January 28, 2016

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Re: Comments on Proposed Rule, Genetic Information Nondiscrimination Act, RIN 3046-AB02

The undersigned members of the Consortium for Citizens with Disabilities (CCD) submit these comments in response to the EEOC’s proposed rule to modify its current rules implementing the Genetic Information Nondiscrimination Act (GINA) and authorize workplace wellness programs to impose large penalties on employees’ covered spouses who decline to disclose disability-related information. CCD is a coalition of national disability organizations working for national public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

We oppose the EEOC’s proposed rule, which would significantly diminish protections for workers’ spouses to keep their disability-related information out of the hands of employers. The Commission’s proposed rule is inconsistent with the plain language and the purpose of GINA, as well as with the GINA regulations already promulgated by the EEOC. It would erode important protections against adverse employment decisions based on fears about the cost of a spouse’s insurance.

Last year, the EEOC proposed to rewrite the ADA’s provisions concerning “voluntary” wellness program inquiries to permit a “choice” between exercising ADA rights and paying hefty penalties. Following on the heels of that proposal, the EEOC’s new proposal—to read “spouse” out of GINA’s statutory protections of family members’ health information and permit staggering financial penalties on families that choose to keep health information private—creates the impression that the agency is improperly rewriting Congressional enactments to serve a new policy goal: enabling workplace wellness programs to make it too costly for employees and their
spouses to exercise their civil rights. It is ironic that an agency created at the height of the civil rights movement to protect workplace rights, including for the poorest and most vulnerable workers, would construe civil rights laws to offer meaningful protections only for workers with sufficient financial means to afford to exercise their rights.

I. The Proposed Rule is Inconsistent with GINA

The proposed rule exceeds the EEOC’s authority because it is not a reasonable interpretation of the plain language of GINA. It is inconsistent with GINA’s definition of “family member,” which includes spouses, and with GINA’s requirement that workplace wellness inquiries seeking employees’ genetic information must be voluntary. The proposed rule flies in the face of Congressional intent to protect the health information of spouses equally with that of children.

The Proposed Rule is Inconsistent with GINA’s Definition of “Family Member”

In GINA, Congress expressly prohibited employers from requesting, requiring, and purchasing employees’ genetic information—including “the manifestation of a disease or disorder in family members of such individual”—with six narrow exceptions, including an exception where the employer offers health or genetic services as part of a wellness program. 42 U.S.C. § 2000ff(4). As the EEOC acknowledges, the statutory definition of “family members” includes spouses.1 Thus, there is a clear statutory prohibition on requesting, requiring or purchasing medical information from an employee’s spouse absent one of the exceptions.

The EEOC now proposes, absent Congressional direction or intent, to remove coverage of spouses from the definition of “family member” for purposes of the wellness program exception. The agency’s logic is that Congress was concerned about family medical information that would reveal something about an employee’s genetic makeup, but a spouse’s medical information would not reveal anything about the employee’s genetic makeup. But the EEOC cannot seriously contend that Congress intended to exclude spouses’ health information from GINA’s protections when Congress explicitly defined “family member” to “a person who becomes . . . a dependent of the individual through marriage.”2 Nor can the agency seriously contend that Congress intended to protect family members’ health information only if it would reveal an employee’s genetic makeup when Congress explicitly protected the health information of “a person who becomes . . . a dependent of the individual through . . . adoption or placement for adoption.”3 Like the medical information of a spouse, that of an adopted child would reveal nothing about an employee’s genetic makeup.


3 Id.
In addition to this plain statutory language, the legislative history of GINA confirms that Congress intended to protect the health information of employees’ spouses and adopted children, regardless of whether it would reveal information about employees’ genetic makeup. Congress’s concerns included protecting employees from discrimination based on fears about these family members’ health care costs. Reports from the House Ways and Means Committee and the Senate HELP Committee state:

Further, the bill applies to spouses and adopted children of an individual because of the potential discrimination an employee or member could face because of an employer’s or other entities’ concern over potential medical or other costs and their effect on insurance rates.\(^4\)

Finally, in reading spouses out of the statutory definition of “family member,” the EEOC effectively reads the statute to contain one set of rules for “voluntary” wellness program inquiries seeking some types of genetic information (including medical information of employees’ children) and a radically different set of rules for inquiries seeking other types of genetic information (including medical information of their spouses). If Congress had intended to distinguish between different kinds of genetic information and impose such dramatically different rules, certainly it would have said so.

The Proposed Rule is Inconsistent with the Statutory Requirement that Inquiries Be “Voluntary”

As the EEOC acknowledges, for GINA’s “wellness program” exception to apply, the provision of medical information by a family member must be voluntary.\(^5\) The ordinary meaning of “voluntary” is “not impelled by outside influence” and “[w]ithout valuable consideration.” Black’s Law Dictionary (9th ed. 2009). See also Merriam Webster Dictionary (“unconstrained by interference” and “without valuable consideration”). Absent a statutory definition of “voluntary,” it must be construed “in accordance with its ordinary or natural meaning.” FDIC v. Meyer, 510 U.S. 471, 476 (1994).

Indeed, the Commission has already defined “voluntary” in its GINA regulations consistent with that plain meaning: a wellness program inquiry is “voluntary” if the covered entity neither requires the individual to provide genetic information nor penalizes those who choose not to provide it.\(^6\) The Commission’s existing GINA regulation further clarifies that an employer “may not offer a financial inducement for individuals to provide genetic information” in a wellness program, and that any inducement for completing a health risk assessment must be


\(^6\) Id. § 1635.8(b)(2)(i)(A) (emphasis added).
offered regardless of whether an employee chooses to answer the questions about genetic information.\footnote{Id. § 1635.8(b)(2).}

Yet the EEOC’s new proposed rule would consider inquiries about a spouse’s medical information to be voluntary when the “choice” not to answer carries staggering financial penalties. Penalties for not disclosing a spouse’s health information are permitted to be almost double the hefty penalties that the EEOC’s proposed ADA wellness rule allows for employees who choose not to respond to wellness program inquiries seeking their health information. Together, the two proposed rules would nearly triple the penalties permitted by the ADA rule if both employee and spouse choose to keep their health information private. This reading of “voluntary” is not only inconsistent with the EEOC’s existing GINA rule, which recognizes that “voluntary” means an employer may not penalize an employee for choosing not to disclose genetic information in response to a wellness program inquiry. It is so far afield from the ordinary meaning of “voluntary” that it is an invalid interpretation of the statute. \textit{See General Dynamics Land System v. Cline}, 540 U.S. 581, 600 (2004) (no level of deference to EEOC’s rulemaking is appropriate when the Commission’s interpretation of a statute “is clearly wrong.”).

The proposed rule would permit penalties of up to 30\% of family health coverage premiums when an employee and spouse both decline to respond to wellness program medical inquiries. Since the average cost of family coverage under a group health plan in 2015 was $17,545,\footnote{Kaiser Family Foundation, 2015 Employee Health Benefits Survey, Summary of Findings, http://kff.org/report-section/ehbs-2015-summary-of-findings.} the average penalty for an employee and spouse who choose not to respond to wellness program requests for their medical information would be $5,264. For many families, the penalty could be higher. For the nearly one-fifth of employees whose cost of family coverage is $21,000 or higher, penalties upward of $6,000 would be permitted.\footnote{Id.} Such penalties constitute a sizeable portion of many families’ annual income.

Medical questions that an employee and spouse may only decline to answer if they agree to pay penalties of this magnitude can hardly be called “voluntary.” The Commission’s statement that such penalties are not coercive suggests that its policymakers may be grossly out of touch with the realities faced by most people with disabilities.

In fact, the rationale that employers have provided for the use of large financial penalties is that these penalties are necessary to boost participation in health risk assessments as few employees and family members choose to participate of their own volition. Making penalties so high that individuals feel they have little choice but to participate is the opposite of “voluntary.”
II. **The Affordable Care Act and HIPAA Do Not Require the Commission to Reinterpret the GINA’s Protections for Family Members’ Health Information**

The Commission proposes to re-interpret GINA to “balance” its goals with the goals in the Health Insurance Portability and Accountability Act (HIPAA) and the Affordable Care Act (ACA) to promote participation in workplace wellness programs. But GINA must be interpreted according to its plain language and purpose, rather than “balanced” to reflect the provisions of an unrelated law that does not supersede GINA’s requirements. As the ACA’s implementing regulations concerning wellness programs expressly state, and the EEOC acknowledges, compliance with ACA and HIPAA rules does not determine compliance with GINA’s requirements. The mere fact that the ACA and HIPAA limit the total penalties imposed in certain types of wellness programs to 30% of premiums does not eliminate the additional limitations imposed by GINA—namely that a subset of wellness program inquiries (those that seek spouses’ medical information) must not penalize workers who decline to answer.

A. **The ACA and HIPAA Regulations Concerning Wellness Programs Explicitly State that GINA’s Provisions Apply Simultaneously**

The 2015 regulations from the Departments of Treasury, Labor, and Health and Human Services concerning the ACA’s wellness provisions explicitly recognize that GINA imposes separate, additional restrictions on wellness programs:

> . . . the Departments recognize that many other laws may regulate plans and issuers in their provision of benefits to participants and beneficiaries. These laws include, but are not limited to . . . the Genetic Information Nondiscrimination Act of 2008. . . . The Departments reiterate that compliance with these final regulations is not determinative of compliance with any other applicable requirements.”\(^1\)

B. **The ACA and HIPAA wellness penalty provisions address insurance discrimination and not employment discrimination**

The provisions in the ACA and HIPAA wellness program penalties address when such penalties constitute *insurance* discrimination. \(^2\) They do not address the separate concern of when such penalties, used in an employer-sponsored wellness program, have the effect of discriminating in

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\(^1\) Incentives for Nondiscriminatory Wellness Programs in Group Health Plans, 78 Fed. Reg. 33158, 33168 (June 3, 2013).


\(^3\) Since its passage in 1996, HIPAA has barred discrimination by group health plans in coverage and premiums “based on” one of eight “health status-related factors,” including “health status,” “medical condition” (including both physical and mental illnesses), and “disability.” Public Law 104-191 (Aug. 21, 1996). The ACA expanded these HIPAA non-discrimination protections to include individual health insurance plans. See Public Law 111-148 (Mar. 23, 2010), § 2705(a); 42 U.S.C. § 300gg-4(a).
employment. GINA defines employment discrimination to include requesting employees’ genetic information, including their spouses’ health information, as part of a wellness program if the inquiries are not voluntary. While it may not be insurance discrimination to impose penalties for employees’ failure to provide their spouses’ medical information, it is employment discrimination under GINA.

C. The ACA did not repeal GINA by implication

The wellness provisions in the ACA do not repeal by implication GINA’s protections of spouses’ health information. If Congress meant to repeal these protections, it would not have done so without saying anything. Nothing in the ACA indicates Congressional intent to repeal these provisions, and repeals by implication are disfavored.13

The fact that two statutes regulate the same conduct and impose different rules does not mean that one repeals the other by implication; “as long as people can comply with both, then courts can enforce both.”14 GINA and the ACA are capable of coexistence, and it is possible to comply with both simultaneously. GINA does not bar employers from imposing the penalties of up to 30% of family premiums permitted by the ACA in health-contingent wellness programs. It permits employers to impose penalties of that amount in order to induce employees and spouses to participate in wellness program services, meet health targets, and/or participate in health risk assessments.

It is routine for two laws that apply to the same conduct to impose independent obligations, and one statute may impose greater or different obligations than the other. For example, the Medicaid Act expressly permits states to limit the number of Medicaid recipients they serve under home and community-based services waiver programs, but the ADA’s integration mandate may require states to seek an increase in the waiver “cap” in order to avoid needlessly institutionalizing people with disabilities. See United States Dep’t of Justice, Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C., Questions and Answers on the ADA’s Integration Mandate and Olmstead Enforcement, Question 7 http://www.ada.gov/olmstead/q&a_olmstead.pdf. See also Makin v. Hawaii, 114 F. Supp. 2d 1017, 1034 (D. Haw. 1999).

The IDEA and ADA also impose independent obligations. See, e.g., Statement of Interest of the United States of America in S.S. v. Springfield Public Schools, Civ. Action No. 3:14-cv-30116, at 2, available at www.ada.gov/briefs/springfield_ma_soi.pdf (“... while the ADA and IDEA provide complementary protections for many students with disabilities, they are not identical in purpose or scope and impose distinct obligations on school districts in furtherance of their respective statutory mandates. ... [the ADA] may require different or additional measures to

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14 Randolph v. IMBS, Inc., 368 F.3d 726, 730 (9th Cir. 2004).
avoid discrimination against children with disabilities than the measures that are required to comply with IDEA.”).

D. Conclusion: The Commission Should Not Modify its Rule to Permit Penalties on Employees for Declining to Provide Spouses’ Health Information to a Workplace Wellness Program

For the reasons described above, the Commission should not eliminate GINA’s protection of spouses’ health information from its protections of employees’ genetic information. It should treat spouses’ health information the same as other genetic information, as required by the statute.

III. The Commission’s Proposed Protections are Inadequate to Prevent the Rule from Causing Harm

The Requirement that Wellness Programs be “Reasonably Designed”

In order to mitigate the harms that may be caused by its proposed rule, the Commission proposes to add a requirement that where an employer requests, requires, or purchases genetic information as part of health or genetic services, those services must be “reasonably designed to promote health or prevent disease.” If the Commission does proceed with its proposal to eliminate protections for spousal health information, the “reasonably designed” requirement must be strengthened if it is to afford any type of meaningful protection.

We urge the Commission to require that, to be “reasonably designed,” a wellness or other program offering health or genetic services must offer services beyond simply telling employees’ spouses to follow up on potential health risks. The “reasonably designed” requirement is a useless protection if programs that exist solely to obtain individuals’ medical information without offering them any help in addressing health or wellness issues are considered reasonably designed.

We also urge the Commission to require that, to be “reasonably designed,” a program must have a solid evidence base demonstrating that the program—including any penalties or rewards that it imposes—results in significant improvement in employees’ health and significant reductions in health care costs. The principal author of the federal government-sponsored RAND study, the lead study on wellness program effectiveness, stated:

Why do employees, and in particular those at high risk, choose not to participate? We do not yet have the evidence or insight to understand and convincingly answer that question. When we do, we will be able to design attractive and accessible programs. In
the meantime, we should not penalize vulnerable employees who are reluctant to join marginally effective programs.\textsuperscript{15}

It is notable that recent studies have repeatedly found that wellness programs have had minimal impact in promoting wellness and in achieving cost savings. If the EEOC permits wellness programs to subject employees and their spouses to staggering financial penalties designed to extract their private health information, it should expect real results from those programs and not just health data mining to generate large profits for the wellness industry.

We also urge the EEOC to state that to be "reasonably designed," a wellness program cannot be used for insurance underwriting purposes. Otherwise, the scheme that the EEOC has attempted to set up in its ADA and GINA proposed rules concerning wellness programs is at risk of being undermined if courts follow recent decisions concerning the ADA’s insurance “safe harbor” provision (which we believe, consistent with the EEOC’s current litigation position, are wrongly decided). The intent of these proposed rules seems to be to limit the maximum penalties on the choice of employees and spouses not to respond to wellness program requests for health information under the ADA and GINA to 30% of family premiums to “comport” with the ACA. If wellness programs that claimed to use this health information for underwriting purposes were permitted by the safe harbor provision to levy any type of penalty they chose on employees not disclosing this information, the penalties under ADA and GINA together could far exceed 30% of family premiums. And while GINA has no safe harbor provision, if an employer were permitted to terminate an employee’s insurance altogether for not disclosing this information, the employee’s spouse would lose dependent coverage.

\textit{The Requirement of Knowing and Voluntary Written Authorization}

The proposed rule requires that a health risk assessment that induces employees’ spouses to provide health information must require that the spouse provide prior, knowing, voluntary written authorization and that the authorization form describe the confidentiality protections and restrictions on the disclosure of genetic information.

While such authorization is required by GINA, the point of the authorization requirement in GINA is not simply to have individuals sign a form, but to ensure that their authorization to disclose genetic information is, in fact, \textit{voluntary}. In order to comport with Congress’s direction that the authorization be voluntary, the EEOC should require that an employee’s indication that his or her participation is not voluntary would enable the employee to receive the reward, or avoid the penalty, without his or her spouse disclosing medical information. Otherwise, the written confirmation would not serve any purpose; signing a form does not eliminate the coercion exerted by imposing huge financial penalties for failure to disclose information.


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IV. **Additional Issues on Which EEOC Seeks Feedback**

**A. The Final Rule Should Require that Employers that Offer Inducements for Spouses to Disclose Health Information Provide Similar Inducements to Spouses Who Provide a Doctor Certification**

The proposed rule solicits feedback on whether employers that offer inducements for employees’ spouses to disclose health information must also offer similar inducements to individuals who choose not to disclose that information but instead provide certification from a medical professional stating that the spouse is under the care of a physician and that any medical risks identified by that physician are under active treatment.

Permitting individuals to avoid penalties by showing that their spouses are already receiving care for any condition asked about by a health risk assessment is an important protection that the EEOC should include in the final rule if it exempts spousal health information from GINA’s protections. The EEOC should require that wellness programs reimburse any fee that the individual must pay to obtain such a certification. In addition, the EEOC should specify that:

* the health professional may submit the certification without letterhead if the letterhead would reveal information about the patient’s medical issues (such as an oncology practice);

* the certification should state that the individual is under the care of “one or more” medical professionals; and

* instead of saying any risks identified are “under active treatment,” the certification should say that any risks identified are “being addressed” (for many people who face medical risks due to a health condition, the appropriate course of action is not to provide “active treatment” such as medication, therapies, or other interventions but simply to monitor the person’s condition on a regular basis and to intervene only if there is a particular reason to do so).

**B. The Authorization Requirement Should Apply to All Wellness Programs Inducing the Disclosure of Spouses’ Health Information**

The proposed rule solicits feedback on whether the authorization requirement should apply only to wellness programs that offer more than de minimis rewards or penalties for the disclosure of spouses’ health information as part of a health risk assessment. The statute requires such authorization any time a person provides genetic information in response to an employer requesting it under a wellness program. The regulation should do so as well. Moreover, any ambiguity in the definition or understanding of “de minimis” will likely result in some employers failing to require the authorization in situations where significant inducements are offered for disclosure of genetic information.
C. The EEOC Should Consult Electronic Data Experts to Ensure the Confidentiality of Genetic Information Stored in Electronic Records

The proposed rule solicits feedback about whether the rule should include more specific guidance concerning how to implement Section 1635.9 with respect to electronically stored records and, if so, what procedures are needed to ensure the confidentiality of genetic information stored as electronic records.

We are not experts in storage mechanisms for electronic records, but ensuring the confidentiality of genetic information—including spouses’ health information—stored as electronic records is critically important. As the EEOC notes, there have been increasingly frequent data breaches to electronically stored records (including a massive data breach of the federal government’s own electronically stored personnel records). We urge the Commission to consult with experts in the area of electronic data storage and to require specific protocols to maximize the safety of electronically stored genetic information. In any event, the Commission should understand that even with good electronic data storage practices, it is placing the confidentiality of individuals’ health information at serious risk.

D. The EEOC Should Restrict Genetic Information Collected by Workplace Wellness Programs to the Minimum Necessary to Directly Support Specific Wellness Activities and Interventions

The proposed rule solicits feedback on whether workplace wellness programs’ collection of genetic information should be restricted to only the minimum necessary to directly support the specific wellness activities, interventions and advice provided through the program. We believe this protection is absolutely necessary to protect the confidentiality of individuals’ genetic information and GINA’s narrow wellness program exception requires it. For this protection to have any meaning, however, the activities, interventions, and advice provided by wellness programs must be something more than simply collecting genetic information and/or informing people of what their information says. They must offer activities, interventions and advice to address any risks identified; otherwise they exist solely for the benefit of the employer and wellness provider, and are not providing health or genetic “services” to individuals as required by the statute.

E. The Final Rule Should Not Allow Inducements in Wellness Programs Outside of a Group Health Plan

The proposed rule solicits feedback on the extent to which the GINA regulations should allow inducements as part of wellness programs offered outside of a group health plan or group health insurance coverage.

According to the Kaiser Family Foundation, nearly half of large employer wellness programs – and more than half of very large employer wellness programs (those with more than 5000
workers) say they are offered outside of the group health plan. The Commission’s rationale for its proposed reading of GINA’s wellness program provisions as applied to spouses’ health information is an asserted need to “balance” GINA’s goals with the goals of the ACA/HIPAA to promote participation in wellness programs. For wellness programs outside of group health plans, there is no need to conform GINA to the ACA and HIPAA, as the relevant provisions of those laws apply only to group health plans.

F. Ensuring that Wellness Programs Are Designed to Promote Health and Do Not Operate to Shift Costs to Employees with Health Impairments or Stigmatized Conditions

The proposed rule solicits feedback on practices that ensure that employer-sponsored wellness programs are designed to promote health and do not operate to shift costs to employees with health impairments or stigmatized conditions. We point the EEOC to the findings of the RAND study sponsored by the Departments of Labor and HHS. This study found that well designed wellness programs succeed in promoting employee participation without the use of incentives. The study notes that comprehensive programs with genuine corporate and manager engagement in wellness and commitment to monitoring and evaluating programs tend to succeed. By contrast, limited programs, such as HRA-only programs, tend not to inspire participation without use of incentives and tend not to reduce costs or improve health.17

G. Ensuring that Spouses’ Current Health Information is Protected from Disclosure

The proposed rule solicits feedback concerning best practices or procedural safeguards to ensure that information about spouses’ current health status is protected from disclosure. If the EEOC adopts the rule as proposed, it will necessarily permit unwanted disclosures of spouses’ health information, but at a minimum, it should include the following protections.

To protect against employment discrimination based on concerns about spouses’ health care costs, the rule should include a requirement that information obtained by an employee health program, through its medical inquiries or exams, regarding the medical information or history of an employee’s spouse may only be collected or received by the employer in aggregate terms that do not disclose, or are not reasonably likely to disclose, the identity of any employee’s spouse. The rule should also require that spousal medical information from health risk assessments is not gathered on or stored on workplace computers or servers, or in paper files kept in the workplace. The EEOC should require that wellness marketing and other communications are not transmitted through work email, intranet, postal mail or telephones. And the EEOC should require the steps


described in its Interpretive Guidance of its ADA rule concerning medical inquiries, see Appendix to Part 1630 regarding Section 1630.14(d)(4)-(6), including that employers adopt clear privacy policies and train employees to protect private information; not allow employees who have access to coworkers’ spouses’ medical information to make employment decisions impacting those coworkers; and encrypt electronically-stored medical information.

To limit unwanted disclosures of spousal health information to third parties, the rule should prohibit wellness programs from seeking waivers of privacy rights with respect to spouses’ medical information furnished where employees are penalized for not providing this information. Currently, many wellness programs’ online health risk assessments require an automatic waiver of HIPAA and other privacy rights by anyone completing those assessments; this practice should not be permitted under the GINA rule.

Finally, the rule should require employers to grant waivers of inducements for the provision of spouses’ health information where necessary to ensure equal opportunity in the wellness program. For example, for many individuals, including those with eating disorders, wellness programs are not only ill-suited to meet their health needs but cause harm.

Sincerely,

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