

Genetic Data and Civil Rights

Ifeoma Ajunwa*

Well-settled legal doctrines prohibit employers from discriminating against job applicants on the basis of physical characteristics such as race, sex, age, or disability. However, the full implications of genetic testing were inconceivable during the promulgation of those doctrines. Technological advancements and social trends in the interpretation of genetic testing create the need to re-examine the legal boundaries of the employer's power to make hiring decisions on the basis of genetic information. Although the Genetic Information Nondiscrimination Act ("GINA") took effect in 2009, there continues to be a steady increase in reported instances of genetic discrimination. This Article argues that Congress should strengthen GINA by adding a provision that authorizes a disparate impact cause of action. Currently, Section 208 of GINA explicitly prohibits disparate impact as a cause of action, but the section mandates the establishment of the Genetic Nondiscrimination Study Commission, which is charged with examining the developing science of genetics and will recommend to Congress whether to provide a disparate impact cause of action for GINA. This Article argues for the addition of a disparate impact clause for four reasons: (1) the addition of a disparate impact clause is in line with the precedent set by prior employment discrimination laws; (2) the EEOC has declared that proof of deliberate acquisition of genetic information is not necessary to establish a violation of GINA, and proof of intent to discriminate, likewise, should not be required to demonstrate genetic discrimination; (3) ease of access to genetic testing and the insecurity of genetic information has increased the likelihood of genetic discrimination in employment; and (4) real world instances of genetic testing have shown that facially neutral testing may result in racial disparities.

TABLE OF CONTENTS

<i>Introduction</i>	76
I. <i>The Origins of Genetic Discrimination</i>	79
A. <i>Genetic Essentialism</i>	80
B. <i>Genetic Determinism</i>	81
C. <i>Foucauldian Biopower and Genetic Coercion</i>	82
II. <i>Genetic Information Nondiscrimination Act</i>	84
A. <i>Background</i>	85
1. <i>The Rise of Genetic Explanations</i>	85
2. <i>The Threat of a Genetic Underclass</i>	87

* Assistant Professor of Law, University of the District of Columbia, David A. Clarke School of Law; Ph.D. Candidate, Department of Sociology, Columbia University; J.D., University of San Francisco School of Law, 2007. Many thanks to Alondra Nelson, Debbie Becher, Peggie Smith, William Robinson, and Lawrence Gostin for their helpful comments and suggestions. Prior versions of this article were presented at the O'Neil Institute for National and Global Health at Georgetown Law School and the Law and Society Association Conference in San Francisco, and I am grateful for the comments that I received there. Finally, I thank the staff and editors of the *Harvard Civil Rights-Civil Liberties Law Review*, and especially David Hotelling, Charlotte Lawson, and Victor Zapana, for meticulous cite-checking and insightful comments.

3. <i>GINA's Provisions and EEOC Enforcement</i>	91
B. <i>GINA's Limitations</i>	93
C. <i>Comparing GINA to Similar Employment Antidiscrimination Laws</i>	95
1. <i>Title VII</i>	96
2. <i>Age Discrimination in Employment Act</i>	97
3. <i>Americans with Disabilities Act</i>	98
III. <i>Support for a Disparate Impact Clause</i>	100
A. <i>A Disparate Impact Clause Follows Precedent</i>	100
B. <i>Like Deliberate Acquisition, Intent is Unnecessary</i>	101
C. <i>Easy Access to Genetic Testing Increases Chances for Discrimination</i>	103
D. <i>Facially Neutral Testing Causes Disparities</i>	105
IV. <i>Answering the Critics</i>	107
A. <i>Non-Special Special Class?</i>	108
B. <i>Antisubordination vs. Anticlassification</i>	109
C. <i>What about the Employer's Interests?</i>	110
1. <i>Bona Fide Occupational Qualification</i>	111
2. <i>Business Necessity</i>	112
<i>Conclusion</i>	112

INTRODUCTION

In February 2014, AOL CEO Tim Armstrong made headline news when he attributed his company's cut of spending on 401K plans to "two AOL-ers that had distressed babies."¹ Treatment for the babies' conditions had resulted in increased healthcare costs for the entire company.² Amid a hail of criticism, Armstrong apologized for his comments, but the implications of his words continue to echo. Imagine if Armstrong were able to determine which potential employees were at a greater risk of having "distressed babies." Should employers be permitted to use this information to exclude individuals from consideration for employment because they fear potential increased healthcare costs for their companies? With recent news of deals between the company 23andMe and companies such as Pfizer and

¹ *The Washington Post* reported:

"We had two AOL-ers that had distressed babies that were born that we paid a million dollars each to make sure those babies were OK in general," said Armstrong, according to a transcript first obtained by Capital New York. "And those are the things that add up into our benefits cost. So when we had the final decision about what benefits to cut because of the increased healthcare costs, we made the decision, and I made the decision, to basically change the 401(k) plan."

Jia Lynn Yang, *AOL Chief Cuts 401(k) Benefits, Blames Obamacare and Two "Distressed Babies,"* WASH. POST (Feb. 10, 2014), <http://www.washingtonpost.com/news/wonkblog/wp/2014/02/06/aol-chief-cuts-401k-benefits-blames-obamacare/2014>, archived at <https://perma.cc/839B-UQZL>.

² *Id.*

Genentech,³ involving the trading of access to large genetic databases for health research and with now-ubiquitous database breaches⁴ in the age of Big Data, we must secure greater legal protection against genetic discrimination.

Consider how often genetic discrimination plays out in the employment arena. In 2010, a few months after she underwent a double mastectomy, Pamela Fink, a resident of Connecticut, was fired.⁵ Fink was not ill. Like the actress Angelina Jolie later did,⁶ Fink chose an elective mastectomy after genetic testing revealed that she was a carrier of BRCA2,⁷ a mutated gene linked to breast cancer.⁸ According to Fink, she had been an exemplary employee, but she received her first negative review after her double mastectomy and the day before her reconstructive surgery.⁹ Although Fink is thought to be the first to file a complaint with the Equal Employment Opportunity Commission (“EEOC”) on the basis of genetic discrimination as prohibited under the Genetic Information Nondiscrimination Act of 2008 (“GINA”),¹⁰ there are many more stories like hers.¹¹ Before GINA was

³ See Matthew Herper, *Surprise! With \$60 Million Genentech Deal, 23andme Has a Business Plan*, FORBES (Jan. 6, 2015), <http://www.forbes.com/sites/matthewherper/2015/01/06/surprise-with-60-million-genentech-deal-23andme-has-a-business-plan/>, archived at <https://perma.cc/8UHP-J4M5>.

⁴ See Ifeoma Ajunwa, *Genetic Testing Meets Big Data: Tort and Contract Law Issues*, 75 OHIO ST. L.J. 1225, 1225–30 (2014) (detailing prevalence of data breaches, particularly for health data, and types of harms that could arise from such breaches).

⁵ Emily Friedman, *Pamela Fink Says She Was Fired After Getting a Double Mastectomy to Prevent Breast Cancer*, ABC NEWS (Apr. 30, 2010), <http://abcnews.go.com/Health/OnCallPlusBreastCancerNews/pamela-fink-fired-testing-positive-breast-cancer-gene/story?id=10510163>.

⁶ Jolie detailed her decision to undergo a preventative mastectomy in an opinion piece in *The New York Times*. See Angelina Jolie, *My Medical Choice*, N.Y. TIMES (May 14, 2013), <http://www.nytimes.com/2013/05/14/opinion/my-medical-choice.html>. Jolie also had her ovaries and uterus surgically removed. See Angelina Jolie Pitt, *Angelina Jolie Pitt: Diary of a Surgery*, N.Y. TIMES (Mar. 24, 2015), <http://www.nytimes.com/2015/03/24/opinion/angelina-jolie-pitt-diary-of-a-surgery.html>.

⁷ According to the National Cancer Institute,

BRCA1 and BRCA2 are human genes that produce tumor suppressor proteins. These proteins help repair damaged DNA and, therefore, play a role in ensuring the stability of the cell’s genetic material. When either of these genes is mutated, or altered, such that its protein product is not made or does not function correctly, DNA damage may not be repaired properly. As a result, cells are more likely to develop additional genetic alterations that can lead to cancer.

BRCA1 and BRCA2: Cancer Risk and Genetic Testing, NAT’L CANCER INST. (Apr. 1, 2015), <http://www.cancer.gov/cancertopics/factsheet/Risk/BRCA>, archived at <https://perma.cc/8WPG-S7JE>.

⁸ See Friedman, *supra* note 5.

⁹ See *id.*

¹⁰ Pub. L. No. 110-233, 122 Stat. 881 (codified as amended at 29 U.S.C. §§ 216 *et seq.* (2012); 42 U.S.C. §§ 1182 *et seq.* (2012)); see also Ewen Callaway, *First Genetic Discrimination Claim Since US Ban*, NEW SCIENTIST (Apr. 30, 2010, 10:44 AM), <https://www.newscientist.com/blogs/shortsharpscience/ewen-callaway/2010/04/>, archived at <https://perma.cc/M7T2-3Q5W>.

¹¹ See Friedman, *supra* note 5. Fink’s case did not proceed to trial; rather, it was settled out of court. See Gina Kolata, *‘Devious Defecator’ Case Tests Genetics Law*, N.Y. TIMES

signed into law in 2008, the Council for Responsible Genetics asserts, there had been as many as 500 cases of documented genetic discrimination.¹² The Council lists personal stories such as an applicant for a government job who was denied employment after medical and genetic tests had revealed that he was an asymptomatic carrier of Gaucher's Disease.¹³

Well-settled legal doctrines prohibit employers from discriminating against job applicants on the basis of physical characteristics such as race, sex, age, or disability.¹⁴ However, the full implications of genetic testing were inconceivable during the promulgation of those doctrines. Technological advancements and social trends in the interpretation of genetic testing create the need to re-examine the legal boundaries of the employer's power to make hiring decisions on the basis of genetic information. While genetic testing has benevolent uses (including the discovery of propensity for disease and the possible early intervention for deadly diseases such as Tay-Sachs disease,¹⁵ cystic fibrosis,¹⁶ and sickle cell anemia¹⁷), the public perception that genetic mutations inevitably lead to future disease opens the door for employment discrimination based on an employee's genetic information.¹⁸ Although GINA took effect in 2009, there has been an increase in reported instances of genetic discrimination in each following year. As part of its Enforcement and Litigation Statistics, the EEOC reported that it had received 201 complaints of genetic discrimination in 2010,¹⁹ 245 complaints in 2011,²⁰ 280 complaints in 2012, and 333 complaints in both 2013 and 2014.²¹ This statistical information suggests a trend towards increased occurrences of genetic discrimination. In fact, incidents of genetic discrimina-

(May 29, 2015), <http://www.nytimes.com/2015/06/02/health/devious-defecator-case-tests-genetics-law.html>.

¹² See *Genetic Testing, Privacy and Discrimination*, COUNCIL FOR RESPONSIBLE GENETICS, <http://www.councilforresponsiblegenetics.org/Projects/PastProject.aspx?projectId=1>, archived at <https://perma.cc/E59R-EQ9Y> (last visited Jan. 18, 2016).

¹³ *Id.*

¹⁴ See *infra* Part II.C.

¹⁵ See *Tay-Sachs Disease*, GTR: GENETIC TESTING REGISTRY, <http://www.ncbi.nlm.nih.gov/gtr/conditions/C0039373/> (last visited Jan. 18, 2016).

¹⁶ See *Carrier Testing for CF*, CYSTIC FIBROSIS FOUND., <https://www.cff.org/What-is-CF/Testing/Carrier-Testing-for-CF/>, archived at <https://perma.cc/2H98-ZQ7D> (last visited Jan. 18, 2016).

¹⁷ See *Sickle Cell Disease*, GENETICS HOME REFERENCE, <http://ghr.nlm.nih.gov/condition/sickle-cell-disease>, archived at <https://perma.cc/SY5X-VTTP> (last visited Jan. 18, 2016).

¹⁸ See *infra* Parts I.A–B; see also *id.* (describing the public perception as genetic essentialism and determinism).

¹⁹ *Charge Statistics FY 1997 through FY 2014*, U.S. EQUAL EMP'T OPPORTUNITY COMM'N, <http://eeoc.gov/eeoc/statistics/enforcement/charges.cfm>, archived at <https://perma.cc/YJ4P-6Z9J> (last visited Jan. 18, 2016).

²⁰ *Id.*

²¹ *Genetic Information Non-Discrimination Act Charges (includes concurrent charges with Title VII, ADEA, ADA, and EPA) FY 2010 – 2014*, U.S. EQUAL EMP'T OPPORTUNITY COMM'N, <http://www.eeoc.gov/eeoc/statistics/enforcement/genetic.cfm>, archived at <https://perma.cc/Y7GL-URV7> (last visited Jan. 18, 2016).

tion may be underreported because the public remains relatively ignorant of the law and of its applications.²²

This Article argues that GINA has been inadequate in preventing employment discrimination and that further action—specifically, the creation of a disparate impact cause of action—is necessary to fulfill the law’s objectives. Part I discusses both the increased significance afforded genetic information and the potential for abuse. Part II provides the background for GINA and analyzes relevant sections of the law, while contrasting it to earlier legislation enacted to check employment discrimination. Part III provides four arguments in favor of a disparate impact clause: (1) the addition of a disparate impact clause is in line with the precedent set by prior employment discrimination laws; (2) the EEOC has declared that proof of deliberate acquisition of genetic information is not necessary to establish a violation of GINA, and, similarly, proof of intent to discriminate should not be required to demonstrate genetic discrimination; (3) ease of access to genetic testing and the insecurity of genetic information has increased the likelihood of genetic discrimination in employment; and (4) real world instances of genetic testing have shown that facially neutral testing may result in racial disparities. Finally, Part IV addresses three anticipated criticisms.

I. THE ORIGINS OF GENETIC DISCRIMINATION

Genetic discrimination is the result of underlying sociological phenomena such as technological advances in the detection of genetic mutations and their links to genetic disease, and social beliefs regarding the probative value of genetic information. The relationship between the presumed agency afforded by genetic testing and the Foucauldian concept of *biopower*²³—a concept that both explains the growing prevalence of genetic testing and bolsters the argument that the State holds a responsibility to further delineate boundaries for an employer’s use of genetic information—further illuminates the origins of genetic discrimination.

²² U.S. Representative Louise Slaughter, who supported GINA, recently wrote:

Despite the fact that Congress passed GINA in 2008, a nationally representative survey from 2011 indicated that fewer than one in five Americans (16%) are aware this law exists. Coupled with the observation that Americans are increasingly concerned about how their genetic information is stored and accessed, this would indicate that lack of understanding is not due to lack of interest. Surprisingly, even among physicians, a staggering [81% of Americans] are not familiar with GINA protections.

Rep. Louise Slaughter, *Genetic Information Non-Discrimination Act*, 50 HARV. J. ON LEGIS. 41, 62–63 (2013).

²³ See *infra* Part I.C.

A. *Genetic Essentialism*

Genetic discrimination primarily stems from genetic essentialism, that is, “a reductionist view of human beings as essentially consisting of their genes.”²⁴ The National Institute of Health describes genetic discrimination as occurring “when people are treated differently by their employer or insurance company because they have a gene mutation that causes or increases the risk of an inherited disorder.”²⁵ Other scholars have defined genetic discrimination as circumstances in which “an individual is subjected to negative treatment, not as a result of the individual’s physical manifestation of disease or disability, but solely because of the individual’s genetic composition.”²⁶

In *The DNA Mystique*, Dorothy Nelkin and M. Susan Lindee provide a compelling overview of the increased importance ascribed to DNA and the pervasiveness of genetic testing in American social life.²⁷ Other contemporary popular media offer a glimpse of the social reification of genetic testing and the information such testing provides. For example, the catchphrase “You are NOT the father” has been passed on to the public by the melodramatic television program *Maury*, in which genetic tests to prove paternity are commonplace.²⁸ Criminal-investigation television shows such as *CSI* and *Law & Order* have inculcated within American society an acceptance of DNA as the ultimate sleuth, manifested as the molecular Sherlock Holmes who always and accurately determines “whodunnit.” Moreover, from the headline-making news of the Innocence Project, the public has come to view DNA as the final truth teller, with the power to exonerate and overturn wrongful convictions and to save the lives of those falsely accused.²⁹ It is not surprising, then, that the public highly favors genetic testing for the discovery of predisposition to diseases and other medical conditions and that the majority of the public would personally undergo genetic testing to detect propensity for genetic disease.³⁰

²⁴ AUSTL. L. REFORM COMM’N, ESSENTIALLY YOURS: THE PROTECTION OF HUMAN GENETIC INFORMATION IN AUSTRALIA § 3.65 (May 30, 2003), <http://www.alrc.gov.au/publications/3-coming-terms-genetic-information/dangers-%E2%80%98genetic-essentialism%E2%80%99>, archived at <https://perma.cc/R63M-DBTJ>.

²⁵ *What is Genetic Discrimination?*, GENETICS HOME REFERENCE (Nov. 14, 2014), <http://ghr.nlm.nih.gov/handbook/testing/discrimination>, archived at <http://perma.cc/WLE9-BFSJ>. In a prior Article, I argue for a re-definition of genetic discrimination that takes into account personalized medicine and that stresses the negative treatment that constitutes genetic discrimination. See Ajunwa, *supra* note 4, at 1235.

²⁶ Ajunwa, *supra* note 4, at 1235.

²⁷ DOROTHY NELKIN & M. SUSAN LINDEE, *THE DNA MYSTIQUE: THE GENE AS A CULTURAL ICON* 198 (1996); see also AUSTL. L. REFORM COMM’N, *supra* note 24, at § 3.72.

²⁸ See generally *Maury* (NBC Universal).

²⁹ THE INNOCENCE PROJECT, <http://www.innocenceproject.org/>, archived at <https://perma.cc/S6BH-FGT9> (last visited Jan. 18, 2016).

³⁰ Celeste M. Condit, *Public Attitudes and Beliefs About Genetics*, 11 ANNU. REV. GENOM. HUMAN GENET. 339, 346 (2010).

The credence given to genetic testing as a preventive measure for heritable diseases is evidenced by the fact that, in the early 1980s over 310,000 Jews volunteered for genetic screening for Tay-Sachs disease,³¹ and that a major endeavor of the Black Panther Party was the establishment of clinics where African Americans could be tested for the sickle cell trait.³² The fact that these two populations with ample reason³³ to be leery of medical tests would willingly subject their genetic material to examination speaks powerfully to the trust and authority now accorded genetic testing. Currently, all 50 states and the District of Columbia mandate newborn testing for 21 or more common disorders.³⁴ Finally, most pregnant women, particularly those of advanced maternal age, now feel social pressure to undergo amniocentesis, during which the unborn child is tested for genetic abnormalities such as those signaling Down Syndrome.³⁵

B. Genetic Determinism

Popular belief in genetic determinism is another reason why genetic information might be employed for discriminatory purposes. “Genetic determinism” is the belief that human health and behavior are predetermined by a person’s genetic profile and that “personal traits are predictable and permanent, determined at conception, ‘hard-wired’ into the human constitution.”³⁶ Genetic determinism derives from the phenomenon of the lay public acquiescing to an over-reliance on genetic information without fully comprehending its complexity. Many do not clearly understand that both genetic and environmental factors cause diseases,³⁷ and therefore, they believe that the presence of a genetic probability for a disease means the certainty of developing the disease.³⁸ The lay public also brings to bear its own social experiences in estimating probabilities or predicting outcomes, resulting in prejudiced or inaccurate conclusions about the likelihood of disease.³⁹

³¹ TROY DUSTER, *BACKDOOR TO EUGENICS* 46 (2d ed. 2003).

³² ALONDRA NELSON, *BODY AND SOUL* 90, 115–16 (2011). This development is particularly interesting given that African Americans had previously perceived genetic testing as a weapon of genocide.

³³ See, e.g., Dorothy E. Roberts, *The Nature of Blacks’ Skepticism About Genetic Testing*, 27 SETON HALL L. REV. 971, 971–72 (1997).

³⁴ See Roni Caryn Rabin, *Screening for Rare Genetic Disorders Now Routine in Newborns*, N.Y. TIMES (Feb. 18, 2009), <http://www.nytimes.com/2009/02/19/health/18screening.html>.

³⁵ MARSHA SAXTON, *Disability Rights and Selective Abortion*, in *ABORTION WARS* 381 (Rickie Solinger ed., 1998).

³⁶ Rochelle Cooper Dreyfuss & Dorothy Nelkin, *The Jurisprudence of Genetics*, 45 VAND. L. REV. 313, 316–21 (1992).

³⁷ Gabrielle Kohlmeier, *The Risky Business of Lifestyle Genetic Testing: Protecting Against Harmful Disclosure of Genetic Information*, 5 UCLA J.L. & TECH. 5, 11 (2007).

³⁸ Celeste M. Condit et al., *Believing in Both Genetic Determination and Behavioral Action: A Materialist Framework and Implications*, 18 PUB. UNDERST. SCI. 730, 731 (2009).

³⁹ Martin Richards & Maggie Ponder, *Lay Understanding of Genetics: A Test of Hypothesis*, 33 J. MED. GENET. 1032, 1032–36 (1996).

With these inaccurate filters for interpretation, information obtained from genetic testing easily may be exploited to discriminate against people based on the assumption, wrongful or not, of certain future illness. In 1997, Paul R. Billings, Deputy Chief of Staff for the San Jose Clinic of the Veterans Administration Palo Alto Health Care System and a clinical associate professor of medicine at Stanford University, raised an early alarm regarding the potential for the misuse of genetic information. Billings noted that “genetic discrimination was already occurring in insurance and employment settings and was reaching into the areas of adoption and military service.”⁴⁰ He added that “the storage of genetic information, in DNA banks like the one maintained by the Department of Defense, has already produced serious problems.”⁴¹ Billings also said that physicians, many of whom may be unaware of the dangers of genetic discrimination, are being asked to sanction the use of genetic tests as a “medical necessity”; Billings further observed that “this important change may increase the incidence of genetic discrimination.”⁴²

C. Foucauldian Biopower and Genetic Coercion

The essentialist view of genetic information has led to the ubiquity of genetic testing and the popular belief that such testing is always beneficial.⁴³ While some concerns exist about false negatives derived from genetic testing,⁴⁴ the prevailing belief is that genetic testing empowers individuals, conferring both the agency and the knowledge necessary to make crucial decisions about one’s health and the health of one’s future children.⁴⁵ However, with the increasing prevalence of genetic testing in American society, to whom does this power truly fall? This Article proffers that the combination of genetic essentialism and genetic determinism has led to “genetic coercion.”

Genetic coercion is the overwhelming economic, social, and moral compulsion to scrutinize and police the genome that an individual experiences. The economic compulsion derives from the lack of universal health-care, which renders life that is infirm or frail financially difficult to sustain. The social compulsion arises from the reification of genetic data as the key

⁴⁰ See *DNA Data Could Spawn ‘Genetic Underclass,’ Says VA Physician*, ONCOLOGY (Mar. 1, 1997), <http://www.cancernetwork.com/articles/dna-data-could-spawn-genetic-underclass-says-va-physician>, archived at <https://perma.cc/4M8C-YHE4>.

⁴¹ *Id.*

⁴² *Id.*

⁴³ Ajunwa, *supra* note 4, at 1227–28.

⁴⁴ *The Promise and Peril of Home Genetic Test Kits*, L.A. TIMES (Apr. 29, 2011), <http://articles.latimes.com/2011/apr/29/opinion/la-ed-genetic-20110429>, archived at <https://perma.cc/PJL6-VQGW>.

⁴⁵ See, e.g., *Benefits of Genetic Testing*, MY MYRIAD, <http://www.myriad.com/patients-families/genetic-testing-101/benefits-of-genetic-testing/>, archived at <https://perma.cc/UT9P-CED3> (last visited Jan. 18, 2016).

to cohesive social life such that non-conforming genes must be exposed. In the *DNA Mystique*, the authors illustrate the high social value accorded DNA information:

As the science of genetics has moved from the laboratory to mass culture, from professional journals to the television screen, the gene has been transformed. Instead of a piece of hereditary information, it has become *the key to human relationships* and the basis of family cohesion. Instead of a string of purines and pyrimidines, it has become the essence of identity and the source of social difference. Instead of an important molecule, it has become the *secular equivalent of the human soul*.⁴⁶

If DNA is the secular equivalent of the soul, then the moral compulsion is the notion of genetic testing as genetic hygiene for the betterment of society; that is, it is the moral duty of the individual to scrub from her germline deleterious genetic mutations that would be passed on to future generations.

The technology of genetic testing could be seen as affording *power* to act to control the *bios*, that is, the body, life, and procreation.⁴⁷ The *idée reçue* is that through genetic testing, an individual can, and should discover latent genetic mutations that point to a predilection toward certain diseases, and that through selective mating, the individual can control whether these mutations are passed on or forever eradicated from the bloodline.⁴⁸ However, the Foucauldian theory of *biopower* points to the concept of a third party appropriating the results of genetic testing and relieving the tested individual of the agency to act based on that information. Michel Foucault writes in *The History of Sexuality* that *biopower* is *governmental* power over other bodies through “an explosion of numerous and diverse techniques for achieving the subjugations of bodies and the control of populations.”⁴⁹ Therefore, *biopower* as applied to the phenomenon of genetic testing speaks to the government’s interest in fostering the health of its population and *regulating* new life, particularly when such life might be deemed burdensome to the state.⁵⁰ Foucault contrasts *biopower* with the more traditional modes of governmental power that were based on the threat of death from a sovereign.⁵¹ As Foucault notes, modern legitimate government employs *biopower* with an emphasis on the protection of life, rather than the menace of death.⁵²

⁴⁶ NELKIN & LINDEE, *supra* note 27, at 198 (emphasis added).

⁴⁷ 1 MICHEL FOUCAULT, *THE HISTORY OF SEXUALITY: THE WILL TO KNOWLEDGE* 140–41 (2008).

⁴⁸ It is important not to lose sight of the eugenic implications of genetic testing. See, e.g., DUSTER, *supra* note 31, at 95–97.

⁴⁹ FOUCAULT, *supra* note 47, at 140.

⁵⁰ *Id.* at 139.

⁵¹ *Id.* at 140.

⁵² *Id.* at 142.

Although the discourse on genetic testing is most frequently framed in positive terms as life promoting, it is also life limiting because it seeks to promote only certain kinds of life; that is, life that is deemed healthy and useful for society. Therefore, one conclusion is that by the *biopower* granted by genetic testing, the state makes the individual a willing agent of the state. As genetic testing is made ubiquitous and socially acceptable, the individual, through social and economic pressures, is now directly or indirectly called upon to police her own *bios*, resulting in genetic coercion.

That workplace wellness programs operate under the aegis of the government makes the employer an agent of the state in the support of *biopower*. Corporate wellness programs are designed to promote healthy behavior among workers by providing incentives (in the form of premium discounts, for example) for weight loss or smoking cessation.⁵³ The government, through the Patient Protection and Affordable Care Act (“ACA”), has instituted support for wellness programs and set guidelines for employer provided incentives for wellness programs, including the allowance for the collection of family medical histories that reveal indicators for genetic disease.⁵⁴ Given the established sociological phenomena of genetic essentialism, genetic determinism, and genetic coercion, the government must intervene with stronger protections against genetic discrimination.

II. GENETIC INFORMATION NONDISCRIMINATION ACT

GINA originated as a form of antidiscrimination legislation and has been touted as “the first civil rights bill of the 21st Century.”⁵⁵ Key GINA provisions include Title I, which prohibits genetic discrimination in health insurance coverage, and Title II, which prohibits genetic discrimination in employment. While GINA shares some similarities with other employment antidiscrimination laws, such as Title VII of the Civil Rights Act of 1964 (“Title VII”)⁵⁶ and the Americans with Disabilities Act of 1990 (“ADA”),⁵⁷ GINA lacks the latter statutes’ disparate impact liability provision.

⁵³ See *Questions and Answers about EEOC’s Notice of Proposed Rulemaking on Employer Wellness Programs*, U.S. EQUAL EMP’T OPPORTUNITY COMM’N, http://www.eeoc.gov/laws/regulations/qanda_nprm_wellness.cfm, archived at <https://perma.cc/2XA2-WDKN> (last visited Jan. 18, 2016).

⁵⁴ See *Incentives for Nondiscriminatory Wellness Programs in Group Health Plans*, U.S. DEP’T OF LABOR (Nov. 26, 2012), <http://webapps.dol.gov/FederalRegister/HtmlDisplay.aspx?DocId=26492&AgencyId=8&DocumentType=1>, archived at <https://perma.cc/DUE4-QNP3>; see also *The Affordable Care Act and Wellness Programs*, U.S. DEP’T OF LABOR (Nov. 26, 2012), <http://www.dol.gov/ebsa/newsroom/fswellnessprogram.html>, archived at <https://perma.cc/7M6J-Q64B>.

⁵⁵ See Ben Feller, *Bush Signs Anti-Discrimination Bill [GINA]*, ASSOCIATED PRESS (May 21, 2008), <http://www.geneticsandsociety.org/article.php?id=4096>, archived at <https://perma.cc/SLY6-GN2S>.

⁵⁶ Pub. L. No. 88-352, § 703, 78 Stat. 241, 255 (1964) (codified at 42 U.S.C. § 2000e-2 (2012)).

⁵⁷ Pub. L. No. 101-336, 104 Stat. 327 (codified at 42 U.S.C. §§ 12113 *et seq.* (2012)).

A. *Background*

GINA is the first federal law to address directly the issue of genetic discrimination. After several years of negotiations in Congress, President George W. Bush signed GINA into law on May 21, 2008.⁵⁸ GINA, which was enacted “[t]o prohibit discrimination on the basis of genetic information with respect to health insurance and employment,”⁵⁹ was a function of the many achievements in the field of genetics, such as the decoding of the human genome by the Human Genome Project and the creation and increased use of genomic medicine. As Congress has recognized, “[n]ew knowledge about genetics may allow for the development of better therapies that are more effective against disease or have fewer side effects than current treatments. These advances give rise to the potential misuse of genetic information to discriminate in health insurance and employment.”⁶⁰

1. *The Rise of Genetic Explanations*

The discovery of genetic factors for some diseases not only spurred the Human Genome Project (“HGP”) but also led to the presupposition of genetic explanations for other human conditions and opened the door to genetic discrimination. The HGP’s inception in 1990 was a significant development in human history, and it heralded the “genomic age.”⁶¹ Completed in 2003, the U.S. Department of Energy and the National Institutes of Health coordinated the HGP, with the participation of partners from the United Kingdom, Japan, France, Germany, China, and others. The HGP’s primary goals were to identify all the approximately 20,000–25,000 genes in human DNA and to determine sequences of the 3 billion chemical base pairs making up human DNA.⁶²

Prior to the completion of the HGP, many scholars had already started to document the “increasing appropriation of genetic explanations.”⁶³ In his groundbreaking book, *Backdoor to Eugenics*, Troy Duster discovers at least two waves in popular and scientific media in which researchers posited genetic explanations for various societal ills.⁶⁴ He notes that from the mid to late 1970s, there arose “a renewed claim to the genetic explanation of matters that the previous two decades had ‘laid to rest’ as social and environ-

⁵⁸ Pub. L. No. 110-233, 122 Stat. 881.

⁵⁹ *Id.*

⁶⁰ *Id.* at § 2(1), 122 Stat. at 882.

⁶¹ See *The Finished Human Genome – Wellcome To The Genomic Age*, THE SANGER INST. (Apr. 14, 2003), <http://www.sanger.ac.uk/news/view/2003-04-14-the-finished-human-genome-wellcome-to-the-genomic-age>, archived at <https://perma.cc/2FX6-HZPW>.

⁶² See *Human Genome Project*, HUMAN GENOME PROJECT INFORMATION ARCHIVE 1990–2003, http://www.ornl.gov/sci/techresources/Human_Genome/home.shtml, archived at <https://perma.cc/L7MX-U7HY> (last visited Jan. 18, 2016).

⁶³ DUSTER, *supra* note 31, at 95.

⁶⁴ *Id.*

mental.”⁶⁵ He finds evidence that from 1976 to 1982, there was a 231% increase in articles asserting “a genetic basis for crime, mental illness, intelligence, and alcoholism.”⁶⁶ This trend continued in the next decade. Duster notes that from 1983 to 1988, articles that attributed a genetic basis to crime appeared more than four times as frequently as the preceding decade.⁶⁷ Amid this clamor for the hereditary causes of societal problems such as crime, a genetic explanation for unemployment was also proffered. Duster notes that Richard Herrnstein, a Harvard psychologist, not only concurred with the proponents of the genetics of intelligence argument but also speculated that someday geneticists could find that “the tendency to be unemployed may run in the genes.”⁶⁸

Similarly, in *Fatal Invention*, Dorothy Roberts documents how genetic testing has served to calcify presumptions about race as a biological fact and how genetic testing has been employed to designate certain diseases as primarily linked to race.⁶⁹ Roberts notes that contrary to the notion that genomic research could transcend race, in actuality, race is frequently discussed as a “key—even essential—classification in the genetic research and testing that informs biocitizenship.”⁷⁰ She points to breast cancer and sickle cell disease as genetic diseases that have become siloed as belonging to a particular race or ethnic group resulting in, for example, at-risk black women not receiving breast cancer screening at the same rates as their equally at-risk white counterparts.⁷¹

Observing the growing phenomenon of reliance on genetic explanations for disease and other human conditions, lawmakers concerned about the potential for discrimination began to introduce bills to curb genetic discrimination. As early as 1995, Representative Louise Slaughter introduced the first piece of antidiscrimination legislation specifically designed to combat genetic discrimination.⁷² She prefaced the legislation on public support for genetic testing for research and health predictive purposes and on public fears, both imagined and realized, of genetic discrimination. In response to these growing ethical and social concerns, Congress passed the Genetic Information Nondiscrimination Act in 2008.⁷³ However, the final bill for GINA that was signed into law did not allow for disparate impact claims.⁷⁴ Some legal

⁶⁵ *Id.*

⁶⁶ *Id.*

⁶⁷ *Id.*

⁶⁸ *Id.* at 97.

⁶⁹ DOROTHY ROBERTS, *FATAL INVENTION: HOW SCIENCE, POLITICS, AND BIG BUSINESS RECREATE RACE IN THE TWENTY-FIRST CENTURY* 209–12 (2012).

⁷⁰ *Id.* at 210.

⁷¹ “White women were almost five times more likely to undergo BRCA1/2 counseling than African American women.” *Id.* at 210–11.

⁷² Slaughter, *supra* note 22, at 41.

⁷³ See Ajunwa, *supra* note 4, at 1240–41.

⁷⁴ See 42 U.S.C. §§ 2000ff-7(a)–(b) (stating that an allegation of “‘disparate impact’ . . . on the basis of genetic information does not establish a cause of action” under GINA); 29 C.F.R. § 1635.5(b) (2011); see also Jessica L. Roberts, *The Genetic Information Nondiscrimi-*

scholars have asserted that this departure from adding a disparate impact clause may reflect that, unlike Title VII or the ADA, GINA was not intended to address any specified protected class.⁷⁵

2. *The Threat of a Genetic Underclass*

The creation of a genetic underclass is a natural consequence of unchecked genetic discrimination in employment. Prior to the promulgation of GINA, the potential for the creation of an unemployable genetic underclass existed as a credible threat. A survey in Massachusetts in 2000 found over 580 people who had been turned down for jobs because of “flaws” discovered in their genes.⁷⁶ In addition, a 1996 nationwide survey found that 13% of respondents claimed that they or a member of their family had lost a job as a direct consequence of a genetic condition.⁷⁷ Examples included employers turning down people with a risk of heart disease or mental problems based on responses to a job test.⁷⁸

The structure of the American healthcare system is one that could enable the creation of an American “genetic underclass.” There is no universal healthcare in the United States. Therefore, the cost of treating or curing an inherited disease is often transferred to the employer, as most Americans rely on the health insurance obtained from employment as their means of access to necessary healthcare.⁷⁹ Previously, American law allowed for discrimination against unhealthy persons by health insurance providers, and this practice had become so ingrained in the health insurance industry that it became a legitimate business application of underwriting and risk-classification principles.⁸⁰ These principles reflected American individualistic attitudes “and a preference for voluntary action,”⁸¹ even as it pertains to health

nation Act As an Antidiscrimination Law, 86 NOTRE DAME L. REV. 597, 631 (2011). This may change in the future, as GINA requires that Congress establish a commission six years after the statute’s enactment “to review the developing science of genetics and to make recommendations to Congress regarding whether to provide a disparate impact cause of action under this Act.” 42 U.S.C. § 2000ff-7(b). As of the writing of this Article, Congress has yet to establish the commission as mandated by GINA.

⁷⁵ See Bradley A. Areheart, *GINA, Privacy, and Antisubordination*, 46 GA. L. REV. 705, 709 n.24 (2012).

⁷⁶ See Leo Lewis, *Job Testing May Create a Genetic Underclass*, THE INDEPENDENT (Oct. 29, 2000), <http://www.independent.co.uk/news/business/news/job-testing-may-create-a-genetic-underclass-6083709.html>, archived at <https://perma.cc/4PJZ-4UZ4>.

⁷⁷ See *id.*

⁷⁸ See *id.*

⁷⁹ About 60% of Americans receive their health insurance from their employer. See *Number of Americans Obtaining Health Insurance Through an Employer Declines Steadily Since 2000*, ROBERT WOOD JOHNSON FOUND. (Apr. 11, 2013), <http://www.rwjf.org/en/library/articles-and-news/2013/04/number-of-americans-obtaining-health-insurance-through-an-employ.html>, archived at <https://perma.cc/ZAXJ-ZWGY>.

⁸⁰ See Mary Crossley, *Discrimination Against the Unhealthy in Health Insurance*, 54 U. KAN. L. REV. 73, 73–74 (2005).

⁸¹ See John V. Jacobi, *The Ends of Health Insurance*, 30 U.C. DAVIS L. REV. 311, 314 (1997).

coverage. Many Americans accept that an individual's costs of coverage should vary with the individual's predicted consumption of medical care as determined by pre-existing diseases or conditions.⁸² Furthermore, other scholars have found that American society has only a "weak and wavering commitment" to the notion that sickness is a condition that should be addressed by mutual aid.⁸³ These attitudes towards sickness are in contrast with European countries, where there is more of an "ideal of social solidarity" than in the United States when it comes to health insurance.⁸⁴

In the recent past, the group insurance offered by the employer was the only resort for many Americans who, as a result of a "pre-existing" condition, were precluded from obtaining individual health insurance or could do so only at a high premium.⁸⁵ The employed unhealthy were "saved" from the financial and medical peril of no health insurance when the government, in passing the Health Insurance Portability and Accountability Act of 1996 ("HIPAA"),⁸⁶ effectively prohibited health insurers from excluding sickly individuals from group insurance and charging them higher premiums based on their health status.⁸⁷ However, HIPAA does not prevent insurance companies from imposing higher premiums on employers because of employees' pre-existing conditions,⁸⁸ and because the employer can pass on only so much of its healthcare costs to the employee, the employer has an incentive not to hire those would-be employees who would pose a financial burden owing to their current or foreseeable physical condition.

The recent passage of the ACA has somewhat abated these issues. Individuals and families are no longer precluded from buying private health insurance because of a pre-existing condition.⁸⁹ Like GINA, the ACA has

⁸² Timothy S. Jost, *Private or Public Approaches to Insuring the Uninsured: Lessons from International Experience with Private Insurance*, 76 N.Y.U. L. REV. 419, 429 n.50 (2001).

⁸³ See Deborah A. Stone, *The Struggle for the Soul of Health Insurance*, 18 J. HEALTH POL'Y & L. 287, 289–90 (1993).

⁸⁴ Jost, *supra* note 82, at 434.

⁸⁵ Studies have shown that the high costs of medical treatment and medicine can cause tremendous medical and financial strains on people with diabetes. See generally Karen Pollitz et al., *FALLING THROUGH THE CRACKS: STORIES OF HOW HEALTH INSURANCE CAN FAIL PEOPLE WITH DIABETES* (Feb. 8, 2005), http://www.healthinsuranceinfo.net/diabetes_and_health_insurance.pdf, archived at <https://perma.cc/J2VL-JX7F>.

⁸⁶ Pub. L. No. 104-191, 110 Stat. 1936 (1996) (codified at 26 U.S.C. §§ 101 *et seq.* (2012); 29 U.S.C. §§ 1003 *et seq.*; 42 U.S.C. §§ 210 *et seq.*).

⁸⁷ HIPAA prohibits group health insurers from discriminating against individual participants on the basis of health status in regards to eligibility rules and in setting premiums. It also includes provisions limiting group plans' use of pre-existing condition clauses, and it helps to prevent gaps in coverage when workers change jobs. See Crossley, *supra* note 80, at 75; see also Jack A. Rovner, *Federal Regulation Comes to Private Health Care Financing: The Group Health Insurance Provisions of the Health Insurance Portability and Accountability Act of 1996*, 7 ANNALS HEALTH L. 183, 184–85 (1998); 29 U.S.C. § 1182(a)(1).

⁸⁸ See 29 U.S.C. § 1182(b)(3)(B) (noting that provisions do not "limit the ability of a health insurance issuer offering health insurance coverage . . . to increase the premium for an employer based on the manifestation of a disease or disorder of an individual who is enrolled in the plan").

⁸⁹ See Patient Protection And Affordable Care Act, Pub. L. No. 111-148, §§ 1101, 2705, 124 Stat. 119, 141, 156–57 (2010) (codified at 42 U.S.C. §§ 300gg-4, 18001).

provisions preventing the use of genetic information to deny health insurance coverage.⁹⁰ However, neither the ACA nor GINA addresses the raising of premiums for group employer-based insurance once a member of the group manifests a genetic disease. This means that employers would still have an incentive not to hire a class of people whom the employers believe will necessitate higher health insurance premiums in the future.

Ultimately, the acceptance of the deterministic nature of genetic testing, and the blind faith in its infallible accuracy to predict disease, does have an impact on an individual's employment prospects. As part of the General Social Survey,⁹¹ the following question was posed to respondents in 1991:

Here are some questions about a new scientific technology called "genetic screening." Using genetic screening, it is now possible to tell whether someone has inherited a tendency to develop certain cancers and certain forms of heart disease. These tests do not mean that a person will always develop the disease, but only that he or she may do so, depending on other conditions. Should employers have the right to give these genetic tests to people who are applying for a job, or shouldn't they have that right?⁹²

While most people (85% of respondents) answered in the negative, it is significant that a non-negligible percentage (15% of the respondents) would allow an employer the right to hire by genetic testing.⁹³

Before the passage of GINA, some employers exercised their perceived right to genetically test their employees, even without the consent of those employees. In 1995, employees of the Lawrence Berkeley Laboratory in California discovered that blood and urine samples they had provided (as a pre-condition to employment) had been subjected to genetic testing for sickle cell anemia as well as testing for syphilis and pregnancy.⁹⁴ Because of this discovery, the employees brought suit under Title VII and the ADA.⁹⁵ While the Ninth Circuit found that screening the women for pregnancy and only minorities for sickle cell anemia was sexually and racially discrimina-

⁹⁰ See *id.* at 156.

⁹¹ See *GSS 1972–2008 Cumulative Datafile*, SDA, <http://sda.berkeley.edu/cgi-bin/hsda?harcstda+gss08>, archived at <http://perma.cc/Z4PA-XQPZ> (last visited Jan. 18, 2016); see also GSS: GENERAL SOCIAL SURVEY, www.norc.uchicago.edu/GSS+Website/, archived at <https://perma.cc/FP7Z-CLTX> (last visited Jan. 18, 2016). "The GSS has been conducted almost annually since 1972. It is the only full-probability, personal-interview survey designed to monitor changes in both social characteristics and attitudes currently being conducted in the United States." *Abstract, 1972–2014 GENERAL SOCIAL SURVEY CUMULATIVE FILE*, <http://sda.berkeley.edu/Abstracts/GSS2014.html>, archived at <https://perma.cc/6T3Y-W53Z> (last visited Jan. 18, 2016).

⁹² *1991 Topical Module: Work Organizations, 1972–1994 GENERAL SOCIAL SURVEY CUMULATIVE FILE*, <http://sda.berkeley.edu/GSS/Doc/gss025.html>, archived at <https://perma.cc/TA46-XUE6> (last visited Jan. 18, 2016).

⁹³ *Id.*

⁹⁴ *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260, 1264–65 (9th Cir. 1998).

⁹⁵ *Id.* at 1265.

tory in violation of Title VII⁹⁶ and state and federal constitutional law,⁹⁷ the court dismissed the plaintiffs' ADA claims because the ADA does not restrict the scope of "employment entrance examinations."⁹⁸ The California case illustrates why GINA was necessary legislation, notwithstanding the existence of the ADA.

However, even after GINA went into effect in 2009, the threat of a genetic underclass has not waned. As discussed earlier, the statistics compiled by the EEOC continue to show yearly growth in the number of claims alleging genetics as the basis for employment discrimination. The trends show that genetic discrimination remains a credible threat to equal opportunity in employment and necessitates legislation that allows the plaintiff to pierce the veil of facially neutral policies and discover genetic discrimination. The danger remains of the growth of an economic underclass, comprised of individuals deemed genetically compromised.

Consider the premise of the 1997 science fiction film *Gattaca*.⁹⁹ In the film, advances in genetic engineering mean that prospective parents, who have no moral compulsions against it and who can afford it, may genetically endow their progeny with superior intelligence and health. The film's protagonist (portrayed by Ethan Hawke) is a man whose parents declined to participate in genetic engineering when he was conceived. Thus, he was born with some congenital defects including respiratory problems that render his aspirations as an astronaut risible in a genetically essentialist and deterministic society. Furthermore, because of his perceived inferior genetic status, and despite his natural intelligence, he is relegated to work as a janitor, while his younger brother, for whom his parents did engage in genetic engineering, enjoys high status as a police detective. From the film, we see how genetic engineering has created a new inequality, between those who are born of genetic engineering, and thus considered superior, and others who are not. We see the protagonist's potential love interest (portrayed by Uma Thurman) testing a strand of his hair (unbeknownst to her, the protagonist has substituted the hair of a genetically modified individual for his own) to determine whether he is a worthy genetic mate.

This fictional scenario is no longer far from reality. Recently, Chinese scientists have started experimenting on editing the genome of a human embryo using a technique called "clustered, regularly interspaced, short palindromic repeat" ("CRISPR").¹⁰⁰ Many scientists view such germline

⁹⁶ *Id.* at 1271–73.

⁹⁷ *Id.* at 1268–71.

⁹⁸ *Id.* at 1273–74.

⁹⁹ *Gattaca* (Columbia Pictures Corp. 1997).

¹⁰⁰ David Cyranoski & Sara Reardon, *Chinese Scientists Genetically Modify Human Embryos*, NATURE (Apr. 22, 2015), <http://www.nature.com/news/chinese-scientists-genetically-modify-human-embryos-1.17378>, archived at <https://perma.cc/P96V-4PL6>. The technique used by Junjiu Huang's team involves injecting embryos with the enzyme complex CRISPR/Cas9, which "binds and splices DNA at specific locations." *Id.* Cyranoski and Reardon explained:

modifications as “dangerous and ethically unacceptable,” particularly because “such research could be exploited for non-therapeutic modifications”¹⁰¹ resulting in “designer babies.”¹⁰² Other scientists have noted that although “genome-editing technologies may offer a powerful approach to treat many human diseases, including HIV/AIDS, haemophilia, sickle-cell anaemia and several forms of cancer. . . . [G]enome editing in human embryos using current technologies could have unpredictable effects on future generations.”¹⁰³ As Francis Collins, leader of the HGP and now Director of the National Institutes of Health, has observed, “Genetic information and genetic technology . . . can be used in ways that are fundamentally unjust. . . . Already . . . people have lost their jobs, lost their health insurance, and lost their economic wellbeing . . . due to the unfair and inappropriate use of genetic information.”¹⁰⁴

3. GINA’s Provisions and EEOC Enforcement

GINA prohibits discrimination in health coverage and employment based on genetic information.¹⁰⁵ It bars employers from using individuals’ genetic information when making hiring, firing, job placement, or promotion decisions.¹⁰⁶ The sections relating to employment (Title II) took effect on November 21, 2009.¹⁰⁷ It is important to note that GINA provides a baseline level of protection against genetic discrimination for all Americans. “Many states already have laws that protect against genetic discrimination in health

The complex can be programmed to target a problematic gene, which is then replaced or repaired by another molecule introduced at the same time. . . .

The team injected 86 embryos and then waited 48 hours, enough time for the CRISPR/Cas9 system and the molecules that replace the missing DNA to act — and for the embryos to grow to about eight cells each. Of the 71 embryos that survived, 54 were genetically tested. This revealed that just 28 were successfully spliced, and that only a fraction of those contained the replacement genetic material. “If you want to do it in normal embryos, you need to be close to 100%,” Huang says. “That’s why we stopped. We still think it’s too immature.”

Id.

¹⁰¹ *Id.*

¹⁰² Kevin Loria, *The Biggest Biotech Discovery of the Century Will Make Designer Babies and Genetically Edited Humans Possible*, BUS. INSIDER (Mar. 13, 2015, 3:00 PM), <http://www.businessinsider.com/how-to-make-a-genetically-edited-human-2015-3>, archived at <https://perma.cc/LGY5-ZU3W> (“Designer babies, genetically engineered to be super-smart, disease free, and physically fit, are the stuff of science fiction. But science fiction often predicts reality.”).

¹⁰³ Edward Lanphier et al., *Don’t Edit the Human Germ Line*, NATURE (Mar. 12, 2015), <http://www.nature.com/news/don-t-edit-the-human-germ-line-1.17111>, archived at <https://perma.cc/V8FC-V578>.

¹⁰⁴ Slaughter, *supra* note 22, at 46.

¹⁰⁵ 29 U.S.C. § 1182.

¹⁰⁶ *Id.*

¹⁰⁷ See U.S. DEP’T OF HEALTH & HUMAN SERVS., GINA: THE GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008, INFORMATION FOR RESEARCHERS AND HEALTH CARE PROFESSIONALS (2009), available at <http://www.genome.gov/Pages/PolicyEthics/GeneticDiscrimination/GINAInfoDoc.pdf>, archived at <https://perma.cc/F8QZ-7Z6N>.

insurance and employment situations.”¹⁰⁸ All entities subject to GINA must, at a minimum, comply with all applicable GINA requirements, and may need to comply with more protective state laws. GINA, together with the already existing nondiscrimination provisions of HIPAA, generally prohibits health insurers or health plan administrators from requesting or requiring genetic information from an individual or the individual’s family members, or using such information for decisions regarding coverage, rates, or preexisting conditions.

The statute defines “genetic information” as information about:

- genetic tests of the individual (including those done as part of a research study);
- genetic tests of the individual’s family members (defined as dependents and up to and including fourth-degree relatives);
- genetic tests of any fetus of an individual or family member who is a pregnant woman, and of any embryo legally held by an individual or family member utilizing assisted reproductive technology;
- the manifestation of a disease or disorder in family members (family history);
- any request for, or receipt of, genetic services or participation in clinical research that includes genetic services (testing, counseling, or education) by an individual or family member.¹⁰⁹

Various federal agencies enforce GINA. The Departments of Labor, Treasury, and Health and Human Services are responsible for Title I of GINA (which relates to health insurance coverage), and the EEOC is responsible for Title II. Remedies for violations include injunctive action and monetary penalties. Under Title II, individuals have the right to pursue private litigation once they have exhausted administrative remedies.¹¹⁰

In 2013, the EEOC filed its first two cases to enforce GINA. In its first lawsuit, the EEOC charged an employer with violating GINA’s general prohibition on requesting family medical history as part of the hiring process. According to the EEOC, Fabricut, Inc. had an applicant undergo a post-offer pre-employment drug test and physical examination by its contract medical examiner. As part of the exam, the applicant was required to fill out a questionnaire that asked whether she had a family history of heart disease, cancer, diabetes, or other medical conditions. After the employer’s medical

¹⁰⁸ *Id.*; see also *Fair Employment Practices Agencies (FEPAs) and Dual Filing*, U.S. EQUAL EMP’T OPPORTUNITY COMM’N, <http://www.eeoc.gov/employees/fepa.cfm>, archived at <https://perma.cc/8DM3-TDHY> (last visited Jan. 18, 2016).

¹⁰⁹ 29 U.S.C. § 1182.

¹¹⁰ *Background Information for EEOC Final Rule on Title II of the Genetic Information Nondiscrimination Act of 2008*, U.S. EQUAL EMP’T OPPORTUNITY COMM’N, <http://www.eeoc.gov/laws/regulations/gina-background.cfm>, archived at <https://perma.cc/8YCY-VNTG> (last visited Jan. 18, 2016).

examiner concluded that the applicant might have carpal tunnel syndrome (“CTS”), Fabricut instructed her to see her personal physician and provide the results to the company. Even though her physician concluded that she did not suffer from CTS, the company allegedly rescinded the job offer based on its medical examiner’s indication that she had CTS. The EEOC maintained that Fabricut violated GINA, by asking for genetic information in the questionnaire, and the ADA, by taking an employment action based on the applicant’s disability or perceived disability. To settle the suit, Fabricut agreed to pay \$50,000 and take other remedial action, such as providing antidiscrimination training to employees with hiring responsibilities.¹¹¹

In its second lawsuit, and first class action lawsuit, the EEOC charged a nursing and rehabilitation facility with violating GINA by asking job applicants for genetic information during post-offer pre-employment medical examinations. The defendant routinely requested family medical history during employees’ return-to-work and annual medical exams. The EEOC alleged that the defendant effectively denied equal employment opportunities to a class of individuals and adversely affected their status as employees.¹¹² In January 2014, Founders Pavilion settled the suit by agreeing to pay \$370,000.¹¹³ As part of a five-year consent decree resolving the suit, Founders Pavilion will provide a fund of \$110,400 for distribution to the 138 individuals who were asked for their genetic information. Founders Pavilion will also pay \$259,600 to the five individuals who the EEOC alleged were fired or denied hire in violation of the ADA or Title VII.¹¹⁴

Although the EEOC enforcement actions described above offer a glimpse as to how GINA is employed to redress genetic discrimination in employment, GINA’s legal reach is limited. The next section will discuss GINA’s statutory limitations and shortcomings in comparison to similar employment antidiscrimination laws.

B. GINA’s Limitations

That GINA’s reach is statutorily limited in addressing all manner of genetic discrimination is reason enough to consider adding a disparate impact clause. For one, the statute defines “genetic test” as an analysis of

¹¹¹ Joint Motion for Entry of Agreed Consent Decree, at 1–7, EEOC v. Fabricut, Inc., No. 13-CV-248-CE-PJC (N.D. Okla. May 7, 2013); *see also* Press Release, U.S. Equal Emp’t Opportunity Comm’n, Fabricut to Pay \$50,000 to Settle EEOC Disability and Genetic Information Discrimination Lawsuit (May 7, 2013), <http://www.eeoc.gov/eeoc/newsroom/release/5-7-13b.cfm>, *archived at* <https://perma.cc/29AX-36AY>.

¹¹² Amended Complaint, EEOC v. Founders, Inc., No. 13-CV-6250-CJS (W.D.N.Y. June 17, 2013).

¹¹³ *See* Press Release, U.S. Equal Emp’t Opportunity Comm’n, Founder’s Release Will Pay \$370,000 to Settle EEOC Genetic Information Discrimination Lawsuit (Jan. 13, 2014), <http://www.eeoc.gov/eeoc/newsroom/release/1-13-14.cfm>, *archived at* <https://perma.cc/7HDD-GT27>.

¹¹⁴ *See id.*

human DNA, RNA, chromosomes, proteins, or metabolites that detect genotypes, mutations, or chromosomal changes.¹¹⁵ Therefore, the results of tests that do not measure DNA, RNA, or chromosomal changes—such as complete blood counts, cholesterol tests, and liver-function tests—are not protected under GINA. This presents a gray area for discrimination, because some genetic diseases such as sickle cell anemia may be determined by a simple blood test.¹¹⁶ Moreover, GINA fails to protect “analys[e]s of proteins or metabolites that are directly related to a manifested disease, disorder, or pathological condition that could reasonably be detected by a health care professional with appropriate training and expertise in the field of medicine involved.”¹¹⁷ Given that some genetic diseases, such as Tay Sachs disease, implicate the metabolizing of or lack of ability to metabolize certain enzymes,¹¹⁸ such an exception opens the door to covert genetic discrimination. The disparate impact theory of action would allow plaintiffs to show a pattern of employers turning away individuals known to carry such genetic diseases from employment even if the employers had not subjected the plaintiffs to a genetic test under GINA’s definitions.

The EEOC makes clear that an individual’s diagnosed disease, disorder, or pathological condition is not considered genetic information. Similarly, information about the individual’s signs or symptoms of disease is not considered genetic information. However, the EEOC further elaborates that such information is still subject to other laws regulating the acquisition and use of medical information, including Title I of the ADA. This is problematic because some diseases are strictly genetic in nature or have strong genetic correlations, such that a manifested condition is evidence of the presence of a mutated gene. For example, because of the known link between mutations BRCA1 and BRCA2 to breast cancer,¹¹⁹ an employer may view applicants with known histories of breast cancer as financial risks to their group insurance coverage. The statutory limitations present in GINA represent both compromises made for the benefit of the healthcare industry as well as Congress’s limited scientific knowledge regarding genetic information.¹²⁰

¹¹⁵ 29 U.S.C. § 1191b(d)(7)(A) (2012).

¹¹⁶ See, e.g., *Sickle Cell Test*, U.S. NAT’L LIBRARY OF MEDICINE, <http://www.nlm.nih.gov/medlineplus/ency/article/003666.htm>, archived at <https://perma.cc/FS8A-HKN6> (last visited Jan. 18, 2016) (explaining how the sickle cell anemia test is performed).

¹¹⁷ 29 U.S.C. § 1191b(d)(7)(B)(ii); 42 U.S.C. § 300gg-91(d)(17)(B)(ii).

¹¹⁸ See, e.g., *2-Methylbutyric Aciduria*, RIGHT DIAGNOSIS FROM HEALTHGRADES, http://www.rightdiagnosis.com/symbol/2_methylbutyric_aciduria/intro.htm, archived at <https://perma.cc/AG55-H6CJ> (last visited Jan. 18, 2016).

¹¹⁹ *BRCA1 and BRCA2: Cancer Risk and Genetic Testing*, NATIONAL CANCER INSTITUTE, <http://www.cancer.gov/about-cancer/causes-prevention/genetics/brca-fact-sheet>, archived at <https://perma.cc/Y6CM-C2MA> (last visited Jan. 18, 2016).

¹²⁰ “GINA suffered in obscurity for a number of years as the result of a Republican led Congress that was hostile to adding additional restrictions on the insurance industry and employer communities.” Jeremy Gruber, *The New Genetic Nondiscrimination Act - How It Came to Pass and What It Does*, COUNCIL FOR RESPONSIBLE GENETICS, <http://www.councilfor>

C. Comparing GINA to Similar Employment Antidiscrimination Laws

Although genetic discrimination represents a new frontier for employment antidiscrimination law, it is important to recognize that GINA shares a similar goal with prior examples of antidiscrimination legislation, including Title VII, the Age Discrimination in Employment Act, and the Americans with Disabilities Act. The goal is to secure, for all Americans, the unfettered opportunity to pursue their livelihood through lawful and gainful employment. This objective has evolved over time to become part of the bedrock of American law.

The newly independent United States of America made no explicit constitutional provisions to protect workers striving for material wealth. In fact, the Lockean expression allowing for a “right to life, liberty and pursuit of property” found in the Declaration of Colonial Rights¹²¹ was altered by Thomas Jefferson to read “pursuit of happiness” when he wrote the Declaration of Independence.¹²² Later, the Due Process clauses of the Fifth¹²³ and Fourteenth Amendments¹²⁴ were read to imply a protection of the rights of individuals to pursue property and thus further interpreted to afford workers protection in an employment context. Yet, the U.S. Supreme Court has not always interpreted the Constitution in favor of workers. An era of “freedom of contract” cases was inaugurated by *Allgeyer v. Louisiana*,¹²⁵ in which the Court interpreted the Due Process Clause of the Fourteenth Amendment as providing substantive protection to private contracts and thus disallowing a variety of social and economic regulation of businesses. Subsequently, the Equal Protection Clause has also been interpreted to afford some employment protection for workers, such as when it was used in *Yick Wo v. Hopkins*.¹²⁶ In *Yick Wo*, the Court curbed economic discrimination against Chinese descendants in California resulting from a seemingly race-neutral regulation of the laundry business that disproportionately impacted the ethnic group.¹²⁷ This recognition of a worker’s right to be free from discrimination in pursuit of her livelihood is what led to the establishment of the first employment antidiscrimination laws, and it is that line of legal reasoning that culminated in GINA. This section compares GINA with employment

responsiblegenetics.org/pagedocuments/pgwoj2f3o.pdf, archived at <https://perma.cc/7KSG-2GMZ> (last visited Jan. 18, 2016).

¹²¹ See *Declaration and Resolves of the First Continental Congress*, THE AVALON PROJECT (Oct. 14, 1774), http://avalon.law.yale.edu/18th_century/resolves.asp, archived at <https://perma.cc/327A-L2FR>.

¹²² GARY WILLS, *INVENTING AMERICA: JEFFERSON’S DECLARATION OF INDEPENDENCE* 240–55 (1978).

¹²³ “No person shall . . . be deprived of life, liberty, or property, without due process of law” U.S. CONST. amend. V.

¹²⁴ “[N]or shall any State deprive any person of life, liberty, or property, without due process of law” *Id.* amend. XIV, § 1.

¹²⁵ 165 U.S. 578 (1897).

¹²⁶ 118 U.S. 356 (1886).

¹²⁷ See *id.* at 373–74.

antidiscrimination laws that carry clauses allowing for disparate impact causes of action. In so doing, the section examines how GINA fits within the body of statutory antidiscrimination law and concludes that, like those of traditional antidiscrimination laws, GINA's objectives would be furthered by the addition of a disparate impact clause.

1. Title VII

Title VII¹²⁸ prohibits discrimination in many more aspects of the employment relationship than GINA does, and Title VII applies to most employers engaged in interstate commerce with more than fifteen employees, labor organizations, and employment agencies.¹²⁹ Title VII prohibits discrimination based on race, color, religion, sex, or national origin.¹³⁰ It prevents employers from discriminating based upon protected characteristics regarding terms, conditions, and privileges of employment.¹³¹ Employment agencies may not discriminate when hiring or referring applicants, and labor organizations are also prohibited from basing membership or union classifications on race, color, religion, sex, or national origin.¹³²

Although GINA tracks the language of Title VII fairly closely,¹³³ important differences exist between the two. Bradley Areheart argues that “the nature of [GINA’s] protections differ in that they are more forward-looking and less responsive to serious social harms.”¹³⁴ Title VII, on the other hand, “was retrospective, legislated in response to a history of widespread racism and civil unrest.”¹³⁵ He further notes that GINA was not promulgated to “counteract systemic disadvantage or inequality, but to prevent genetic discrimination and promote the use of genetic technologies.”¹³⁶ Areheart argues that the rationale for GINA was prefaced on the recognition that “only a few cases of genetic discrimination have been documented.”¹³⁷ And, as he mentions, other scholars have referred to GINA as “the first preemptive antidiscrimination statute in American history.”¹³⁸ Perhaps the documented history of race and sex discrimination in America is the reason why, unlike GINA, Title VII has a disparate impact clause. Specifically, Title VII expressly prohibits employers from using any “particular employment practice that causes a disparate impact on the basis of race, color, religion, sex, or

¹²⁸ Pub. L. No. 88-352, § 703, 78 Stat. 241, 255 (1964) (codified at 42 U.S.C. § 2000e-2).

¹²⁹ See 42 U.S.C. § 2000e.

¹³⁰ See *id.* § 2000e-2.

¹³¹ See *id.*

¹³² See *id.*

¹³³ Areheart, *supra* note 75, at 707.

¹³⁴ *Id.*

¹³⁵ *Id.*

¹³⁶ *Id.*

¹³⁷ *Id.*

¹³⁸ *Id.* at 707 n.10.

national origin,” unless the practice is both job-related and consistent with business necessity.¹³⁹

Although Congress enacted GINA as a preemptive strike at genetic discrimination in 2008, GINA no longer remains merely a preemptive law. As the steadily growing EEOC-compiled statistics of genetic discrimination claims demonstrate, there is now a real and present need for GINA to address currently occurring genetic discrimination in employment. Furthermore, sociological phenomena (notably genetic essentialism and genetic determinism), coupled with technological advances that make genetic testing more affordable and therefore more accessible to a wider demographic, provide a ripe environment for the misuse of genetic information for discrimination in employment.

2. *Age Discrimination in Employment Act*

Like Title VII, the Age Discrimination in Employment Act of 1967 (“ADEA”)¹⁴⁰ was a remedial statute enacted to curb extant age discrimination in employment. Accordingly, the language of the ADEA is similar to that of Title VII, and the courts look to Title VII cases as authoritative for deciding ADEA cases.¹⁴¹ The ADEA generally prohibits employment discrimination against individuals who are forty years old or older.¹⁴² The Act also applies to employment agencies¹⁴³ and labor organizations,¹⁴⁴ while making an exception for individuals hired or to be hired as firefighters and police officers.¹⁴⁵ The ADEA is unlike GINA in that it makes this exception for a group of people that would normally fall under its protected class. More significantly, unlike GINA but akin to Title VII, the ADEA has been read to provide for a disparate impact cause of action.¹⁴⁶ It is important to parse that the ADEA does not have an explicit disparate impact clause like that found in Title VII. Rather, the reading of a disparate impact cause of action for the ADEA was based on some similar language between the ADEA and Title VII¹⁴⁷ and on the recognition that the ADEA was enacted

¹³⁹ 42 U.S.C. § 2000e-2(k).

¹⁴⁰ Pub. L. No. 90-202, 81 Stat. 602 (codified as amended at 29 U.S.C. §§ 621–34 (2012)).

¹⁴¹ See, e.g., EEOC v. Reno, 758 F.2d 581, 583–84 (11th Cir. 1985) (holding that because “prohibitions of the Age Discrimination in Employment Act were derived *in haec verba* from Title VII, . . . decisions under [the] analogous section of Title VII [are] highly relevant” (internal citation omitted)).

¹⁴² See 29 U.S.C. § 631(a).

¹⁴³ See *id.* § 623(b).

¹⁴⁴ See *id.* § 623(c).

¹⁴⁵ See *id.* § 623(j).

¹⁴⁶ See *Smith v. City of Jackson, Miss.*, 544 U.S. 228, 233–40 (2005) (interpreting 29 U.S.C. § 623(a)(2) of the ADEA by virtue of identical text in Title VII and the Supreme Court’s interpretation of Title VII in *Griggs v. Duke Power Co.*, 401 U.S. 424 (1971)).

¹⁴⁷ Title VII explicitly proscribes employers from using any “particular employment practice that causes a disparate impact on the basis of race, color, religion, sex or national origin.” 42 U.S.C. § 2000e-2(k)(1)(A)(i).

with the intention of mirroring Title VII's provisions in the ADEA's redress of age discrimination in employment.¹⁴⁸

3. *Americans with Disabilities Act*

Congress enacted the ADA to eliminate discriminatory barriers against qualified individuals with a disability, a record of a disability, or a perceived disability.¹⁴⁹ The law prohibits discrimination based on a physical or mental handicap and requires employers to make reasonable accommodations for workers with disabilities.¹⁵⁰ President George H.W. Bush signed the ADA into law in 1990, in part “to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.”¹⁵¹ The term “disability” means, with respect to an individual: (1) a physical or mental impairment that substantially limits one or more major life activities of such individual; (2) a record of such an impairment; or (3) the perception that the individual has such an impairment.¹⁵² The Americans with Disabilities Act Amendment Act (“ADAAA”) broadened the definition of disability under the ADA so that it covers individuals with systemic or cellular-level pathologies.¹⁵³ Thus, courts have also found that the HIV-positive status of an individual is enough for the ADA to protect the individual, despite the fact that the disease has not progressed to AIDS.¹⁵⁴

It is true that, prior to GINA, many of the traditional employment antidiscrimination laws already in place could provide prospective employees some protection against genetic discrimination. For one, many genetic defects, such as spina bifida, can result in visible disabilities, such as the use of braces, crutches, or a wheelchair for mobility.¹⁵⁵ Thus, a wheelchair-bound

¹⁴⁸ See *Smith*, 544 U.S. at 238 (“As we have already explained, we think the history of the enactment of the ADEA, with particular reference to the Wirtz Report, supports the pre-*Hazen Paper* consensus concerning disparate-impact liability.” (citing *Hazen Paper Co. v. Biggins*, 507 U.S. 604 (1993))).

¹⁴⁹ See *Rehabilitation Act*, A GUIDE TO DISABILITY RIGHTS LAWS, U.S. DEP’T OF JUSTICE (July 2009), <http://www.ada.gov/cguide.htm#anchor65610>, archived at <https://perma.cc/KQY7-GTR9>.

¹⁵⁰ 42 U.S.C. § 12112(b)(5).

¹⁵¹ *Id.* § 12101(b)(1).

¹⁵² *Id.* § 12102(1).

¹⁵³ Tasneem Dharamsi, *Human Embryonic Stem Cells: Will Sherley v. Sebelius Expand the Definition of the Disabled Individual?*, 14 N.C.J.L. & TECH. ONLINE 239, 253 (2013).

¹⁵⁴ Dharamsi states:

Because conditions like cancer and HIV are the result of mutations in an individual’s genetic machinery, it seems that the changes to the ADA, as manifested in the ADAAA, have forced courts to acknowledge that some genetic mutations are disabling, even if the genetic mutations do not have physical effects on the individual. The step from categorizing some genetic mutations as disabling to categorizing all genetic mutations as disabling is not a large one.

Id. at 254–55.

¹⁵⁵ See *NINDS Spina Bifida Information Page*, NAT’L INST. OF NEUROLOGICAL DISORDERS & STROKE (Feb. 23, 2015), http://www.ninds.nih.gov/disorders/spina_bifida/spina_bifida.htm, archived at <https://perma.cc/D7VM-QYTX>.

applicant who suffers from spina bifida might be able to sue under the ADA. Consider also that in 2001, the Burlington Northern Santa Fe Railway Co. agreed to stop testing its employees for genetic defects. This came as part of a workplace discrimination settlement of a case where the EEOC found that the tests violated the ADA. The settlement—the first of its kind—curbed the genetic tests of employees who had filed claims for work-related injuries stemming from carpal tunnel syndrome.¹⁵⁶

It is important to note, however, that traditional employment antidiscrimination laws like the ADA could typically protect only workers who had a manifested disability. Workers or job applicants who did not have visible disabilities were unable to rely on those laws.¹⁵⁷ The fact remains that many genetic “defects” are not readily visible or may present themselves only later in life. One example of the former is sickle cell anemia,¹⁵⁸ and an example of the latter is autosomal dominant familial Alzheimer’s.¹⁵⁹ As these genetic diseases might not result in readily apparent disabilities, individuals who live with them and are stigmatized as “undesirable job applicants” might have a tougher time proving that the cause of their lack of employment stems from an actual disability. A disparate impact clause for GINA would protect those individuals without a manifest disability.

Finally, it should be considered that the ADA has a disparate impact clause. As explicitly stated within the statute, the phrase “discriminate against a qualified individual on the basis of disability” includes neutral policies and practices “that have the effect of discrimination on the basis of disability.”¹⁶⁰

¹⁵⁶ See Sarah Schafer, *Railroad Agrees to Stop Gene-Testing Workers*, WASH. POST (Apr. 19, 2001), <http://www.washingtonpost.com/archive/business/2001/04/19/railroad-agrees-to-stop-gene-testing-workers/9ff240ca-64ff-45bd-a840-5997fb8d0c29>, archived at <https://perma.cc/9YNV-WZ4D>.

¹⁵⁷ See Dharamsi, *supra* note 153, at 255–56 (arguing that the ADA expands the definition of “disability” to include genetic diseases).

¹⁵⁸ Samir K. Ballas & Margaret Lusardi, *Hospital Readmission for Adult Acute Sickle Cell Painful Episodes: Frequency, Etiology and Prognostic Significance*, 79 A.J. HEMATOLOGY 17, 17 (2005). An individual with sickle cell disease is generally asymptomatic and superficially indistinguishable from the rest of the population. *Id.* However, as a result of the disease, his red blood cells can become sickle-shaped under certain adverse conditions and lead to periodic “crises,” which involve symptoms such as pain in the legs and arms and can last approximately five to seven days. *Id.*

¹⁵⁹ Kaj Blennow, Mony J. de Leon & Henrik Zetterberg, *Alzheimer’s Disease*, 368 LANCET 387, 387 (2006). The vast majority of cases of Alzheimer’s disease are not genetically inherited, although some genes may act as risk factors. See *id.* at 388. Still, about 0.1% of the cases are familial forms of autosomal-dominant inheritance, which usually have an onset before age 65. See *id.* Most of autosomal dominant familial cases of Alzheimer’s disease can be attributed to mutations in one of three genes: amyloid precursor protein (APP) and Presenilins 1 and 2. See *id.*

¹⁶⁰ See 42 U.S.C. §§ 12112(a), (b)(3)(A); see also *id.* § 12112(b)(6).

III. SUPPORT FOR A DISPARATE IMPACT CLAUSE

The three disparate impact provisions discussed above operate in similar ways, and all have their origins in the disparate impact theory of discrimination for allegations of employment discrimination that originated from Title VII.¹⁶¹ Under Title VII, a plaintiff may bring suit based on two theories of discrimination: disparate impact or disparate treatment.¹⁶² The disparate impact theory for employment discrimination is unlike the disparate treatment theory in that there is no requirement to demonstrate intent.¹⁶³ The disparate impact theory requires a plaintiff to demonstrate that a facially neutral employment practice falls more harshly on one group than another; while a disparate impact employment discrimination claim does not require a plaintiff to prove the defendant's intent to discriminate, the plaintiff must nonetheless demonstrate a connection between the challenged practice and the resulting disparities between protected and non-protected classes.¹⁶⁴ In order to make out a *prima facie* case of disparate impact under Title VII, the plaintiff must: (1) identify a policy or practice by the defendant; (2) demonstrate that there is an existing disparity; and (3) establish that the disparity was caused by the policy or practice.¹⁶⁵

Congress should strengthen GINA by adding a clause that, like Title VII, allows for disparate impact cases. The following four reasons support the addition of such a clause: (1) a disparate impact theory of action is in line with the precedent set by prior employment discrimination laws; (2) the EEOC has declared that proof of deliberate acquisition of genetic information is not necessary to establish a violation of GINA, and proof of intent to discriminate likewise should not be required to demonstrate genetic discrimination; (3) ease of access to genetic testing and the insecurity of genetic information has increased the likelihood of genetic discrimination in employment; and (4) real world instances of genetic testing have shown that facially neutral testing may result in racial disparities.

A. *A Disparate Impact Clause Follows Precedent*

Adding a disparate impact clause to GINA would be in keeping with the spirit of prior employment antidiscrimination laws and with the precedent set by Supreme Court rulings on employment. Both Title VII and the ADA carry explicit statements allowing for a disparate impact theory of discrimination.¹⁶⁶ And although the ADEA does not have an explicit provision,

¹⁶¹ See *Griggs v. Duke Power Co.*, 401 U.S. 424, 436 (1971).

¹⁶² *Agoh v. Hyatt Corp.*, 992 F. Supp. 2d 722, 731 (S.D. Tex. 2014).

¹⁶³ *Geller v. Markham*, 635 F.2d 1027, 1031 (2d Cir. 1980).

¹⁶⁴ *Tartt v. Wilson Cty.*, Tenn, 982 F. Supp. 2d 810, 822 (M.D. Tenn. 2013), *aff'd*, 592 F. App'x 441 (6th Cir. 2014).

¹⁶⁵ *Meadors v. Ulster Cty.*, 984 F. Supp. 2d 83, 98 (N.D.N.Y. 2013).

¹⁶⁶ See *supra* Part II.C.

the courts have read it to imply one based on the statute's legislative intent and historic ties to Title VII.¹⁶⁷ Courts' reading of the ADA as including a disparate impact provision recognizes the high hurdle of proving discriminatory intent when it comes to employment practices. Some might argue that, unlike the ADEA, Congress *explicitly* excluded disparate impact theory as a cause of action under GINA, and that this exclusion represents Congress's conclusion that this theory of action is unnecessary. However, the mandate for a Genetic Nondiscrimination Study Commission underscores that Congress understood that, in 2009, it was operating with a limited understanding of genetic discrimination and that the years to come could bring more advances in the technology for genetic testing, thereby creating more opportunities for genetic discrimination and highlighting the need for a disparate impact theory of action.

Consider also the Supreme Court's recent June 25, 2015, ruling in *Texas Department of Housing v. Inclusive Communities Project*,¹⁶⁸ a Fair Housing Act case, which allowed for a disparate impact method of proving discrimination that is not typically employed in housing discrimination cases.¹⁶⁹ The Supreme Court found that the Texas housing department had violated the Fair Housing Act and engaged in racial discrimination based on the established pattern of putting more subsidized housing in predominantly black urban neighborhoods and too little in white suburban neighborhoods. The Court ruled that this practice had disparately impacted Black people as a protected group, since it discouraged more low-income Black people from moving to majority white areas and thus perpetuated *de facto* housing segregation.¹⁷⁰ This recent housing case opens the door for a disparate impact theory of action for the Fair Housing Act, much like the one that was read into the ADEA. These developments represent precedent in favor of a disparate impact cause of action for antidiscrimination law; GINA, as an antidiscrimination law with growing relevance in a world with advanced genetic testing technology and access, also merits a disparate impact theory provision.

B. *Like Deliberate Acquisition, Intent is Unnecessary*

The EEOC, which is charged with enforcing GINA's employment protection provisions, has decided that the deliberate acquisition of genetic information is not necessary for an employer to be charged with violating GINA's prohibitions. Thus, an employer who inadvertently acquires genetic information and then uses the said information for purposes of employment discrimination would be found liable under GINA. On November 9, 2010,

¹⁶⁷ See *Smith v. City of Jackson, Miss.*, 544 U.S. 228, 238–39 (2005); see also *supra* Part II.C.2.

¹⁶⁸ 135 S. Ct. 2507 (2015).

¹⁶⁹ See *id.* at 2512.

¹⁷⁰ See *id.* at 2511–12.

the EEOC implemented rule 29 C.F.R. part 1635, which provides regulations for Title II of GINA, which itself relates to employment discrimination.¹⁷¹ The rule prevents employers and other entities covered by Title II from requesting, requiring, or purchasing genetic information, and it strictly limits such entities in disclosing genetic information.¹⁷² The regulation incorporates by reference many of the familiar definitions, remedies, and procedures from Title VII and other statutes protecting federal, state, and Congressional employees from discrimination.¹⁷³

The EEOC administrative rule addressed many issues regarding the implementation of GINA. For example, § 1635.1 of the rule clarified the purpose for GINA. The language in this section of the final rule was slightly modified in response to several comments that disagreed with the characterization of Title II as prohibiting the “deliberate acquisition” of genetic information. Organizations such as the ACLU and the Coalition for Genetic Fairness noted that the term “deliberate acquisition” suggested that a covered entity must have a specific intent to acquire genetic information in order to violate the law. The above-mentioned organizations submitted comments to the EEOC arguing that

a covered entity violates GINA by engaging in acts that present a heightened risk of acquiring genetic information, even without a specific intention to do so, such as when they fail to inform an individual from whom they have requested documentation about a manifested disease or disorder not to provide genetic information or when they access other sources of information¹⁷⁴

According to the preamble to “Regulations Under the Genetic Information Nondiscrimination Act of 2008,” the EEOC determined that covered entities could acquire genetic information in violation of GINA *without a specific intent*. As a result, the EEOC removed references to “deliberate acquisition” from 29 C.F.R. § 1635.1.¹⁷⁵ In removing the language, the EEOC has recognized the difficulty for a claimant to prove deliberate acquisition of genetic information by the accused. Like showing deliberate acquisition, proving intent to discriminate often is an insurmountable hurdle for plaintiffs. Legal scholars have noted the difficulty: “[S]ince it is rare for a plaintiff to have direct evidence of discrimination in a case alleging disparate treatment, most litigants must rely on indirect evidence to prove their ulti-

¹⁷¹ See Regulations Under the Genetic Information Nondiscrimination Act of 2008, 75 Fed. Reg. 68,912 (U.S. Equal Emp’t Opportunity Comm’n Nov. 9, 2010) (to be codified at 29 C.F.R. pt. 1635).

¹⁷² 29 C.F.R. § 1635.8.

¹⁷³ Before GINA went into effect on November 21, 2009, Executive Order 13,145 had prohibited federal executive branch agencies from discriminating against applicants and employees on the basis of genetic information, and limited access to and use of genetic information. See Exec. Order No. 13,145, 65 Fed. Reg. 6,877 (Feb. 8, 2000).

¹⁷⁴ See 75 Fed. Reg. at 68,913.

¹⁷⁵ *Id.*

mate case that the employer's actions were the result of discriminatory animus.¹⁷⁶ Consequently, given the similarities between deliberate acquisition and intent to discriminate, disparate impact should be permitted.

A recent case brought under GINA involved DNA being collected from employers as part of an investigation of workplace vandalism.¹⁷⁷ This case reflects the growing trend that courts may prefer to remain agnostic about the multiplicity of motivations for which an employer might acquire genetic information from an employee, instead recognizing that the mere act of an employer requesting genetic information from employees that is then used for dismissal could violate GINA. Significantly, that case has the distinction of being the first GINA case to proceed to trial and to result in a monetary award.¹⁷⁸ Yet many would argue that the allegations in the case do not squarely fit into the type of harms that GINA was intended to prevent. This case points to the appropriation of GINA to stretch to other areas of worker discrimination involving genetic data. The recognition of this necessary stretch bolsters the arguments for the addition of a disparate impact theory to GINA's provisions.

C. *Easy Access to Genetic Testing Increases Chances for Discrimination*

The genomics age has brought both scientific advancements in our understanding of how the human genome works and technological advancements allowing for the affordability of genetic testing. Therefore, many more people may discover that they have genetic susceptibility to specific diseases.¹⁷⁹ This in turn increases the likelihood of wrongful disclosure or capture of an individual's genetic information and its misuse for the purposes of employment discrimination.¹⁸⁰ Key Supreme Court cases such as *Association for Molecular Pathology v. Myriad Genetics, Inc.*,¹⁸¹ which forbids patents on human genes,¹⁸² have further cleared the path to a flood of genetic testing. Already, the number of genetic tests available has grown 72% between 2008 and 2012 (from 1,680 to 2,886 tests).¹⁸³ In 2011, the genetic

¹⁷⁶ Daniel Schlein, *New Frontiers for Genetic Privacy Law: The Genetic Information Non-discrimination Act of 2008*, 19 GEO. MASON U.C.R.L.J. 311, 329 (2009).

¹⁷⁷ See *infra* Conclusion; see also *Lowe v. Atlas Logistics Grp. Retail Servs., LLC*, No. 1:13-CV-2425-AT, 2015 WL 2058906 (N.D. Ga. May 5, 2015).

¹⁷⁸ See *infra* Conclusion; see also *Lowe*, 2015 WL 2058906.

¹⁷⁹ See generally Ajunwa, *supra* note 4 (detailing the advances in genetic testing that makes testing for genetic predisposition to diseases like breast cancer and Alzheimer's disease more easily accomplished).

¹⁸⁰ See *id.* at 1234 (detailing the prevalence of data breaches, particularly regarding health data, and the types of harms that could arise from such breaches).

¹⁸¹ 133 S. Ct. 2107 (2013).

¹⁸² See *id.* at 2111. The Court held that merely isolating genes found in nature does not make them patentable. See *id.* at 2117.

¹⁸³ TIMATHIE LESLIE ET AL., BOOZ ALLEN HAMILTON, MARKET TRENDS IN GENETIC SERVICES: IMPACTING CLINICAL CARE THROUGH BETTER PREDICTION, DETECTION AND CARE SELECTION, 5 (2012), available at http://www.boozallen.com/media/file/GeneticTesting_VP.pdf, archived at <https://perma.cc/R6JP-MVGV>.

testing market size amounted to \$5.9 billion.¹⁸⁴ A recent survey indicates that 81.5% of consumers would have their genome sequenced if they could afford it.¹⁸⁵

The company 23andMe is now the most visible leader in the provision of genetic testing services.¹⁸⁶ 23andMe's mission was to provide a detailed report on about 240 health conditions¹⁸⁷ and genealogy.¹⁸⁸ All that is required of the consumers is to register and send for a "spit kit" with which they collect and send a saliva sample. The resulting information obtained from the DNA in the sample is made available to the consumers online. A potential consumer has ample reason to be wary. In fact, a survey of about 22 genetic testing companies reveals that none of their agreements include a provision regarding the redress of inadvertent disclosures of the information entrusted to their care.¹⁸⁹ It is also of legal concern that recently, a programmer employed 23andMe's open API to create a screening mechanism for websites that works to grant or deny access to a particular website based on a user's genetic make-up (focusing on such factors as race, sex, and ethnic background).¹⁹⁰ Although 23andMe quickly moved to block the programmer from using its API, citing its rules against "hate speech," that such a screening mechanism is now possible demonstrates how much more facile technology has made genetic discrimination.¹⁹¹

In the digital age, obtaining the genetic information of others has become much easier than most consumers of genetic testing realize. It is now shockingly commonplace for a third party to access an individual's genetic

¹⁸⁴ See *id.*

¹⁸⁵ See *id.* at 4.

¹⁸⁶ See Sarah Zhang, *23andMe Ordered to Halt Sales of DNA Tests*, NATURE (Nov. 25, 2013), <http://www.nature.com/news/23andme-ordered-to-halt-sales-of-dna-tests-1.14236>, archived at <https://perma.cc/7DSU-5WAX> ("23andMe, based in Mountain View, California, is the dominant player in the direct-to-consumer genomics market.").

¹⁸⁷ The FDA has temporarily halted 23andMe's provision of health diagnostic information to consumers. The company now provides raw genetic information related to disease without any diagnostic information. See *id.* In February 2015, "the F.D.A. approved a test from 23andMe that would be administered to prospective parents to see if they carry mutations that could cause a rare disorder called Bloom syndrome in their children." Andrew Pollack, *F.D.A. Reverses Course on 23andMe DNA Test in Move to Ease Restrictions*, N.Y. TIMES (Feb. 19, 2015), <http://www.nytimes.com/2015/02/20/business/fda-eases-access-to-dna-tests-of-rare-disorders.html>.

¹⁸⁸ 23ANDME, <https://www.23andme.com/ancestry/>, archived at <https://perma.cc/S7LP-EW8J> (last visited Jan. 18, 2016).

¹⁸⁹ See, e.g., *Privacy Highlights*, 23ANDME, <https://www.23andme.com/about/privacy/>, archived at <https://perma.cc/LT6A-3CAN> (last visited Jan. 18, 2016); *Privacy Policy*, AFRICAN DNA, <http://www.africandna.com/privacy.aspx>, archived at <https://perma.cc/U9PA-32HK> (last visited Jan. 18, 2016); *Privacy Policy*, ANCESTRY BY DNA, <https://www.ancestrybydna.com/privacy-policy.php>, archived at <https://perma.cc/BG6X-5T8R> (last visited Jan. 18, 2016).

¹⁹⁰ Pavithra Mohan, *App Used 23andMe's DNA Database to Block People From Sites Based on Race and Gender*, FAST COMPANY (July 23, 2015), <http://www.fastcompany.com/3048980/fast-feed/app-used-23andmes-dna-database-to-block-people-from-sites-based-on-race-and-gender>, archived at <https://perma.cc/R69D-WUB8>.

¹⁹¹ *Id.*

information online.¹⁹² Going beyond the classic hacking case, in which criminals access sensitive data accompanied by identifying information, even information formerly thought to be anonymous has proven penetrable by third parties. In an article in *Science*,¹⁹³ a group of researchers from the Whitehead Institute of Biomedical Research at M.I.T. demonstrated how they had been able to discover the identities of randomly selected people based on online anonymous genetic information collected as part of a voluntary study.¹⁹⁴ The researchers revealed that they had been able to uncover the identities of individuals within entire families, eventually exposing the identities of nearly fifty people, including relatives who had not taken part in the study.¹⁹⁵ Similarly, other researchers have discovered through their work that RNA expression can be used not only to identify an individual but also to uncover other information about the person, such as weight, diabetic profile, and HIV status.¹⁹⁶ This easy access to genetic information holds dire implications for incidences of genetic discrimination. The greater protection that disparate impact theory affords is necessary to extend GINA's reach to cases in which the plaintiff is unable to obtain actual evidence of genetic discrimination.

D. *Facially Neutral Testing Causes Disparities*

Moreover, although GINA does not include race as a protected category, it is important to contemplate that facially neutral genetic testing, in which the employer evinces no racial animus, may nonetheless result in racial disparities in employment. Consider the case of Stephen Pullens, a black man who was forced to resign from the Air Force Academy when blood tests revealed that he was a carrier of the recessive gene for sickle-cell anemia.¹⁹⁷ Pullens was a former state champion hurdler and a mountain climber who claimed to have never had any problems at high altitudes (a problem associated with the sickle cell gene). However, based on an Air Force Academy policy, the Air Force summarily disqualified Pullens from flying.¹⁹⁸

Pullen's case is a classic example of the intractability of genetic determinism; even in the presence of contrary evidence, the Air Force held firm

¹⁹² See Drew Olanoff, *Are You Ready for Developers To Get Into Your Genes?*, TECHCRUNCH (Sept. 17, 2012), <http://techcrunch.com/2012/09/17/are-you-ready-for-developers-to-get-into-your-genes-23andme-is-launches-api/>, archived at <https://perma.cc/S2G6-3BDT>.

¹⁹³ Melissa Gymrek et al., *Identifying Personal Genomes by Surname Inference*, 339 *Sci.* 321, 321 (2013).

¹⁹⁴ See Gina Kolata, *Web Hunt for DNA Sequences Leaves Privacy Compromised*, N.Y. TIMES (Jan. 17, 2013), <http://www.nytimes.com/2013/01/18/health/search-of-dna-sequences-reveals-full-identities.html>.

¹⁹⁵ See *id.*

¹⁹⁶ See *id.*

¹⁹⁷ See DUSTER, *supra* note 31, at 28.

¹⁹⁸ See *id.*

to its belief that Pullens' genetic makeup was his destiny. Although he had no experience of problems in high altitudes, the Academy believed that, as a carrier for the sickle cell trait, Pullens' medical status was predetermined, and he could not escape his "destiny" of problems with high altitude. It is important to note that although the sickle-cell gene is prevalent in people of sub-Saharan descent, it can also be found in some Indian and middle-eastern populations.¹⁹⁹ However, sickle cell was perhaps the first "racialized" genetic disease in America, as it became associated with people of African descent.²⁰⁰ Similarly, other genetic conditions have become correlated to racial and ethnic groups. For example, mutations in the BRCA genes,²⁰¹ which are known to be a risk factor for breast cancer, have been predominantly detected in the Ashkenazi Jewish population.²⁰² Accordingly, some argue that Ashkenazi Jewish women have been singled out as being "mutant" or "high risk" for breast cancer.²⁰³ These genetic categorizations hold troubling implications for employment discrimination.

Consider, also, the case of college athletes. In spring 2010, the National Collegiate Athletic Association ("NCAA") started implementing its first mandatory genetic screening program for athletes.²⁰⁴ Ostensibly, the NCAA's objective was to protect athletes with the sickle cell trait ("SCT") from sudden death during exercise and physical conditioning. The screening program came on the heels of a settlement obtained against the NCAA by the family of a nineteen-year-old football player sickle cell carrier who died after conditioning wind sprints.²⁰⁵ Proponents of the screening claim that during exercise, "exertional sickling" can occur in athletes with SCT, triggering fatal muscle breakdown. However, there is some scientific debate over this theory, with opponents noting that some deaths ascribed to "exertional sickling" could also have resulted from cardiac disease.²⁰⁶ The new NCAA mandate is that all Division I college athletes must undergo SCT testing or sign a waiver releasing schools from liability.²⁰⁷ Thus, there exists the impression that the new genetic screening program is ultimately about limiting legal liability.²⁰⁸

¹⁹⁹ See Sandra Soo-Jin Lee et al., *The Meanings of "Race" in the New Genomics: Implications for Health Disparities Research*, 1 YALE J. HEALTH POL'Y L. & ETHICS 33, 34–35 (2001).

²⁰⁰ *Id.* at 35.

²⁰¹ See NAT'L CANCER INST., *supra* note 7 ("BRCA1 and BRCA2 are human genes that produce tumor suppressor proteins.").

²⁰² See Lee *supra* note 199, at 34–35.

²⁰³ *Id.*

²⁰⁴ See *Genetic Screening in NCAA Has Potential to Be Discriminatory*, CINCINNATI.COM (Sept. 8, 2010), <http://archive.cincinnati.com/article/20100909/EDIT02/9090364/Genetic-screening-NCAA-has-potential-discriminatory>, archived at <https://perma.cc/JQ97-WLEC>.

²⁰⁵ Vence L. Bonham et al., *Screening Student Athletes for Sickle Cell Trait - A Social and Clinical Experiment*, 363 NEW ENG. J. MED. 997, 997 (2010).

²⁰⁶ CINCINNATI.COM, *supra* note 204.

²⁰⁷ See Bonham, *supra* note 205, at 999.

²⁰⁸ See *id.*

A group of authors from the legal and medical fields writing in *The New England Journal of Medicine* concluded that the NCAA genetic screening program has “the potential for unintended consequences.”²⁰⁹ The authors note that in the 1970s, mass screenings for SCT were conducted with “the aim of benefiting individual health and assisting carriers in making reproductive decisions” but that those programs were “thought to do more harm than good.”²¹⁰ The authors also point to a military screening program for SCT that led to discrimination against carriers who were “banned from performing certain duties.”²¹¹ Furthermore, the authors argue that there is an issue of whether screening is truly the answer to the problem of student athlete deaths or whether “changing the practice and culture of college athletics” is the real solution.²¹² The authors also express concern that screening could lead to stigmatization that might “alter a student athlete’s self-image” or “affect his or her employability in professional sports.”²¹³

Other critics echo the concern that SCT testing is a slippery slope to employment discrimination. As one legal scholar has remarked, does the slope “now slide from protection of the athlete who has [SCT] by sitting them out, to maybe losing a scholarship, to maybe not being recruited at all?”²¹⁴ The medically accepted correlation and the layperson’s categorization of certain diseases as endemic to certain racial groups should prompt concern regarding the potential for genetic testing to serve the purposes of covert racial discrimination. A disparate impact clause specific to GINA would allow another litigation opportunity for a plaintiff who is unable to obtain redress under Title VII.

IV. ANSWERING THE CRITICS

There are three anticipated criticisms to the call for a disparate impact theory of action for GINA. The first is that carriers of genetic mutations do not represent a special class and therefore should not be granted the level of protection afforded by the disparate impact theory of action that special classes enjoy. The second has to do with the GINA’s identity crisis, that is, whether GINA is an anticlassification law or an antisubordination law. The third criticism is that a disparate impact theory does not recognize the employer’s interest. In this section, I show that (1) carriers of a genetic mutation may be considered a special class (even if one that is in waiting); that (2) GINA has no identity crisis, and, akin to Title VII, Congress may choose to endow GINA with both anticlassification and antisubordination proper-

²⁰⁹ *Id.* at 998.

²¹⁰ *Id.*

²¹¹ *Id.*

²¹² *Id.*

²¹³ *Id.*

²¹⁴ Chika Duru, *Out for Blood: Employment Discrimination, Sickle Cell Trait, and the NFL*, 9 HASTINGS RACE & POVERTY L.J. 265, 270–71 (2012).

ties; and that (3) the employer, with the help of affirmative defenses, may still vindicate its interests even after the addition of a disparate impact clause.

A. *Non-Special Special Class?*

Some scholars might be leery of the idea of strengthening GINA any further, because they argue that the protected class under GINA is a nebulous one. Jessica Roberts has noted: “[W]e are all potential members of a genetic underclass. . . . Moreover, since we all have multiple genetic flaws, individual people could be members of more than one genetically disadvantaged group, depending on which tests are developed and which conditions related to those tests become stigmatized.”²¹⁵ Other scholars, however, have interpreted “class” a bit differently and have noted that the absence of a disparate impact theory under GINA would mean that some people would lack legal avenues through which to remedy unlawful discrimination. Phillip Vacchio and Joshua Wolinsky state: “The lack of a disparate impact theory as a cause of action under GINA could potentially prevent a *class* of individuals who were denied jobs based on their genetic information from litigating directly against the employer.”²¹⁶ Thus, the idea is that the protected class is not everyone or even anyone who has a genetic defect; rather, it is all individuals who would want to bring a claim for employment discrimination based on genetic information and can meet certain burdens of proof. It is important to understand that a disparate impact theory of action does not mean an automatic win for the plaintiff; the plaintiff still needs to establish a clear pattern of discrimination based on the trait in question.

Note that this construction of a protected class is akin to the one for the ADEA. After all, all human beings have the potential to age. The odds of living to be forty years old, at which time one joins the class protected by the ADEA, has vastly improved for all human beings. Thus, to follow Roberts’ argument, almost everyone would be a potential member of the protected class for ADEA. But this fact did not prevent the enactment of the ADEA, and it did not prevent the Supreme Court from later reading it to imply a disparate impact theory of discrimination. The same protection should be afforded to those who have suffered employment discrimination as a result of their genetic propensity for disease.

Some might still argue that the ADEA and GINA are different. Everyone ages, the changes that come with aging generally are visible to employers, and age discrimination affects each victim more or less in the same way. Therefore, everyone justifiably could be considered part of a cohesive pro-

²¹⁵ Roberts, *supra* note 74, at 631.

²¹⁶ Phillip K. Vacchio & Joshua L. Wolinsky, *Genetic Information Nondiscrimination Act of 2008: It’s in Title VII’s Genes*, 29 HOFSTRA LAB. & EMP. L.J. 229, 239–40 (2011) (emphasis added).

tected group protected by the ADEA. On the other hand, each person has a unique genetic makeup, and thus genetic discrimination may vary and result in a class with too many differences. Accordingly, it becomes more difficult to see why everyone should benefit from the disparate impact claim.

The rebuttal to this argument is that the ADA and ADEA are quite similar. First, although everyone ages, each person will age differently based on environmental and other factors. Second, most age discrimination is deterministic—that is, it is based on the chronological age rather than actual age presentation. For example, a policy may ban the hiring of anyone over thirty years of age, regardless of the individual’s appearance.²¹⁷ Age discrimination is similar to genetic discrimination because the latter is based on the propensity for genetic disease, rather than the actual manifestation of the disease. Although genetic profiles may differ, the variation is irrelevant because the individual was denied or dismissed from employment on the basis of their genetic *potential* for future disease. The specific disease, which the individual does not currently have, is irrelevant.

B. *Antisubordination vs. Anticlassification*

Much has been made of the dichotomy between antidiscrimination laws reflecting antisubordination values and those reflecting anticlassification values.²¹⁸ Roberts, Areheart, and others have written extensively on the topic.²¹⁹

²¹⁷ For example, police departments typically have a maximum age cut-off. See, e.g., N.J. DEPT OF PERSONNEL, MUNICIPAL POLICE OFFICER MAXIMUM HIRING AGE INFORMATION SHEET (Mar. 16, 2005), available at http://www.state.nj.us/csc/about/publications/pdf/2005hiring_age.pdf, archived at perma.cc/HY4M-8UT4. But see *Youth, Fitness No Longer Police Prerequisites*, ASSOCIATED PRESS (June 8, 2007), http://www.nbcnews.com/id/19116778/ns/us_news-life/t/youth-fitness-no-longer-police-prerequisites/#.VpLcNRFOLzI, archived at perma.cc/U4J5-HU45 (“Police departments around the country are relaxing age and fitness standards, . . . easing . . . requirements to relieve shortages in their ranks and find officers who are wiser, more worldly, and cool-headed in a crisis.”).

²¹⁸ See Roberts, *supra* note 74, at 627–28. Roberts states:

These two versions of the antidiscrimination principle employ differing accounts of the meaning of equality. The antisubordination principle roughly holds that covered entities should not act in a way that reinforces the social status of subjugated groups. Antisubordination would, therefore, permit affirmative action designed to improve the status of a disadvantaged group and forbid facially neutral policies that perpetuate lowered group status, even absent the intent to discriminate. Its complement, the anticlassification principle, maintains that covered entities should not consider certain classes of forbidden traits under any circumstance, adopting a formal equal treatment model of equality.

Id.

²¹⁹ See, e.g., Areheart, *supra* note 75, at 709–15; Bradley A. Areheart, *The Anticlassification Turn in Employment Discrimination Law*, 63 ALA. L. REV. 955 (2012); see also Roberts, *supra* note 74, at 630–41. See generally Reva B. Siegel, *Equality Talk: Antisubordination and Anticlassification Values in Constitutional Struggles over Brown*, 117 HARV. L. REV. 1470 (2004) (providing the background for the development of competing theories on equal protection law); Jack M. Balkin & Reva B. Siegel, *The American Civil Rights Tradition: Anticlassification or Antisubordination?*, 58 U. MIAMI L. REV. 9 (2003) (relating the history of the development and application of two distinct antidiscrimination threads in American law).

Roberts argues that the protection of genetic information could be viewed in “either antisubordination or anticlassification terms,” meaning that “an antisubordination-based law would seek to prevent the formation of a genetic underclass,” while “an anticlassification-based statute would prohibit any decision—positive, negative, or value-neutral—about individuals based on their genetic information.”²²⁰ Both Roberts and Areheart decry what they perceive as GINA’s anticlassification stance. Areheart argues that “GINA . . . [represents] a turn toward anticlassification principles and a possible turn away from antisubordination norms.”²²¹ He bases his arguments on the fact that GINA does not have a disparate impact clause. Of course, the addition of a disparate impact clause to GINA would address Professor Areheart’s concerns. And in parsing extant antidiscrimination laws such as Title VII, it becomes evident that the antisubordination versus anticlassification debate is an unnecessary one. As Roberts herself notes, “Title VII includes both anticlassification and antisubordination protections.”²²² For example, Title VII both prohibits the use of race and gender in employment *and* allows for disparate impact suits for when purportedly benign classifications result in a harsher impact on those protected categories. There is no reason why GINA could not follow a similar model.²²³ GINA need not be considered solely an anticlassification or antisubordination law.

C. *What about the Employer’s Interests?*

It is true that the employer has a reasonable interest in employing individuals who are healthy enough to do the job. But employers cannot deny individuals the opportunity to earn a livelihood based merely on a future potential for increased healthcare costs that may never occur. The question here is how the law should instruct an employer’s behavior when the employer is confronted with a potential employee who has the genetic potential for a disease. Older employment antidiscrimination laws offer employers the opportunity to provide defenses against allegations of discrimination—notably, the bona fide occupational qualification (“BFOQ”) defense and the business necessity defense.²²⁴ Accordingly, this Article proposes that the disparate impact clause allow for BFOQ and business necessity as affirmative defenses.

²²⁰ Roberts, *supra* note 74, at 630.

²²¹ Areheart, *supra* note 75, at 709.

²²² Roberts, *supra* note 74, at 642.

²²³ Professor Roberts does ultimately propose this in her article. *See id.*

²²⁴ Susan Glover, *Symposium, The Business Necessity Defense in Disparate Impact Discrimination Cases*, 30 GA. L. REV. 387, 398 (1996).

1. *Bona Fide Occupational Qualification*

BFOQ operates as an affirmative defense when an employer must discriminate against candidates who are unsuitable for the job because of the tasks required by the position. Both Title VII and the ADEA allow for BFOQ exceptions.²²⁵ For example, under the ADEA, whether age is a BFOQ will depend on the facts in the case. To establish a BFOQ defense, the defendant must show that (1) the age limit is reasonably necessary to the essence of the business, and that (2) either (a) all or substantially all individuals over the specified age would be unable to perform the duties of the job or (b) it is highly impractical to determine the fitness of older employees on an individualized basis.²²⁶

Although BFOQ generally is used for a facially discriminatory policy because it involves an employer's admission of the alleged practice,²²⁷ GINA, could permit a similar defense for disparate impact claims. Employers could rely on a BFOQ defense if, and only if, they could prove the two prongs of the affirmative defense.

Notably, race is not allowed as a BFOQ, and some scholars might argue that genetic profile, which is similarly deemed an immutable characteristic, should not be allowed as a BFOQ. Nonetheless, BFOQ should remain available for genetic discrimination claims. There is little danger in allowing a BFOQ defense to genetic discrimination because the genetic profile of an

²²⁵ The BFOQ for Title VII reads:

[I]t shall not be an unlawful employment practice for an employer to hire and employ employees, for an employment agency to classify, or refer for employment any individual, for a labor organization to classify its membership or to classify or refer for employment any individual, or for an employer, labor organization, or joint labor-management committee controlling apprenticeship or other training or retraining programs to admit or employ any individual in any such program, on the basis of his religion, sex, or national origin in those certain instances where religion, sex, or national origin is a bona fide occupational qualification reasonably necessary to the normal operation of that particular business or enterprise

42 U.S.C. § 2000e-2(e).

The BFOQ for the Age Discrimination in Employment Act reads:

It shall not be unlawful for an employer, employment agency, or labor organization (1) to take any action otherwise prohibited under subsections (a), (b), (c), or (e) of this section where age is a bona fide occupational qualification reasonably necessary to the normal operation of the particular business, or where the differentiation is based on reasonable factors other than age, or where such practices involve an employee in a workplace in a foreign country, and compliance with such subsections would cause such employer, or a corporation controlled by such employer, to violate the laws of the country in which such workplace is located.

29 U.S.C. § 623(f)(1).

²²⁶ See *Western Air Lines, Inc. v. Criswell*, 472 U.S. 400 (1985); see also *Monroe v. United Air Lines, Inc.*, 736 F.2d 394 (7th Cir. 1984); see also 29 C.F.R. § 1625.6 (2015).

²²⁷ See *bona fide occupational qualification (BFOQ)*, LEGAL INFO. INST., http://www.law.cornell.edu/wex/bona_fide_occupational_qualification_bfoq, archived at <https://perma.cc/AS7X-WNWW> (last visited Jan. 18, 2016).

asymptomatic individual rarely would render that individual unable to carry out the duties of the job.²²⁸

2. *Business Necessity*

The affirmative defense that business necessity dictates the employment practice is available in traditional antidiscrimination disparate impact claims and should be available in GINA claims.²²⁹ While an employer's self-protective instinct might be to exclude a genetically "impaired" employee from consideration, it could in fact be feasible for the employer to reasonably accommodate the employee. Plaintiffs would be given an opportunity to demonstrate that an alternative employment practice could meet the employer's legitimate needs without a similar discriminatory effect.²³⁰

Consider the recent case of Ryan Clark, a player for the Pittsburgh Steelers.²³¹ Although Clark knew that he had the SCT, he was unaware of the severity of the risk when he played in Denver in 2007. At that high altitude, Clark's blood began to sickle,²³² negatively affecting his spleen. In the following weeks, doctors had to remove Clark's spleen and gallbladder, and Clark feared that he would die.²³³ He lost more than 30 pounds and did not play again that season.²³⁴ Based on the incident, the Steelers' coach, Mike Tomlin, decided to keep Clark out of a January 2012 playoff game in Denver, rather than to risk his health and life—a decision that Clark welcomed with relief.²³⁵ Tomlin's decision illustrates how an employer could protect its business interest without sacrificing the interests of the employee. The coach recognized that Clark's value to the team outweighed any benefits derived from forcing him to risk his life or dismissing him altogether.

CONCLUSION

Employment discrimination is a many-headed hydra that the law must continue to valiantly battle. Although genetic testing and human engineering were inconceivable during the promulgation of traditional antidiscrimination laws, scientific advancements have created a liminal space between opportunities for employment discrimination and the reach of legal

²²⁸ Compare Duster, *supra* note 31, at 28–29 (Stephen Pullens), with Judy Battista, *Steeler's Sickle Cell Trait and Denver Do Not Mix*, N.Y. TIMES (Jan. 3, 2012), <http://www.nytimes.com/2012/01/04/sports/football/steelers-sideline-safety-clark-because-of-blood-trait.html> (Ryan Clark).

²²⁹ See 42 U.S.C. § 2000e-2(k)(1); see also Pub. L. No. 101-336, 104 Stat. 327.

²³⁰ See *Menoken v. Whipple*, 605 F. Supp. 2d 148, 153 (D.D.C. 2009).

²³¹ See Battista, *supra* note 228.

²³² See *id.*; see also R.L. Green et al., *The Sickle-Cell and Altitude*, 4 BRIT. MED. J. 593, 593 (1971).

²³³ See Battista, *supra* note 228.

²³⁴ See *id.*

²³⁵ See *id.*

protections. Consider the recent case of the “devious defecator”²³⁶ that made headlines because it revealed that genetic testing had become so affordable as to become yet another invasive tool of surveillance available to employers. The facts of the case detail a mystery regarding the culprit responsible for deposits of feces around the workplace.²³⁷ The employer, Atlas Logistics Group Retail Services—a grocery distributor in Atlanta, Georgia—requested that two employees, Jack Lowe and Dennis Reynolds, submit DNA samples in the form of cheek swabs in 2012.²³⁸ Atlas then sent these employees’ DNA samples to a lab for genetic testing.²³⁹ The tests revealed that Lowe and Reynolds’ samples did not match the DNA found in the fecal matter.²⁴⁰ In 2013, the workers brought suit against Atlas under GINA.²⁴¹ And on June 22, 2015, a federal court jury in Georgia awarded \$2.25 million to the two aggrieved employees.²⁴² The verdict marked the first time that a case brought under GINA had resulted in a money award.²⁴³

What the “devious defecator” case highlights is that genetic testing has become so ubiquitous that employers may seek to wield it for employment discrimination in idiosyncratic ways.²⁴⁴ It is worth noting, however, that there was a “smoking gun” in the “devious defecator” case: The employer intentionally and overtly demanded that its employees undergo genetic testing, the results of which could result in employment termination. Many would-be plaintiffs seeking to bring a traditional GINA case may not have access to such overt evidence, and therefore, a clause allowing a disparate impact theory of action is a necessary addition to GINA.

Genetic discrimination vis-à-vis employment has proven to be a concrete threat, but newer antidiscrimination laws such as GINA have not quite met the challenge. Although genetic testing can afford knowledge and confer agency, the government must remain alert to its potential misuses, which can engender greater inequality, particularly in the field of employment. Moreover, while the U.S. government has become hyper-vigilant in blocking any effort to discriminate on the basis of visible physical difference, Congress should recognize the growing deterministic social attitudes towards

²³⁶ The case was nicknamed the “mystery of the devious defecator” by Amy Totenberg, the presiding federal judge. Natasha Gilbert, *Why the ‘Devious Defecator’ Case is a Landmark for US Genetic-Privacy Law*, NATURE (June 25, 2015), <http://www.nature.com/news/why-the-devious-defecator-case-is-a-landmark-for-us-genetic-privacy-law-1.17857>, archived at <https://perma.cc/42MZ-2DP2>.

²³⁷ See *Lowe v. Atlas Logistics Grp. Retail Servs., LLC*, No. 1:13-CV-2425-AT, 2015 WL 2058906, at *1 (N.D. Ga. May 5, 2015).

²³⁸ See *id.*

²³⁹ See *id.*

²⁴⁰ See *id.*

²⁴¹ See *id.*

²⁴² See Gilbert, *supra* note 236.

²⁴³ See *id.*

²⁴⁴ When describing the case to *Nature*, John Conley, a genetics law professor, said: “This is an application of the law that no one thought of in a million years. . . . But the ruling is not controversial. You can’t use genetic testing for dismissal purposes.” *Id.*

genetic testing and genetic disease. With widespread use of genetic testing and the ease of access to the genetic data it obtains, Congress must prevent the insidious creation of a genetic underclass that is denied participation in the liberal economy. GINA should no longer be thought of as merely preemptive; rather, Congress should strengthen it with a disparate impact cause of action to ensure that workers are truly protected from genetic discrimination in employment.