154229532

productivity and underlying wellness. Individuals with eating disorders have experienced significant relapses as a direct result of their participation in wellness program medical surveys, screenings, and openly encouraged weight loss “challenges”. (Please see Appendix)

The messages that wellness programs typically send concerning weight and health run precisely counter to effective treatment for people with eating disorders. Those with eating disorders are tempted to believe that weight and shape are more important than proper nutrition, rest, stress reduction, body acceptance and healthy boundaries because of their disorder. As a consequence, the messages of weight metrics based programs are a steady hindrance to self-care and recovery. Beyond the fragile process of recovering from an eating disorder, the pressure to participate in screenings and assessments is compounded when employers impose large financial penalties.

The impetus for these programs is to shift the financial burden of insurance coverage from the employer to the employee if the individual chooses not to participate in biometric screenings and medical inquiries. These screenings typically involve discussions about weight (contrary to standard treatment for individuals with eating disorders), being referred to a weight management program that fails to take into account eating disorders, and being told that they should pursue weight loss. All of this is contraindicated in the treatment of, and recovery from, this serious health condition.

The screenings are generally lead by the same companies who administer employee benefits, not only unqualified in eating disorders, but questionably close to commingling employee health information and data collection on behalf of the employer organization.

For so many individuals with eating disorders, the ability to keep their health status confidential in the workplace is critically important to their wellbeing. Because of the stigma attached to mental health, and especially eating disorders, employees are rightly concerned that their struggle is viewed as a “lifestyle choice” based on vanity rather than as a neurobiological and psychosocial disorder. These rule changes undermine longstanding employee protections that are necessary to overall employee wellness, not just weight related health.

Moreover, forcing the employee to share what was private health history information has the potential to negatively affect the individual and their career. It essentially forces the employee to divulge the information once protected under the ADA to employers and benefits managers who, though bound by HIPAA, have successfully found ways in which to share and commodify that private data.

We ask that it be made clear in the proposed rule that reasonable accommodations are a requirement of employee wellness programs. Beyond that we strongly encourage the EEOC to allow for the possibility that waiving participation may be required as a reasonable accommodation.

People who suffer from eating disorders are some of the most vulnerable among us with high rates of trauma histories. They are being subjected to additional daily trauma when forced to endure wellness programs that violate privacy rights and threaten financial ruin in order to coerce participation. For the invisible community of over 30 million people, we ask that you not dismantle the ADA; we ask at the very least, that you interpret the ACA and HIPAA as coexisting

with the ADA and its intended protections of barring penalties on wellness program medical exams and inquiries.

Sincerely,

BingeBehavior.com

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Washington, DC 20002

Academy of Nutrition and Dietetics

1120 Connecticut Avenue NW, Suite 460
Washington, D.C. 20036

Alliance for Eating Disorders Awareness

1649 Forum Place #2
West Palm Beach, FL 33401

American Society of Bariatric Physicians (ASBP)

2821 S. Parker Road, Ste. 625 | Aurora, CO 80014-2735

American Society for Metabolic and Bariatric Surgery (ASMBS)

100 SW 75th Street, Suite 201
Gainesville, FL 32607

Binge Eating Disorder Association (BEDA)

637 Emerson Place
Severna Park, MD 21146

Council on Size & Weight Discrimination (CSWD)

Mount Marion, NY

Eating Disorders Coalition for Research, Policy & Action (EDC)

PO Box 96503-98807
Washington, DC 20090

Multiservice Eating Disorder Association (MEDA)

288 Walnut Street, #130
Newtonville, MA 02460

National Association of Anorexia Nervosa & Associated Disorders, Inc. (ANAD)

750 E Diehl Road #127
Naperville, IL 60563

National Eating Disorder Association (NEDA)

165 West 46th Street, #402
New York, NY 10036

National Association to Advance Fat Acceptance (NAAFA)

Foster City, CA 94404

Obesity Action Coalition (OAC)

4511 North Himes Ave., #250

Tampa, FL 33614

PeopleOfSize.com

Portland, Maine

The Strategic Training Initiative for the Prevention of Eating Disorders (STRIPED):

A Public Health Incubator

Boston, MA 02115

The Elisa Project

10300 North Central Expressway, Suite 330

Dallas, Texas 75231

The Obesity Society (TOS)

8757 Georgia Ave., #1320

Silver Spring, MD 20910

Treatment Centers:

Andrea's Voice Foundation
Eating Disorders Awareness/Prevention
1383 Rosewood Lane
Napa, CA 94558

Chicago Center for Overcoming Overeating,
Inc.
PO Box 108
Deerfield, IL 6001

Eating Disorders Coalition of Tennessee
2120 Crestmoor Road, Suite 3000
Nashville, TN 37215

Hynes Recovery Services
396 Washington Street, Suite 392
Wellesley, MA 02481

Oliver-Pyatt Treatment Centers
5830 SW 73rd St
South Miami, FL 33143

The Center for Eating Disorders
111 N 1st St #2,
Ann Arbor, MI 4810

The Women's Therapy Centre Institute
562 West End Ave #1C, New York, NY 100

Individuals:

Over 240 individuals and treatment providers signed on to this letter

Appendix

Testimonials from individuals and treatment providers:

Jane

I am a corporate executive in a Fortune 500 company. My employer operates a wellness program. Every year, as part of that program, we are required either to have blood drawn and have our weight, height, blood pressure and other things measured or contribute more toward our health insurance. This testing is done on site at the workplace.

I have anorexia. I have been in treatment for four years. Over the years I have built a relationship with my dietician, my therapist, my psychiatrist, and my medical doctor. Their familiarity with my needs, including what helps and what triggers the symptoms of my disability, is critical to ensuring that I receive effective treatment. In contrast, the wellness program at my workplace is operated by people who have no familiarity with my particular needs and no knowledge of how to address them. Among other things, the program requires employees to undergo weight-related screenings administered in a manner that undermined the treatment regimen carefully designed by my treating professionals and resulted in my relapse and admission to an intensive outpatient treatment program.

I would never have participated in this wellness program of my own accord, but due to the large financial incentives to participate, I felt like I had no choice but to do so. When I found out that the wellness program required me to be weighed, I told my dietician, who was extremely concerned. She wrote a letter indicating that I was receiving intensive nutrition therapy with her and that I should not be weighed or have my body mass index measured by the program, as that would be detrimental to the progress that I had made under her care. The wellness program nurse read the letter but proceeded to weigh me and, despite my stepping on the scale backward so I would not see my weight, she announced how much I weighed and what my body mass index was. She remarked that “it wouldn’t hurt you to enroll in our healthy eating program.” This is precisely the type of trigger that my treatment – and the treatment of people with similar eating disorders – is designed to avoid. She was telling me I was fat—exactly what I needed to hear to stop eating again.

After this incident, I stopped eating for two weeks and ultimately ended up in an intensive outpatient treatment program. My dietician was furious about the damage caused by the wellness program.

I am dreading participating in the wellness program again this year. I am uncomfortable about having to tell my employer about my eating disorder – a very personal matter—and I do not want to repeat the experience of questions and screening that are counterproductive to my treatment. If I don’t participate, however, I will have to pay an additional \$750.00 for my health insurance, so I cannot afford to avoid it.

John

I'm 37 and have put a lot of work into recovering from bulimia. I have been in treatment for bulimia for 12 years. I see a therapist, a doctor specializing in eating disorders, and a psychiatrist.

For the last five years, I've worked at a technology company. I've noticed that every year, their "wellness program" has become more and more triggering, as it has become increasingly tied to health biometrics and "rewards" on my paycheck. The "rewards" for taking answering the health risk assessment, taking various biometric tests, and meeting certain health outcomes are so significant that I felt I had to participate. These rewards now come to a total of \$2470 per year for taking the tests and meeting all of the health targets. With a family and a child in day care, I cannot afford to forego such a large amount of money.

A couple of years ago, the wellness program started to require that employees' weight, triglycerides, and blood pressure be checked. These biometric screenings happen every year, and I dread it. If my body mass index does not fall into what the program considers "normal," then I don't get a "reward" on my paycheck—or, to put it another way, I'm penalized. If I forego even one part of the biometric screens, such as the weight check, I lose the reward for all of the screenings. In addition, the program's instructions for employees, including to keep their meal portions "as small as possible" (to "fit into your skinny jeans") are inconsistent with and undermine all the work that I have done to overcome my disability.

The wellness program allows employees to have their own physicians perform the screenings. When my doctor heard about the screenings, he was incredulous. He indicated that, out of concern for my health, he did not want me to participate in these tests. But I felt compelled to do so given the large sum at stake. My doctor wrote a letter explaining that having me step on a scale and having my weight read out loud would be extremely damaging. After three months of requests and negotiations, I was ultimately able to get the program to permit me to apply for the incentive without my doctor filling out the screening form (a special "manual process" was used), but this process was extraordinarily stressful and I have no assurance that I will be permitted to do this in the future. I was the first person who was able to forego the screening without losing the incentive—and to my knowledge, the only person. And guess what? It's time to do the entire thing again for this year's screening!

Mary

I am a journalist. I used to work for a county health program that established a workplace wellness program. One cold January morning, I returned to work for the first time in nearly eight weeks. I had taken a leave of absence after a suicide attempt and inpatient treatment for chronic depression and anorexia. I had gained a few pounds and my depression had stabilized, and I was looking forward to returning to work I found meaningful.

But when I walked in the door, I was inundated with signs about our workplace weight loss contest—a “Biggest Loser”-style competition. For someone who was struggling desperately to gain weight, this was nothing less than an affront. Signs told me that "Nothing tastes as good as skinny feels." Besides being the same slogans plastered all over the pro-anorexia websites I used to visit, I had spent the past decade feeling exactly how skinny could make you feel—miserable enough to complete a near-lethal overdose.

I pulled my chin up, set my things down at my desk and walked into the break room for a hot cup of coffee. There, on a big sheet of blue posterboard, was a tally of how much weight everyone had lost. Veronica in accounts receiving had already lost 3.4 pounds. Then, flooding in my inbox were the emails encouraging us to only eat half our lunch, and to try to sneak in an extra workout during our lunch break. Never mind that these behaviors were exactly what had landed me in the hospital. I had a prescribed diet developed in consultation with my dietitian.

For several months, I tried to grin and bear it, but eventually, the madness was just too much. I couldn't bear the meetings about how good steamed broccoli was. I couldn't stand working in an external environment that was, quite possibly, more toxic than the internal chatter I endured all day. The poster listing everyone's weight loss statistics was removed upon my request, but the fact remained that the workplace wellness program had created an environment that was anything but healthy. I had to quit my job.

My workplace wellness program did not use financial penalties or rewards. I was able to remove myself from certain aspects of it, but being surrounded by it was enough to drive me out of the workplace. Had there been financial penalties used to force me to participate in all aspects of the program, that would have been even worse.

Perhaps my experience is an unavoidable side effect of a war against obesity that some have determined should be won at all costs (and regardless of evidence that existing wellness programs work). But when you consider that around one in 20 Americans will struggle with an eating disorder at some point in his or her lifetime, that's a lot of collateral damage.

Sue

I struggle with bulimia. My employer instituted a wellness program that requires employees to undergo yearly medical screenings of cholesterol, blood sugar, blood pressure, and body mass index. We also have to fill out an annual health questionnaire. Employees who undergo the screenings and complete the questionnaire receive a reduction in their health insurance premiums, whereas employees who decline to do either of these things cannot receive this reduction. If an employee's spouse is covered under his or her insurance, the spouse must undergo the screening as well in order for the employee to receive the premium reduction.

The program recommends that you join coaching and weight management classes if the screening identifies your body mass index as "too high." It suggests that being thin means being healthy, and being heavier means being less healthy, even though this is far from true for many people. For individuals who have struggled with eating disorders, it is particularly troubling to be labelled as having a weight problem or a problem with body mass index despite having worked closely with treating professionals to manage the disorder. Telling such individuals that they have a weight problem is precisely the type of response that professionals who treat eating disorders know to avoid. When nurses with no knowledge of our treatment history or progress, and no knowledge of eating disorders generally, respond this way, it undermines our treatment and progress. It is even worse when that undermining happens at one's place of work.

Like the screenings, the health questionnaire inappropriately suggests that thinner is always better. Based on my answers, the wellness program assumes that I have unhealthy eating habits, but it does not account for the fact that my diet is carefully prescribed by my treating doctor in response to a multitude of food allergies. I am allergic to all grains, and as a consequence, in 2013 I switched to a natural fat, unprocessed, grain-free diet. My health markers began to improve at that time. The wellness program, however, identified my eating as unhealthy because of the fats included in my diet. As a result, I was docked "health points" and was given recommendations such as "eat less," "unsupersize your meals," and "go Mediterranean to transform your health and your weight," and attend Weight Watchers. After receiving these messages that suggested I was overweight and eating poorly, I began experiencing greater symptoms of my eating disorder and began purging. While the wellness program did not start my eating disorder, it has certainly made it worse.

Elizabeth

I have bulimia. I had bulimia. I will always be dogged by the bulimia that was triggered by my abuse at the hands of my parents and the bizarre and extremely restrictive diets they began to force on to me when I was a small child.

I have extremely bad anxiety as a result of the abuse. I get debilitating panic attacks. And I find being weighed to be extremely triggering of my anxiety, so I decline when I am at the doctor's office.

But a couple of years ago, I had to participate in my company's biometric screenings, or there would be a fine on my health insurance rates.

The screening was conducted at my office. When I went in, I told the nurse I didn't want to be weighed. She said I had to, or the screening wouldn't count. At this point, I disclosed that I had an eating disorder, which is an extremely painful thing for me to talk about, but I didn't see any way around it.

I am a fat woman, so I know she didn't believe me. I find that most people don't believe that fat people can have eating disorders.

So I told the nurse I was ok with being weighed, as long as I didn't have to see the amount. I was starting to feel severe anxiety at this point because I was being forced to be weighed-- something that is extremely bad for my mental health.

I closed my eyes while she was weighing me, and once I stepped off the scale, she shoved a paper into my face with my weight written on it in red pen and circled several times.

I was in tears as she said to me, "You need to see this," shoving the paper into my face- so close that I couldn't avoid seeing it.

I couldn't believe medical personnel would act in such a callous and cruel way, especially after I disclosed a history with an eating disorder. I cried at my desk, because I was humiliated in front of other people I work with, triggered into a panic attack, and treated with the same abusive mindset I endured the entire time I was a child.

It was a horrible experience.

Joan

The school where I work recently instituted a wellness program. In order for our insurance premiums to not increase, we had to go through a series of tests: total cholesterol, blood pressure, BMI, LDL cholesterol and fasting glucose. If we did not “pass” 4 out of 5 of these biometric screenings, we had to go through six weeks of phone therapy and then have the screenings done again after that time.

If, after the six weeks of phone therapy, the results did not change, our insurance would go up about \$50.00/month.

The whole experience was a nightmare. They conducted the screenings in the music room at school, with different tables and stations set up. About 10 or 12 teachers and staff members were in the room at one time, so there was little privacy.

We moved from one station to the next as each of our results was written down and passed to the next person.

When we got to the end, a wellness “counselor” went over our results. The lady saw my triglycerides number and immediately asked, “Does diabetes run in your family?” “Is obesity an issue in your family?” I asked why. She said that a high level of triglycerides means that the body has “too many fat cells” and that I am at an “increased risk.”

To someone who has struggled with an eating disorder, as I have, this was tantamount to saying “Because of your high triglycerides, you are fat. You are obese.”

Being weighed is always a humiliating and shameful experience for me, as it is for many people with eating disorders, and it can trigger exacerbations of my disorder (treating professionals familiar with eating disorders are well aware of this phenomenon and structure treatment accordingly). To have to be weighed in front of my peers made that experience even worse.

This biometric screening triggered my disorder. I was in tears by the time I got to the last “counselor” and had a very hard time controlling my feelings. Right after this, I needed to get into my classroom and be with my kids. I had to “suck it up,” until the end of the day.

It was horrible and it makes me wonder what is in our future in regard to all of this.

Katie

My workplace, an addiction treatment facility, has an employee “wellness” program.

If employees want to obtain the insurance “wellness rate” (the lower of two rates available to employees), we are required to start every year in January with a “health fair” and a “know your numbers screen” where they check weight, blood pressure, glucose levels and cholesterol. Then we are “advised” by a registered nurse to exercise more and eat less (as if that had never occurred to anyone previously).

This year, the medical assistant drawing my blood engaged in numerous behaviors that would trigger most people with an eating disorder. She informed me she “used to be as big as” I am until she “got bypass surgery.” Despite mentioning several times that I see a nutritionist who recommends that I not weigh myself or know my weight, I was asked to guess my weight before I stepped on the scale. I turned around when I stepped on the scale to avoid seeing my weight, but the assistant nonetheless chattered on about my weight.

I was reminded of embarrassing weigh-ins with school nurses and weight loss programs before I was exposed to eating disorder recovery.

This year we are also assigned to a “wellness team” where everyone is supposed to wear pedometers every day and log their steps weekly on a website. Everyone can see everyone else’s steps on the site and a competitive spirit is encouraged.

I am especially saddened and concerned that we have this potentially damaging environment that encourages obsession with weight and numbers in a facility that treats addiction, where one would hope we would be steered away from, rather than toward, the process of addiction to disordered eating.

Rhonda Lee Benner, LCSW

I have worked with hundreds of patients over the 13 years during which I have worked with people with eating disorders. In the past two years, I have seen a number of patients who were quite negatively impacted by the wellness programs at their place of work.

In one instance, a patient with binge eating disorder reported that she would be financially penalized if she didn't set weight loss as a goal and make progress toward this goal. However, this was in direct conflict with her treatment goals to stabilize eating and set any goals for weight loss aside. This patient could see how focusing on weight loss increased her binge eating; however, she felt shame and anxiety as a result of these pressures put on her by her employer. She did not feel that as a larger-sized person she could speak up about this injustice.

In another instance, a patient reported that her employer required her to complete a health screening or be charged \$600.00, and when she didn't meet the health targets she was given an opportunity to still get the monetary "rewards" by meeting with a dietician three times. She was also informed that she could get a "Healthy Weight Improvement Reward" by losing five pounds since her last health screening. Again, this is a patient with binge eating disorder whose condition is destabilized by focusing on weight loss. She too felt that as a larger-sized person she could not speak up about how this program could cause her harm.

Kari Anderson, DBH, LPC, CEDS

I have worked with several eating disorder clients who worked for large companies in the area with “robust” wellness programs in the Phoenix area and beyond.

One such company encouraged my very ill client to sign up for “free” counseling services over the phone for her problem with weight (active bingeing and purging) with their specialists instead of paying out of pocket for “out of network” counseling services with me. My client returned and said that she was going to get treatment from her company instead of continuing her treatment with me. Their wellness program was sponsored by their insurance program.

Not only did they dangle the “free” card to this woman, they saved having to pay me for services once she met her out of network for counseling services. This company was a call center with a food incentive/reward philosophy for their employees. Every holiday, birthday and quota goals met was “celebrated” with elaborate spreads of treats for those laboring for hours in their cubical to “graze” on. The irony of this company, is that they have very high incidents of lifestyle related “health problems” such as obesity and their insurance company is pushing weight loss programs and online nursing counseling.

These employees are caught in a trap set up by their employer.