

Predictive Health Information and Employment Discrimination under the ADA and GINA

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On the first page of my book, *Medical Screening and the Employee Health Cost Crisis*, I wrote:

Increasingly, “predictive screening” attempts to identify whether currently capable individuals are at risk of developing a medical impairment at some future time. This newer form of medical screening is greatly affected by technological advancements and is likely to be an increasingly important part of the employee selection process.¹

The book was published in 1989, before the Human Genome Project, precision medicine, polygenic risk scores, or big data predictive analytics. It was also before enactment of the Americans with Disabilities Act (ADA)(1990),² Health Insurance Portability and Accountability Act (HIPAA)(1996),³ Genetic Information Nondiscrimination Act (GINA) (2008),⁴ Affordable Care Act (ACA) (2010),⁵ and other laws to prevent health-based discrimination in employment, health insurance, or other aspects of daily life.

Although I had some sense of the emerging problem, I could not anticipate the scientific developments shaping health risk assessment in the twenty-first century or the complicated legal issues arising under legislation enacted before the latest scientific advances and constrained by political considerations. In this article, I revisit employer use of predictive health information and attempt to follow up on my earlier work in three ways: (1) updating the science of predictive health risk

assessment; (2) analyzing the legislative inadequacies evidenced in recent case law; and (3) proposing comprehensive solutions to the lack of antidiscrimination protection for individuals with an increased risk of future impairment.

Growth of Predictive Health Information

Assessing the current health status and likely future condition of patients have long been mainstays of medical practice, but the science of predicting health has been advanced greatly by two transformative technologies. First, the 2001 completion of a draft sequence of the human genome facilitated the study of genomic variation, including research using single nucleotide variants, genome-wide association studies (GWAS), genotype-phenotype associations, and other methods. Genomics also led to numerous other “omics” technologies that explore the dynamic functions and interactions of gene products, the gene-mediated effects of environmental exposures, and genetic variation beyond human DNA. Proteomics, transcriptomics, metabolomics, pharmacogenomics, toxicogenomics, epigenomics, and microbiomics are among dozens of omics fields of investigation.⁶ Individually and in combination, omics increasingly can aid fine-grained predictive assessments, diagnostics, monitoring, and eventually therapeutics.⁷

One of the newest predictive genomic technologies involves computing “polygenic risk scores.” Unlike Mendelian or monogenic disorders, more common complex conditions are the result of many genes with smaller effect size acting over time in

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combination with environmental factors.⁸ Based on data from GWAS and using statistical models derived from large samples, an individual's risk of certain diseases or ill health in general can be calculated and expressed as a polygenic risk score. The scores may have clinical utility in identifying individuals needing a heightened level of medical surveillance for specific conditions,⁹ such as Alzheimer's disease,¹⁰ coronary artery disease,¹¹ and obesity.¹² They also have unmis-

sion medicine research and practice, including health histories and vital statistics of family members, military service records, employment records, financial and consumer information, educational records, travel information and geo-location data, social media postings, and various governmental records.¹⁴ Although the significance of any single data point may not be apparent, the essence of big data analytics is developing algorithms to decipher unexpected asso-

HIPAA "covered entity"), it is subject to the HIPAA Privacy Rule.¹⁸ Contrary to common misconceptions, this does not mean that the information is well protected, because numerous exceptions to the Privacy Rule permit uses and disclosures of individually-identifiable health information without the knowledge or authorization of the individual.¹⁹ Third, individuals may be compelled to sign a HIPAA-compliant authorization to disclose extensive health information as a condition of applying for employment, insurance, or other government or commercial uses. There are at least 25 million such compelled disclosures each year in the United States.²⁰

Particularly as genetic research at a population level becomes increasingly prevalent, it is essential to develop normative frameworks. Ethical and legal questions, such as how to handle the likelihood of developing a disease based on genetic susceptibility that is highly variable, reflecting complex gene-gene and gene-environment interactions, will require the participation of the general public and the individuals, groups, and organizations that represent them.

Employer Use of Predictive Health Information

There are two main categories of predictive medical screening of workers: (1) screening to determine whether a prospective or current employee is predisposed to injury or illness from workplace exposures, such as toxic substances;²¹ and (2) screening to determine whether a prospective or current employee is predisposed to ordinary diseases of life, such as cancer or cardiovascular disease.²² In addition to legitimate concerns about the health and well-being of their employees, many employers have substantial financial motivation for not hiring or retaining employees who are likely to become ill in the future. These financial interests include decreased productivity, increased absenteeism, increased presenteeism,²³ increased use of short-term and long-term disability benefits, increased turnover (requiring recruitment and retraining costs), increased healthcare costs,²⁴ increased workers' compensation costs,²⁵ and possible liability costs for harms to customers or members of the public caused by ill employees.

takable significance for many entities, including employers, with a financial interest in an individual's future health.

A second development causing a substantial growth in predictive health risk assessment is the application of multi-factorial big data analytics to health care, especially precision medicine. As exemplified by the All of Us research program directed by the National Institutes of Health, a million or more volunteers in the United States will have whole genome sequencing, and their sequence data will be combined with health data from electronic health records (EHRs), biometric measures, biological and environmental monitoring, wearable devices, and mobile health apps.¹³ In theory, new associations and directions for research will emerge from this application of big data. Other types of health information also could be relevant to preci-

ciations or correlations in disparate datasets.¹⁵ The possible application of big data health analytics also goes beyond research to the clinic.¹⁶

Privacy and Security Concerns

The compilation of huge and diverse datasets of highly sensitive information raises significant concerns about privacy and security, regardless of whether the information leads to employment discrimination or other tangible harms.¹⁷ First, security issues may arise from lost or stolen mobile devices, hacking, or unauthorized uses of information by authorized users. Second, for individuals to obtain health benefits from health research using precision medicine, research records or other sources of nonclinical data would need to be integrated with individuals' EHRs maintained by health care providers. Once health information is under the control of a healthcare provider (a

Prospective and current employees who are well, but who have an increased risk of future illness, may be difficult to identify. Nevertheless, employers can obtain predictive health information about employees through various lawful means, including voluntary disclosures by employ-

ees via application forms, interviews, social media, and casual remarks to supervisors; disclosures by references and coworkers; results of employer-conducted medical examinations and health records generated or obtained at post-offer and periodic medical assessments; information disclosed in employee wellness programs; data generated by wearable devices and smartphone applications; Family and Medical Leave Act²⁶ and other leave applications; disability insurance claims; workers' compensation claims; and health insurance claims. Some employers also might be tempted to purchase employee health information from data brokers, reidentify deidentified employee health information, or engage in other dubious practices.²⁷

Once in possession of predictive health information employers could take actions adversely affecting prospective or current employees. Besides refusing to hire or terminating an individual, an employer might disclose an employee's health status to supervisors, managers, or other employees; reassign the employee; deny an employee's requested promotion, transfer, or change in working conditions or hours; increase monitoring of an employee; or pressure an employee to resign or retire. The lawfulness of any of these actions depends, in the first instance, on whether the individual is covered by an antidiscrimination law. As discussed in the following section, current laws do not apply to employer use of predictive health information, except for genetic information.

Future Risk of Illness under the ADA and GINA

Americans with Disabilities Act (ADA)

The ADA makes it unlawful for an employer to discriminate "against a qualified individual with a disability because of the disability of such individual in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment."²⁸ This broad language was adopted from the Rehabilitation

Act of 1973,²⁹ as was the ADA's three-part definition of disability. Under the ADA, as amended, a person with a disability is defined as an individual: "(1) [with] a physical or mental impairment that substantially limits one or more of the major life activities of the individual; (2) [with] a record of such an impairment; or (3) [who is] regarded as having such an impairment."³⁰ Thus, the ADA prohibits discrimination because of an individual's current impairment, past impairment, or "actual or perceived physical or mental impairment whether or not the impairment limits or is perceived to limit a major life activity."³¹ Despite the ADA's intent to provide broad coverage, the definition of disability does not mention a predisposition to or increased risk of a future impairment, nor is there any evidence the issue was considered by Congress.³²

Recent judicial decisions under the ADA have highlighted the lack of coverage for individuals who allege discrimination in employment because of predictive health information. In *Shell v. Burlington Northern Santa Fe Railroad Co.*,³³ the plaintiff successfully worked for 33 years in physically demanding positions at a railyard. When the ownership of the railyard changed hands, the plaintiff applied for employment with the successor employer as an intermodal equipment operator, another physically demanding position. At the required preplacement medical examination,³⁴ the plaintiff was measured as being 5'10" tall and weighing 331 pounds, giving him a body-mass index (BMI) of 47.5. The defendant railroad had a policy of refusing to hire individuals with a BMI over 40. Instead of rejecting him simply because of his obesity, however, the railroad said it considered him to be at a substantially higher risk of developing conditions such as sleep apnea, diabetes, and heart disease. Furthermore, it claimed that these conditions can have unpredictable onset, possibly resulting in sudden incapacitation, and thereby presenting serious threats to anyone at the railroad yard.³⁵

The United States District Court for the Northern District of Illinois

denied the defendant's motion for summary judgment, and the defendant appealed to the Seventh Circuit. Under the circuit's controlling precedent obesity alone is not a physical impairment under the ADA unless there is evidence that the individual's obesity is caused by an underlying physiological condition or disorder.³⁶ Consequently, the plaintiff argued that his "disability" consisted of the various conditions the defendant feared he could develop -- sleep apnea, diabetes, and heart disease. The Seventh Circuit summarized the key issue as "whether the ADA's 'regarded as' prong covers a situation where an employer views an applicant as at risk for developing a qualifying impairment in the future."³⁷

Using a linguistic interpretation, the court stated that the present tense used in the definition of "regarded as" — "having an impairment" — precludes its applicability to future impairments. "If the impairment does not yet exist, it can be neither actual nor perceived."³⁸ The court also cited recent decisions of the Eighth,³⁹ Ninth,⁴⁰ and Tenth⁴¹ Circuits for similar holdings. The court rejected the two arguments in the Equal Employment Opportunity Commission's (EEOC's) *amicus curiae* brief. First, the EEOC cited to its Compliance Manual, which provides that discrimination against an individual because of genetic susceptibility to cancer is covered under the "regarded as" prong of the definition of disability.⁴² The court held that this interpretation conflicts with the EEOC's Interpretive Guidance, which provides that the definition of disability does not include "characteristic predisposition to illness or disease."⁴³ The court said that because the example of genetic susceptibility to cancer is "unmoored from the ADA's text and in tension with other EEOC interpretive guidance, [] it lacks the power to persuade us away from the statute's unambiguous text."⁴⁴ Construing genetic predisposition as an exception to the general Interpretive Guidance would eliminate the seeming inconsistency, but not the court's concern about fidelity to the statutory language.

The EEOC's second argument relied on the ADA's overall purpose to combat "society's accumulated myths and fears about disability and disease."⁴⁵ The court acknowledged that the ADA Amendments Act of 2008 intended to have the definition of disability construed in favor of broad coverage, but the court said it could not adopt an interpretation in conflict with the statute's plain language.

Although no other circuit court decision has held that future health risk is covered under the ADA, there is a minority position. In *EEOC v. Rockwell International Corp.*,⁴⁶ the EEOC brought an action to challenge an employer's refusal to hire individuals who failed preplacement nerve conduction tests. The Seventh Circuit held that the individuals were not covered under the "regarded as" provision of the ADA. Judge Diane Wood dissented.

And it is not at all clear to me that as a matter of law the ADA permits an employer to refuse to hire a person who is fully qualified to perform certain work, simply because that individual might at some unspecified time in the future develop a physical or other disability that would render her unable at that later date to meet the employer's reasonable expectations. This smacks of exactly the kind of speculation and stereotyping that the statute was designed to combat.⁴⁷

Judge Wood is unquestionably correct about the legislative intent of the ADA, but it does not appear to be a promising strategy to wait for a favorable resolution by the Supreme Court or a change in sentiment by the circuit courts on the issue of ADA coverage of future risks.

Genetic Information Nondiscrimination Act (GINA)

Whereas the ADA has been construed as not applying to future impairments, GINA *only* applies to future impairments. As discussed below,

inconsistencies and gaps in coverage often characterize the nation's employment discrimination laws.⁴⁸ Title II of GINA prohibits discrimination in employment based on genetic information. "The term 'genetic information' means, with respect to any individual, information about – (i) such individual's genetic tests, (ii) the genetic tests of family members of such individual, and (iii) the manifestation of a disease or disorder in family members of such individual."⁴⁹ Notably, genetic information does not include information about the individual's own manifestation of a disease or disorder and therefore discrimination based on a genetic condition that has "manifested" is not prohibited by GINA.⁵⁰ The reason for this seemingly illogical exclusion is that Title I of GINA prohibits discrimination in health insurance, and the effect of prohibiting exclusions based on manifested conditions would be to prohibit health insurers from denying coverage based on an individual's preexisting condition. Congress was not prepared to enact such a ban in 2008 when it enacted GINA, but it did so in 2010 when it enacted the ACA.⁵¹

The "mirror-image" coverage provisions of the ADA and GINA would not be a problem if the composite picture was comprehensive coverage of genetic-related conditions, but that is not the case. GINA applies only to discrimination based on genetic information about a condition that has not manifested. By contrast, the ADA applies only to symptomatic individuals who have an impairment that constitutes a substantial limitation of a major life activity. Two gaps in coverage remain. First, individuals who have "manifested" a genetic-related condition that does not currently constitute a substantial limitation of a major life activity are not covered by either the ADA or GINA. This category of uncovered conditions is expanding because new technologies can identify biological changes earlier in the disease process by using, for example, biomarkers and endophenotypes indicative of subclinical expressions of genetic conditions.⁵² Second, asymptomatic

individuals who are at an increased risk of a non-genetic related impairment also are not covered by either the ADA or GINA.

The Illogic of the ADA and GINA

The employment discrimination provisions of the ADA were enacted to eliminate and redress pervasive discrimination against individuals with substantially limiting impairments. They were not enacted to prohibit *any* adverse treatment based on an individual's health status;⁵³ more comprehensive legislation banning all health-based discrimination undoubtedly would not have been enacted.⁵⁴ From a cost perspective, it is illogical to prohibit discrimination against individuals who require ongoing reasonable accommodation while permitting discrimination against individuals who have a temporary health condition that will last only a few days. Yet, from a civil rights perspective, it is reasonable to target the most entrenched, insidious, and devastating forms of discrimination against individuals with substantially limiting impairments. Thus, employers are required to hire individuals with disabilities, including bearing the costs of providing reasonable accommodations, unless doing so would constitute an "undue hardship."⁵⁵

Many parts of the employment title of GINA are seemingly illogical, starting with the law's intent to allay individuals' fears of genetic discrimination, despite the lack of confirmed instances of such discrimination.⁵⁶ GINA prohibits discrimination based on information about future impairments, precisely the kind of discrimination that the ADA has been held not to cover for non-genetic impairments. Giving greater legal protection to individuals discriminated against because of genetic information is a form of "genetic exceptionalism."⁵⁷ Although it is appropriate to have genetic-specific policies in limited circumstances,⁵⁸ there is no justification for maintaining or adopting more general policies based on genetic exceptionalism. The increased availability of detailed genomic information and the growing use of predictive risk assessment using non-genetic

information support the adoption of policies based on context.⁵⁹

GINA attempts to protect genetic privacy as well as to prohibit genetic discrimination.⁶⁰ Section 202 of GINA generally prohibits employers from requesting, requiring, or purchasing genetic information about an employee or a family member of an employee, except in limited circumstances. One circumstance, detailed in section 202(b)(5), permits an employer to acquire information for use in genetic monitoring of the biological effects of toxic substances in the workplace, but only if the employer provides written notice of the genetic monitoring to the employee; the employee provides written authorization; the employee is informed of individual monitoring results; and the employer receives only aggregate results that do not disclose the identity of employees.⁶¹ Employers, however, are not permitted to provide optional genetic testing at the preplacement stage, even with the same protections in place, so that prospective employees can learn whether they have a heightened risk if they are exposed to certain toxic substances in the workplace.⁶² Thus, GINA deprives prospective employees of the ability to obtain and act upon potentially valuable toxicogenomic information.⁶³

Toward Reasonable, Consistent Public Policy

Many individuals with disabilities who are currently covered by the ADA have illnesses likely to worsen over time, and therefore they will be unable to work in the future with or without reasonable accommodation. The ADA protects these individuals, notwithstanding their prognosis. In addition, an EEOC regulation provides that “[a]n impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active.”⁶⁴ Extending coverage to individuals who have a future health risk would be consistent with these other interpretations of the ADA.

Individuals with an increased health risk, currently not protected by the ADA, would be covered by the

ADA if they became symptomatic with an impairment that constitutes a substantial limitation of a major life activity.⁶⁵ It makes little sense that such individuals can be legally denied employment at a time when they are able to work, but when they become ill and are finally covered by the ADA, they might require accommodations or they might be unable to work at all.

Public policy should facilitate the employment of all individuals with the present ability to perform specific job-related tasks with or without reasonable accommodation and regardless of their future health risks. This position would be consistent with other federal antidiscrimination laws. For example, in 1978, the Pregnancy Discrimination Act (PDA) amended Title VII of the Civil Rights Act of 1964 to provide that pregnant women “shall be treated the same for all employment-related purposes” as other persons “not so affected but similar in their ability or inability to work.”⁶⁶ Even though a pregnant woman would likely take maternity leave at some time in the future she would be protected as long as she was currently able to perform job-related functions safely and efficiently.⁶⁷ In addition, the Age Discrimination in Employment Act (ADEA), as amended, prohibits discrimination in employment against individuals at least 40 years old,⁶⁸ regardless of their age or future health risks so long as they are currently able to perform job-related functions safely and efficiently.

By enacting the PDA, ADEA, ADA, and GINA, Congress recognized it was imposing additional costs on covered employers (and other entities and the public to the extent the costs are externalized), but believed it was necessary to provide employment opportunities to classes of individuals that have been subject to exclusionary policies and who have much to contribute to the economy and the nation. Extending coverage to individuals who are predicted to be at an increased risk of health problems would be consistent with these policies.

Moving Forward

Professor Sharona Hoffman has argued persuasively that Congress should broaden the ADA’s “regarded as” provision to include individuals who “are perceived as likely to develop physical or mental impairments in the future.”⁶⁹ Although this would be an important step, more comprehensive measures also should be enacted. According to the EEOC’s regulations, there is no duty to provide reasonable accommodation to an individual whose coverage is under the “regarded as” prong of the definition of an individual with a disability.⁷⁰ Nevertheless, many individuals at heightened risk of future illness would benefit from reasonable accommodations to reduce their risks, such as using respirators or other personal protective equipment when working with toxic substances, reducing certain physically demanding activities, or limiting exposure times in extreme environments (e.g., heat, cold, high altitude).⁷¹

If the ADA’s coverage is extended to individuals with future health risks, a question arises as to whether all future health risks should be covered regardless of their likely time of onset. For example, suppose an applicant seeks employment today, but there is medical evidence that the individual will only be able to work for a few months before becoming seriously ill. If the individual is seeking employment for a job with a long training period, it would be unreasonable to require the employer to hire and train the individual, only to have that person resign for health reasons before being able to perform the job.

In the ADA Amendments Act of 2008, Congress defined a “transitory impairment,” excluded from ADA coverage under the “regarded as” prong, as “an impairment with an actual or expected duration of 6 months or less.”⁷² Applying this standard to predictive health risks, an individual should be protected under the ADA’s “regarded as” prong if the individual is regarded as having a future health risk that would not manifest for at least six months. This extends protection of the ADA with-

Recent cases holding that ADA protections do not apply to individuals at increased risk of substantially limiting impairments illustrate the incongruity between, on the one hand, the ADA and GINA, and on the other hand, modern technologies that generate predictive health assessments. Genomics and other omics analyses, polygenic risk scoring, and big data health algorithms are expanding the number of individuals who could be subject to employment discrimination, but who have no protection under federal law. It is imperative to amend the ADA and GINA to advance the public policy goals of nondiscrimination in an age of rapid technological change.

out creating unreasonable burdens on employers.⁷³ Another way of limiting employer access to information about an individual's future health risks would be to amend the ADA to provide that all medical examinations and inquiries after a conditional offer of employment must be job-related and consistent with business necessity,⁷⁴ the same standard applicable to current employees.⁷⁵

The other main federal statute directly applicable to future health risk, GINA, is inadequate and outdated. It should be restructured to broaden and update the definition of genetic information;⁷⁶ extend coverage beyond health insurance and employment to other important areas, such as life, disability, and long-term care insurance;⁷⁷ and permit the beneficial uses of genetic information to increase protection for sensitive employees and allow them to choose whether to work in personally hazardous environments.⁷⁸ Other laws beyond the scope of this article also should be amended to advance important public policies.⁷⁹

Conclusion

Recent cases holding that ADA protections do not apply to individuals at

increased risk of substantially limiting impairments illustrate the incongruity between, on the one hand, the ADA and GINA, and on the other hand, modern technologies that generate predictive health assessments. Genomics and other omics analyses, polygenic risk scoring, and big data health algorithms are expanding the number of individuals who could be subject to employment discrimination, but who have no protection under federal law. It is imperative to amend the ADA and GINA to advance the public policy goals of nondiscrimination in an age of rapid technological change.

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Note

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References

1. M.A. Rothstein, *Medical Screening and the Employee Health Cost Crisis* (Washington, DC: BNA Books, 1989): at 1.
2. 42 U.S.C. §§ 12101-12213.
3. 42 U.S.C. §§ 300gg-300gg-2.
4. 42 U.S.C. § 2000ff.
5. Patient Protection and Affordable Care Act, as amended by the Health Care

and Education Reconciliation Act, Pub. L. No. 111-148, 124 Stat. 119-1025 (2010).

6. Wikipedia, List of Omics Topics in Biology, available at <en.wikipedia.org/wiki/List_of_omics_topics_in_biology> (last visited January 20, 2020). See Y. Hasin, M. Seldin, and A. Lusic, "Multi-omics Approaches to Disease," *Genome Biology* (2017): 18:83, DOI 10.1186/s13059-017-1215-1; E.C. Nice, "Challenges for Omics Technologies in the Implementation of Personalized Medicine," *Expert Review of Precision Medicine and Drug Development* 3, no. 4 (2018): 229-231.
7. Omics is increasingly useful for many diseases, including asthma, B.M. Donovan et al., "The Current States of Omics Technologies in the Clinical Management of Asthma and Allergic Diseases," *Annals of Allergy, Asthma & Immunology* 123, no. 6 (2019): 550-557; breast cancer, G. Judes et al., "High-Throughput 'Omics' Technologies: New Tools for Triple-Negative Breast Cancer," *Cancer Letters* 382, no. 1 (2016): 77-85; and hypertension, G. Currie and C. Delles, "The Future of 'Omics' in Hypertension," *Canadian Journal of Cardiology* 33, no. 5 (2017): 601-610.
8. L.P. Sugrue and R.S. Desikan, "What Are Polygenic Scores and Why Are They Important?" *Journal of the American Medical Association* 321, no. 18 (2019): 1820-1821.
9. A. Torkamani, N.E. Wineinger, and E.J. Topol, "The Personal and Clinical Utility of Polygenic Risk Scores," *Nature Reviews Genetics* 19, no. 9 (2018): 581-590. Current polygenic risk scores are much more accurate for individuals of European descent because of larger sample sizes. A.R. Martin et al., "Clinical Use of Current Polygenic Risk Scores May Exacerbate Health Disparities," *Nature Genetics* 51, no. 4 (2019): 584-591.
10. M.W. Logue et al., "Use of an Alzheimer's Polygenic Risk Score to Identify Mild Cognitive Impairment in Adults in their 50s," *Molecular Psychiatry* 24, no. 3 (2019): 421-430.
11. M. Inouye et al., "Genomic Risk Prediction of Coronary Artery Disease in 480,000 Adults: Implications for Primary Prevention," *Journal of the American College of Cardiology* 72, no. 16 (2018): 1883-1893. Compare J.D. Mosely et al., "Predictive Accuracy of a Polygenic Risk Score Compared with a Clinical Risk Score for Incident Coronary Heart Disease," *Journal of the American Medical Association* 323, no. 7 (2020): 627-635 (polygenic risk score was not better than conventional predictors) with J. Elliott et al., "Predictive Accuracy of a Polygenic Risk Score-Enhanced Prediction Model vs a Clinical Risk Score for Coronary Artery Disease," *Journal of the American Medical*

- Association* 323, no. 7 (2020): 636-645 (polygenic risk score when added to pooled cohort equations resulted in “significant, yet modest” improvement in predictive accuracy).
12. A. Torkamani and E. Topol, “Polygenic Risk Scores Expand to Obesity,” *Cell* 177, no. 3 (2019): 518-520.
 13. The All of Us Research Program Investigators, “The ‘All of Us’ Research Program,” *New England Journal of Medicine* 381, no. 7 (2019): 668-676.
 14. M.A. Rothstein, “Structural Challenges of Precision Medicine,” *Journal of Law, Medicine & Ethics* 45, no. 1 (2017): 274-279, 276.
 15. M.A. Rothstein, “Ethical Issues in Big Data Health Research,” *Journal of Law, Medicine & Ethics* 43, no. 2 (2015): 425-429. See also B.A. Areheart and J.L. Roberts, “GINA, Big Data, and the Future of Employee Privacy,” *Yale Law Journal* 128, no. 3 (2019): 710-790.
 16. See generally I.G. Cohen et al., “The Legal and Ethical Concerns that Arise from Using Complex Predictive Analytics in Health Care,” *Health Affairs* 33, no. 7 (2014): 1139-1147; E.J. Topol, “High-Performance Medicine: The Convergence of Human and Artificial Intelligence,” *Nature Medicine* 25, no. 1 (2019): 44-56. For an article asserting the need to regulate this technology, see S. Hoffman, “What Genetic Testing Teaches about Predictive Analytics Regulation,” *North Carolina Law Review* 98, no. 1 (2019): 123-163.
 17. M.A. Rothstein, “Some Lingering Concerns about the Precision Medicine Initiative,” *Journal of Law, Medicine & Ethics* 44, no. 3 (2016): 520-526, 522. 45 C.F.R. Parts 160, 164.
 18. See M.A. Rothstein, “The End of the HIPAA Privacy Rule?” *Journal of Law, Medicine & Ethics* 44, no. 2 (2016): 352-358. See also M.A. Rothstein and S.A. Tovino, “Privacy Risks of Interoperable Electronic Health Records: Segmentation of Sensitive Information Will Help,” *Journal of Law, Medicine & Ethics* 47, no. 4 (2019): 771-777.
 19. M.A. Rothstein and M.K. Talbott, “Compelled Disclosures of Health Records: Updated Estimates,” *Journal of Law, Medicine & Ethics* 45, no. 1 (2017): 149-155.
 20. See M.A. Rothstein, *Medical Screening of Workers* (Washington, DC: BNA Books, 1984).
 21. See Rothstein, *supra* note 1.
 22. Presenteeism refers to a situation where employees are physically at work, but they are unable to perform their duties adequately because of illness or injury. See P. Hemp, “Presenteeism: At Work – But Out of It,” *Harvard Business Review* 82, no. 10 (2004): 49-58.
 23. Discrimination against individuals because of increased health care costs would violate the Affordable Care Act and the Americans with Disabilities Act. See J.L. Roberts, “Healthism and the Law of Employment Discrimination,” *Iowa Law Review* 99, no. 2 (2014): 571-635.
 24. Impaired employees are more likely to be involved in accidents causing injury to themselves or co-employees.
 25. 29 U.S.C. §§ 2601-2654.
 26. See S. Hoffman, “Big Data and the Americans with Disabilities Act,” *Hastings Law Journal* 68, no. 4 (2017): 777-793, 780-784.
 27. 42 U.S.C. § 12112(a).
 28. 29 U.S.C. §§ 701-796. The Rehabilitation Act applies to federal agencies (§ 501), federal government contractors (§ 503), and recipients of federal financial assistance (§ 504).
 29. 42 U.S.C. § 12102(2).
 30. ADA Amendments Act of 2008, § 4(a)(3)(A), amending ADA § 3(2)(C), 42 U.S.C. § 12102. See generally S. Befort, “Let’s Try This Again: The ADA Amendments Act of 2008 Attempts to Reinvigorate the ‘Regarded As’ Prong of the Statutory Definition of Disability,” *Utah Law Review* 2010 (2010): 993-1028.
 31. For a discussion of the ADA’s legislative history, see L.J. Davis, *Enabling Acts: The Hidden Story of How the Americans with Disabilities Act Gave the Largest US Minority Its Rights* (Boston, MA: Beacon Press, 2015).
 32. 941 F.3d 331 (7th Cir. 2019).
 33. See M.A. Rothstein, J. Roberts, and T.L. Guidotti, “Limiting Occupational Medical Examinations under the Americans with Disabilities Act and the Genetic Information Nondiscrimination Act,” *American Journal of Law & Medicine* 41, no. 4 (2015): 523-567 (2015) (discussing preplacement medical examinations).
 34. Although the defendant’s rationale clearly implicates the “direct threat” language of the ADA, see *Chevron U.S.A. Inc. v. Echazabal*, 536 U.S. 73 (2002), it is not clear that medical evidence would substantiate the fear of sudden incapacitation. Nevertheless, other cases have decided the “future risk” issue without the need to assert sudden incapacitation. See the cases cited in notes 39-40 *infra*.
 35. *Richardson v. Chicago Transit Authority*, 926 F.3d 881 (7th Cir. 2019). ADA coverage for obesity remains unresolved, but some state disability discrimination statutes clearly apply to individuals with obesity. See *Taylor v. Burlington Northern Railroad Holdings, Inc.*, 444 P.3d 606, 608 (Wash. 2019) (“obesity always qualifies as an impairment” under Washington law).
 36. *Shell v. Burlington Northern Santa Fe Railroad Co.*, 941 F.3d 331, 335-336 (7th Cir. 2019).
 37. *Id.* at 336.
 38. *Morriss v. BNSF Railway Co.*, 817 F.3d 1104, 1113 (8th Cir. 2016).
 39. *EEOC v. BNSF Railway Co.*, 902 F.3d 916, 923 (9th Cir. 2018).
 40. *Adair v. City of Muskogee*, 823 F.3d 1297, 1306 (10th Cir. 2016). See also *EEOC v. STME, LLC*, 938 F.3d 1305 (11th Cir. 2019) (J. Jordan, concurring). In *Darby v. Childvine, Inc.*, 964 F.3d 441 (6th Cir. 2020) (BRCA1 mutation and precancerous cells qualified as a disability under the ADA).
 41. EEOC Compliance Manual § 902.8, 2009 WL 4782113. This interpretation was adopted in 1995, the year an earlier version of GINA was first introduced in Congress and 13 years before GINA’s enactment. In the interest of full disclosure, in 1995 I served as Special Legislative Counsel to NIH and worked with the late EEOC Commissioner Paul Steven Miller and his staff to develop this interpretation.
 42. 29 C.F.R. Pt. 1630, App. § 1630.2(h).
 43. *Shell*, 941 F.3d at 337.
 44. *School Board of Nassau County, Florida v. Arline*, 480 U.S. 273, 284 (1987) (case decided under the Rehabilitation Act has been cited with approval in ADA cases).
 45. 243 F.3d 1012 (7th Cir. 2001).
 46. *Id.* at 1019 (Wood, J., dissenting).
 47. See M.A. Rothstein, “GINA, the ADA, and Genetic Discrimination in Employment,” *Journal of Law, Medicine & Ethics* 36, no. 4 (2008): 837-840 (arguing that gaps remain in the coverage of genetic-related impairments).
 48. 42 U.S.C. § 2000ff (4)(A).
 49. See A.E.R. Prince and B.E. Berkman, “When Does an Illness Begin: Genetic Discrimination and Disease Manifestation,” *Journal of Law, Medicine & Ethics* 40, no. 3 (2012): 655-664.
 50. See *supra* note 5.
 51. See *supra* note 48 (discussing gaps in coverage of GINA and the ADA).
 52. See generally J.L. Roberts and E. Weeks, *Healthism: Health-Status Discrimination and the Law* (New York, NY: Cambridge University Press, 2018) (discussing health-status discrimination in various contexts).
 53. See L. Rothstein, “Would the ADA Pass Today?: Disability Rights in an Age of Partisan Polarization,” *Saint Louis Journal of Health Law and Policy* 12, no. 2 (2019): 271-309.
 54. 42 U.S.C. § 12112(b)(5)(A); 29 C.F.R. § 1630.2(p).
 55. GINA was enacted so that individuals would not be reluctant to undergo genetic testing, participate in genetic research, or avail themselves of genetic services. GINA § 2(5), 42 U.S.C. § 2000ff note. See J.L. Roberts, “Preempting Discrimination: Lessons from the Genetic Information Nondiscrimination Act,” *Vanderbilt Law Review* 63, no. 2 (2010): 439-490.
 56. See T.E. Murray, “Genetic Exceptionalism and ‘Future Diaries’: Is Genetic Information Different from Other Medical Information?” in M.A. Roth-

- stein, ed., *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* (New Haven, CT: Yale University Press, 1997): 60-73; M.A. Rothstein, "Genetic Exceptionalism and Legislative Pragmatism," *Hastings Center Report* 35, no. 4 (2005): 27-33.
58. See J.P. Evans, W. Burke, and M. Khoury, "The Rules Remain the Same for Genomic Medicine: The Case Against 'Reverse Genetic Exceptionalism,'" *Genetics in Medicine* 12, no. 6 (2010): 342-343 (arguing that some special treatment of genetic information is warranted, such as genetic links to mental illness); M.A. Rothstein, "Time to End the Use of Genetic Test Results in Life Insurance Underwriting," *Journal of Law, Medicine & Ethics* 46, no. 3 (2018): 794-801 (arguing that banning genetic test results in life insurance underwriting will save lives because some genetically at-risk individuals decline beneficial testing and follow-up because they are worried about being excluded from life insurance coverage).
59. See N. Garrison et al., "Genomic Contextualism: Shifting the Rhetoric of Genetic Exceptionalism," *American Journal of Bioethics* 19, no. 1 (2019): 51-63 (arguing that as policy focus shifts from genetics to genomics, contextualism rather than exceptionalism is a better analytic approach).
60. See E.W. Clayton et al., "The Law of Genetic Privacy: Applications, Implications, and Limitations," *Journal of Law and the Biosciences* 6, no. 1 (2019): 1-36, 13-14, doi:10.1093/jlb/lsz007.
61. 42 U.S.C. § 2000ff-1(b)(5).
62. See M.A. Rothstein, "Genetics and the Workforce of the Next Hundred Years," *Columbia Business Law Review* 3, no. 3 (2000): 371-402 (proposing optional, confidential genetic testing and monitoring at both the preplacement and periodic stages of employment).
63. See M.A. Rothstein, "Legal Conceptions of Equality in the Genomic Age," *Law & Inequality* 25, no. 2 (2007): 429-463.
64. 29 C.F.R. § 1630.j(1)(vii).
65. See 29 C.F.R. § 1630.2(i) (defining major life activities).
66. 42 U.S.C. § 2000e(k).
67. Pregnant women are not entitled to reasonable accommodation under Title VII. *Young v. United Parcel Service, Inc.*, 135 S. Ct. 1338 (2015). See L.C. Hébert, "Disparate Impact and Pregnancy: Title VII's Other Accommodation Requirement," *American University Journal of Gender, Social Policy & the Law* 24, no. 1 (2015): 107-173.
68. 29 U.S.C. §§ 621-634. There is no duty of reasonable accommodation under the ADEA.
69. Hoffman, *supra* note 27, at 787.
70. 29 C.F.R. § 1630.2(o)(4).
71. Another way of broadening the coverage of the ADA to include future health risks while also providing for reasonable accommodation is to amend section 3(2) of the ADA by adding a fourth prong to the definition of disability: "(D) having a risk of a future physical or mental impairment that would substantially limit one or more of the major life activities of such individual, having a record of such a risk, or being regarded as having such a risk." See M.A. Rothstein, "Genetic Secrets: A Policy Framework," *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era*, M.A. Rothstein, ed. (New Haven: Yale University Press, 1997): 451-495, 477.
72. ADA Amendments Act of 2008, § 3(3)(B); 42 U.S.C. § 12102(3)(B).
73. This provision would not apply to seasonal or temporary employment, and thus an employer might be required to hire short-term employees with more immediate future impairments. On the other extreme, the six-month rule should be a presumption that can be rebutted by an employer upon a showing that the job requirement (e.g., one-year stay at a remote location) or training period (during which time the individual is unable to obtain certification or make significant contributions to the enterprise) extends beyond six months.
74. 42 U.S.C. § 12112(d)(3). The current provision does not limit the scope of medical examinations and inquiries, but if a conditional offer is withdrawn based on an "employment entrance examination," the exclusion must be job-related and consistent with business necessity. 42 U.S.C. § 12112(b)(6).
75. 42 U.S.C. § 12112(d)(4).
76. For example, GINA defines a genetic test as "an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes." 42 U.S.C. § 2000ff(7)(A). By focusing on "DNA and RNA" it omits epigenetic testing, see M.A. Rothstein, "Epigenetic Exceptionalism," *Journal of Law, Medicine & Ethics* 41, no. 3 (2013): 733-736, and by limiting coverage to "human" DNA and RNA, it excludes microbiome testing, see R. Schlaberg, "Microbiome Diagnostics," *Clinical Chemistry* 66, no. 1 (2020): 68-76.
77. See Clayton et al., *supra* note 60.
78. See Rothstein, *supra* note 62.
79. State laws prohibiting discrimination on the basis of disability or genetic information generally follow the framework of federal legislation and therefore ought to be amended in a similar fashion.