The Unexpected Virtue of Congressional Ignorance

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Bradley A. Areheart & Jessica L. Roberts, GINA, Big Data, and the Future of Employee Privacy, 128 **Yale L. J.** 710 (2019).

When enacted in 2008 at the end of the Bush Administration, the Genetic Information Nondiscrimination Act (GINA) seemed like it had come from the future. Although the hard-won result of over a decade of advocacy by Rep. Louise Slaughter of New York, GINA addressed a problem that seemed more hypothetical than real. Genetic testing had been around for a while, introduced to the public in part through the O.J. Simpson trial. It seemed unlikely, though, that employers or insurers would not only secure DNA testing but then use it to discriminate on the basis of genetic difference. Yes, it made sense as a plot for a science-fiction movie like *Gattaca*, but not as a depiction of current reality.

This assessment is largely borne out in the empirical results in *GINA, Big Data, and the Future of Employment Privacy* by Bradley Areheart and Jessica Roberts. Examining GINA cases from federal courts during the statute's first decade of existence, Areheart and Roberts found a mere 48 unique GINA cases, only 26 of which involved terminations. Moreover, most plaintiffs failed to find relief, often losing because of fundamental flaws: they had voluntarily disclosed their genetic information; they could not prove the employer possessed the genetic information; or their information was not considered "genetic." In fact, the authors "uncovered no cases alleging discrimination based on genetic-test results." (P. 744.) The article makes a plausible case that GINA has been a failure—or, perhaps more charitably, addressed a nonexistent problem.

Most law review articles would stop there, having provided a solid sense of the litigation picture for a relatively new statute. But Areheart and Roberts flip the script by illuminating a completely alternative justification: namely, GINA as information privacy regulation. Rather than simply a nonentity as an antidiscrimination statute, GINA is instead a powerful deterrent against employer snooping into an employee's genetic background. Areheart and Roberts persuasively argue that the absence of GINA litigation is in fact evidence of GINA's success in staking out genetic information as a no-fly zone, and that the Act can be a model for other employee privacy protections. A statutory phoenix rises from the ashes!

It wasn't intended this way. Areheart and Roberts chronicle the history of the Act, one that was rooted in the ability of health insurers to identify and fence out riskier patients. When insurers were able to hike rates or deny coverage because of pre-existing conditions, exploring one's own genetics became a financially hazardous endeavor. People were passing up the opportunity to find out genetic predispositions to certain conditions and illnesses to avoid being labeled as a poor risk. And since employers were the source of health insurance coverage for a vast swath of Americans, they too might decide to terminate an employee or pass on hiring someone due to genetic danger signs. Congress stepped in to prevent this type of discrimination, even though the feared phenomenon had not really manifested itself in significant numbers.

Two years after the passage of GINA, the Affordable Care Act prohibited consideration of pre-existing conditions as part of health insurance coverage and rate-setting decisions. So one of GINA's big rationales was no longer in play. Predictably, the courts have not seen much in the way of GINA-related litigation based on employment discrimination. However, Areheart and Roberts have unearthed a hidden set of imperatives that GINA has placed on employers. The Act prohibits employers from seeking, obtaining, or possessing their employees' genetic information. That narrow but complete prohibition has carved out genetic information from the panoply of data that employers are otherwise free to collect. As Areheart and Roberts report, the few GINA cases that have been litigated "show that employers are

seeking information about their employees, and employees are pushing back." (P. 734.)

GINA's "unexpected second life as a privacy statute" (P. 755) is especially important in the employment context. The current state of privacy law has left workers largely exposed. Many assume that the Health Insurance Portability and Accountability Act (HIPAA) protects all health information, but the statute is much narrower in focus. It only applies to health care providers, health care clearinghouses, and health plans, and specifically exempts information within employee personnel files. The Americans with Disabilities Act (ADA) places restrictions on required medical examinations but has a number of exceptions. Although GINA's scope is also narrow, it is comprehensive in its protection of this information. Moreover, the definition of "genetic information" goes beyond the paradigmatic DNA test to include family medical history. This routine part of employee health fitness forms is now protected by GINA.

Beyond the ramifications for employee genetic privacy, Areheart and Roberts pull out larger implications from GINA's unexpected impact. They note that GINA's privacy provisions have a two-pronged effect: they protect the information itself and also prevent the employer from discriminating based on that information. In contrast, the Pregnancy Discrimination Act (PDA) does not prohibit employers from asking about an employee's pregnancy status—which leaves pregnant workers more vulnerable to discrimination. (P. 770.) The article acknowledges that there may be benefits from the sharing of genetic data between worker and firm that GINA forecloses. (Pp. 773-76.) But this loss may be the necessary expense to preserve the confidentiality of employees' genetic makeup in such an effective manner.

GINA's future remains to be written; Areheart and Roberts' empirical investigation shows only a small number of current cases, whatever the underlying theory. But their article tells an important story of how the original Congressional plan went awry—and nevertheless led to a surprising and potentially influential new way of protecting employee information. Given the dizzying accumulation of innovative and disturbing encroachments—from RFID chips to round-the-clock health and location monitoring—protecting workers from ever-mounting surveillance and dissection has become an imperative. Areheart and Roberts have staked a claim for GINA as a model for how employee privacy might be protected in other areas of their lives. Their article is a terrific contribution to our understanding of the future of employment.

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